

**Cognitive Stimulation Therapy for Dementia:  
Evidence for Benefit  
Supported with a Targeted Survey of  
Provision for People in Norfolk Care Homes  
and Day Centres**



Prepared for NHS North Norfolk Clinical Commissioning Group

Authors

Dr Jane Cross

Dr Alethea Cooper

Dr Toby Smith

Prof Chris Fox

September 2015

## Index

<b>Executive Summary</b> .....	3
<b>Introduction</b> .....	5
What is Cognitive Stimulation Therapy (CST)? .....	5
Background: Clinical and UK Context .....	6
How this report was produced .....	7
<b>Part 1: Systematic Review</b> .....	8
What does the qualitative research tell us about the everyday life experience of CST? .....	8
Papers investigating perceptions of CST .....	8
Conclusion: A place for CST in therapy, in people with dementia .....	10
<b>Part 2: Regional Survey</b> .....	11
What do local data tell us? .....	11
Materials and Methods .....	12
Results .....	15
Survey Conclusions .....	22
<b>Conclusions and Recommendations</b> .....	23
Suggested Future Work .....	23
<b>Appendices</b> .....	25
Appendix 1 .....	25
Appendix 2 .....	26
Appendix 3 .....	27
Appendix 4 .....	32
<b>References</b> .....	36

## **Executive Summary**

Benefit is to be gained from participation in Cognitive Stimulation Therapy (CST) by people with mild to moderate dementia (Zhan et al, 2014). The World Alzheimer Report (Prince et al, 2011) recently supported the NNICE-SCIE 2006 Guideline that recommends all people with mild to moderate dementia should have the opportunity to participate in group CST independent of whether or not they are receiving Acetylcholinesterase inhibitors (AChEIs).

Cognitive stimulation is engagement in a range of activities and discussions (usually in a group) aimed at general enhancement of cognitive and social functioning. Generally, CST is usually delivered in small groups (five to seven participants) by a trained carer/facilitator. To be effective, it is recommended that sessions last for at least 45 minutes, approximately twice a week, for a minimum of 14 sessions and that a treatment manual is used to guide the intervention content. NICE (2006) recommends:

*People with mild-to-moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care staff with appropriate training and supervision, and offered irrespective of any drug prescribed for the treatment of cognitive symptoms of dementia.*

What is less clear is what dose of CST should be made available, whether individual CST is effective and whether maintenance programmes are effective following an initial course (studies currently underway elsewhere in the United Kingdom).

This literature is in contrast to the results that were obtained from the survey of care homes and day care facilities undertaken for this project. Approximately two-thirds (7/11) of responding care homes confirmed provision of CST but just one of the care homes followed the treatment manual (Clare, 2004). This care home also mentioned provision of maintenance sessions following the 14-session programme. In day care, four out of the six responders cited provision of CST for people with a diagnosis of dementia. As with the care homes, just one of these used the guided manual. However, in contrast to the care homes, CST was delivered either by a trained external facilitator or by formally trained staff. As with the care homes, the majority incorporated all of the recommended activities.

The following recommendations are made to inform commissioning of CST in North Norfolk

- Investigation of the barriers and facilitators for delivering evidence-based CST in care homes and day care in Norfolk.
- Develop evidence based commissioning criteria for CST to reflect the evidence set out in this report. This includes that CST should be delivered:
  - Twice a week
  - In 45 minute sessions

- By appropriately trained staff
- Using the manualised approach

In this report the term 'care home' is used to cover care home, nursing home and residential care home; the terms 'day care' covers community hub, day care centre, day centre and day care.

## Introduction

### What is Cognitive Stimulation Therapy (CST)?

Cognitive stimulation is engagement in a range of activities and discussions (usually in a group) aimed at general enhancement of cognitive and social functioning. Generally, CST is usually delivered in small groups (five to seven participants) by a trained carer/facilitator. It offers:

- A range of enjoyable activities providing general stimulation
- Stimulation of memory, concentration, thinking through:
  - Discussion of past / present events
  - Topics of interest
  - Word games
  - Puzzles
  - Music
  - Practical activities baking/indoor gardening

To be effective, it is recommended that sessions last for at least 45 minutes, approximately twice a week, for a minimum of 14 sessions (Clare and Woods, 2004). For best practice, it is also recommended the treatment manual (Making a Difference 2: Hawker Publications) is used (Clare and Woods, 2004) to guide the intervention content. Training events and treatment manuals are available via <http://www.cstdementia.com> which is supported through the International Cognitive Stimulation Therapy Centre at University College London directed by Dr Aimee Spector. The sessions often include key themes: (1) the senses, (2) remembering the past, (3) people and objects, and (4) caring for oneself/everyday practical issues. Activities include naming objects and people, association of words, remembering the past, discussion of hobbies, activities and current affairs, using money, knowing the way around and orientation topics. Clare and Woods (2004) distinguish CST from Cognitive training and Cognitive Rehabilitation thus;

*Cognitive training is guided practice on a set of standard tasks designed to reflect particular cognitive functions; a range of difficulty levels may be available within the standard set of tasks to suit the individual's level of ability. It may be offered in individual or group sessions, with pencil and paper or computerised exercises.*

*Cognitive rehabilitation is an individualised approach where personally relevant goals are identified and the therapist works with the person and his or her family to devise strategies to address these. The emphasis is on improving performance in everyday life rather than on cognitive tests, building on the person's strengths and developing ways of compensating for impairments.*

## **Background: Clinical and UK Context**

In the UK there are approximately 850,000 people with dementia in 2015 (Alzheimers.org.uk, 2014). In context, approximately one in 14 people over the age of 65 (the age group most likely to be affected) have dementia and the likelihood of developing dementia increases with age.

The brain cell damage, characteristic of dementia, causes symptoms that are predominantly cognitive (problems with thinking or memory). Difficulties experienced include problems with day-to-day short-term memory, concentration (planning and organising previously straightforward tasks), language recall, visuospatial skills and orientation. Associated changes in mood may include increased anxiety, becoming easily distressed, frustrated, angry or withdrawn. Alzheimer's disease (AD), the most common form of dementia in people aged over 65 years old, is caused by an abnormal protein which surrounds the cell resulting in internal cellular damage with eventual cellular death. Symptoms may also be caused by damage to brain cells through narrowing or blockage of blood vessels (vascular dementia) such as through minor strokes or a major stroke. Due to the progressive nature of the disease a person with dementia will need increasing support to remain independent (carrying out usual activities of daily living) over time, although speed of progression varies from person to person.

Approved (licensed) anti-dementia drugs include acetylcholinesterase inhibitors (AChEI's) (mild to moderate AD) or an N-methyl-D-aspartate antagonist memantine (moderate to severe AD). Although these licensed medicines which have become available in the last decade provide some relief of clinical symptoms, their effect is time-limited and does not represent a cure.

A non-pharmacological (psychological) intervention was first described in relation to helping people with dementia in the 1960s in an attempt to alleviate confusion and disorientation (Khan et al, 2014). Reality orientation (RO) originally developed to help severely traumatised war veterans, involved the presentation of orientation and memory information; for example time, place, and person (Spector et al, 2000).

In the dementia care setting RO appeared to deliver some benefit in terms of outcomes relating to cognitive function, activities of daily living and social functioning (Dietch et al, 1989). However, shortcomings of RO highlighted a less than person-centred approach with associated doubts expressed on the improvement of overall quality of life and the efficacy of an intervention with the emphasis purely on repetition of orientation to current time and place. Over the last few decades a broader, rehabilitative, cognitive approach, referred to most recently as cognitive stimulation therapy (CST), has been the subject of investigation and review.

## **How this report was produced**

Using National Institute for Health Research (NIHR) Research Capability Funding (RCF), NHS North Norfolk Clinical Commissioning Group (NNCCG) commissioned the development of a systematic review and survey of practice to increase understanding of the use of CST in their area, and to inform future commissioning.

The purpose of this RCF funding was to allow a research team to undertake developmental work to support a formal research application. In light of the recently published systematic reviews (Cooper et al, 2012; Woods et al, 2012), the research team undertook a comprehensive review of published research papers for CST.

To support the development of a research application, the team:

- Part 1: Summarised the systematic reviews (search strategy for trials and systematic reviews detailed in Appendix 1)
- Produced a narrative review of the qualitative literature, (this was performed according to the search strategy detailed in Appendix 2)
- Part 2: Conducted a survey of CST delivery/practice in selected care homes and day care facilities in Norfolk.

## **Part 1: Systematic Review**

### **What does the qualitative research tell us about the everyday life experience of CST?**

There is no doubt that systematic reviews of clinical trials of CST have shown positive benefits in measurable outcomes for people with dementia. However, the question of subjective experience of interventions, for people with dementia, staff of day-centres/care homes and care-givers including family members remains. The Medical Research Council (MRC) Guidelines for evaluation of complex interventions (MRC, 2008) state the need to determine which aspects of an intervention, including the manner and context in which it is delivered, are effective hence a search of qualitative literature is justified. A search was undertaken as outlined in Appendix 2. Just two papers concerning CST were found, although three others investigating non-pharmacological interventions with an element of cognitive engagement/reminiscence/social interaction are also mentioned below. Additionally a mixed methods synthesis concerning a broad range of psycho-social interventions for people with dementia in a range of international care settings was found which sought to uncover what underlies the successful implementation of such interventions in the residential setting (Lawrence et al, 2012). The nature of the interventions ranged from ‘doll therapy’ to ‘animal interventions’ and thus are not reported in detail here but this review of qualitative research revealed beneficial aspects of interventions for people with dementia including the opportunity to connect with others, reminisce and to gain benefit from the perception of making a meaningful contribution (Lawrence et al, 2012). Successful implementation was dependent on the active engagement of staff and family and the continued provision of tailored interventions and support. Care home staff reported benefits from the interventions, namely becoming more aware of the personal individuality of the residents, seeing a person beyond the symptoms of dementia; however there were also concerns with regard to the practicality of delivering interventions which required extra work and necessitated flexibility in relation to usual working hours.

### **Papers investigating perceptions of CST**

Spector et al (2011) conducted focus groups and interviews with people attending existing National Health Service (two) and charitable (one) CST groups in London or Greater London. Seventeen people with mild dementia (five male and 12 female) based in the community with a mean age of 82 years were included. Fourteen carers (11 relatives, one friend, one neighbour and one a paid carer) and seven staff facilitating the groups were also interviewed. Two main themes emerge from this analysis; ‘positive experiences of being in the group’ and ‘changes experienced in everyday life’. CST was seen as a positive emotional experience with the majority of participants reporting some cognitive benefits, gaining confidence and finding the group fun. As a result of participating in the group, participants reported improved memory, concentration and alertness and improved ability to converse. A third of caregivers confirmed that that participants showed improvement in verbal fluency and skills, and group facilitators reported greater awareness of time and ability of the participants to recall the activities that took place previously within the group.

A second qualitative study conducted by the same group of authors, plus others, explored the views of people with dementia, staff and family carers in relation to the use of a

maintenance programme manual (Aguirre et al, 2011). Three one-hour focus groups were undertaken with 17 people with mild to moderate dementia (eight men, nine women mean age 78 years), 13 staff members (three men and ten women, mean age 36 years) from residential homes, day centres or a day hospital and 18 family caregivers (six men, 12 women mean age 53 years) who had at least one contact episode a month. Whilst people with dementia valued the opportunity to continue to take part in the maintenance CST sessions, citing they kept them 'healthy and active' family members and staff did cite some concerns. They questioned the 'blanket' effectiveness of some aspects of the programme (specifically the 'use it or lose it' mantra). Family members expressed concern that dementia sufferers could experience distress as a result of confronting their cognitive problems when faced with challenging mental activity during the CST.

## **Conclusion: A place for CST in therapy, in people with dementia**

From recent meta-analyses of quantitative data from RCTs (Appendix 3) as well as in-depth exploration of the views of individuals with dementia, family/other caregivers and staff, it would appear that interest and benefit are to be gained from participation in CST (Zhan et al, 2014). Importantly, the World Alzheimer Report (Prince et al, 2011) recently supported the NNICE-SCIE 2006 Guideline that recommends all people with mild to moderate dementia should have the opportunity to participate in group CST; this is independent of whether or not they are receiving AChEIs.

Questions remain such as whether there are longer-term benefits. However, a trial of maintenance CST is on-going (Streater et al, 2012). Individualised CST is also currently being investigated (Orrell et al, 2012) There is also scant information on the cost-effectiveness of CST in care homes. Knapp et al (2006) examined cost-effectiveness for the outcomes cognition and quality of life (data taken from Spector et al, 2003) and concluded that for both outcomes 'under reasonable assumptions; there is a high probability that CST is more cost-effective than treatment as usual'.

At present it is not known to what extent people are able to access CST or indeed whether its role is understood by the people responsible for managing the care of people with dementia in community settings, both in care homes or day care. In order to investigate this question we conducted a local survey. The following section reports the findings of a survey of CST provision in care homes and community hubs North Norfolk and other sites identified by NNCCG specifically where this service is not currently part of commissioned care home provision.

## **Part 2: Survey**

### **What do local data tell us?**

#### *Aim*

To conduct an electronic survey of managers and staff in community hub/day care facilities and care homes in North Norfolk and other sites identified by NNCCG in order to investigate the current understanding and practice of CST and its local provision to elderly people with dementia.

Specifically we wished to determine:

- The prevalence of mild/moderate dementia in elderly people in care homes/attending day care.
- The current awareness of the content and value of cognitive stimulation therapy for people with dementia among carers/staff in the community.
- The availability and use of CST for people with dementia (either living in care homes or attending day care) in North Norfolk. Where CST is delivered to ascertain:
  - How frequent are CST sessions?
  - Is the CST guided by a formal treatment manual/guidelines?
  - Who is delivering the CST (care home staff/outside psychologist etc.)?
  - The current attitudes (specifically worries/concerns) of staff/carers towards participating in research of CST among people with dementia.

#### *Design*

An online-survey design was used in order to obtain a 'snap-shot' of the current practices in care homes/day care. This method allows the same data from multiple settings to be obtained relatively quickly.

#### *Ethical Approval*

The study received full ethical approval from the Faculty of Medicine and Health Sciences Research Ethics Committee at the University of East Anglia, Norwich (reference: 2014/2015 31).

## **Materials and Methods**

### *Participants*

The target population for the survey was managers and/or staff working in care homes and managers or coordinators of community hubs (Day Care) for the elderly with dementia in North Norfolk and other sites identified by NNCCG. These were obtained from carehome.co.uk and cross-referenced to the Care Quality Commission's (CQC) website. Only those care homes that had undergone an inspection check and met all standards with a rating of good or above were included. Those facilities not yet inspected or under new management and pending re-inspection were not included. The names of the care homes and day care facilities are shown in Table 1.

**Table 1:** List of Day Care / Care Homes included in the Survey

<b>Name of Service (area)</b>	<b>Provider</b>
<b>Day Care Facility n=21</b>	
Acle Day Service* (Acle, NR13 3RA)	Acle Voluntary Aid
Aylsham Day Service* (Aylsham, NR11 6YA)	Aylsham Care Trust
Briston Day Service* (Briston, NR24 2LA)	Volunteer led
Broadland Day Support Club (Acle War Memorial Recreation and Social Club) (Acle NR13 3RA)	AgeUK Norfolk
Fakenham Day Service* (Fakenham, NR21 9AW)	First Focus
Friday Club* (North Walsham, NR28 9BT)	Griffon Area Partnership
Furze Hil Day Centre* (North Walsham, NR28 9HD)	The Salvation Army
Glaven Day Centre* (Blakeney, NR25 7PH)	Glaven District Caring Committee
Grays Fair Court Day Centre (Norwich, NR5 OSN)	AgeUK Norfolk
Heritage House* (Wells-next-the-Sea, NR23,1RF)	Heritage Day Care
Holt Day Service* (Holt Community Hub) (Holt, NR25 6DA)	Independence Matters
Marion Road Day Centre (Norwich, NR1 4BN)	Norwich Age UK
Norwich Day Support Club (Norwich, NR5 OSN)	Age UK Norfolk
Poppy Centre* (Holt, NR25 6BB)	Volunteer led (Holt and District Dementia Support Group)

Rose Day Centre* (Now Ashfields House) (Rackheath, NR13 6PD)	Barchester Care Ltd.
Sheringham Day Centre (Sheringham, NR26 8DZ)	Age UK North Norfolk
Taverham and District Day Centre* (Taverham, NR8 6JR)	Volunteer/Charitable Status
The Lawns Day Centre (The Lawns Community Hub) (Great Yarmouth, NR30 4DQ)	Independence Matters
The Swallows Day Centre (Salhouse, NR13 6NY)	Adult Day Care Ltd.
William Booth Day Centre (Norwich, NR2 1LL)	The Salvation Army
Worstead Day Care Centre* (North Walsham, NR28 9LR)	Volunteer/Charitable Status
<b>Care Home n=18</b>	
Bilney Hall (Dereham, NR20 4AL)	Healthcare Homes Group Ltd.
Broadland House (Great Yarmouth, NR29 5JB)	Hollyman Care Homes Ltd.
Creswick House (Fakenham, NR21 8HH)	Jeesal Residential Care Services Ltd.
Dorrington House (Wells-next-the-Sea, NR23 1BY)	Dorrington House
Felmingham Old Rectory (North Walsham, NR28 0LD)	Akari Care Ltd.
Furze Hill House (North Walsham, NR28 9HD)	The Salvation Army Social Work Trust
Glendon House (Cromer, NR27 0PS)	Mr and Mrs R Smart
Halsey House (Cromer, NR27 0BA)	The Royal British Legion
Hickling House (Norwich, NR12 0AY)	Mr and Mrs R Smart
Highfield Residential Care Home (Cromer, NR27 9DJ)	Sterling Care (UK)
Ingham Old Hall Care Home (Norwich, NR12 0TW)	Ingham Healthcare Ltd.
Mill House and Cottages (Fakenham, NR21 0ED)	Prime Life Ltd.
Pineheath (Holt, NR25 6QD)	Diamond Care (UK) Ltd.
Shipbourne House Limited (Cromer, NR27 9DQ)	Miss C McCrory
The Aylsham Manor (Aylsham, NR11 6BN)	Mr Carl Denis
The Manor House (North Walsham, NR28 0LU)	Health Care Homes Group Ltd.
The Mount Residential Home (Aylsham, NR11 6QT)	Sunrise Care Homes Ltd.
Woodspring House (Fakenham, NR21 9AX)	Woodspring Care Ltd.

\*Centre details provided by North Norfolk Clinical Commissioning Group

### Procedure

The email addresses of all care homes/day care for the elderly were identified through either the CQC website, the respective care home/day care websites or through telephone calls to the relevant contact asking for the managers' email address. In total, 21 care homes and eight day care facilities were identified. One care home had not yet

been assessed by CQC and two, on further investigation, provided residential facilities for young people with learning disabilities leaving a total of 18. On review of the lists thirteen further day care facilities were identified by North Norfolk Clinical Commissioning Group giving a total of 21.

An email was sent to Managers/Coordinators of all care homes/day care. The cover email comprised the participant information sheet regarding the study and each email contained a hyperlink to the Survey Monkey questionnaire. A target response rate of 60% was stipulated to enable generalisation of the study's findings. Therefore we aimed to receive at least 11 responses from the possible 18 care homes identified from the CQC list and 13 from the possible 21 day care facilities. An opt-out option was given on the cover email to signal unwillingness to participate and/or to request no further follow-up contact.

### SurveyMonkey Questionnaire

The first two pages of the questionnaire comprised the consent form. The remaining 33 questions (tailored according to whether they were sent to the residential home or day care facility) comprised questions regarding: the job title of the member of staff completing the survey, resident numbers, approximate proportion of those with mild to moderate dementia; staff awareness of CST, current provision of CST and full details of CST (if this was provided); provision of activities where CST was not provided; current participation in research on the part of the care home/day care facility and willingness to participate in future research. As well as collecting data from closed questions, open-ended questions with comment box responses were provided to gain a deeper insight into as yet undetermined issues that may impact on CST delivery or availability.

### Follow-up

Provided no recipient had taken the opportunity to opt out of further contact, a reminder email was sent three weeks after the original email. Two weeks later a telephone call was made to the email recipient to offer the choice of completion over the telephone or to resend the link a final time.

## **Results**

### *Summary of care home provision*

Table 2 shows a summary of the data from closed questions from the responders providing information on their respective care homes. Table 3 illustrates a summary of the components of CST provided to respondent's residents.

**Table 2:** Summary of the data on the characteristics of the respondent's care homes

	<b>Number (%)</b>
<b>Responders</b>	<b>11/18 (60%)</b>
<i>Role of responder</i>	
Manager	7 (64%)
Deputy Manager	2 (18%)
Senior Carer	1 (9%)
Senior Carer & dementia care coach	1 (9%)
<i>Number of residents</i>	
<25	3 (27%)
25-30	3 (27%)
30+	5 (45%)
<i>Proportion of Residents with mild to moderate dementia; (Apr. number with dementia)</i>	
Less than 25%	2 (18%)
25-50%	3 (27%)
Over 50%	6 (55%)
<i>Provision of CST</i>	
Yes	7 (64%)
No	4 (36%)
<i>Previous participation in a Research Project</i>	
Yes	3 (27%)
No	5 (45%)
Unsure	2 (18%)
Skipped question	1 (3%)
<i>Would you personally be interested in participating in a research project at work?</i>	
Yes	6 (55%)
No	0 (0%)
Possibly	4 (36%)
Skipped question	1 (3%)

**Table 3:** Components of CST Provided for Residents

	<b>Providers of CST (N=7)</b>
<i>Who organises the CST?</i>	
Care Home	7 (100%)
External Provider	0 (0%)
<i>What is provided in the CST?</i>	
Discussion of past life events	7 (100%)
Topics chosen by residents	7 (100%)
Word games	7 (100%)
Puzzles	6 (86%)
Music	7 (100%)
Practical activities e.g. baking/gardening	6 (86%)
Other: Exercises	1 (14%)
Physical games	1 (14%)
<i>Who leads the sessions?</i>	
Current staff (some formal training)	3(43%)
Current staff (no formal training)	2 (29%)
Trained external facilitator	2 (29%)
<i>How is the format decided?</i>	
Follows the CST manual 'Making a Difference'	1 (14%)
Up to the session leader	2 (29%)
Up to session leader & residents	2 (29%)
Suggestions from residents	1(14%)
Manager trained in CST & residents	1 (14%)
<i>How frequently are the sessions held?</i>	
Monthly	0 (0%)
Fortnightly	1 (14%)
Weekly	4 (57%)
Twice Weekly	2 (29%)
<i>How long is each session?</i>	
One hour	2 (29%)
45 minutes	0 (0%)
30 minutes	2 (29%)
Other:	
1hr 30 minutes	1 (14%)
2 hours	1 (14%)
Depends on residents	1 (14%)
<i>Number of participants per session</i>	
<5	2 (29%)
5-10	3 (43%)
>10	2 (29%)
<i>How regularly do the residents attend each session?</i>	
Usually every session	1 (14%)
Fairly regularly	6 (86%)
Infrequently	0 (0%)

	<b>Providers of CST (N=7)</b>
<i>Do you think the residents generally value the session?</i>	
Yes	7 (100%)
No	0 (0%)

Just one of the care homes followed the treatment manual ‘Making a Difference’ (Clare, 2004) which recommends two 45-minute sessions are provided weekly for a total of 14 sessions. This care home also mentioned provision of maintenance sessions following the 14-session programme. One respondent used the free text option to comment that timing:

*‘varied according to the residents’ attention span on the day’*

*Is there understanding of the content/role of CST in those care homes not currently delivering a programme?*

Four care homes reported they did not provide CST. These homes catered for 22 and 40 residents of whom 25-50% has a diagnosis of dementia, and 23 and 34 residents of whom over 50% have a diagnosis. Of these three answered further questions. Two (a Deputy Manager and a Manager) reported to understand what CST is. One (a senior care assistant) of a care home with over 50% of over 30 residents diagnosed with dementia was unsure.

*Barriers to provision of CST*

The opportunity to use free-text to expand on possible barriers to CST provision was not taken but the care home responder (a Manager) who felt that residents did not value the activity sessions reported feeling unsure about whether they would provide CST, listing lack of interest from residents, their family members as well as financial constraints as key factors. This was a care home with 23 residents over 50% of whom were reported as having mild to moderate dementia. Lack of interest by residents was cited by a second home and staff time by a third.

*Engagement with research*

Just three responders stated they were currently participating in a research project although all except one, who skipped this question, indicated they would consider it.

Only one responder cited a possible barrier to participation in a research project and voiced concerns about availability of staffing and time pressure. When asked to comment about possible incentives to participation four responders provided comments:

*‘Further knowledge’*

*‘Value for the residents’ ‘enjoyment’ (for residents)*

*‘We already take part in research projects’*

*'Apart from value to residents, manager is studying evidence-based practice at Bradford University as part of Masters Course'*

Summary of Day Care CST Provision

Table 5 shows a summary of the data from closed questions from the responders providing information on their respective day care facilities. Table 6 illustrates the components of CSP provided for respondent's clients in day care.

**Table 5:** Summary of the characteristics of responding day care facilities.

	<b>Number (%)</b>
<b>Responders</b>	6/21 (29%)
<i>Role of responder</i>	
Manager	6 (100%)
Other	0 (0%)
<i>What type of Day Care Facility</i>	
Local authority provider	0 (0%)
Private Provider	3 (50%)
Mixed Provider	3 (50%)
Others (please specify)	X2 Local Charity
Please describe the client groups using the Day Care facilities (including age range)	<input type="checkbox"/> Age 55 upwards <input type="checkbox"/> Elderly physically disabled (16-85) & younger mental health <input type="checkbox"/> 70-90 years <input type="checkbox"/> Mainly >50 years (long term health conditions: clinical depression to clinical illness) <input type="checkbox"/> Wide variety of groups <input type="checkbox"/> 55-92
<i>Approximately how many clients are aged over 65 years old?</i>	
Less than 25%	0 (0%)
25%-50%	1 (17%)
Over 50%	5 (83%)

	Number (%)
<i>How many clients over 65 years have a diagnosis of mild to moderate dementia?</i>	
Less than 25%	3 (50%)
25-50%	1 (17%)
Over 50%	2 (33%)
<i>Do people with dementia regularly take part in CST at the centre?</i>	
Yes	4 (67%)
No	2 (33.3%)
<i>Previous participation in a Research Project?</i>	
Yes	3 (27%)
No	5 (45%)
Unsure	2 (18%)
Skipped question	1 (4%)
<i>Would you personally be interested in participating in a research project at work?</i>	
Yes	2 (33%)
No	1 (17%)
Possibly	3 (50%)

*Provision of CST including open-text comments*

Important open text responses included:

*'All of the above (recommended activities) and more as laid out in the CST manual 'Making a Difference 2' that we use.'*

One day care centre commented:

*'Customers who use our service choose each day what they want to do when they arrive so we do not offer this on a formal basis.'*

Attendance was regular and open text responses suggest a positive experience for the clients:

*"People love to reminisce but also enjoy discussing current affairs with a daily paper for example. Music is brilliant as it brings the group together with lots of laughter but also offers individual memories. Cooking, household tasks and gardening offer some normal daily routine to a session. I would not be able to say we can measure how valuable they find it as they cannot always recall what they have done but they all seem to leave the service smiling saying that they have had a lovely day".*

*“We are not a day centre (response from a Community Centre) so people are referred to us for CST which we deliver as per the manual and when this is complete they go on to Maintenance CST which we also run here.”*

*Barriers or facilitators to provision of CST*

Staff time and potential financial cost were cited as barriers to providing CST, (despite the large number of activities provided) by the day care facility described above.

**Table 6:** Components of CST provided for clients in day care facilities

	<b>Providers of CST (N=4)</b>
<i>Who organises the CST?</i>	
Day Care Facility	6 (100%)
Other: staff member and trained volunteers	0 (0%)
<i>What is provided in the CST?</i>	
Discussion of past life events	4 (100%)
Topics chosen by residents	4 (100%)
Word games	4 (100%)
Puzzles	4 (100%)
Music	3 (75%)
Practical activities e.g. baking/gardening	4 (100%)
Other: As laid out in the CST 'Making a Difference' manual	1 (25%)
<i>Who leads the sessions?</i>	
Current staff (some formal training)	3 (75%)
Current staff (no formal training)	0 (0%)
Trained external facilitator	1 (25%)
<i>How is the format decided?</i>	
Follows the CST 'Making a Difference' manual	1 (25%)
Up to the session leader	3 (75%)
Suggestions from residents/family members	1 (25%)
Other: chosen by residents so offered informally	0 (0%)
<i>How frequently are the sessions held?</i>	
Monthly	0 (0%)
Fortnightly	1 (25%)
Weekly	2 (50%)
Twice Weekly	1 (25%)
<i>How long is each session?</i>	
One hour	1 (25%)
45 minutes	1 (25%)
30 minutes	2 (50%)
Other: Depends on how well clients respond so flexible timings	0 (0%)
<i>Number of participants per session</i>	
<5	1 (25%)
5-10	3 (75%)
>10	0 (0%)
<i>How regularly do the residents attend each session?</i>	
Usually every session	3 (75%)
Fairly regularly	1 (25%)
Infrequently	0 (0%)

Consequently funding and implementation of a structured plan were cited as barriers or facilitators to CST provision.

### Engagement with research

Again, a positive response has been recorded in relation to possible participation in a research project. Just one respondent replied no, two stated 'yes' (both had been engaged with previous research, see comment below) and three would possibly consider it.

*"I was one of the unblinded researchers for the University College London research trial into Individual CST. So have only just finished being involved in an 18 month commitment to this research. So in no hurry for that level of commitment at present but am always prepared to consider it."*

### **Survey Conclusions**

It is difficult to engage care home managers and day care facility Managers/Coordinators with research through approaches that include an impersonal email contact, even when it is clearly locally run (University of East Anglia), locally relevant and requires minimal input of time and effort. However, it is a positive sign that a general willingness to take part in research is prevalent and an approach using a more personal approach could be adopted.

Currently one out of eleven care homes and one out of six day care facility responders show an evidence-based practice with regard to provision of CST, although delivery of weekly rather than the recommended twice-weekly sessions were reported. A further six homes and three day care facilities stated they did provide CST, showed an awareness of CST and provided sessions encompassing a variety of topics as suggested by the CST manual 'Making a Difference'.

For those homes/day care facilities reporting as not providing CST, organised activity sessions with a similar content to CST are part of care routines for residents/clients indicating that the profile of provision of these homes/day care facilities which do not purport to follow the CST manual 'Making a Difference' may nonetheless have similarities to the profile of those who state they are CST providers.

## **Conclusions and Recommendations**

There appears to be both objective benefit to be gained from participation in CST and also interest in this from family/other caregivers and people with dementia.

The World Alzheimer Report (Prince et al 2011) supported the NICE-SCIE 2006 Guideline that recommends that all people with mild to moderate dementia should have the opportunity to participate in group CST; independent of whether or not they are receiving licensed drugs for dementia.

The literature demonstrates sufficient evidence to support the role and implementation of CST for elderly people with mild to moderate dementia in a care home or day care setting.

The survey suggests that group member attendance at CST or other organised activity sessions provided by care homes/ day care facilities is regular and that their participation is valued by them.

A standardised treatment manual 'Making a Difference' is available and training in the use of this is currently offered locally, nonetheless it is infrequently used. The amount of CST being offered in these settings is not in line with current NICE recommendations.

For commissioning purposes we would suggest for delivery of CST in care homes and day facilities standards should be set to reflect the evidence set out in this report:

- CST should be delivered twice a week
- In 45 minute sessions
- By appropriately trained staff
- Using a recommended manualised approach

## **Suggested Future Work**

Based on this report, the following recommendation for future work have been made:

- Increasing the engagement of research activity in care homes/day care facilities through a more personalised initial approach either by letter or a letter requesting face-to-face meetings.
- Gaining a deeper knowledge of the understanding of CST through face-to-face interviews with managers/deputy managers (preferably in group format although this may prove impractical) to explore willingness to engage in evidence-based practice of CST.

- Gaining the views of care home owners, as they, rather than managers, may control any financing delivery or reshaping delivery of current practice. Their awareness and input into CST, its worth and their willingness to engage with delivery is therefore relevant.
- Alert those not providing CST to its history, evidence of effectiveness and recommendations for use in context of provision of best practice.
- Explore the possibility of links between day care facilities that provide manual-led CST and CST maintenance to include a training package in CST (in particular Aylsham Day Service supported by Aylsham Care Trust) and care homes that may wish to initiate provision of CST or formalise their current delivery of organised activity sessions.
- Given the variability in implementation and attitudes towards CST in different care settings, and with the NICE guidelines and evidence-base supporting the effectiveness of a manualised CST approach, a National Institute for Health Research (NIHR) study investigating the barriers and facilitators of developing optimal practice in care homes and day care facilities may be warranted. Such a study could inform NHS and social care staff on how to effectively and sustainably adopt a manualised CST approach.

## Appendices

### Appendix 1

Search strategy for trials specifically regarding CST (included results for systematic reviews).

OvidSP: an interface to Ovid Online and SP (SilverPlatter) databases.

Core biomedical databases including AMED, BIOSIS, EMBASE, HMIC, International Pharmaceutical Abstracts, Medline and PsycInfo.

Also including Global Health database, a specialist database dedicated to public health research and practice covering: Communicable diseases (including HIV); Tropical and Parasitic Diseases; Nutrition; Community Public Health; Social Medicine and Environmental and Occupational Health. Global Health brings together the resources of two internationally renowned databases - the Public Health and Tropical Medicine (PHTM) database, previously produced by the Bureau of Hygiene and Tropical Diseases (BHTD), and the human health and diseases information extracted from CAB ABSTRACTS

1. dement*.mp.	123879
2. "cognitiv* stimul*".mp.	831
3. 1 and 2	237
4. trial.mp. [mp=ti, ab, ot, nm, hw, kf, px, rx, ui, an, tc, id, tm]	930449
5. study.mp. [mp=ti, ab, ot, nm, hw, kf, px, rx, ui, an, tc, id, tm]	6843852
6. 4 or 5	7157578
7. 3 and 6	145
8. remove duplicates from 7	104

## **Appendix 2**

Search Strategy for Qualitative Literature regarding CST.

1. dementia.mp. [mp=ao, ab, ec, ei, fa, fc, fi, fm, hw, ie, lc, oi, sa, si, sm, ti, ot, rw, nm, tn, kf, px, rx, an, ui, tc, id, tm, tx, sh, ct, bt, de, dm, mf, dv, kw, cc, ri, rl, ro, rr, rt, ru, rv, au, pt]
2. "cognitiv\* stimul\*".mp.
3. 1 and 2
4. qualitative.mp. [mp=ao, ab, ec, ei, fa, fc, fi, fm, hw, ie, lc, oi, sa, si, sm, ti, ot, rw, nm, tn, kf, px, rx, an, ui, tc, id, tm, tx, sh, ct, bt, de, dm, mf, dv, kw, cc, ri, rl, ro, rr, rt, ru, rv, au, pt]
5. 3 and 4
6. limit 5 to english language
7. remove duplicates from 6

## **Appendix 3**

### *Summary of existing systematic reviews*

The increasing focus into research on the critical aspects of non-pharmacological interventions for improving function and quality of life for dementia sufferers led to a systematic review of general non-pharmacological interventions, conducted by Cooper et al (2012). Of 20 randomised controlled trials (RCTs) included in the review, 16 were rated 'higher quality studies' based on their use of valid and reliable outcome measure(s). Six studies that addressed family carer coping interventions for people with dementia living at home (two of which were combined with patient activities) did not individually achieve statistical significance but when pooled the authors concluded "might improve quality of life"; (pooled socio economic status for post-intervention follow-up assessments was 0.24 (range 0.03-0.45; n=420). Although four of the studies were categorised as 'high quality', the cautious interpretation stems from the disparity between the interventions investigated. One was a ten session home/telephone contact with the carer over four months, tailored to individual needs but comprising education, modifications to the home environment, communication training, stress reduction, how to engage the person with dementia in activities, simplifying tasks, and problem solving (Gitlin et al, 2010). A second comprised weekly sessions for eight weeks and four telephone calls following a standardised manual-led intervention focusing on behavioural management, communication and increasing pleasant events for the care recipient. Caution in interpretation was also urged because individually the interventions' groups showed no difference to the standard care groups. Three further studies included in the review by Cooper et al (2012) assessed CST, thus did not involve carer intervention.

Two of the studies were rated as high quality (Spector et al, 2003; Chapman et al, 2004). Spector et al (2003) combined group RO and CST, focusing on themes allowing natural reminiscence with an additional focus on the present time, information processing (rather than factual knowledge) and multisensory stimulation. This was delivered twice weekly for 45 minute sessions over seven weeks in either day facilities or residential homes. The second study of people with dementia living in the community comprised eight weekly 1.5 hour sessions followed by ten monthly sessions comprising discussions requiring homework, interactive sessions about AD and discussions using real-life stories. The third (lower rated quality) trial comprised five one-hour sessions of individual CST vs attention control (Davis et al, 2001). Although in the study by Spector et al (2003) the authors' original analysis led them to report Quality of Life (QoL) to be higher in the intervention vs usual activity group, when subsequently the data are re-analysed separately for the five day facilities versus 18 residential home participants, Cooper et al (2012) conclude that there is insufficient evidence that group CST improves QoL in people with dementia living at home. Similarly there was no significant difference between the intervention and control groups at four, eight or 12 months after baseline in the community-based study conducted by Chapman et al (2004) The content of the remaining studies in the review included individual cognitive rehabilitation, exercise,

staff training and individualised care plans and ‘other interventions’: none of which were evaluated to be effective for improving QoL for people with dementia.

Whilst Cooper et al (2012) conclude Group CST to be effective in residential care homes but not in the community a clearer picture of CST can be ascertained from the systematic review carried out by Woods et al (2012) which included only studies investigating CST. The Cochrane Dementia and Cognitive Improvement Group assessed 15 RCTs investigating CST defined as:

*‘Cognitive stimulation is engagement in a range of activities and discussions (usually in a group) aimed at general enhancement of cognitive and social functioning.’*

(Clare and Woods, 2004)

However, for inclusion in the review, it was not sufficient for an intervention to be described as ‘cognitive stimulation’ - evidence of the intervention including exposure to generalised cognitive activities was necessary. At least one month’s duration was necessary, although there was no prerequisite for the number of sessions within this month.

Studies were included (for review) if an outcome included a measure of cognitive change. The majority of studies (11) used the Mini Mental State Examination (MMSE) (Folstein et al, 1975) and some (8) also used the Alzheimer Disease Assessment Scale-Cognition (ADAS-Cog) (Rosen et al., 1984). In total 718 participants (407 receiving active intervention, 311 control) were included in the analyses.

With regard to participant characteristics and a breakdown of the sub-type of dementia present, four studies (Baines et al, 1987; Ferrario et al, 1991; Wallis et al, 1983; Woods, 1979) specified general criteria using cognitive measures for a broad diagnosis of dementia but no sub-type diagnosis. Coen et al (2011) described their participants as having mild to moderate dementia. Breuil et al (1994) specified DSM-III criteria for dementia as did Spector et al., 2001 and 2003 but again, did not break down according to sub-type. Baldelli et al (1993a) stated a diagnosis of “degenerative senile dementia of the Alzheimer’s type (SDAT)” and in 2002a included participants with SDAT as well as “vascular multi-infarct dementia”. Five more recent studies (Bottino et al, 2005; Buschert et al, 2011; Chapman et al, 2004; Onder et al, 2005; Requena et al, 2006) specified a diagnosis of probable Alzheimer’s disease using National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) and the Alzheimer’s Disease and Related Disorders Association (ADRDA) criteria linked with either International Classification of Diseases 10th version (ICD-10) or Diagnostic and Statistical Manual of Mental Health Disorders (1980) (DSM-III criteria). Importantly these authors also reported that the participants were on a stable dose of an AChEI.

The majority of the studies measured outcome immediately after the intervention was completed although a few allowed for analysis of maintenance effects. Studies needed to

include a 'no treatment' 'standard care' or 'placebo' group. The quality of the studies was rated overall as low largely due to methodological issues: maintaining blinding of randomisation and problems with blinded outcome assessment over long periods of time when a variety of staff may become responsible for delivering interventions and/or assessing outcome measures. The majority of the participants had mild to moderate dementia. The CST was delivered by a broad range of people including volunteers, family caregivers, speech and language therapists, occupational therapists, nurses, care workers and research staff.

In all except one study, CST was delivered in small groups (five to seven participants); in one trial, with caregivers as therapists, the assessed intervention was one-to-one CST delivery (Onder et al, 2005). The caregivers had received a single training session delivered by physicians, therapists and psychologists which comprised background information, a question and answer session based around a RO manual and a simulated therapy session. Overall, therapy duration ranged from the prerequisite minimum of four weeks to 24 months. The length of session ranged from 30 minutes to 90, with a median of 45 minutes and in general, the longer-length sessions were associated with less frequent delivery; frequency ranged from one to five times per week with a median of three times per week. Overall participant exposure varied greatly, from a minimum of 10 to 12 hours to a maximum of 375 (a two year study) hence quoting the median of 30 hours per participant is perhaps less helpful in this context. The intervention content was similar and described well by the majority of studies although the mode of delivery varied. Two studies (Spector et al, 2003; Coen et al, 2011) used a treatment manual. The sessions were designed along four themes: (1) the senses, (2) remembering the past, (3) people and objects, and (4) everyday practical issues. Activities included naming objects and people, association of words, remembering the past, discussion of hobbies, activities and current affairs, using money, knowing the way around and orientation topics. Seven themes comprising orientation, bodily awareness, family and society, caring for oneself, reminiscing, household activities and animals provided the focus of the intervention by Requena et al (2006). This computerised approach comprised visual images being shown on a television screen to the small groups with discussion of topics following viewing. The remaining studies used similar themes and activities with three studies (Bottino et al, 2005; Buschert et al, 2011; Onder et al, 2005) encouraging 'homework' facilitated by the home caregiver (use of external memory aids, engaging in RO based communication) in-between sessions.

It is not possible to further explore the conclusion drawn by Cooper et al (2012) that CST was effective in residential care homes, but not the community, since in the Woods et al review (2012) data were not analysed according to study setting. Nine studies were conducted in a residential setting, although one of these also included participants in their own home and one also included those in a day care setting; two other studies comprised participants living at home, three were conducted in an out-patient setting and one more solely in a day care setting.

However, with regard to whether CST improves cognitive function in people with dementia, overall, the authors concluded a statistically significant benefit on cognitive

function ( $p < 0.00001$ ) Standard Mean Difference (SMD) 0.41, 95% Confidence Interval (CI) 0.25, 0.5) evident one to three months following participation in the CST. The authors report a SMD (standardised mean difference) which is a summary statistic expressing the size of the intervention effect (the difference between the control and intervention group) in each study relative to the variability observed in that study. Importantly its use in meta-analyses takes into account the different measures used to assess the same outcome - results are standardised to a uniform scale. The use of a 95% Confidence Interval (CI) tells us the range within which we would expect 95% of results to fall. This finding is based on the results of 14 studies (using one or more of the MMSE, the Alzheimer's Disease Assessment Scale-cognitive subscale (ADAs-Cog) or Cape-Information/Orientation Scales including 377 intervention participants and 281 control subjects. It is difficult to attribute dose (length of intervention duration) to this benefit, the authors note that although the two largest effect sizes (the greatest impact of the intervention) were seen in studies with above average duration of CST, (Baldelli et al, (1993a); SMD 0.99 on MMSE (almost a whole score difference) and Requene et al (2006) SMD 0.70 on ADAs-Cog (over two-thirds of a whole score difference) twenty hours over one month and 375 hours over two years respectively, one study with just 10 hours duration of intervention also had an above average effect size (Breuil et al (1994) SMD 0.63 on global cognitive score) and a study with a longer than average exposure (105 hours) (Ferrario et al, 1991) had a below average effect size. Benefits on self-reported quality of life and well-being (SMD 0.38 95% CI 0.11, 0.65) and on staff ratings of communication and social interaction (SMD 0.44, 95% CI 0.17, 0.71) were noted on secondary analysis with smaller total sample sizes (four studies with a total of 219 participants and four studies with a total of 223 participants respectively). It should be noted that no benefit on mood (self-reported or staff reported; five studies, 201 participants), activities of daily living (four studies; 160 participants) general behavioural function (eight studies; 416 participants) or problem behaviour (three studies; 166 participants) were noted. Family caregiver outcomes did not support a benefit from CST, although just three studies examined possible benefits for the caregiver, which included self-reported measures of strain, coping, distress and well-being. However, it is encouraging that in the one study where family caregivers were trained as facilitators, no increased strain was reported on their part.

Questions remain regarding the training needs, implementation and maintenance of CST (trial underway see protocol - Khan et al, 2104) and the views of service users and wider stakeholders (people with dementia, staff, family carers). In a separate review of 12 studies of CST interventions undertaken in Canada "a trend towards delayed cognitive decline following CST" was reported. This review also examined the compatibility of CST with occupational therapy staff (OT) values (Yuill and Hollis, 2011). Congruence between the CST content/outcome and that of OT values was revealed, paving the way for a guide to deliver rehabilitation programmes for this patient population.

#### Current limitations in the literature

Psychological interventions can present particular methodological difficulties; these arise because interventions are not always standardised (this may be difficult because

individuals have different needs) and also because delivery is often reliant upon training people from different backgrounds and with different skill sets. Also it is not clear who will and should do the training or be trained. Problematic issues identified from the existing literature include:

- Lack of intention-to-treat analysis (a more robust statistical analysis method when drop out from studies or movement between groups is expected) of the majority of reported studies. This must be taken into account when considering the impact of CST interventions.
- While it is important that a standardised treatment protocol is produced and followed, allowance has to be made for tailoring the content of activities so they maintain personal meaning for the participants. Quality assessment of the delivery must be conducted and independently reviewed on a regular basis.
- Difficulty with blinding participants and staff to treatment group in psychological interventions (contamination between groups and from staff involved in the therapy delivery).
- Uncertainty regarding in what setting an intervention may be most effective; home based interventions are generally delivered by a family caregiver but this raises questions regarding blinding and potential for objective quality assessment as mentioned in points 3 and 2 above.
- Cost effectiveness is rarely addressed in current trials. However the Cochrane review suggests there is some evidence of cost effectiveness.

## **Appendix 4**

**Table 4:** Activities offered by those care homes not providing CST

	<b>Non-Providers of CST (N=4)</b>
<i>Do you have an understanding of what CST involves?</i>	
Yes	2 (50 %)
No	0 (0%)
Unsure	1 (25%)
Skipped question	1 (25%)
<i>Would you like to provide CST for your residents?</i>	
Yes	2(50%)
No	0 (0%)
Unsure	1 (25%)
Skipped question	1 (25%)
<i>Possible barriers to CST</i>	
Lack of resident interest	2 (50%)
Staff time	1 (25%)
Lack of family interest	1 (25%)
Financial cost	1 (25%)
Not heard of it	1 (25%)
Staff training	1 (25%)
Skipped question	1 (25%)
<i>Are there factors that may enable provision?</i>	
Unsure	2 (50%)
No	1 (25%)
Skipped question	1 (25%)
<i>Do your residents take part in any organised activities?</i>	
Yes	2 (50%)
No	1 (25%)
Skipped Question	1 (25%)
<i>Do your residents take part in any of the following?:</i>	
Discussion of past life events	2 (50%)
Topics chosen by residents	3 (75%)
Word games	2 (50%)
Puzzles	2 (50%)
Music	3 (75%)
Practical activities e.g. baking/gardening	2 (50%)
Other: Exercise	1(25%)
Skipped question	1 (25%)
<i>Who leads the sessions?</i>	
Current staff (some formal training)	1 (25%)
Current staff (no formal training)	1(25%)
Trained external facilitator	1(25%)

	<b>Non-Providers of CST (N=4)</b>
Skipped question	1(25%)
<i>How is the format decided?</i>	
Up to the session leader	2 (50%)
Suggestions from residents/family members	2 (50%)
Other (please specify)	0 (0%)
Skipped question	1 (25%)
<i>How frequently are the sessions held?</i>	
Monthly	0 (0%)
Fortnightly	0 (0%)
Weekly	1 (25%)
Twice Weekly	1 (25%)
Daily	1 (25%)
Skipped question	1 (25%)
<i>How long is each session?</i>	
One hour	2 (50%)
45 minutes	2 (50%)
30 minutes	1 (25%)
Skipped question	1 (25%)
<i>Number of participants per session</i>	
<5	1 (25%)
5-10	0 (0%)
>10	2 (50%)
Skipped question	1 (25%)
<i>How regularly do the residents attend each session?</i>	
Usually every session	0 (0%)
Fairly regularly	2 (50%)
Infrequently	1 (25%)
Skipped question	1 (25%)
<i>Do you think the residents generally value the session?</i>	
Yes	2 (50%)
No	1 (25%)
Skipped question	1 (25%)

**Table 7:** Activities offered by day care facilities for those not providing CST

	<b>Non-Providers of CST (N=2)</b>
<i>Do you have an understanding of what CST involves?</i>	
Yes	2 (100%)
No	0 (0%)
<i>Would you like to provide CST for your clients with dementia?</i>	
Yes	1 (50%)
No	1 (50%)
<i>Possible barriers to CST</i>	
Do not feel it is appropriate	1 (50%)
Staff time	1 (50%)
Lack of family interest	0 (0%)
Financial cost	1 (50%)
Not heard of it	0 (0%)
Staff training	0 (0%)
<i>Are there factors that may enable provision?</i>	
Yes	1 (50%)
No	1 (50%)
<i>Do your residents take part in any organised activities?</i>	
Yes	2 (100%)
No	0 (0%)
<i>Do your residents take part in any of the following?:</i>	
Discussion of past life events	1(50%)
Topics chosen by residents	1(50%)
Word games	1(50%)
Puzzles	2(100%)
Music	1(50%)
Practical activities e.g. baking/gardening	1(50%)
Other: (1)	1(50%)
<i>Who leads the sessions?</i>	
Current staff (some formal training)	1 (50%)
Current staff (no formal training)	1 (50%)
Trained external facilitator	0 (0%)
<i>How is the format decided?</i>	
Up to the session leader	1 (50%)
Suggestions from residents/family members	1 (50%)
<i>How frequently are the sessions held?</i>	
Monthly	0 (0%)
Fortnightly	0 (0%)
Weekly	2 (50%)
Twice Weekly	0 (0%)
Daily	0 (0%)
<i>How long is each session?</i>	
One hour	0 (0%)

	<b>Non-Providers of CST (N=2)</b>
45 minutes	2 (100%)
30 minutes	0 (0%)
<i>Number of participants per session</i>	
<5	0 (0%)
5-10	1 (50%)
>10	1 (50%)
<i>How regularly do the residents attend each session?</i>	
Usually every session	1 (50%)
Fairly regularly	1 (50%)
Infrequently	0 (0%)
<i>Do you think the residents generally value the session?</i>	
Yes	2 (100%)
No	0 (0%)

## References

\*1papers relevant to CST (qualitative)

\*2Papers relevant to CST (included in 2012 Cochrane review of RCTs of CST)

\*1Aguirre E, Spector A, Streater A, Burnell K, Orrell M. Service users' involvement in the development of a maintenance cognitive stimulation therapy (CST) programme: A comparison of the views of people with dementia, staff and family carers. *Dementia* 2011; 459-73.

\*2Baines S, Saxby P, Ehlert K. Reality orientation and reminiscence therapy A controlled cross-over study of elderly confused people. *British Journal of Psychiatry* 1987; 151: 222–31.

\*2Baldelli MV, Boiardi R, Fabbo A, Pradelli JM, Neri M. The role of reality orientation therapy in restorative care of elderly patients with dementia plus stroke in the subacute nursing home setting. *Archives of Gerontology and Geriatrics* 2002; 35 Suppl 8: 15–22.

\*2Baldelli MV, Pirani A, Motta M, Abati E, Mariani E, Manzi V. Effects of reality orientation therapy on elderly patients in the community. *Archives of Gerontology and Geriatrics* 1993a; 17: 211–8.

\*2Bottino CMC, Carvalho IAM, Alvarez AM, Avila R, Zukauskas PR, Bustamante SEZ, et al. Cognitive rehabilitation combined with drug treatment in Alzheimer's disease patients: a pilot study. *Clinical Rehabilitation* 2005; 19: 861–9.

\*2Breuil V, De Rotrou J, Forette F, Tortrat D, Ganansia Ganem A, Frambourt A, et al. Cognitive stimulation of patients with dementia: Preliminary results. *International Journal of Geriatric Psychiatry* 1994; 9: 211–7.

\*2Buschert VC, Friese U, Teipel SJ, Schneider P, Merensky W, Rujescu D, et al. Effects of a newly developed cognitive intervention in amnesic mild cognitive impairment and mild Alzheimer's disease: a pilot study. *Journal of Alzheimer's Disease* 2011; 25: 679–94.

Camic PM, Williams CM, Meeten F. Does a 'Singing Together Group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study. *Dementia* 2013; 12: 157-76.

\*2Chapman SB, Weiner MF, Rackley A, Hynan IS, Zientz J. Effects of cognitive-communications stimulation for Alzheimer's disease patients treated with donepezil. *Journal of Speech, Language and Hearing Research* 2004; 47: 1149-63.

Clare L, Woods RT. Cognitive training and cognitive rehabilitation for people with early-stage Alzheimer's disease: a review. *Neuropsychological Rehabilitation* 2004; 14: 385-401.

\*2Coen RF, Flynn B, Rigney E, O'Connor E, Fitzgerald L, Murray C, et al. Efficacy of a cognitive stimulation therapy programme for people with dementia. *Irish Journal of Psychological Medicine* 2011; 28: 145–7.

Cooper C, Mukadam N, Katona C, Lyketsos CG, Ames D, Rabins P, Engedal K, de Mendonça Lima C, Blazer D, Teri L, Brodaty H, Livingston G, on behalf of the World Federation of Biological Psychiatry – Old Age Taskforce. Systematic Review of effectiveness of non-pharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics* 2012; 24: 856-70.

Damiasnakis T, Crete-Nishihata M, Smith K, Baecker R, Marziali E. The Psycho-social impacts of Multi-media biographies on persons with cognitive impairment. *Gerontologist* 2010; 50: 23-35.

Davis RN, Massman PJ, Doody RS. Cognitive interventions in Alzheimer Disease: a randomised placebo-controlled study. *Alzheimer Disease and Associated Disorders*. 2001; 15: 1-9.

Dietch JT, Hewett LJ, Jones S. Adverse effects of reality orientation. *Journal of the American Geriatric Society* 1989; 37: 974-76.

\*2Ferrario E, Cappa G, Molaschi M, Rocco M, Fabris F. Reality orientation therapy in institutionalized elderly patients: Preliminary results. *Archives of Gerontology and Geriatrics* 1991; 12 Suppl 2: 139–42.

Folstein MF, Folstein SE, McHugh PR. 'Mini Mental State': a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* 1975; 12: 189-98.

Gitlin LN, Winter L, Dennis MP, Hodgson N, Hauck WW. A biobehavioural home-based intervention and the well-being of patients with dementia and their caregivers: the COPE randomized trial. *Journal of the American Medical Association* 2010; 304: 983-91.

Khan Z, Corbett A, Ballard C. Cognitive stimulation therapy: training, maintenance and implementation in clinical trials. *Pragmatic and Observational Research* 2014; 5: 15-19.

Knapp M, Thorgrimsen L, Patel A, Spector A, Hallam A, Woods B, Orrell M. Cognitive stimulation therapy for people with dementia: cost-effectiveness analysis. *British Journal of Psychiatry* 2006; 188: 574-80.

Lawrence V, Fossey J, Ballard C, Moniz-Cook E, Murray J. Improving quality of life for people with dementia in care homes: making psychosocial interventions work. *The British Journal of Psychiatry* 2012; 210: 344-51.

Medical Research Council Developing and evaluating complex interventions: New guidance. 2008. London: MRC Health Services and Public Health Research Board.

NICE-SCIE Dementia: Supporting people with dementia and their carers in health and social care: Clinical Guideline 42. London: NICE-SCIE, Issued 2006, Modified 2105.

\*2Onder G, Zanetti, O, Giacobini E, Frisoni GB, Bartorelli L, et al. Reality orientation therapy combined with cholinesterase inhibitors in Alzheimer's disease: randomized controlled trial. *British Journal of Psychiatry* 2005; 187: 450–5.

Orrell M. New developments in cognitive stimulation therapy. *European Psychiatry* (27) Suppl. 1, 2012, Pages 1: Abstracts of the 20th European Congress of Psychiatry

Orrell M, Yates L, Burns A, Russell I, Woods R, Hoare Z, Moniz-Cook E, Henderson C, Knapp M, Spector A and Orgeta V. Individual Cognitive Stimulation Therapy for dementia (iCST): study protocol for a randomized controlled trial. *Trials* 2012; 13: 172.

Prince M, Bryce R, Ferri C. World Alzheimer Report 2011: the benefits of early diagnosis and intervention. London: Alzheimers Disease International, 2011. [<http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>]

\*2Requena C, Lopez-Ibor MI, Maestu F, Campo P, Lopez-Ibor JJ, Ortiz T. Effects of cholinergic drugs and cognitive training on dementia. *Dementia and Geriatric Cognitive Disorders* 2004; 18: 50–4.

\*2Requena C, Maestu F, Fernandez A, Ortiz T. Effects of cholinergic drugs and cognitive training on dementia: 2-year follow-up. *Dementia and Geriatric Cognitive Disorders* 2006; 22: 339–45.

Rosen WG, Mohs RC, Davis KL. A new rating scale for Alzheimer's disease. *American Journal of Psychiatry* 1984; 141: 1356-64.

Spector A, Davies S, Woods B, Orrell M. Reality orientation for dementia: a systematic review of the evidence of effectiveness from randomised controlled trials. *Gerontologist* 2000; 40: 206-12.

\*1Spector A, Gardner C, Orrell M. The impact of cognitive stimulation therapy groups on people with Dementia: views from participants, their carers and group facilitators. *Aging & Mental Health* 2011; 15: 945-9.

\*2Spector A, Orrell M, Davies S, Woods B. Can reality orientation be rehabilitated? Development and piloting of an evidence-based programme of cognition-based therapies for people with dementia. *Neuropsychological Rehabilitation* 2001; 11: 377–97.

\*2Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M, et al. Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *British Journal of Psychiatry* 2003; 183: 248–54.

Streater A, Spector A, Aguirre E, et al. Maintenance Cognitive Stimulation Therapy (CST) in practice: study protocol for a randomized controlled trial. *Trials* 2012; 13: 91.

Tolson D, Schofield I. Football reminiscence for men with dementia: lessons from a realistic evaluation. *Nursing Inquiry* 2012; 19: 63-70.

\*2Wallis GG, Baldwin M, Higginbotham P. Reality orientation therapy-a controlled trial. *British Journal of Medical Psychology* 1983; 56: 271–7.

Woods B, Aguirre E, Spector AE, Orrel M. Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of systematic Reviews* 2012, Issue 2. Art. N.:CD005562. DOI10.1002/146518.CD005562.pub2.

\*2Woods RT. Reality Orientation and Staff attention: A Controlled Study. *British Journal of Psychiatry* 1979; 134: 502–7.

Yuill N, Hollis V. A systematic review of cognitive stimulation therapy for older adults with mild to moderate dementia: an occupational therapy perspective. *Occupational Therapy International* 2011; 18: 163-86.