

<b>Institution:</b> University College London
<b>Unit of Assessment:</b> 4 - Psychology, Psychiatry and Neuroscience
<b>Title of case study:</b> Cognitive Stimulation Therapy - a new therapy for dementia
<p><b>1. Summary of the impact</b></p> <p>Cognitive Stimulation Therapy (CST) is an evidence-based, brief, group therapy for people with mild to moderate dementia. It was developed and evaluated by UCL in collaboration with Bangor University. Our research showed significant benefits in cognition and quality of life plus cost-effectiveness. Cognitive Stimulation for people with mild/moderate dementia of all types is recommended by NICE and is now in widespread use across the UK and the rest of the world in a variety of settings including care homes, hospitals and the community. A recent audit by the Memory Services National Accreditation Programme reported that 66% of UK memory clinics surveyed were using CST.</p>
<p><b>2. Underpinning research</b></p> <p>Dementia is a common condition that affects about 800,000 people in the UK. Our research over the last 15 years has led to the development of an evidence-based group therapy for people with dementia, which is now in widespread use across the UK and beyond.</p> <p>The key underpinning research was a multi-centre, single-blind RCT which ran between 1998 and 2001. It was led by Professor Martin Orrell (UCL Mental Health Sciences) and Professor Bob Woods (University of Bangor), with Dr Aimee Spector being the lead researcher/PhD student (now Senior Lecturer in Clinical, Educational &amp; Health Psychology at UCL). It aims to improve cognitive skills and quality of life for people with dementia through activities such as categorisation, word association and discussion of current affairs. The 'key principles' of CST seem to be the main mechanisms of change – these include stimulation of language and executive functioning, encouraging implicit learning and a focus on opinions rather than facts.</p> <p>201 participants were randomised to receive CST over 7 weeks, compared to a 'treatment as usual' control group. There were significant improvements in cognition and quality of life following CST. The cognitive benefits were of a similar magnitude to those found using anti-dementia drugs [1]. An economic analysis conducted in collaboration with partners at the London School of Economics (LSE) showed CST to be cost-effective [2]. A pilot study of longer-term CST showed that cognitive function can continue to improve for a six-month period using weekly CST sessions following from the initial programme [3]. Subsequent analysis of the trial data showed that CST benefits memory, language and executive functioning in dementia, with the most marked impact on language [4]. A study using complex neuropsychological tests showed significant changes in verbal memory, non-verbal memory, language comprehension and orientation [5]. Qualitative interviews with service-users and staff showed that changes generalised into everyday life such as improvements in mood and concentration [6]. Our recent Cochrane review has confirmed the effectiveness of cognitive stimulation approaches [7].</p> <p>Research into CST has continued at UCL. As part of the NIHR-funded SHIELD Programme (led by Orrell) a 26-week maintenance CST programme has been evaluated as an RCT, showing continued benefits in quality of life. The SHIELD programme is also supporting a trial looking at implementation of CST in practice, which is currently underway. The individual CST trial (led by Orrell and supported by the Health Technology Assessment grants programme), involves the development and evaluation of a one-to-one, carer-led CST programme and has just completed recruitment.</p>
<p><b>3. References to the research</b></p> <p>[1] Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M, Orrell M. Efficacy of</p>

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an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. Br J Psychiatry. 2003 Sep;183:248-54. <http://doi.org/b664td>

- [2] Knapp M, Thorgrimsen L, Patel A, Spector A, Hallam, A, Woods B, Orrell M. Cognitive Stimulation Therapy for dementia: is it cost effective? Br J Psychiatry. 2006 Jun;188:574-80. <http://doi.org/fcs8qz>
- [3] Orrell M, Spector A, Thorgrimsen L, Woods B. A pilot study examining the effectiveness of maintenance Cognitive Stimulation Therapy (MCST) for people with dementia. Int J Geriatr Psychiatry. 2005 May;20(5):446-51. <http://doi.org/bkrnqb>
- [4] Spector A, Orrell M and Woods B. Cognitive Stimulation Therapy (CST): effects on different areas of cognitive function for people with dementia. Int J Geriatr Psychiatry. 2010 Dec;25(12):1253-8. <http://doi.org/dwwm33>
- [5] Hall L, Orrell M, Stott J, Spector A. Cognitive stimulation therapy (CST): neuropsychological mechanisms of change. Int Psychogeriatr. 2013 Mar;25(3):479-89. <http://doi.org/ngp>
- [6] Spector 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 Ment Health. 2011 Nov;15(8):945-9. <http://doi.org/d53j54>
- [7] Woods B, Aguirre E, Spector A, Orrell M. Cognitive Stimulation to improve cognitive functioning in people with dementia. Cochrane Database. 2012 Feb 15;2:CD005562. <http://doi.org/cmb9pb>

#### Grants (M Orrell - lead)

1997-9. **Developing a psychological therapy package for dementia** (M Orrell, B Woods, H Cayton, S Davies). North Thames NHS Executive Project Grant, £47,000.

1999-2002. **A randomised controlled trial of psychological therapies in dementia** (M Orrell, L Royan). BHB Community Healthcare NHS Trust, £90,000.

1999-2001. **A randomised controlled trial of psychological therapies in dementia** (M Orrell, B Woods, S Davies, A Spector, M Butterworth, M Knapp). NHS Executive London Region, Responsive Funding, £85,000.

2007-12. **Support at Home - Interventions to Enhance Life in Dementia (SHIELD)** (M Orrell, B Woods, I Russell, D Challis, E Moniz-Cook, M Knapp, G Charlesworth, J Wilson). National Institute of Health Research – Programme Grant, £1,981,952.

2010-14. **Individual Cognitive Stimulation Therapy for dementia (iCST Trial)** (M Orrell, B Woods, I Russell, E Moniz-Cook, M Knapp, A Spector, A Burns). Health Technology Assessment – Trials Grant, £1,131,252.

#### **4. Details of the impact**

CST involves 14 or more sessions of themed activities which aim to actively stimulate and engage participants, whilst providing an optimal learning environment and the social benefits of a group. CST can be administered by any suitably-trained person working with people with dementia, such as care workers, occupational therapists or nurses. CST groups take place in settings including residential homes, hospitals and day centres.

#### **Dissemination of CST**

Following our development of the CST treatment programme, we have facilitated its dissemination through the publication of three training manuals [a], and the development of a training programme [b]. Sales of the manuals in 2008-13 amounted to 5,143 copies [c], and in the same period we

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trained over 2,000 people. Courses took place across the UK and in Italy and Spain, including attendees from as far afield as Australia and South Africa. In 2010 and 2011 we conducted training workshops at Alzheimer's Disease International conferences in Toronto and Malaysia, and for the 0/66 international dementia group which organised a training workshop in Cuba. We also run a CST website ([www.cstdementia.com](http://www.cstdementia.com)), which has c.8,000 hits per month.

In 2006, NICE recommended that "people with mild/moderate dementia of all types should participate in group Cognitive Stimulation which should be commissioned and provided by a range of health and social care workers with training and supervision. This should be delivered irrespective of any anti-dementia drug received by the person with dementia" [d]. CST was the only non-drug intervention recommended to treat cognitive symptoms of dementia. Our study was referenced as supporting evidence which underpinned the decision to recommend CST.

### Use of CST in the UK

Many people with dementia in the UK and beyond are now benefitting from CST. It is routinely offered in many NHS trusts – for example, in the Isle of Wight, our CST protocol has been followed since 2009, with one practitioner reporting that "*CST is the gold standard because the evidence is that it does produce an improvement in people's memory scores, and certainly in their quality of life*" [e]. The following NHS Trusts are known to be offering CST as at July 2013: Berkshire; Birmingham and Solihull; Camden and Islington; Cornwall; Gloucestershire; Greater Glasgow and Clyde; Isle of Wight; Kent and Medway; Milton Keynes; Norfolk and Suffolk; North East London; Northamptonshire; Nottinghamshire; Rotherham, Doncaster and South Humber; Sussex; South Essex, Tees, Esk and Wear Valley and West London [f].

CST is also used in other settings such as care homes. For example, the London Borough of Redbridge recently implemented CST in 11 care homes across the borough [g]. Through use of our manual and training courses, it is also possible for individuals to set up groups themselves. In an article in the Mail on Sunday in 2011, one carer gives her account of setting up a CST group herself, which has now developed into a local programme [e, h]

The impact on the lives of people who undertake such programmes is considerable. One patient reported that "*I noticed people becoming more fluent and you could see people trying to express themselves more.*" Similarly, the positive impacts are valued by carers. One reported that "*There is no argument that my wife's brighter*" and another said "*she's started remembering things since coming to the group*" [i]. The carer who set up local groups herself concluded that "*I want more people to have access to CST, which helps people to start living again*" [e].

CST is beginning to be recommended more widely in government policy. In 2011, the NHS Institute for Innovations concluded that CST can save the NHS £54.9 million a year through reduced use of antipsychotic medication [j]. In 2012, the Memory Services National Accreditation Programme (MSNAP) (run by the Royal College of Psychiatrists) included CST as one of their key standards for accreditation [k]. They now report that as a result, CST is used in 66% of memory clinics [l]. Also in 2011, the National Clinical Director for Dementia for England drew attention to our Cochrane Review, highlighting the positive benefits of CST and its use in community, care home and hospital settings [m].

### International impacts

In 2011, the World Alzheimer's Report stated that CST should routinely be given to people with early stage dementia [n]. It advocates using CST to provide an effective low cost intervention to help improve cognition for people with dementia in developing countries. The CST manual has been translated into several languages including Japanese, Spanish, Italian, German, Portuguese, Dutch and Swahili. Since 2008 CST is being used in Australia, USA, South Africa, New Zealand, Germany, Canada, Chile, Italy, Japan, Nepal, the Philippines, the Netherlands, Tanzania, Brazil, China, Hong Kong, Indonesia, India, Ireland, Nigeria, Singapore, South Korea, Turkey and

Portugal [o].

## 5. Sources to corroborate the impact

- [a] CST training manuals (available on request):
- Spector A, Thorgrimsen L, Woods B and Orrell M (2005). Our Time: An evidence-based programme to offer cognitive stimulation to people with dementia. Freiberg Press: USA.
  - Spector A, Thorgrimsen L, Woods B and Orrell M (2006). Making a difference: An evidence-based group programme to offer Cognitive Stimulation therapy (CST) to people with dementia. Hawker Publications: UK.
  - Aguirre E, Spector A, Streater A, Hoe J, Woods B and Orrell M (2011). Making a Difference 2. Hawker Publications: UK.
- [b] <http://www.cstdementia.com/page/training-and-events>
- [c] Publisher's data – copy of emails available on request
- [d] National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (NICE-SCIE): Dementia: supporting people with dementia and their carers in health and social care. Clinical Guideline 42. <http://www.nice.org.uk/cg042>
- [e] The Daily Mail: "A little-known drug-free treatment can have an amazing effect on Alzheimer's sufferers. So why does a top charity refuse to endorse it?" (Dec 2011) <http://dailym.ai/sprcz9>
- [f] Full details and links to each trust can be found here: <http://www.cstdementia.com/page/cst-in-practice>
- [g] Email from Research Assistant, North East London Foundation Trust. Available on request.
- [h] Cognitive Help and Therapy (CHAT) – local group set up in Horsham which now offers programmes across the local area: <http://www.cognitivehelpandtherapy.org/index.html>
- [i] Presentation on CST, Dementia UK networks: [http://www.dementiauk.org/assets/files/what\\_we\\_do/networks/memory\\_clinic/october\\_2009/CS\\_T.ppt](http://www.dementiauk.org/assets/files/what_we_do/networks/memory_clinic/october_2009/CS_T.ppt)
- [j] NHS Institute for Innovation and Improvement. An economic evaluation of alternatives to antipsychotic drugs for individuals living with dementia. The NHS Institute for Innovation and Improvement, Coventry House, University of Warwick Campus, Coventry, UK; 2011. [http://www.institute.nhs.uk/qipp/calls\\_to\\_action/dementia\\_and\\_antipsychotic\\_drugs.html](http://www.institute.nhs.uk/qipp/calls_to_action/dementia_and_antipsychotic_drugs.html)
- [k] MSNAP standards: [http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/qualityandaccreditation/memory\\_services/memoryservicesaccreditation/msnapstandards.aspx](http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/qualityandaccreditation/memory_services/memoryservicesaccreditation/msnapstandards.aspx)
- [l] Email from Project Worker, Memory Clinics Audit, MSNAP. Copy available on request.
- [m] National Clinical Director for Dementia for England highlights our Cochrane Review: [http://webarchive.nationalarchives.gov.uk/20130402145931/http://dementia.dh.gov.uk/cochran\\_e-review-supportive-of-cognitive-stimulation-therapy-for-people-with-dementia/](http://webarchive.nationalarchives.gov.uk/20130402145931/http://dementia.dh.gov.uk/cochran_e-review-supportive-of-cognitive-stimulation-therapy-for-people-with-dementia/)  
 Also discussed on the Dementia News blog: <http://dementianews.wordpress.com/2012/07/29/dementia-tsar-shines-positive-light-on-cognitive-stimulation-therapy-for-people-with-dementia-department-of-health-dementia/>
- [n] World Alzheimer report (2011) <http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>
- [o] <http://www.cstdementia.com/page/international-cst-groups>