

MODEM

modelling outcome and cost impacts
of interventions for dementia

START: Strategies for Relatives

STrAtegies for RelaTives (START) aims to reduce [depression](#) and anxiety in family carers. Carers receive an eight week programme of individual [psychological](#) therapy sessions.

Key points:

- the START programme helps reduce depression and anxiety in family carers of a person with dementia
- the programme offers value for money (is cost effective)
- further research is looking at if START helps reduce depression and anxiety for five years after taking part in the programme and if it helps people with dementia stay at home longer.

What is START?

The eight week START programme is given by trained and supervised psychology graduates. Carers can choose where they have their therapy sessions, in the research most of them chose to have them at home.

The sessions include information on:

- what dementia is and how it affects people
- carer stress, how to recognise it and techniques for managing it
- how to manage difficult behavior
- how to access support that is available for people with dementia and family carers
- how to use the skills learnt and planning for the future.

Carers are given a plan, a manual and a relaxation CD for each session. They are asked to practice what they have learnt in the sessions, complete the questions in the manual and write down the skills and techniques that they have tried and what has worked for them. They keep the manuals and CD's so they can use them again.

The sessions were adapted from an American programme called 'Coping with Caregiving'. (1)

Why is START important for family carers?

Many people with dementia live at home and are cared for by a member of their family and it is important to find the best ways to support them. Caring for people can be challenging and stressful and about 40% of those caring for a family member with dementia have symptoms of depression or anxiety. (5,6)

Does START work?

The START programme helps reduce depression and anxiety in people caring for a family member with dementia. (5)

START has been assessed to find out if it works (we call this evaluated) in a [randomised controlled trial \(RCT\)](#), 260 family carers took part in the trial. They were divided into two groups using a computer. The first group were given the individual therapy sessions in addition to their usual care and the second group were given their usual care, without START. (6)

Family carers in both groups were interviewed every 4 months for the first year and then again 2 years after the first interview. (6) They were asked questions about their income, education, employment and general health and questions to assess:

- symptoms of anxiety and depression
- their quality of life
- the quality of life of the person with dementia they look after signs of abusive behavior towards the person with dementia.

They were asked to keep a record of their own use of health and other services, and also the use of services by the person with dementia they were caring for.

The research found that taking part in START reduced depression

and anxiety in family carers and improved their quality of life in both the short term (at 8 months) and in the longer term (2 years after the study started). Carers having their usual care, without START, were four times more likely to have depression in the short term. This figure increased to seven times more likely in the longer term.

There was no difference between the two groups on how the family carers rated the quality of life of the person with dementia that they cared for, or in their behavioural difficulties. Similarly, there was no clear difference between carer groups with regards to abusive behavior by carers or admission of the person with dementia to a care home. (5)

Carers had different views on which parts of START were most helpful for them and this supports the importance of offering a range of activities and approaches. (8)

Is START cost-effective?

The research found that START offers value for money (is cost-effective) in the short and the longer term.(6)

The START randomised controlled trial (RCT) also looked at whether START was cost-effective. From the interviews researchers found that the people in the group taking part in START used fewer health and social care services (in the short and the longer term). This meant that the additional cost of running the START programme was balanced by the saving in health and social care service costs.

The START programme reduced anxiety and depression in people caring for a family member with dementia, and improved their quality of life at no extra cost to the health and social care system.

The cost of START for the NHS

In the study the START sessions were run by trained post-graduate psychologists, often in the family home. The average cost for the START intervention was £253 per carer (2015/16 prices).

What carers say about START

Carers taking part in START were asked to complete a questionnaire two years after the study started to find out what they thought about the programme.(8) These are some of the things that carers said:

What they liked

Many were still using the learning from the sessions and finding that an understanding of the condition made it easier for them to cope with some of the challenges.

“the CDs are very relaxing... still very much being used today” (p.3)

“some of the problems that I eventually had to face had been discussed, making me aware of them and able to care better” (p.3)

Difference it made

Carers valued the personal contact with the therapist and the opportunity to share their concerns with a health professional.

“I felt it OK to be angry, upset, made to feel less guilty” (p.4)

“NHS services gave a lot of information at diagnosis; too much negative info at once. I felt START was more supportive and gave smaller bits at a time” (p.3)

Suggestions for improvement

Comments were received on how long after diagnosis the programme should be offered and on the length of the programme. Some would have liked more sessions and a couple of people commented that the sessions were too demanding on their time.

Others suggested that support from other carers or voluntary organisations through group sessions would have been helpful or a joint session with the family member with dementia.

“The Alzheimer’s café could have been used as the basis of a carer’s group which would be of both practical and emotional help” (p.6)

Further information about START

England

START is currently available through the NHS in some areas of the country.

Contact your Community Mental Health Team, [Improving Access to Psychological Therapies \(IAPT\)](#) clinic or memory clinic to find out if it

is available in your area. You can find out where your local IAPT clinic is on the [NHS Choices website](#).

The [START website at University College London \(UCL\)](#) has further information for people interested in delivering the programme including details of their train the trainer course. Copies of the manuals for people leading the course and the manuals for carers can be downloaded from the website. You can ask for copies of the relaxation CD's to be emailed or posted.

International

A new zoom (online video conferencing) version of START is being developed in Australia to deliver the programme to people in remote communities.

Further research

Gill Livingston and [the START team at University College London](#) are interviewing carers who took part in the study for a further five years to find out if START continues to help depression and anxiety in family carers. They will also look at if the programme helps people with dementia stay at home longer.

Resources

Reviews, reports and guidance:

NIHR Dissemination Centre Signal (2015): [A coping programme moderately reduces depression and anxiety in carers of people with dementia](#)

[START programme website](#) - University College London (UCL)

Organisations:

[Find out more about organisations that have information or offer support to people with dementia and their families.](#)

Authors: Klara Lorenz, Martin Knapp and Adelina Comas-Herrera

Edited by: Helen Hayes with support from members of the MODEM User and Carer Reference Group

Overall Findings for START

Does it work for the person with Dementia?	Does it work for family and carers?	Is it cost-effective?	Strength of evidence	Implemented in the UK?
Quality of life =	Anxiety and Depression ✓			
Behavioural Difficulties =	Quality of life ✓	✓	✓✓✓	✓

Findings of individual studies

Study	Does it work for the person with Dementia?	Does it work for family and carers?	Is it cost-effective?	Strength of evidence
Knapp et al, 2013 (based on Livingston et al 2013)			Quality Adjusted Life Year (QALY) ✓ Anxiety and Depression ✓	✓✓✓
Livingston et al, 2013 Randomised Controlled Trial (RCT), 260 carers, UK	Quality Adjusted Life Year (QALY) = Behavioural Difficulties =	Anxiety and Depression ✓ Quality of Life ✓ Admission to care home ✓		✓✓✓

The Evidence Table Key

Does it work?

- ✓ Worked well
- ✓= Worked well in some studies and made no difference in others
- ✓=X Mixed results it worked well in some studies, made no difference in others and some found negative impacts
- = Made no difference
- =X Made no difference in some studies and others found negative impacts
- X Negative impact

Is it cost effective?

- ✓ It was cost effective
- ✓X It was found to be cost effective in some studies and not in others
- X It was not cost effective

What is the strength of evidence?

This rating will depend on a range of factors such as the type of research for example if it was a Randomised Controlled Trial (RCT) and the number of people who participated in the study.

- ✓✓✓ High Quality
- ✓✓ Moderate quality

The support of the Economic and Social Research Council (ESRC) and National Institute for Health Research (NIHR) is gratefully acknowledged. The views expressed in this publication are those of the author(s) and not necessarily those of the ESRC, NIHR or Department of Health

References

1. Gallagher-Thompson D. et al (2002) Coping with caregiving: reducing stress and improving your quality of life. Stanford University School of Medicine and VA Palo Healthcare System.

[2. Knapp, M.; King, D.; Romeo, R.; Schehl, B.; Barber, J.; Griffin, M.; et al. Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people with dementia \(the START \(STrAtegies for RelaTives\) study\): a pragmatic randomised controlled trial BMJ, BMJ; 2013, f6342-f6342](#)

[3. Li, Ryan; Cooper, Claudia; Barber, Julie; Rapaport, Penny; Griffin, Mark; Livingston, Gill; et al. Coping strategies as mediators of the effect of the START \(strategies for RelaTives\) intervention on psychological morbidity for family carers of people with dementia in a randomised controlled trial Journal of Affective Disorders, Elsevier BV; 2014, 298-305](#)

4. Livingston, G (2011) Research Protocol (Version 0.2) START (STrAtegies for RelaTives) study: A pragmatic randomized controlled trial to determine the effectiveness of a manual based coping strategy programme in promoting the mental health of carer of people with dementia (Short study title: START Study). London: University College London.

5. Livingston, G.; Barber, J.; Rapaport, P.; Knapp, M.; Griffin, M.; King, D.; et al. Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial BMJ, BMJ; 2013, f6276-f6276

[6. Livingston, Gill; Barber, Julie; Rapaport, Penny; Knapp, Martin; Griffin, Mark; King, Derek; et al. Long-term clinical and cost-effectiveness of psychological intervention for family carers of people with dementia: a single-blind, randomised, controlled trial The Lancet Psychiatry, Elsevier BV; 2014, 539-548](#)

[7. Livingston, Gill; Barber, Julie; Rapaport, Penny; Knapp, Martin; Griffin, Mark; Romeo, Renee; et al. START \(STrAtegies for RelaTives\) study: a pragmatic randomised controlled trial to determine the clinical effectiveness and cost-effectiveness of a manual-based coping strategy programme in promoting the mental health of carers of people with dementia Health Technology Assessment, National Institute for Health Research; 2014, 1-242](#)

[8. Sommerlad A., Manela M., Cooper C., Rapaport P., Livingston G., START \(STrAtegies for RelaTives\) coping strategy for family carers of adults with dementia: qualitative study of participants' views about the intervention BMJ Open, BMJ; 2014, e005273-e005273](#)