

ESSENCE SUMMARY 3

# A coping programme for family carers of people living with dementia: economic evidence

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## KEY POINTS

- The START coping programme helps to reduce depression and anxiety in family carers of a person living with dementia without increasing costs.
- The programme is cost-effective and offers value for money for the health and social care system.
- Longer-term follow-up evidence is needed to see if the START coping programme delays the admission of people living with dementia to care homes, given encouraging short-term findings.

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## CONTEXT

Caring for people can be challenging and stressful and about 40% of people caring for a family member living with dementia have symptoms of depression or anxiety (1, 2).

The STRategies for RelaTives (START coping programme) aims to reduce depression and anxiety in family carers. Carers receive an 8-week programme of individual psychological therapy sessions.

## WHAT IS START?

The 8-week START coping programme was delivered by trained and supervised psychology graduates.

The sessions included 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 behaviour

- how to access support that is available for people living with dementia and family carers
- maintaining skills learned and planning for the future.

A manual and relaxation CDs were provided so that carers could practice the skills and techniques they learned in the sessions at home.

The sessions were adapted from an American programme called 'Coping with Caregiving' (3).

## IS START EFFECTIVE?

START has been evaluated in a randomised controlled trial in which 260 family carers took part, receiving either the START coping programme or usual support (2). Carers were interviewed after 4, 8, 12 and 24 months..

The START programme helped reduce anxiety and depression in people caring for a family member living with dementia (1). Carers who had taken part in the eight psychological therapy sessions had better scores on measures for anxiety, depression and general mental health compared to those carers who had not been on the programme. Scores improved in both the short term (8 months after the study started) (1) and in the longer term (24 months after the study started) (2). Overall, over the 24-month period, START reduced scores on the Hospital Anxiety and Depression Scale (4) by an average of 2.58 points more than the comparison group, which was considered to be clinically significant (5).

Another way to express this finding is that carers

who only got the usual kind of support were four times more likely to have clinically significant depression than carers who got the additional coping intervention by 8 months, and seven times more likely by 24 months.

Carers who received the START coping programme had significantly better health-related quality of life by the 24-month follow-up point than carers who got usual support.

In addition to those effects on carers, the evaluation also looked at the effects on people living with dementia after 24 months. No differences were found – either negative or positive – between people whose carers had received START and those whose carers had received usual support. The measures examined were dementia severity, neuropsychiatric symptoms and quality of life (2).

There was also no clear difference between carer groups with regards to abusive behaviour by carers (2).

## WHAT DO CARERS SAY ABOUT START?

Carers who took part in the START coping programme were asked to complete a questionnaire two years after the study started: 75 carers participated (6). Two-thirds of these carers said that they continued to use the techniques they had been taught. Many were 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.'*

*'Some of the problems that I eventually had to face had been discussed, making me aware of them and able to care better.'*

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.'*

*'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.'*

Suggestions were made for improvement. Some carers would have liked more sessions, while a couple of people commented that the sessions were too demanding on their time.

## IS START COST-EFFECTIVE?

An economic evaluation was included in the RCT, examining cost-effectiveness by looking at the health and health-related quality of life effects on both carers and people living with dementia, and by measuring the costs of health and social care services used by both groups (including the cost of delivering START itself).

The short-term evaluation looked at effects and service costs only for carers. It was found that the cost of START was offset by reduced use of other services by carers over the first 8 months. Overall, there was no statistically significant difference in costs between the two groups of carers. Combined with the positive outcome findings, the START coping programme was clearly cost-effective (7).

The longer-term evaluation looked at effects and costs for both carers and people living with dementia. The costs of services used by carers were slightly higher in the START group (£186 at today's prices) but the difference was not statistically significant. The costs of services used by people living with dementia were slightly lower in the START coping programme group (£1494 at today's prices), but again the difference was not significantly different between groups (2).

The cost-effectiveness analyses considered carer-only costs as well as carer and person living with dementia costs combined. When both sets of costs are included, and looking first at carer outcomes, the START coping programme is clearly cost-effective since outcomes are better and costs are the same. When both sets of costs are included and instead we look at outcomes for the person living with dementia, there is a high probability that the START coping programme is cost-effective compared to usual the National Institute for Health and Care Excellence thresholds for cost per additional quality-adjusted life year. For other outcome measures the cost-effectiveness case for START is also strong (2).

When looking only at carer-only costs, the pattern of cost-effectiveness is the same.

## POSSIBLE LONGER-TERM IMPACTS?

The 24-month evaluation found that service costs had increased in both the START and usual care groups over time, which is not surprising given that dementia is a progressive disease. Care home costs increased more for the usual care group. Although there appeared to be a difference between the two groups in admission rates into

care homes for people living with dementia, in fact it was not statistically significant. There will be a further follow-up after 5 years to see whether there has been a sustained difference in care home admissions.

## THE OVERALL ECONOMIC CASE

Mean cost for the START coping programme was £253 per carer (at today's prices). However, the evaluation shows that these additional costs of running the sessions and supporting carers were

counterbalanced by a reduction in health and social care service, even in the short term.

Overall, therefore, the START coping programme was cost-effective in both the short and the longer term. This low-cost intervention helps carers to develop their coping abilities. They experience the intervention positively. The people they support do not experience any changes (positive or negative) in their health or quality of life, but do use fewer services. And START is cost-neutral in that it does not add to the overall cost of dementia care.

## WHAT IS THE QUALITY OF EVIDENCE ON START?

A strength of the START trial was that the study population included carers with heterogeneous characteristics, and recruited from varied services. In addition service users had mild dementia, making the intervention generally acceptable to and applicable to family carers around the UK looking after individuals living with dementia.

The localities in which the study was conducted – North London and Essex – are not unusual in either the range of care and support services available or the population, and so the results of the study should be generalizable to other parts of England.

## HOW IS START IMPLEMENTED?

The START coping programme has been implemented in Camden and Islington NHS Foundation Trust (both in Improving Access to Psychological Therapies and the memory clinic). It is also being provided in NHS Trusts in London

and in Cheshire, Durham, Sheffield, Sussex, Edinburgh, Northamptonshire, Manchester and Surrey. There are plans to set it up in other locations.

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## MORE INFORMATION

- Further information on START is available at [www.ucl.ac.uk/psychiatry/start](http://www.ucl.ac.uk/psychiatry/start).
- The NIHR Dissemination Centre recently published one of its Signal summaries on the START coping programme and it is available at <https://discover.dc.nihr.ac.uk/content/signal-000140/a-coping-programme-moderately-reduces-depression-and-anxiety-in-carers-of-people-with-dementia>.

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