

<b>Institution:</b> University College London		
<b>Unit of Assessment:</b> 4 Psychology, Psychiatry and Neuroscience		
<b>Title of case study:</b> Reducing depression and anxiety in family carers of people with dementia across the world		
<b>Period when the underpinning research was undertaken:</b> 2009 to present		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Prof Gill Livingston	Professor of Psychiatry of Older People	1991 to present
<b>Period when the claimed impact occurred:</b> 2014 - 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> No		
<b>1. Summary of the impact</b> <p>Caring for a family member with dementia can take a huge toll on a carer's mental health. Some 40% of such carers (~240,000 people in the UK) develop clinical depression or anxiety. Research at UCL developed START, a programme to prevent and treat depressive and anxiety symptoms in family carers that is clinically- and cost-effective in the short- and long-term. START is recommended by NICE, and it underpinned the 2015 Prime Minister's Challenge on Dementia. It is used in the UK by at least 24 services across 12 NHS Trusts, as well as the charity sector. START has been translated into Spanish, Japanese, Urdu, Hindi and Kannada, and adapted for use in 5 other countries including Australia, Japan, Hong Kong, India and Spain.</p>		
<b>2. Underpinning Research</b> <p>Most care of people with dementia is provided by family. Caring for a family member who has this progressive declining condition (often accompanied by agitation, sleep disturbance, depression and apathy) adversely affects family carers' mental health. Prof Livingston's group at UCL found that approximately 40% of these carers develop clinical depression or anxiety, while others have significant symptoms [R1]. However, some carers do not develop such symptoms and an epidemiological and systematic review of evidence conducted by Livingston suggested that this relates to coping strategies, and that individually-delivered psychological interventions for carers positively impact their mental health. It is critical to develop strategies (e.g., relaxation methods, sharing small, pleasant events and relieving burden) to decrease carers' distress, particularly as the number of people with dementia in the UK is projected to almost triple by 2050 and dementia is the most expensive disorder in terms of care.</p> <p>In 2009, Livingston led a National Institute for Health Research (NIHR) HTA funded multi-disciplinary team to develop and trial the STrategies for RelaTives (START) intervention, delivered in 8 sessions by trained, supervised facilitators (with no clinical training) to individual family carers of dementia patients [R2, R3, R4]. The team comprised academic clinical psychiatrists, a clinical psychologist, neurologist, health economist and statistician.</p> <p>The trial recruited and randomly allocated 260 carers to intervention (START) or treatment as usual (TAU) control arms in a 2:1 ratio. Intervention participants received eight sessions of individually-delivered manual-based coping strategy therapy, with facilitators' fidelity to the intervention monitored. This was the first UK randomised controlled trial (RCT) of clinical-effectiveness (for depression and anxiety) and cost-effectiveness of individual manual-based therapy for dementia carers. Participants were initially followed up for two years and Livingston successfully applied to the HTA for an extension to follow up to six years [R5].</p> <p>Carers in the START programme were six times less likely to be depressed at 4 and 8 months compared to TAU carers and used fewer services in the first 8 months. The latter easily offset the intervention cost. They demonstrated improved quality of life, meaning that START was cost-effective up to two years for both carer and patient outcomes, and National Institute for Health and Care Excellence (NICE) thresholds. Clinical effectiveness was maintained at the 2-year follow-up, and at 6 years the mental health outcomes of carers remained significantly better in the intervention group. The START per patient service use costs were median GBP5,759 for the</p>		

intervention group versus GBP16,964 in the TAU group in the final year [R5]. START is therefore clinically effective for at least 6 years and reduces service use costs on average by 63% per patient in the sixth year.

Livingston was awarded a dissemination grant from the Alzheimer's Society to train future trainers, to allow more widespread UK practice. She then gained funding to lay the foundations for future implementation by culturally tailoring the therapy for Black and South Asian UK carers and investigating the feasibility of delivery in the voluntary sector. This is one of the only psychological interventions which has been tailored and tested for minority groups. Livingston has collaborated on adapting and evaluating START for use in Japan [R6], India and remotely in Australia.

#### References to the research

- [R1] Mahoney, R., Regan, C., Katona, C., & Livingston, G. (2005). Anxiety and depression in family caregivers of people with Alzheimer disease: the LASER-AD study. *American Journal of Geriatric Psychiatry*, 13, 795–801. doi: [10.1176/appi.ajgp.13.9.795](https://doi.org/10.1176/appi.ajgp.13.9.795)
- [R2] Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E., & Cooper, C. (2013). 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*, 347: f6276. doi: [10.1136/bmj.f6276](https://doi.org/10.1136/bmj.f6276)
- [R3] Knapp, M., King, D., Romeo, R., Schehl, B., Barber, J., Griffin, M., Rapaport, P., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E., Cooper, C., & Livingston, G. (2013). 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*, 347: f6342. doi: [10.1136/bmj.f6342](https://doi.org/10.1136/bmj.f6342)
- [R4] Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Romeo, R., Livingston, D., Mummery, C., Walker, Z., Hoe, J., & Cooper, C. (2014). Long-term clinical and cost-effectiveness of psychological intervention for family carers of people with dementia: a single-blind, randomised, controlled trial. *Lancet Psychiatry*, 1(7), 539-548. doi: [10.1016/S2215-0366\(14\)00073-X](https://doi.org/10.1016/S2215-0366(14)00073-X)
- [R5] Livingston, G., Manela, M., Rapaport, P., Cooper, C., O'Keeffe, A., Knapp, M., King, D., Romeo, R., Mummery, C., Walker, Z., Hoe, J., & Barber, J. (2020). Clinical effectiveness of START (STrAtegies for RelaTives) psychological intervention for family carers and the effects on cost of care for people with dementia: six year follow-up of a randomised controlled trial. *British Journal of Psychiatry*, 216(1), 35-42. doi: [10.1192/bjp.2019.160](https://doi.org/10.1192/bjp.2019.160)
- [R6] Kashimura, M., Rapaport, P., Nomura, T., Ishiwata, A., Tateno, A., Nogami, A., Yamashita, M., Kawanishi, T., Kawashima, Y., Kitamura, S., & Livingston, G. (2020). Acceptability and feasibility of a Japanese Version of STrAtegies for RelaTives (START-J): A manualized coping strategy program for family caregivers of relatives living with dementia. *Dementia*. doi: [10.1177/1471301220919938](https://doi.org/10.1177/1471301220919938)

#### 4. Details of the impact

The number of people living with dementia is rising rapidly owing to increased longevity. It is crucial, both for their wellbeing and for economic reasons, for as many dementia sufferers as possible to remain at home receiving care from family. Two-thirds of the ~567,000 people with dementia in the UK currently do so [S1]. According to an estimate by the Alzheimer Society, this represents more than 600,000 family members providing GBP13,900,000,000 of unpaid dementia care annually [S1] and family care exerts a 20-fold protective effect against the risk of care home admission [S2]. However, about 40% of these carers have clinical depression or anxiety, while others have substantial psychological symptoms as a result of their caring commitments. The provision of effective support to protect the wellbeing of family caregivers is crucial.

The clinically- and cost-effective STrAtegies for RelAtives (START) programme has been shown to support this wellbeing in both the short and long term since approximately 66% of trial participants continued to use the techniques they had been taught even after the programme ended [S3]. The

manual and associated resources to deliver the intervention are freely available and can be downloaded (in English, Urdu, Spanish and Japanese) from the UCL website [S4]. The page has been viewed 29,844 times since it launched in July 2017 (18,835 unique pages views) with interest rising steadily from 3,986 views in the first half of 2018 to nearly double that in the same period of 2020 (7,835) [S5].

### **Impact on UK dementia policy and guidance**

The clear evidence of START's effectiveness has led policymakers to cite it in national guidance and policy documents. The UK Government included START in The Prime Minister's Challenge on Dementia 2020 (published in 2015), which set actions to improve dementia care, support and research in England [S6]. They noted that *"Carers of people with dementia undoubtedly provide a vital role and we know that the availability of appropriate care and support and the quality of services has a significant bearing on whether carers feel able to take a break from their caring responsibilities"*. The government recommended that carers of people with dementia need to be aware of and offered the opportunity for respite, education, training, emotional, and psychological support so that they feel able to cope with their caring responsibilities and have a life alongside caring. It also recommended that employers should have carer-friendly policies and practice that enable more carers to continue working and caring. NHS England was mandated in 2016-2017 to provide measurable improvements in all areas of the policy, including quality of post-diagnosis treatment and support for people with dementia and their carers.

The Chief Executive of Alzheimer's Research UK (the country's leading dementia research charity) acknowledged START's importance: *"Around 23,000,000 people in the UK – roughly a third of the population – have a close friend or family member with dementia, and it's these unsung heroes who take on much of the strain of the condition. It's important to find ways to support carers and protect their health, and these results suggest that the START programme can help reduce anxiety and depression for carers"* [S7].

START was evaluated in the National Institute for Health and Care Excellence (NICE) guidelines on Dementia (NG97 *Assessment, management and support for people living with dementia and their carers*; June 2018). The NG97 evidence committee noted *"the evidence from the 2014 Livingston HTA report which demonstrated that successful non-pharmacological interventions for managing non-cognitive symptoms could be cost-saving, due to the reductions in subsequent treatment costs for those receiving early interventions. The committee agreed that this recent HTA report represented the best quality economic evidence available and supported the recommendation for the first line use of non-pharmacological management"*. Whilst the document recommended a variety of approaches for carer support, such as START or a similar intervention, the committee agreed that *"the topics covered by START are a good representation of the topics that should be covered in this type of intervention"* [S8].

The START intervention has also been adopted by the international community and has so far been delivered to at least 93 carers in five countries [S9]. A new online video conferencing version of START was developed in Australia to enable delivery of the intervention from Melbourne and Perth to people in remote communities and by November 2018 20 carers had completed the 8-week program. Translation of the START manual into Japanese (2019) enabled 14 people to receive the intervention in an ongoing study in Japan [R6], with 26 receiving it by February 2020. A START pilot project was conducted in Hong Kong in 2018 (the manual was translated into Chinese in 2017). Pilots of translations into Tamil and Hindi were launched with 15 people in Chennai and 7 in Mysore. In Spain it was trialled in 4 people after consultation about the translation. Unfortunately, plans for the regional authorities to begin implementation in Northern Spain have been halted by the COVID pandemic.

### **Impact on dementia patients and their carers in the UK**

The results from the START intervention and subsequent dissemination activities have encouraged other NHS trusts to implement the programme. The Alzheimer's Society (the UK's leading dementia support charity) supported and funded the dissemination of START, thus allowing training of 134 clinical psychologists and 39 admiral nurses in 9 UK locations from October 2014 to September

2015. The newly trained professionals then cascaded training to others in their area, and this resulted in START being delivered locally to 136 carers across 11 service areas in 2016. The UCL team has provided training for 30 staff members of North East London NHS Foundation Trust, and others are being trained by the members of the dissemination groups. A survey carried out in July 2018 by the UCL team indicated that START is being used by at least 24 services over 12 NHS trusts, with 192 carers having received the intervention in 2017 [S10].

Carers who have completed the training reported better understanding of the condition and how it can cause challenging behaviour. This understanding made it easier for them to cope with some of the challenges they face and improved their own wellbeing, with a related improvement in their ability to provide care: “She [the Dementia Support Worker] obviously knew what she was talking about... here is someone who is affirming what I am doing and she’s telling me I’m doing well” [S10].

START has been adapted (in collaboration with the UCL team) for delivery in different populations [S11]. Work in 2018-20 enabled delivery in the third sector and to South Asian communities (translated into Urdu). The UCL Institute of Neurology adapted and trialled START for patients with Parkinson’s Disease dementia, and it has been adapted to Lewy Body Dementia, with training already delivered to carers for both conditions through third sector partners. Furthermore, the success of the START intervention built a team and a method which led to funding further research programmes focused on dementia. This includes NIHR-funded evaluation of DREAMS-START involving a similar style of intervention to improve sleep in people with dementia living at home which was feasible and acceptable to patients in a pilot RCT; and the Economic and Social Research Council’s *Managing Agitation and Raising Quality of Life* (MARQUE) project which improved quality of life in people with dementia living in care homes.

## 5. Sources to corroborate the impact

- [S1] *Dementia – the true cost: Fixing the care crisis*. Alzheimer’s Society. May 2018; ‘Dementia Tax’. Alzheimer’s Society website, <https://bit.ly/2RtbFbc>.
- [S2] Collated articles providing evidence of data on dementia patients and their carers
- [S3] Sommerlad, A., Manela, M., Cooper, C., et al. (2014). START (STrategies for RelaTives) coping strategy for family carers of adults with dementia: qualitative study of participants’ views about the intervention. *BMJ Open*, 4: e005273. doi: [10.1136/bmjopen-2014-005273](https://doi.org/10.1136/bmjopen-2014-005273)
- [S4] START Manual and START Training on UCL website. <https://www.ucl.ac.uk/psychiatry/research/mental-health-older-people/projects/start/start-resources>
- [S5] Page views for START website
- [S6] Policy Paper: *Prime Minister’s Challenge on Dementia 2020*. Prime Minister’s Office. 21<sup>st</sup> February 2015. <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>
- [S7] Alzheimer’s Association International Conference 2014 Highlights, blog post published by Premier Care Plus 16<sup>th</sup> July 2014. <http://premiercareplus.co.uk/alzheimers-association-international-conference-2014-selected-highlights/>
- [S8] Guidelines on Dementia NG97. NICE. June 2018. <https://www.nice.org.uk/guidance/ng97/evidence/full-guideline-pdf-4852695709>
- [S9] Collated evidence of START use by practitioners in India, Japan, Australia, Hong Kong and Spain
- [S10] Collated evidence of START implementation by practitioners in the UK
- [S11] Collated evidence of START adapted to: Third Sector providers and South Asian British populations; Parkinson’s Disease Dementia; Dementia with Lewy Bodies; DREAM-START; MARQUE.