



HEALTH TECHNOLOGY WALES (HTW) GUIDANCE 031 (October 2021)

Strategies for Relatives (START) intervention to improve the mental health of carers of people with dementia

HTW Guidance:

The evidence supports the routine adoption of the Strategies for Relatives (START) intervention for carers of people with dementia.

The use of START leads to a reduction in symptoms of depression and an improvement in quality of life of the carer as compared to usual care. Benefits are evident in the short term but are also maintained over a longer time period.

Health economic modelling suggests that START is cost effective compared to usual care with an incremental cost effectiveness ratio (ICER) of £12,400 per QALY and may lead to cost-savings when benefits and cost for the recipients of care are also considered.

Why did Health Technology Wales (HTW) appraise this topic?

The vast majority of people with dementia are cared for at home and it is estimated that 700,000 people in the UK act as unpaid informal carers. Dementia is characterised by difficulties with cognition, communication, motor performance, and everyday functioning. The nature and extent of these difficulties can vary according to the stage of progression and dementia sub-type. Due to these difficulties, people with dementia may need support from close relatives or friends.

Caregiving presents serious challenges and can be a highly stressful experience that places strain on relationships and wellbeing. Recent estimates suggest that the prevalence of anxiety and depression is over 30% in carers and the COVID-19 pandemic may have exacerbated this situation. Addressing this issue is of high importance to ensure the health and wellbeing of carers who take on an essential role within society and to prevent the breakdown of care that could lead to need for residential care. Welsh Government has highlighted that effective psychological interventions play an important role in supporting carers but availability is currently limited in Wales.

HTW considered this topic after it was proposed by Social Care Wales and Carers Trust Wales.

The status of HTW guidance is that NHS Wales should adopt this guidance or justify why it has not been followed. HTW will evaluate the impact of its guidance.

Evidence Summary

Refer to Evidence Appraisal Report 031 (EAR031) for a full report of the evidence supporting this Guidance.

- The EAR aimed to identify and summarise evidence that addresses the following question: What is the clinical effectiveness and cost effectiveness of the Strategies for Relatives (START) intervention aimed at improving the mental health of carers of people with dementia?
- A series of studies that report on a UK-based trial of the START intervention were identified. START appears effective in reducing symptoms and cases of depression and improving the quality of life of carers compared with usual care, but there was no difference reported in quality of life for people accessing care or time before needing residential care. Results for anxiety were more equivocal and varied according to adjustments of the analysis. Follow-up of up to six years show that outcome improvements are maintained over time and that the intervention has long-lasting impact.
- Recent meta-analyses on the effectiveness of similar interventions were also included to provide evidence on whether the findings of the START trial are plausible and reflective of findings with similar interventions. Two included reviews suggest that these similar interventions using cognitive behavioural and psychoeducational approaches have small to medium effects on reducing the burden felt by carers, depression, wellbeing and health-related quality of life compared to usual care. Results for anxiety were more equivocal and interventions did not appear to improve symptoms of people accessing care over the longer term or reduce placement in residential care.
- Economic evidence from the START trial suggests that the use of START is cost-effective for carers of people with dementia with an incremental cost effectiveness ratio (ICER) of £12,400 per QALY. When the costs accrued to both carer and recipient of care are included, START may be cost saving. As benefits have been shown to be maintained over longer follow-up, these findings may become more favourable over the long term. It should be noted that economic evidence adopted a wider perspective than that of the NHS and included resource costs for services provided by social care.
- The appropriate mechanism for patient engagement was determined and the patient perspective was considered where possible. HTW worked with the Alzheimer's Society and attended focus groups with people with dementia and carers to discuss relevant issues. The Alzheimer's Society also disseminated a questionnaire to their wider patient and care community. One study providing information on carer perspectives on the START intervention was identified during the literature search and was also included in the EAR. The focus groups, questionnaires, and literature highlight significant burden placed on the mental health and wellbeing of people who provide care for people with dementia as well as a current paucity of support.

Appraisal Panel considerations

- The Appraisal Panel heard from a representative of Alzheimer's Society that acting as a carer is very challenging with wide-ranging impacts on people's lives. Caring takes place over a long and uncertain period of time and the tasks that need to be completed can dominate people's lives. It was also highlighted that the COVID-19 pandemic has reduced the support available to people with dementia and their carers and has added challenges that have the potential to impact negatively on carers' health and wellbeing. The representative suggested that there is widespread discontent with the current support available for carers. The Appraisal Panel concluded that evidence-based interventions that provide effective support to carers of people with dementia is a high priority.

- The Appraisal Panel discussed the evidence on the clinical effectiveness of START. It was noted that there is a high quality randomised controlled trial (RCT) that was undertaken in the UK and that the results showed benefits on a range of outcomes. It was considered that the trial results are generalisable to decision-making in Wales. Academic and clinical experts advised that the results of the START RCT demonstrates that this intervention has a role in preventing the development of anxiety and depression and in providing treatment for carers in whom these problems are already present. The Appraisal Panel also noted that secondary evidence provides corroboration that the results of the START trial are plausible. Clinical experts highlighted that there may also be unquantifiable benefits of providing interventions, such as START, which may improve carer engagement with services and improve service awareness for those who need support.
- The Appraisal Panel discussed the evidence on cost effectiveness and reviewed the costs included in the analysis to ensure that they were reflective of the likely real world costs. It was noted that START was estimated to have a therapy cost of £232 per carer but that it provided sufficient benefits to be cost effective when considering costs and benefits to carers and potentially cost saving if costs for both carers and recipients of care were considered.
- The Appraisal Panel highlighted that delivery of START would have significant workforce implications. The intervention would need to be delivered by professionals with relevant skills and would need to be embedded in a service that could refer carers and provide supervision. Academic and clinical experts highlighted that in the trial, START was delivered by psychology graduate therapists but that professionals from other backgrounds (e.g. specialist nurses, dementia link workers, social care practitioners) could facilitate delivery as long as they had relevant experience and skills. This could be flexible according to the needs and resources of local services. It was also noted that there is an opportunity for enhanced links and multidisciplinary working between health and social care and third sector organisations in the delivery of a START programme.
- The Appraisal Panel considered whether it would be appropriate and feasible to deliver START to all carers of people with dementia or whether it should be made available more selectively to a sub-population of carers or at a particular stage in the care pathway. Academic and clinical experts outlined that START is predominantly offered to carers when the diagnosis of dementia is made but there is flexibility to deliver START at any stage of the pathway. Members of the Appraisal Panel concluded from the evidence reviewed and the expert advice received that START should be made available to all carers of people with dementia in Wales.
- The Appraisal Panel also discussed whether it might be feasible to deliver this intervention in groups to overcome some of the workforce challenges and make the intervention more cost effective. Experts highlighted that while this may be a feasible approach, there are specific benefits from allowing carers to work with therapists on a one-to-one basis since they are likely to share highly personal and difficult situations in this context. This can then form the basis of the development of individualised coping strategies.
- Based on the clinical and cost effectiveness evidence, the Appraisal Panel concluded that the evidence supports the routine adoption of START for carers of people with dementia. The appraisal panel noted that START could be delivered by individuals from a range of backgrounds so long as they have received appropriate training and possess skills of working in a psychologically informed way and developing therapeutic relationships.

Responsibilities for consideration of this Guidance

Health Technology Wales (HTW) was established by Ministerial recommendation^{1,2} to support a strategic, national approach to the identification, appraisal and adoption of non-medicine health technologies into health and care settings. The HTW Appraisal Panel comprises senior representation from all Welsh boards with delegated authority to produce guidance 'from NHS Wales, for NHS Wales'. The status of HTW guidance is 'adopt or justify'. There is an expectation from Welsh Government that HTW guidance is implemented with adoption regularly audited by HTW.³

The guidance in this document is intended to assist Welsh care system decision makers to make evidence-informed decisions when determining the place of health technologies and thereby improve the quality of care services.

The content of this HTW guidance was based upon the evidence and factors available at the time of publication. An international evidence base was reviewed and external topic experts and HTW committee members consulted to contextualise available evidence to Wales. Readers are asked to consider the generalisability of the evidence reviewed to NHS Wales and that new trials and technologies may have emerged since first publication and the evidence presented may no longer be current. It is acknowledged that evidence constitutes only one of the sources needed for decision making and planning.

This guidance does not override the individual responsibility of health professionals to make decisions in the exercise of their clinical judgment in the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

No part of this guidance may be used without the whole of the guidance being quoted in full. This guidance represents the view of HTW at the date noted. HTW guidance is not routinely updated. It may, however, be considered for review if requested by stakeholders, based upon the availability of new published evidence which is likely to materially change the guidance given.

Standard operating procedures outlining HTW's evidence review methods and framework for producing its guidance are available from the HTW website.

Acknowledgements. HTW would like to thank the individuals and organisations who provided comments on the draft Evidence Appraisal Report or HTW guidance.

Declarations of interest were sought from all reviewers. All contributions from reviewers were considered by HTW's Assessment Group. However, reviewers had no role in authorship or editorial control and the views expressed are those of Health Technology Wales.

Chair, Health Technology Wales Appraisal Panel

1. National Assembly for Wales, Health and Social Care Committee. Access to medical technologies in Wales. December 2014.
2. Response to Recommendations from the Health & Social Care Committee: Inquiry into Access to Medical Technologies in Wales. February 2015.
3. Gething, V. Letter to all Health Board Chairs re Funding for Sacral Nerve Stimulation in Wales. VG_01655_17. September 2017.



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