

Delivering Excellent Care Every Day for People Living with Advanced Dementia: Namaste Care Intervention UK

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Background: Namaste is a multi-component intervention developed in the USA shown to reduce distress behaviours, pain, use of antipsychotics, hypnotics and depressive symptoms and inappropriate hospitalisation in people living with advanced dementia. The evidence of effectiveness is not yet conclusive. However, the approach has high face validity across a number of countries with families, and staff. It fits well with expert opinion on what needs to be delivered to meet the end of life needs of people with advanced dementia. It does represent a significant change in priorities in delivering care within care homes. Fundamental to implementing innovative practice in any setting is to recognise the barriers and facilitators and to provide a means to ensure implementation.

Focus: This research will focus directly on implementation issues in UK care homes. In order to research its effectiveness we need to be able to describe the standard intervention and how it should be implemented taking all the contextual issues into account. We will establish the evidence from research and practice of all the components of Namaste Care. We will address the best ways of managing barriers and facilitators including the practical issues of time, staff competencies and leadership and undertake an estimate of costs to implement. We will also work with a larger group of interested care providers and people living with dementia to assess their opinion on the application of the programme and also to generate a "community of practice" that can continue beyond the life of the project.

Aim: To lay the foundations for the scale-up of an evidence based intervention that provides a practical, systematic approach to meet the physical, sensory and emotional needs of people living with advanced dementia.

Design: This is a three-year project (2016-19) and comprises of 6 interlinked Work-Packages.

WP1: Establishing theory and evidence: Namaste is a complex multi-component intervention. There are different levels and quality of evidence for the different component parts and for their combinations. This WP will bring all the evidence together, link it to theory, and describe the

rationale for the components, how they are put into practice, the costs associated with each and the potential outcomes.

WP 2: Learning from practice: Consists of 3 sequential lines of enquiry including a short on-line survey targeted at those already implementing or attempting to implement Namaste Care; telephone interviews to help contextualise the survey results. The results and the evidence synthesis (WP1) will be reviewed at a round-table half day meeting with Namaste practitioners and the research project team. The data will be analysed using content analysis method to identify the pertinent facilitators and barriers and strategies for action for WP3.

WP3 Implementation Case Studies: The optimal intervention will be trialled in 6 care homes delivered sequentially. It enables clarification of the nature of the intervention (acceptability, feasibility, practicability, cost and development over time) and implementation issues in care homes of different types (size, skill mix and registration). An Advanced Dementia Practice Coach (ADPC) will be employed to work directly with the care homes to guide and supervise practice. Each home will act as a case study.

WP4 Evaluation of costs and benefits: Establish the costs of the service and the potential benefits; I develop a preliminary costing model for the intervention using the standard resource-use approach, which uses price weights to create costs for the intervention. We will use the approach of "decision-making under uncertainty" to perform decision analytical modelling. This will allow the outcomes of the intervention to be estimated and parameters for the economic evaluation to be performed.

WP 5 Views of people directly affected by dementia: To date there has been little direct feedback from people living with advanced dementia receiving the intervention or from people at earlier stages about their opinion. We will address this in a number of ways throughout the programme including reflective interviews and observations.

WP6 Community of Practice and Sustainability: There is currently there is no systematic way of keeping track of how Namaste Care is being used or what lessons people are learning from its implementation. This research, particularly through WP2, will identify a large number of people who will be interested in forming a more sustainable community of practice. We propose to develop a web platform through our University of Worcester Values Exchange.

Outcome: In-depth description of the optimal intervention (manualised guidance available on-line and in print with expert practitioners who can mentor new programmes) that can be rolled out across care homes, and that is operationalised in terms of staff and resources and costs. This will include guidance on how to deal with common barriers eg competing priorities, lack of time, staff changes, engaging families and regulators. An on-line "Community of Namaste Practice" will be built to gather feedback from multiple sites throughout the research. This will also be a major vehicle for generating and maintaining interest in implementation for further roll-out.