

**Participant Information Sheet**  
**Namaste Phase 2: Consultation Workshops**

***The Namaste Care intervention to improve the quality of dying for people with advanced dementia living in care homes: A realist review and feasibility study for a cluster randomised controlled trial: Phases 1 and 2***

My name is Katherine Froggatt and I am conducting this research at Lancaster University, Lancaster, United Kingdom in collaboration with researchers from the Universities of Hertfordshire, Bristol, Liverpool and St Christopher's Hospice, London.

**What is the study about?**

This research study aims to research the use of a multi-sensory programme of care (Namaste Care), for people with advanced dementia living in nursing care homes. Namaste Care has been developed to provide care for people with advanced dementia at the end of life, particularly in care homes. The core elements of the programme address 1) the physical setting; for the person with dementia 2) a daily comfort assessment; 3) ongoing, sustained engagement provided by staff; 4) that engages the individual's senses; and 5) provides meaningful activities that reflect the person's life and interests.

In the second phase of the study we would like you to review and prioritise materials that have been prepared to help care home staff use the Namaste Care programme with people with advanced dementia. We will use the findings from this work to inform a feasibility trial of Namaste Care for people with advanced dementia in nursing care homes, where we test out if it is possible to use the programme of care in care homes and also collect data about its impact.

**Why have I been approached?**

You are being invited to join the study because you have experience of working in a nursing care home that offers care to people with advanced dementia. We would like to use your experiences of caring for people with advanced dementia to inform our work.

**How much time do I have to decide?**

At the very least, you will have 48 hours to decide if you would like to take part in the workshop but you will be given more time if required.

**Do I have to take part?**

No. It is completely up to you to decide whether or not you take part. If you decide to take part you are able to withdraw up to two weeks after participation in the informal workshop, without giving a reason and without detriment to yourself.

What will I be asked to do if I take part?

If you decide you would like to take part, you will be asked to participate in an informal workshop.

**1. Consultation Workshops**

We will hold one informal workshop which will last half a working day (including travel time), and during the day we will present written resources on delivering Namaste Care from the research team. During the workshops you will be asked about what you think about the written resources in

with respect to the way they are written and presented. The feedback will be captured through field notes and written feedback.

### **Will my data be identifiable?**

The information you provide will be anonymised, but participation in the informal workshops means that quotes may be attributable to individuals at a later date.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- The files on the computer will be encrypted (that is no-one other than the research team will be able to access them) and the computer itself password protected.
- Data will be kept for ten years after the end of the study.
- Anonymised direct quotations from your interview may be used in the reports or publications from the study, in presentations at future conferences, and for future training events and resources. Your name will not be attached to them.
- Anonymous data from this study may be shared and used by researchers for further analysis in the future.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said during the workshop makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

### **What will happen to the results?**

The results will be summarised and reported to the funding body (the National Institute for Health Research). The results will be used to refine the design of a feasibility trial being conducted as part of this research project. We will also aim to submit findings for publication in an academic or professional journal and also undertake conference presentations.

### **Are there any risks?**

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher.

### **Are there any benefits to taking part?**

Although you may find participating interesting, there are no direct benefits in taking part.

### **Who has reviewed the project?**

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

### **Where can I obtain further information about the study if I need it?**

If you have any questions about the study, please contact the main researcher:

Professor Katherine Froggatt  
International Observatory on End of Life Care  
Division of Health Research  
Faculty of Health and Medicine  
Lancaster University  
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Tel: 01524 593308

Email: [k.froggatt@lancaster.ac.uk](mailto:k.froggatt@lancaster.ac.uk)

### **Complaints**

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Steve Jones  
Division of Health Research  
Lancaster University  
Lancaster  
LA1 4YG  
Tel: 01524 593382  
Email: [s.jones7@lancaster.ac.uk](mailto:s.jones7@lancaster.ac.uk)

If you wish to speak to someone outside of the Division of Health Research you may contact:

Professor Roger Pickup Tel: +44 (0)1524 593746  
Associate Dean for Research Email: [r.pickup@lancaster.ac.uk](mailto:r.pickup@lancaster.ac.uk)  
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Thank you for taking the time to read this information sheet.

  
***National Institute for  
Health Research***

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