

Family Member Participant Information Sheet Namaste Phase 2: Consensus 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. In the second phase of the study we would like 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 are currently a family member or friend of a person with advanced dementia living in a care home, or a bereaved family member or bereaved friend of a person with advanced dementia who lived in a care home. We would like to use your personal experiences to inform our work.

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 consensus 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 one day consensus workshop. The workshop will last for a working day (including travel time). The workshop aims are to:

1. To learn about the findings of the realist review and factors that shape the use of Namaste Care programme;
2. To refine and prioritise the implementation process for the delivery of the Namaste Care programme on the basis of the realist review findings;
3. To inform the format of the Namaste Care programme and implementation resources

During the day we will present findings from Phase 1 of the study and ask you to consider their relative importance in shaping the content and form of the resources developed to help care home staff use the Namaste care programme. Materials will be sent to you two weeks before the

workshop. The discussions will be tape recorded and transcribed and structured fieldnotes made during the workshop.

Will my data be identifiable?

The information you provide will be anonymised, but participation in the consensus 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:

- Audio recordings will be destroyed and/or deleted once the final report has been submitted and accepted by the funding body.
- Hard copies of transcripts will be kept in a locked cabinet.
- 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.
- At the end of the study, hard copies of interview transcripts will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name.
- 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 in the interview 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, discussion of care for a person with dementia might evoke memories and emotions of difficult personal experiences. If this should happen, a member of the research team will support you on the day. Sources of further support are identified at the end of this participant information sheet, and will be made available on the day.

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
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Division of Health Research
Faculty of Health and Medicine
Lancaster University
Lancaster LA1 4YW

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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
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Tel: 01524 593382

Email: 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
Associate Dean for Research
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
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Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Alzheimer's Society runs a National Dementia Helpline on **0300 222 1122**

The Helpline is usually open from: 9am - 8pm Monday to Wednesday, 9am - 5pm on Thursday and Friday, 10am - 4pm on Saturday and Sunday

Cruse Bereavement Care offers a telephone helpline: **freephone** on **0808 808 1677**

The helpline is open Monday-Friday 9.30-5pm (excluding bank holidays), with extended hours on Tuesday, Wednesday and Thursday evenings, when we're open until 8pm.

Information about more local sources of support , if available, will be added once we know the location of the care homes involved in the study.



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