

1. NAME OF INTERVENTION	The Family Carer Decision Support Intervention
2. WHY?	<p>The aim of the intervention is to inform family carers about end of life care options for people living with advanced dementia. Where it has been determined that a person living with dementia is unable to make a decision for themselves, care home staff must deliver care that is in the person's best interests. Ideally, decisions should be made involving those close to the person, typically a family carer, and the health and social care providers caring for the person.</p> <p>Research evidence highlights the importance of involving family members in decision-making on goals of care at the end of life. However, a recent systematic review of families' experiences supporting a dying relative in care homes found family carers were disappointed by the limited contact and lack of meaningful communication they experienced with care home staff. The evidence suggests that families who are not given an opportunity to discuss their relative's illness, prognosis, and treatment suffer uncertainty about phase of illness and nearness of death, have difficulties with decision-making and can feel unprepared for their relative's death.</p>
3. WHAT? MATERIALS	<p>The intervention consists of two parts:</p> <ol style="list-style-type: none">1. The booklet, "<i>Comfort Care at the End of Life for persons with Alzheimer's Disease or other Degenerative Diseases of the Brain</i>". Originally developed in Canada, this booklet provided information on the trajectory of the disease, clinical issues, decision-making processes and symptom management.2. A questionnaire prompt list to guide the family care conference meetings3. Advanced care plan (optional)
4. WHAT? PROCEDURES	<p>The procedure is comprised of 3 components:</p> <p>Environmental Scan: We will conduct an environmental scan where key individuals (residents (where able), family carers, personal support workers, registered nurses, care home managers, health care providers in the community) will be interviewed. Questions will be asked on their attitudes, level of support,</p>

¹ Hoffmann et al., Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. BMJ 2014; 348:g1687

barriers to implementation and potential cooperation related to the intervention. The implementation strategy will be identified via the environmental scan.

Training and facilitation:

A 2-hour training module will be delivered to care home staff that have been identified to deliver the intervention. The curriculum will be adapted from material developed in the original study augmented with material from the Residential Aged Care Palliative Approach Toolkit. Training content will include:

- a review of the 'comfort care booklet'
- how to select families
- organize and conduct a family care conference
- reflection on communication skills required for effective family care conferences
- documenting family care conference processes and outcomes

Trained facilitators external to the care homes will deliver the care home staff training module. Facilitators will conduct outreach visits to each care home for ongoing shared learning, reflective practice as well as supporting staff in employing resources (38 hours of contact time per care home). It is anticipated that these activities will facilitate the development of a community of practice pertaining to the intervention.

Family meetings:

The structure (preparing, conducting and documentation) of the family meeting was based on clinical practice guidelines developed for conducting family meetings. The family meeting will last approximately 1 hour. The contents of the booklet will be reviewed and the family carers, assisted by the advance care planning facilitator, will have the opportunity to reflect on the resident's goals, values, beliefs and end-of-life care options in order to facilitate best interest decision-making.

During the meeting, family carers have the opportunity to review a draft advance care plan developed by the facilitator based on their previous discussion, to address any outstanding issues, and sign the standardized advance care plan document, retaining a personal copy. As a follow-up to the family meetings, the advance care plan is placed in the resident's medical records following orientation on the contents with the nurse-in charge, and a copy sent to the resident's general practitioner. Participants to determine whether a follow up meeting may be required to further discuss any issues.

5. PROVIDERS

Environmental scan: a research assistant will complete the environmental scan at each of the care homes. This will include interviews with key individuals such as residents (where appropriate), family carers, care home staff, support workers, key workers, members of the allied health professional team and health care providers in the

community.

Training and facilitation: trained facilitators will deliver the 2-hour training module to care home staff that have been identified to deliver the intervention within their respective care homes. The Research assistant will follow up with outcome measure assessments and outreach meetings.

Family meetings: the key worker who will be a care home member, (dependent on country/jurisdiction, can include general practitioner/social worker etc.) will conduct the family care conference. The family care conference will take approximately one hour

6. HOW IS IT DELIVERED?

Environmental scan: the research assistant will meet with family carers, support workers, registered nurses, managers and healthcare providers, face to face at the care home or in the community. Participants will be asked to partake in an interview with the research assistant to understand their perspectives of the intervention, and potential barriers or potential facilitators to its implementation.

Training and facilitation: training will be delivered by the facilitator in a group setting to facilitate shared learning amongst care home staff. Training will consist of a 2-hour module delivered onsite at Queen's University Belfast. Additionally, the key worker will be available to provide advice or guidance to any participant at an individual level should they require it.

Family Care Conference: the key worker will conduct the family care conference meetings face to face with family carers onsite at the care facility. Based on previous literature it is anticipated that there will be a maximum of two meetings for each family.

7. WHERE?

For the purpose of this study, 'care home' is used to refer to a collective institutional setting in which care is provided to older adults on-site 24 hours a day, including on-site or off-site nurses and medical staff.

Transnational study:

The Transnational study will be conducted in two nursing care homes per country.

Countries included:

Ireland
Netherlands
Canada
Czech Republic
Italy

National UK study:

The National UK study will be delivered in both residential care homes and nursing care homes.

UK locations included:

Northern Ireland (Belfast)

North West England (Lancashire, Cumbria)

Central England (Nottinghamshire, Leicestershire)

8. WHEN AND HOW MUCH?**Intervention steps and timeline:****Conduct environmental scan on wave one care homes**

Key consenting individuals will participate (family carers, personal support workers, registered nurses, care home managers, health care providers in the community) in face-to-face interviews. Questions will be asked on their level of support towards the intervention, barriers to its implementation and potential cooperation relating to the intervention.

Estimated duration: approx. 5 weeks

Train external staff trainers

The research team will prepare a 4-day training programme that will include e-resources, held at Queen's University Belfast, UK involving a nurse trainer from the participating partner countries. Two days of interactive workshops will be delivered based on the previous work of the team covering the following topics: communication skills for effective family care conference, principles of shared decision-making and how to use the booklet, "Comfort Care at the End of Life for persons with Alzheimer's Disease or other Degenerative Diseases of the Brain" (Comfort Care Booklet) in the family care conference. The remaining two days will focus on how to train others in delivering the intervention including potential cultural differences, barriers and ways to overcome them within each of the participating countries.

Estimated duration: 5 days

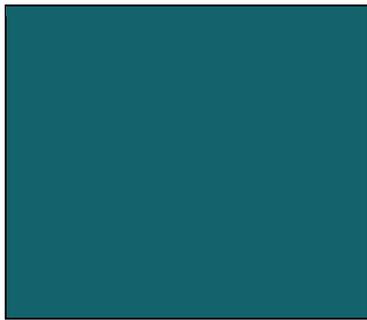
Train and support care home staff

Facilitators who participated in the four-day training course held at Queen's University Belfast will provide an estimated 2-hour training module for care home staff who have been identified to deliver the intervention. The curriculum will be adapted from material developed in the original study. Training content will include a review of the 'comfort care booklet'; how to select families, organize and conduct a family care conference; reflection on communication skills required for effective family care conferences and documenting the process and outcomes.

Estimated duration: 2 hours

Implement the intervention in care homes

Family care conferences will be scheduled in the care homes by the facilitator. Family carers will either be posted a hard copy of the Comfort Care booklet or it will be provided to them on attendance at the family



care conference. The designated staff person (e.g. keyworker) in the care home will review and discuss the contents of the booklet with family participants, facilitating awareness of comfort care practices at the end of life. Family care conference participants will determine the option of follow-up meetings.
Estimated duration: Meetings will last for approx. 1 hour. Based on previous literature it is anticipated that there will be a maximum of two meetings for each family.

9. TAILORING

N/A

10. MODIFICATIONS

The implementation strategy will be modified to address identified barriers from this assessment. We will provide an estimated 2-hour training module for care home staff that have been identified to deliver the intervention. The curriculum will be adapted from material developed in the original study augmented with material from the Residential Aged Care Palliative Approach Toolkit. Training content will include: a review of the 'comfort care booklet'; how to select families, organize and conduct a family care conference; reflection on communication skills required for effective family care conferences and documenting the process and outcomes.

**11. HOW WELL?
PLANNED**

The research team have a wealth of experience in this area and the study design and intervention have undergone several revisions both by steering groups and the wider research team. PPI feedback has also been sought contributing to the development of this intervention.

**12. HOW WELL?
ACTUAL**

n/a



For further information: W: www.mysupportstudy.eu | E: info@mysupportstudy.eu | Twitter: [@mysupportstudy](https://twitter.com/mysupportstudy)

