



PROMOTING INFORMED DECISION MAKING AND
EFFECTIVE COMMUNICATION THROUGH ADVANCE
CARE PLANNING FOR PEOPLE WITH DEMENTIA AND
THEIR FAMILY CARERS.

End of Project Report to HSC R&D Division, Public
Health Agency

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Background

As populations in Western societies age, more people than ever before are living with chronic medical conditions. For example, dementia is rising in prevalence and becoming one of the leading causes of death worldwide (Ferri et al, 2005). The World Health Organisation (2012) reports that the number of people living with dementia is expected to double every 20 years, with 7.7 million new cases reported worldwide each year or one new case every 4 seconds. This will have a major impact not only on patients and their families but also on service provision and on society as a whole where costs associated with caring for and supporting those living with dementia will rise substantially (Department of Health and Social Services and Public Safety Northern Ireland, 2011).

Dementia is a progressive and largely irreversible clinical syndrome of the brain which leads to disturbances of higher order cortical functioning, including memory, orientation, thinking, comprehension, the capacity to learn, calculation, judgement and communication difficulties (World Health Organisation, 2012). The progression of dementia can vary markedly between patients, but is usually described in stages (early, middle and late), where health deteriorates over time. As an approximation, the early stage occurs within the first one to two years, the middle stage in the second to fifth year and the final stage in the years thereafter. For the majority of patients who experience these symptoms it is usually caused by Alzheimer's disease (in roughly 60-70% of incidences; Knopman et al, 2003). Other common causes of

dementia include diseases that contribute to front-temporal dementia, such as dementia with Lewy bodies and/or vascular disease.

Dementia is associated with complex needs and, in the later stages of the illness is characterised by high levels of dependency and morbidity. These health and care needs often challenge the abilities of family members to provide care and as such, in Western countries, a substantial number of dementia patients are institutionalised or admitted to a nursing home for 24/7 care. With advanced disease, comes the need for specialised care, and this can lead to frequent transfers to acute hospitals where aggressive and overly burdensome treatments may be provided (Gillick, 2000; Mitchell et al, 2004; Lamberg et al, 2005).

From both an ethical and clinical standpoint, understanding when a treatment becomes futile for someone with dementia is highly contested, especially when patients enter the later stages of the disease. It is made more challenging if their wishes relating to their future health care have not been stated in advance. The question of whether treating physical complications in the later and more severe stages of dementia is, on balance, a burden or a benefit for the patient is still mostly answered by family members acting as Best Interest Decision Makers, in conjunction with physicians acting on behalf of the patient (de Boer et al, 2010). Family carers may therefore find themselves in a situation where they may be required to make difficult and emotional choices about whether or not to proceed with a life sustaining treatment (Caron et al, 2005; Sachs et al, 2004; Livingston et al, 2010).

Person-centred care and the patient's right to self-determination have become key ethical principles in all areas of healthcare. Person-centred care has been described by people living with dementia and their carers as promoting the continuation of self and normality in daily life (Edvardsson et al, 2010). The ethical principle of self-determination highlights that dementia patients have the right to accept or refuse treatments. However, due to the nature of the disease, dementia patients will eventually lose capacity to express such preferences; consequently best interest decision makers and medical staff will be required to make healthcare decisions on behalf of the patient. Advance Care Planning (ACP) is seen as a mechanism to support family carers in the difficult decision-making process of determining such goals of care (NHS End of Life Care, 2008; NHS Improving Quality, 2014; Seymour et al, 2010). However, given the relative importance of advanced care planning in dementia care, the prevalence of ACP among patients with dementia is low (Laakkonen et al, 2008; Godwin and Waters, 2009).

Advance care planning can be defined as a process of discussion between a patient, their health care providers, and those close to them, about their future care in the event that the patient may lose capacity to make decisions for themselves as their illness progresses (Royal College of Physicians, 2009). As such, it has become viewed as a means of navigating the uncertainties often faced at the end of life by identifying and supporting patients' needs and determining their preferences for care.

Advance Care Planning is in line with the principle of self-determination where an ACP document is a written or verbal record of a person's choices about their future medical care. An ACP document is created when the person is still capable of making informed decisions about their future care and only enacted when the person is no longer able to demonstrate mental capacity to make or communicate their own decisions about their medical treatment. It works as a guide to best interest decision makers and doctors who can then make informed choices about the person's future treatment if they become incapable of making or communicating such decisions themselves. ACP is an on-going process, which documents and describes the patient's preferences, values and aims for future medical treatments and care. An ACP may include the completion of an advance decision to refuse treatment (ADRT); this informs people involved in the patient's care about treatments that they wish to refuse or have withdrawn in the future, in specific circumstances, should they no longer be able to communicate their wishes. The ACP process may also include the appointment of best interest decision makers and written documentation describing their agreed role; this gives power to nominated best interest decision makers to make decisions about medical treatments for the patient when they are no longer able to do so for themselves.

The best interest decision maker's role is complex and can place a significant burden on the family members or caregivers who have to make these decisions. When a patient has advanced dementia a large number of treatment decisions are made by legally appointed best interest decision makers such as family members or

physicians in the dementia population (Caron et al, 2005). Best interest decision makers may be required to make many difficult and emotionally burdensome choices about whether or not to proceed with a life sustaining treatment, which could potentially contribute to their loved one's death at a time when they feel unprepared for making such decisions (Caron, et al, 2005; Sachs et al, 2004; Livingston et al, 2010). Regrettably, given the relative importance of ACP in the dementia population, the available research examining the prevalence of ACP in dementia patients demonstrates that the provision of ACP for persons with dementia is poor (Godwin et al, 2008).

Although most ACP guidelines for patients with dementia suggest that ACP should commence as early in the disease trajectory as possible (World Health Organisation, 2012; Hertogh, 2006; Brown et al, 2005), the research evidence reveals that most residents with advanced dementia who are living in nursing homes have not completed an ACP (Mitchell et al, 2004; Caplan et al, 2006). Again, research evidence shows that nursing home staff support the use of ACP among this patient population however, most staff report having limited experience in developing ACP with nursing home residents (Hertogh 2006; Silvestere et al, 2013). This situation has generated recommendations for a systematic approach to the implementation of ACP in nursing homes to ensure best practice is provided and sustained (Detering et al, 2010; Molloy, et al, 2000). A recent systematic review (Robinson et al, 2012) identified only four ACP intervention studies for patients with cognitive impairment or dementia; the majority of included studies had been undertaken in nursing homes

with patients in the later stages of dementia, when competency was diminished and the focus of the interventions was on end-of-life decisions made by best interest decision makers. There is some evidence that ACP based interventions undertaken in nursing homes can help to ensure patient self-determination and assist in the provision of quality care. This is reflected in reduced hospital admissions (Caplan et al, 2006; Sampson et al, 2011b) and is also evidenced through the improved concordance between a patient's previously expressed preferences about medical treatments and the treatments provided to patients when they are no longer able to express their wishes (Morrison et al, 2005).

Family carers have an important role in treatment decision-making where uncertainty has characterized end of life dementia care (Goodman et al, 2015). To help family carers participate in decision-making on goals of care at the end of life they need information to help them understand the course of dementia, possible complications and, therapeutic options (Arcand et al, 2013).

Hence, the purpose of this study was to articulate a family focused ACP intervention and evaluate its impact in dementia care nursing homes. Recognizing the uncertainty experienced by family carers in this decision making process the primary hypothesis of this study was that, the ACP intervention would reduce family carer uncertainty in decision-making concerning the care of the family member. We also wanted to test whether the ACP intervention would yield higher family carer

satisfaction with nursing home care; reduce family carer psychological distress; reduce nursing home resident hospitalisations; reduce hospital deaths; and, increase the number of completed Do Not Resuscitate (DNR) orders. In addition, we were also interested in exploring the lived experience of family carers who had undertaken the role of best interest decision maker on behalf of a relative with severe dementia as they made the transition from living in the community to living in a care home.

Description of the ACP intervention

The combination of components for this intervention comprised elements identified in the research literature as important to successful ACP: a trained ACP facilitator; family education; family meetings; documentation of advance care plan decisions; and, orientation of GPs and nursing home staff to the intervention (Royal College of Physicians, 2009; NHS End of Life Care, 2008; NHS Improving Quality, 2014; Detering et al, 2010; Institute of Medicine, 2015; General Medical Council, 2010; Robinson et al, 2012). Prior to the launch of the trial two nursing homes participated in a pilot study of the intervention and protocol. Following this exercise and, in consultation with stakeholders, it was determined that no changes were necessary to either the intervention or the study procedures.

The ACP facilitator selected for this role was a Registered Nurse with more than three years post registration experience and a more than two years working in a field related to palliative care (see Appendix One). In preparation for their role in this project the selected candidate also completed the Respecting Choices 'Online ACP

Facilitator Curriculum' (Gundersen Health System 2013) and 'The End of Life Care for All' (e-ELCA) (NHS - Health Education England 2014) online training programmes, augmented with additional face-to-face training on ACP and dementia by local experts.

Family meetings were typically scheduled to take place in the nursing home by the ACP facilitator. Prior to these meetings, participants were mailed a copy of the booklet "Comfort care at the end of life for persons with Dementia – a guide for caregivers (Northern Ireland version)". Originally developed in Canada, this booklet provided information on the trajectory of the disease, clinical issues, decision-making processes, and symptom management (Arcand and Caron, 2005). Prior to use in this study the original booklet was reviewed by an expert panel including a service user, before being pilot tested to assure that the contents resonated with both culture and practice in Northern Ireland (NI). The Comfort Care Booklet has shown a high level of acceptability (Arcand et al, 2013; van der Steen et al, 2011a; van der Steen et al, 2012) and has been identified as an example of a best practice instrument (World Health Organisation, 2011) (see Appendix Two or a copy, as used during this study, is available online <http://bit.ly/2ixMZLn>).

The structure (preparing, conducting and documentation) of the family meeting was based on clinical practice guidelines developed for conducting family meetings (Hudson, et al, 2008). During the initial family meeting the contents of the booklet were reviewed and the family carers, through discussion with the facilitator were

asked to reflect on the resident's goals, values, beliefs, and end of life care options in order to facilitate best interest decision-making. In the second meeting, family carers had 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. Family carers also received a personal copy of the ACP documentation to retain for their records (see Appendix Three). The content of the advance care plan document was developed on the basis of a review of similar documents used in the United Kingdom as well as a review of the literature (Silvester et al, 2013). The ACP documentation recorded the resident's details; those present at the family meeting; documents already held by the nursing home (e.g. advance decision to refuse treatment (ADRT) or Do Not Resuscitate (DNR) orders); future care preferences highlighting the elements of care that were important to the individual; and, what they would want and not want to happen; the proxy or next of kin details; a signed declaration, and a record of where copies of the ACP would be kept (see Appendix Three). As a follow-up to the family meetings, the advance care plan was placed in the resident's medical records following orientation on the contents with the nurse-in-charge, and a copy was circulated to the resident's GP.

Personal and Public Involvement (PPI)

The design and implementation of this study recognised and acknowledged the important role played by service users, carers and the public in developing services and shaping research. This study employed a variety of patient and public

involvement strategies to enhance the development, relevance and conduct of the study. Through consultation with current carers, past carers and professional colleagues we were able to provide opportunities for our partners to contribute to the development of the intervention as well as comment on the methodology employed during the trial and the outcome measures used. The perspectives of service users and their families was also essential to assist in the interpretation of results, determine the effectiveness of the intervention and, inform the future development of the intervention. For example, as part of this consultation process a bereaved carer of a person who lived with dementia read and provided feedback on the Comfort Care Booklet. This involvement was essential in order to allow us to produce a version of the booklet that was appropriate for the Northern Ireland population and which was both comprehensive and understandable from a lay person's perspective.

To facilitate stakeholder engagement the research team established an Advisory Committee which included stakeholders identified during the development of the project. This committee had representation from the voluntary sector; a regional manager from Four Seasons Health Care; clinicians and decision makers who were engaged in the dementia/ palliative policy portfolios in the Northern Ireland government; and finally, a bereaved carer who provided the perspective of someone who had lived experience of caring for a relative with dementia who had been cared for in a nursing home. This group were consulted on the design and development of the project and kept informed of progress throughout the study period. Committee

members provided impartial advice based on their own personal/clinical experiences, and consulted informally with the research team when required (Appendix Four).

Prior to launching the study, all family carers of nursing home residents were invited to attend engagement events convened in their family member's nursing home. During these meetings family carers were given the opportunity to meet with the chief investigator and other members of the study team. These meetings were designed to give potential participants an opportunity to meet with the research team, discuss ACP, familiarise themselves with the study process and, fully understand what their involvement would entail. In all, 24 engagement events were conducted by the chief investigator (see Appendix Five).

At the conclusion of the study, all participants who had completed a baseline questionnaire were mailed a brief written feedback sheet (see Appendix Six). This communication thanked carers for their participation, provided a summary of the study and explained the implications of the results. Participants were also given the contact details of the chief investigator should they require any further information. A similar information sheet was also provided to Four Seasons Health Care to be distributed around staff in participating nursing homes.

Methods

This study employed a mixed-methods design with both quantitative and qualitative components. The quantitative component comprised a paired cluster randomised controlled trial. This methodology was employed as ACP was introduced into practice at the unit level (rather than at individual level). In the qualitative component of the study we evaluated two elements: the experience of family carers as a best interest decision maker and their perceptions of participating in the ACP process; and, staff perceptions on the process of implementing the intervention. Interviews were conducted at the conclusion of the intervention period. Nursing Home managers were recruited from the intervention sites and family carers were recruited from both the intervention sites and usual care nursing homes. Interviews with family carers provided an opportunity to understand the lived-experience of family carers who were required to act as a best interest decision makers for family members who no longer had the capacity to make decisions about their future medical care. The interviews with nursing home managers focused on two major themes: how have the components of the ACP intervention helped or hindered the provision of care in their nursing home; and, recommendations on how to implement the program and overcome potential barriers to its future use. The results of this work are the subject of two publications currently in development (Carter et al, 2017; and, Brazil et al, 2017). The study was developed to follow the Medical Research Council's recommendations for the evaluation of complex interventions and, as such, this project can be thought of as an exploratory (Phase II) project.

Participants and recruitment procedure

Within the United Kingdom the term 'Nursing Homes' describes facilities that provide care to residents who require continual nursing care and have significant difficulty in undertaking activities of daily living. In this study, nursing homes were drawn from the largest independent private provider of health and social care services in Northern Ireland (NI). When this study began (September 2014), this provider had 74 nursing homes in NI. The type of nursing homes that were eligible to participate in this study were those given a dementia nursing category by NI's Regulation and Quality Improvement Authority (RQIA); an independent body that is responsible for monitoring and inspecting the availability and quality of health and social care services in NI and, encouraging improvements in service provision. In total, 24 nursing homes were identified and matched into pairs by the number of dementia beds in the facility. Randomisation occurred at the paired facility level where the 24 nursing homes were randomly assigned (12 nursing homes per treatment) to ACP with usual care (intervention group) versus usual care alone (control group). The random number generator in Excel was used when a pair of nursing homes was ready to be enrolled, such that one was allocated to intervention and one to usual care at the same time. This was done by a member of the research team with no knowledge of the nursing home, and the allocation was concealed until both homes in the pair had confirmed their willingness to join the study. Recruitment of the 24 homes took place in a staggered manner over nine months.

In the participating nursing homes, resident records were reviewed by the nursing home manager to identify those individuals classified as having dementia and judged as not having decisional capacity to complete an ACP. For each eligible resident, the nursing home manager also completed a Functional Assessment Staging Tool (FAST) (Sclan and Reisberg, 1992). This tool was designed to assess the level of dementia experienced by a patient by outlining key symptoms and grading the level of impairment experienced on a seven point scale where Stage 1 indicated no impairment and Stage 7 indicated a severe level of impairment (see Appendix Seven). Following the identification of eligible residents, the family member(s) most responsible for the care of each resident were identified as potential study participants. These individuals were mailed a pre-notification letter by the nursing home manager endorsing the study and extending an invitation to an information event held at the nursing home (see Appendix Eight). In parallel, the nursing home manager identified the resident's General Practitioners (GPs) and other health and social care providers who they felt should receive a letter to inform them about the study. Following the information event and randomization, a recruitment baseline questionnaire package was mailed to the potential participant's home address by the nursing home administrator (see Appendix Nine). Non-respondents were sent a reminder postcard and then, if necessary, a replacement questionnaire. Respondents in the intervention group were invited to participate in up to two family meetings with the ACP facilitator. A follow-up questionnaire was mailed to them six weeks after baseline. Participants in the usual care group completed a follow-up questionnaire only. The research team mailed the follow-up questionnaire package

to participants, and, as in baseline data collection, with two further points of contact if necessary.

Participants who completed both questionnaires were also invited to participate in a semi-structured, face-to-face individual interview (see Appendix Ten) with a member of the research team (GC). These interviews facilitated an in-depth investigation of the experience of family carers who were responsible for best interest decision making on behalf of their relative during their transition from community living to nursing home care. Interviews were undertaken until no new data or themes were being encountered and it was felt that data saturation had been achieved. In total 20 individual interviews were held with carers with representation from both arms of the trial (intervention group n = 12, usual care n = 8). In addition, interviews were undertaken both with the study ACP facilitator and with the nursing home managers from (n=10) from homes in the intervention and the usual care arm of the study. Again, these interviews were undertaken until no new themes were identified and it was felt that data saturation had been achieved.

DATA COLLECTION (INSTRUMENTS AND PROCEDURE)

Quantitative

Study objectives and measures are summarised in Table 1. The primary outcome for the study was family carer uncertainty and difficulty in making decisions about the care of the resident. This was measured using the 16-item version of the Decisional

Conflict Scale (DCS; O'Connor et al, 1995) in which responses are recorded on a 5 - point scale (1 = 'strongly agree'; 5 = 'strongly disagree'). Items were scored, averaged and transformed to provide an overall score (0 = low decisional conflict; 100 = high decisional conflict). The instrument contains five subscales:

- 1) 'Informed Subscale', which measures awareness of options, benefits, and risks
- 2) 'Values Clarity Subscale', which measures feelings of support, advice, and pressure from others
- 3) 'Support Subscale', which measures the perceived level of support in decision making
- 4) 'Uncertainty Subscale', which measures the respondent's degree of confidence about the decision
- 5) 'Effective Decision Subscale' measures the likelihood of adhering to the decision and satisfaction with the decision.

The instrument has been used extensively within the United Kingdom and has demonstrated satisfactory reliability (Cronbach's alpha 0.78) and good construct validity (Song et al, 2006).

Secondary outcomes included family carer satisfaction with nursing home care, measured by the Family Perceptions of Care Scale (FPCS). The FPCS (Vohra, et al, 2004) is a 25-item scale designed to assess family carer perceptions of the care provided to a family member in the last four weeks of life. Following our initial pilot

study, the tense of this instrument was adjusted to recognise that the resident was not deceased. Respondents were asked to indicate agreement with 25 items on a 7 - point Likert scale ranging from 'strongly disagree' to 'strongly agree'. The total possible score for the FPCS ranges from 25 (negative assessment) to 175 (highly positive). The FPCS provides four subscales:

- 1) 'Resident Care', which measures family members opinions of care provided to the resident
- 2) 'Family Support', reports on perceptions of nursing home care directed towards family members to assist family members to assist them with decision-making
- 3) 'Communication', concerning the timeliness, comprehensiveness, and clarity of the communication between staff and the family member
- 4) 'Rooming' assessing perception of appropriate placement of the resident in the facility.

Family members were also asked to identify three of the 25 items in the instrument as the highest priorities for providing quality care in the nursing home. Respondents were also invited to include written comments. Reliability analysis of the FPCS has demonstrated high levels of internal consistency for the measure with a Cronbach's alpha of 0.96 (Vohra et al, 2004).

Participating carers were also invited to complete the 12 item General Health Questionnaire (GHQ-12; Goldberg and Williams, 1988). This 12-item instrument is a

self-report measure of psychological morbidity. It is widely used in clinical practice, epidemiological research and for research in psychology. The GHQ-12 is often used to assess general distress. It is designed to cover four identifiable elements of distress: anxiety, depression, social impairment, and hypochondriasis. Each item on the scale has four responses from 'better than usual' to 'much less than usual'. For the purposes of this study the GHQ Likert scoring method 0-1-2-3-4 was chosen as it facilitates an assessment of symptom severity (GL Assessment). The scores are summed up by adding all the items on the scale ranging from 0 to 36. A higher score is indicative of higher levels of psychological distress. The instrument is one of the most thoroughly tested instruments on reliability and validity and has been identified as one of the leading examples of how health measures should be developed (McDowell, Newell, 1996).

The DCS, GHQ-12 and FPCS were completed by the family member identified as the best interest decision maker for the nursing home resident with dementia. Participating family members received a questionnaire pack and stamped-addressed-envelope via mail, these measures were completed at baseline and again, six weeks later (see Appendix Nine).

Additional measures included the Quality of Dying in Long-Term Care (QOD-LTC) questionnaire (Munn et al, 2007). This questionnaire was designed to be completed by either a family member or staff member of a resident who has died in a nursing home, residential facility or assisted living facility. The QOD-LTC contains 11 items,

possible scores range from 11 - 60, with higher scores indicating positive ratings. The instrument includes three domains: Closure (3 items); Preparatory tasks prior to death (3 items); and, Personhood (5 items). The internal consistency of the measure is good (Cronbach's alpha, 0.66) and it demonstrated good content validity as it covers multiple domains relevant to palliative care (Parker and Hodkinson, 2011).

The QOD-LTC measure was completed by healthcare professionals. When a participant with advanced dementia died, the nursing home manager identified the providers who were most responsible for the resident's care at the end of life (approximately three individuals). Providers were asked to complete the form in the week after the death of the resident. These assessments were pooled to describe the quality of resident comfort at the end of life. The questionnaire was mailed to the designated family member. However, during the study only a small number of residents (n = 6) died. Bereavement questionnaires were completed by four family members (3 intervention carers and 1 carer from the usual care arm of the study) and only one professional returned a bereavement questionnaire (from the usual care arm of the study). Therefore, on statistical advice, neither summary nor comparative statistics are reported here.

A review of nursing home records was undertaken during the six month period following the intervention. This information was collected by administrators from participating nursing homes who were able to extract information from routinely recorded information (e.g. number of hospitalizations, emergency transfers to

hospitals (A & E), ambulance calls, place of death and, care received in the nursing home or hospital).

In addition, the ACP nurse facilitator maintained a log of activities completed and time allocated to tasks during the delivery of the intervention (see Appendix Ten). The log also included a reflective account of the facilitator's experiences of delivering the intervention and her experience of completing ACP with family members.

Qualitative

Family carers were informed at commencement of the study that on completion of both quantitative components they would be offered the opportunity of an individual interview with a member of the research team. It was explained in the interview invitation letter (see Appendix Eleven) that this interview would provide them with an opportunity to openly discuss their lived experience of being a carer for a family member with dementia who resided in a care home, and to also help provide a greater understanding of the impact of acting as a best interest decision maker for a family member. This invite was mailed by the research team along with a participant information sheet and response slip (see Appendix Eleven). Through completion of a mailed response slip they were then contacted to arrange an interview at a time and location most convenient to them. In total, 20 family carers were interviewed (intervention group n = 12, usual care n = 8) before it was clear that data saturation had been reached and additional interviews would provide no further information.

A semi-structured interview schedule (developed from the literature, consultation with the research team and the study advisory committee) guided discussion around

- 1) The pressures and responsibilities of being a carer for a family member living with dementia both before and after admission to a care home
- 2) The experiences of making decisions on goals of care for a family member; conflict or disagreements with health care staff regarding their relative's current and future care needs
- 3) How valued and understood they felt as a primary carer by the health care staff
- 4) What elements they believed could be changed and examples of good practice in their nursing home/other homes to improve the experience of a carer who was the decision maker for a family member's goals of care.

All interviews with the family carers (See Appendix Twelve) took place in their relative's nursing home in a private room with minimal disruption. They lasted on average 30 minutes, were conducted in a sensitive manner and, were audio recorded with the participants consent. All participants were provided with a support sheet (see Appendix Thirteen) detailing support and counselling services to contact if they felt this was needed.

In addition, a qualitative interview was undertaken with the ACP Facilitator and with Nursing Home Managers (intervention group n=5, usual care n=5) in order to identify

and explore aspects of feasibility and acceptability relating to the ACP intervention. Each participant was interviewed face-to-face in their place of work by one member of the study team (GC). A semi-structured interview approach was used as it allowed specific topics to be explored with each participant. Key questions asked of all participants related to barriers in implementing the ACP intervention as well as the feasibility and acceptability of the intervention as a means to facilitate ACP within a nursing home setting.

ANALYSIS

Quantitative

For the quantitative data, frequencies were determined for categorical variables and summary statistics (using mean and standard deviation for approximately symmetrical variables) were calculated for quantitative variables. The primary analysis for the continuous outcomes was conducted using a two-stage method, using meta-analysis models, recommended for the analysis of paired cluster randomized trials (Thompson et al, 1997). In the first instance, for each outcome, analysis of covariance was used to calculate the difference in mean (and accompanying standard error) between the intervention and control group adjusting for baseline (Vickers and Altman, 2001) within the 11 pairs of homes. This difference in mean (and standard error) was then pooled using a random effects meta-analysis model to calculate the pooled difference in mean and 95% CI.(Thompson, Pyke et al. 1997) Chi-squared tests were conducted and I^2 statistics (measuring the proportion of the variation in the treatment estimate due to

heterogeneity) were calculated to determine the consistency of the treatment effect across the paired clusters (Higgins et al, 2003).

Secondary outcomes based upon proportions which had small cell counts (e.g. hospitalisations, DNRs and place of death) were analysed by calculating the proportion at the home level and then using a Wilcoxon-signed rank test to compared these proportions between the intervention and control groups.(Donner and Klar, 2000). A separate sensitivity analysis, recommended for missing outcome data when a baseline is available (Groenwold et al, 2012), was conducted for the primary outcome measure. Specifically, within the pairs of homes a covariate adjusted complete-case analysis was conducted with variables included in the model (specifically age, gender and FAST score) which could be associated with outcome or probability of missingness and the random effects meta-analysis model was used to pool these estimates as previously (not reported as estimates were similar to the main analysis). All analyses were conducted in STATA 14 (StataCorp, 2015).

Qualitative

For qualitative data, semi-structured interviews were transcribed verbatim and transferred to QSR NVivo 11. In this study we sought to generate qualitative data that would provide a better understanding of the lived experiences of best interest decision makers as they made decisions on behalf of their family member living with advanced dementia. We further sought to explore the views of the ACP facilitator

and Nursing Home Managers regarding the feasibility and acceptability of implementing the intervention within a Nursing Home setting. Data were subjected to a thematic analysis (Hayes, 2000; Braun and Clarke, 2006) a method of analysis that is particularly suited to the exploration of relatively unknown fields of enquiry. Thematic analysis may be used to identify, compare, contrast and make sense of themes within transcribed data (Taylor and Ussher, 2001). Employing thematic analysis allowed the examination of participants' thoughts experiences and views of reality through a detailed examination of their expressed thoughts and, as such, allows the analyst access to their 'internal world' (Burman and Parker, 1993). Analysis was aided through the use of a recognised framework (Braun and Clarke, 1983). To ensure validity and rigor, transcripts were also independently analysed by one other team member (DMcL) and agreement on themes reached through discussion (Denzin and Lincoln, 2005).

Ethics

Ethical approval was obtained from the regional Office of Research Ethics Committees Northern Ireland (ORECNI) (Ref. 14/NI/0082) and the Queen's University Belfast Research Governance Office (See Appendix Fourteen). Participants were provided with an information pack and provided their written, informed consent before taking part in the study (e.g. see Appendices Five and Eight).

Data Protection

Codes for the residents, family members, staff members, and nursing homes were used on all documents relating to the study. Codes linking staff members and family carers with nursing homes, and for identifying the nursing homes themselves, were kept separate from the other data collection forms and locked in a filing cabinet in the research office located in the School of Nursing and Midwifery, Queen's University Belfast. Only members of the research staff had access to these codes. Digital recordings of qualitative interviews did not use nursing home names or participant names. Participants were provided with information on confidentiality and anonymity prior to providing their written informed consent. Information which would allow the reader to identify individuals or nursing homes was removed during transcription. Data were entered and stored on password-protected computers.

RESULTS

Quantitative

Subsequent to pilot testing, 24 homes were randomized before baseline data collection. One nursing home in the usual care group withdrew from the study prior to family carers being contacted because of competing workload priorities and the inability to accommodate the project. Participants were recruited from January 2015 until September 2015.

Figure 1 reveals that 695 family carers were eligible to participate in the trial: 38 were removed from the study as their mailing address was incorrect or their family member had either recently died or were discharged prior to the mailing of baseline questionnaires. This resulted in an adjusted sample of 657 family carers who were mailed the baseline questionnaire. The overall response rate in the initial baseline mail-out was 197 (30%), 36% response rate in the usual care group and 24% for the intervention group.

In the intervention group 67 (84%) of the 80 individuals who completed the baseline questionnaire also completed the intervention with 61 family carers completing the follow-up questionnaire (Figure 1). In the usual care group 117 family carers completed the baseline questionnaire and 98 (84%) family carers completing the follow-up questionnaire.

Table 2 shows the characteristics for family carers and their relative residing in the nursing home. Most family carers were identified as daughters of the resident and most residents were identified as having moderately severe to, severe dementia.

ACP family meetings were delivered to 67 out of 80 participants who completed the baseline questionnaire in the intervention group (Figure 1). On average the meetings lasted 60 minutes. Most family carers attended the family meetings on their own 69% (n= 46) but typically reported that they consulted with family members between the meetings. ACP facilitator time for each family encounter was on

average 130 minutes, including administration, conducting the meetings, drafting an ACP and liaising with nursing home staff.

Family carers identified preferences for future care that typically included their relative be kept pain free and in comfort; non-essential medication should be discontinued; their relative to be able to die in the nursing home; availability of religious support; nursing home staff to provide the resident with emotional support in the family's absence and, to notify the family when the resident's condition deteriorated. Family carers specified that they wanted to be consulted on decisions concerning transfer to a hospital to avoid unnecessary hospitalizations; to avoid life prolonging measures if there was little or no significant hope of improving quality of life; and for those family residents who had completed a DNR in place that their wishes would be honoured and resuscitation was avoided.

Decisional Conflict scale

An examination of the total mean score and sub-scores of the DCS at baseline (T1) and follow-up (T2) in the intervention and control groups suggests evidence of effectiveness (Table 3). There was evidence of a difference between the intervention and usual care group on the total DCS score at 7 weeks after adjusting for baseline (-10.5, 95% confidence interval (CI) -16.4 to -4.7; $p < 0.001$).

There was marked heterogeneity in the association across the 11 pairs of homes ($I^2=58\%$, heterogeneity $p = 0.01$). On closer inspection (see Figure 2), this was largely due to a larger effect in Pair 2. After omitting Pair 2 from the overall analysis, the effect remained (-8.4, 95% CI -13.1 to -3.7; $p = 0.001$) and the heterogeneity was reduced ($I^2=32\%$, heterogeneity $p = 0.15$). Evidence of differences between the intervention and usual care group on all subscales of the DCS (Table 3) were also revealed.

General Health Questionnaire and Family Perceptions of Care Scale

Table 4 reports the findings for the secondary outcomes GHQ and the FPCS at T1 and T2. There was little evidence of a difference between the intervention and usual care group on the total GHQ score at 7 weeks after adjusting for baseline scores. This result was fairly consistent across pairs ($I^2=26\%$, heterogeneity $p= 0.19$). There was evidence of a difference in the total FPCS total score between the intervention and usual care group after adjusting for baseline measurement (8.6, 95% CI 2.3 to 14.8; $p = 0.01$), which was also fairly consistent across pairs ($I^2=14\%$, heterogeneity $p= 0.31$). Total FPCS scores are calculated by summing the measure's four subscales. The significant difference in total score noted here was largely the result of significant changes to two of these subscales: 'Family Support' and 'Communication'.

Table 5 shows the increase in DNRs, and reductions in hospital admissions and deaths in the intervention group compared with the usual care group but none of

these differences were statistically significant. While there was a reduction in admissions in the ACP group of around 11% (7% versus 18%) we cannot rule out the possibility of a Type 2 error i.e. that there are reductions in hospital admissions but we did not detect them as statistically significant.

Qualitative – the experience of family carers

Under an overarching theme of 'Transitions of Care' four underpinning themes were identified to reflect the experience of family carers responsible for the decision-making of a relative living with advanced dementia (Table 6).

Impact of caring for someone living with dementia

This theme relates to the personal impact of caring and coping, together with the individual experiences of being a decision-maker for someone living with dementia.

The carers spoke of the enduring emotional stress they had or were continuing to experience. One respondent expressed their family's reaction to the diagnosis and the long-term implications:

“...the day mummy was diagnosed . . . my sister said to me that she wishes mummy had been diagnosed with cancer, would've been easier...and I though how awful, how could you say that? And now [I] know exactly what she means . . . it's so true, it's far harder for the people . . . far harder for the family, mummy's content, she's in her own wee world” (R01)

The conveyed stresses of the respondents' situations were perpetuated by significant mental and emotional exhaustion and of the inability to relax, with one individual remarking that they had not had a holiday for five years. For some, their

circumstance became too much for them to endure unfortunately leading to an over-reliance on alcohol. Nonetheless, it was clearly revealed by the respondents that the loss of the person that they once knew was the most debilitating aspect; it was described as caring for someone who resembled the person they remembered but agonisingly that was where the similarity ended:

“...she’s in this horrible limbo state and has been for a long time where she’s neither dead nor alive” (R19)

Additionally, guilt was deemed to have a powerful influence on the carer, one respondent was very remorseful in saying that being deceitful to their relative was the only way to get their relative into care.

The experience of being a substitute decision maker was noted to be a significant responsibility, with some recognising that this role was a natural progression for them as they had previously been the major decision maker, or in fact they were the only relative. For others due to family circumstances or having a medical background, without discussion delegation became their responsibility. Subsequent decision-making rationales were a reflection of the carer’s personal circumstance, one family used a risk management approach, but ultimately the feeling of loyalty and responsibility for relatives was strong amongst all the respondents.

Ensuring the safety of their relative was a key feature in the decision for transition to a nursing home. This was coupled with the inability of the carer to no longer provide the level and intensity of care required, so the best interest choice was formal care

provision. For some this circumstance arose from a hospitalisation from their own home due to a medical emergency or because the situation was no longer manageable and the risk too great. The impact of transition into a nursing home was described as a combination of guilt, relief and for some carers continued anxiety:

“she’s literally out of the house, she’s out of my sight, she’s out of my control...and I find that really difficult” (R19)

There was a sense of failing their relative, amplified with sadness of handing their care over to someone else. For another individual they described that following what was initially a particularly difficult transition for them that ultimately they realised how content their relative had become which helped to lessen their distress. This reduction of anxiety over time was common among the carers. For most, the recognition that their relative was safe, happy, reasonably content and well looked after, helped to appease anxieties.

Differing levels and sources of support

This theme highlights the levels of formal and informal support networks or resources available to the carers and their effectiveness.

For some carers their first line of support was through their family and friends. However for others this was not an option with previous friendship networks collapsing or strained relationships with family members causing conflict:

“It’s painful to watch someone completely change. And it’s isolating because . . . we’d a big circle of friends and slowly but surely everything just disappeared. People came, kept calling for a little while and then one by one they faded away” (R05).

“I know that I can’t talk to him [brother] . . . because I know there’s this belief that she doesn’t have an illness that warrants her being here 24-7” (R04).

Within the nursing home environment friendships were also noted to naturally develop with other residents and their families, nonetheless the inevitability of the resident dying was a sad consequence of such a relationship:

“I establish friendships with them and I’m talking about the relatives, it’s very hard when somebody passes along because you go to the funeral you say goodbye and its almost [like] the grieving starts again . . .you take on the sadness for the other person” (R19).

The nursing home staff were also recognised and commended for their support by some carers. It was felt that the staff and affiliated GPs recognised the role of the carers; in particular the continual communication with updates and feedback on the resident’s care was welcomed. Even so, due to an alleged frequent turnover and shortage of staff, confidence with this line of support was diminishing for some.

The discussion of having access to family forums within the nursing home was appealing, one respondent noted that their nursing home manager held such events giving the opportunity of open questioning and peer support. Nonetheless, ambivalence remained highlighting that individual needs of the person reflected the support sought.

Incidences of poor support as a reflection of conflict with some health care providers were also revealed. Prior to admission to the nursing home, perceived meagre

social support and deceit were reported. Health care professionals unfamiliar with the family and the resident's individual wishes were also noted to cause unnecessary anxiety. Additionally, in one case poor communication from a consultant resulted in a self-diagnosis of dementia as no information was forthcoming with the presumption instead that they were already aware. Despite these negative reports, recognition of excellent compassionate care were given alluding to social workers, GPs, nurses and formal carers.

Outside support resources from the community or charitable organisations were a key feature for some carers. A reliance on neighbours or being members of a close community gave reassurance of their relative's safety when they were not present. Volunteering with the Alzheimer's Society was seen as a rewarding and supportive experience, although some carer's reported that they were hesitant to approach them as their relative had not been diagnosed with Alzheimer's disease. Unfortunately, a sense of disillusionment of where to seek help was also reported:

“...there isn't an advice centre you can go and have a chat . . . where do you go, it's not citizen's advice, it's not cruse bereavement” (R14).

Knowledge and understanding

This theme encapsulates the level of awareness for the characteristics of the illness, including the availability of education and training for carers and health care staff, and the systems and processes in place for end of life care discussions.

Past experience of caring for another relative with dementia was the foundation of knowledge for some carers and also in some instances for the resident. Some had a medical or nursing background which aided their understanding; nonetheless in general the perception was there was a distinct lack of awareness of the disease:

“dementia starts as this mental illness and then becomes a physical one, again ye don’t know it until ye go down that road . . . I just don’t think there is enough awareness of this horrendous illness” (R19).

Educating family carers about dementia was a key opinion; it was felt that improving knowledge would allow some anticipation of the disease’s progression:

“I don’t think some of the stuff you need to know is easily available and I think the more anybody can do to further the knowledge and the understanding so you get there quicker and sort things out as soon as you can to give that person the best quality of life they can have [the better]” (R13).

The level of training completed by the staff caring for relatives was also questioned. Some were particularly perturbed by the discontinuity of staff and their perceived lack of expertise with dementia:

“make sure that the staff they do . . . have been properly trained, not trained on the job but go through . . . an intensive week . . . give them some idea because they haven’t a clue about dementia (R20).

Decisions with regards to goals of care for the end of life was a topic that, for the majority of respondents, hadn’t previously been discussed. Naivety and a lack of understanding of the disease progression were reasons given for not approaching such discussions but, it was also considered a somewhat taboo matter. Some carers commented that they did try to broach the subject with their relative but without success, resulting with decisions being made on their behalf:

“we tried to talk to mummy about what care she would like further down the line, but she never discuss it . . . she just wouldn’t get into that conversation...and I suppose just when we had to start making those decisions mummy was beyond having any input really in it” (R01).

Family members also commented that nursing home staff had not discussed end-of-life care with them. It was felt to be a topic that was avoided and there was uncertainty whether this was a reflection of the care home staffs’ knowledge and training. Family members who had been able to discuss end of life choices with their relative and or with healthcare staff, believed it had made best interest decision making much easier. For others, such conversations held before diagnosis or by following their relative’s personal philosophies allowed self-assured choices to be made.

Experience of health care environment

This theme demonstrates the carers’ experiences of care for their relative in both the hospital and nursing home environments.

When the carers spoke of their experiences of hospitalisation of their relative they spoke of significant stress not just for them but also their relative. Disorientation was a primary cause of concern; one individual spoke of an admission to the Emergency Department and expressed the distress they felt at witnessing their relative so upset due to their heightened confusion. This anxiety was further increased for others following admission to what they referred as a “normal ward” (R12) in their case a medical ward, where they felt the necessary experience for caring for someone with

dementia was lacking. Furthermore the humorous reactions of other patients in a ward due to their relative's behaviour left one carer feeling very distraught. Concern was also raised at unnecessary hospitalisations believing it to be a default action of some out-of-hours doctors and staff to avoid blame.

“Whenever they have a problem it's all so easy to ring the out-of-hours doctor, who ships them up to A and E . . . that's a massive problem area for families and their loved ones . . . but they still send them up, somebody from out-of-hours who doesn't want the responsibility” (R14).

Within the nursing home environment the concerns with regards to turnover of staff affecting the continuity of care had implications on the perceived quality of care provided, and also was noted to cause some residents undue anxiety. As such there was a desire for more interaction between the staff and the residents, however it was recognised that for a lot of the staff their first language wasn't the national language and this had perceived implications for communication with the carers and also their relatives. Nonetheless, examples of good practice were discussed, recognising the loving, family-like care received.

Qualitative – views on the acceptability and feasibility of the ACP intervention.

Themes relating to the acceptability and feasibility of implementing the ACP intervention within the nursing home setting have been grouped separately. In terms of acceptability, themes were grouped under three main headings: education and support for family carers; Continuing Professional Development (CPD) and enhanced training for nursing home staff; and, communication and shared decision making allowing family centred care. In relation to the feasibility of the intervention,

themes were grouped under four main areas: nursing home staff's willingness to enhance knowledge and skills; background experience of nursing staff and their capacity to fulfil the ACP role; communication and shared decision making; and finally, resource constraints.

Acceptability – education and support for family carers.

Nursing home managers believed that a major element limiting the acceptability of an ACP intervention was that the majority of family carers had an inadequate knowledge of dementia. In particular, relatives, even those with medical backgrounds, were unaware of the likely trajectory of the illness or that dementia should be treated as a palliative condition. Nursing home managers believed that this lack of knowledge was a potential barrier to end-of-life discussions and the acceptability of the ACP intervention. The lack of awareness in family members also acted as a barrier to nursing home staff who, in some instances, were reluctant to have ACP discussions with family members as there was a presumption that, it could potentially contribute to upsetting the family member.

“I think it was a subject that none of the families would have had broached, because their family member may have a diagnosis of dementia but they may present as being quite well at the minute and quite often our nurses will wait until they are near the end of life before they broach this subject” (Nursing Home Manager #26).

“Nobody had ever discussed dementia with them [family carers], they didn't really know what stage their loved one was at or they didn't really know about the stages of dementia. They really didn't understand how the resident would

deteriorate with the dementia....nobody had ever taken time to talk to them about advanced care planning”. (ACP Nurse Facilitator).

Healthcare professionals reported that the Comfort Care Booklet had been useful in providing clear information to family members about the likely trajectory of dementia and the types of challenges that may be encountered as the disease progressed. The provision of the Comfort Care Booklet prior to the family conference was seen as an important element of the intervention although, it was felt that for some family members, the information contained in the booklet could be upsetting.

“It’s quite a difficult subject for families sometimes to think about so it is, I think that was breaking ground for the families, in having the booklet to read first because I’m sure people do have a lot of questions then...” (Nursing Home Manager #26).

“Some people found themselves crying and having to set it down. And some people thought that everything that was in the booklet was actually going to happen. Some people just couldn’t think that their loved one was ever going to reach that stage, so again, they were in denial of the illness. But they found the booklet very easy to understand, it answered all the questions that they would never have thought to ask nursing staff.” (ACP facilitator).

Nursing home managers reported that often, a family member’s lack of knowledge about dementia allowed them to carry on with their daily lives without acknowledging the reality that their relative would continue to decline. Whilst being unaware or denying the likely course of the illness may provide some comfort to carers, it consequently left some unprepared to participate in a discussion about ACP.

“A lot of people are not ready for the notion that their mother or father or aunty or uncle might die..... and so sometimes they need a wee session where they can have some food for thought and then they can come back with their ideas at the second meeting...” (Nursing Home Manager #6).

[We have carers who say] “I don’t know anything about dementia, she didn’t know what the progression of the condition is...a lot of people say they know dementia affects their... memory. They don’t realize that they forget how to eat, they’re going to forget how to walk, they forget how to do the basic things. So, they don’t know what the progression of the disease is, so just even to have that Comfort Care Booklet that would say that this is the reality of the condition” (Nursing Home Manager #18).

Acceptability – continued professional development and enhanced training for nursing home staff.

Nursing home managers recognised that facilitating ACP discussions with family members would not be considered to be a part of normal routine care in the majority of nursing homes. Managers recognised that providing this type of care would be challenging for many of their staff who may not have the knowledge or communication skills required to undertake the role. Managers felt that experienced staff members could be trained to undertake an ACP facilitation role but that this would require additional training in both dementia and communication skills.

“I think the training for staff is very important. I think that we could benefit from more in depth training in end-of-life care; it’s hard to source that training at times. Communication is key, obviously in this very difficult situation with families and every nurse would approach that situation in a different manner. But knowing what to say, the way to say it and how to work with compassion means a lot” (Nursing Home Manager #26).

“I think you could have a lead in ACP, someone who has more specialised training and knowledge and give them extra time to meet with the families...” (Nursing Home Manager #20).

Respondents recognised that facilitating ACP discussions was a specialist role that needed to be developed within the nursing home setting. Respondents believed that to successfully undertake this role a facilitator required specialist skills and knowledge. Integral to the success of the current ACP intervention was the manner in which it had been configured as it was centred on the needs of the patient and their family members. In particular, this intervention allowed the facilitator to contact families to build rapport, provide information using the Comfort Care Booklet and sit with families for up to an hour to discuss ACP and answer questions, before following up with families to discuss the care plan and ensure that family members agreed with the proposed ACP. Managers felt that this type of measured approach to such a sensitive topic was fundamental to the success of the discussions.

“It is very important that you understand the illness of dementia and caring for the dementia client and also, what the relative requires... You have to have the experience of being able to talk to people, but not only just talk to them, but actually listen to them and take on board what they are saying as well” (ACP Facilitator).

“I think that the project nurse [ACP facilitator] was an outside person coming in and she had time for them [family carers], she very nicely set up meetings, telephoned them first then arranged to meet at their convenience...and not put them under pressure, so I think that was excellent” (Nursing Home Manager #26).

Acceptability – communication and shared decision making allowing family centred care.

Nursing home managers believed that the ACP intervention had created an environment where the facilitator could actively listen to family members allowing an open exchange of information in a neutral setting. Consequently this empowered the family members to speak candidly about the future care of their relative. These open discussions gave the facilitator the opportunity to gain a greater understanding of the families' concerns allowing them to respond to family members' fears in a manner which contributed to shared decision making, This process was seen to be beneficial and was reassuring to the family member as they contemplated the future care of the resident.

“So to us it's about having that plan. It gives reassurance to families, they know where we are going, and it gives reassurance to us that we also know the families wishes and the patient's wishes going forward. I think it benefits both parties a lot” (Nursing Home Manager #16).

“With the research you have targets...it was really helpful, it is more person centred, they agree really well to the person's preferences and the families as well” (Nursing Home Manager #5).

Feasibility – Nursing Home staff willingness to enhance knowledge and skills

Nursing Home Managers recognised that in order to implement this model of ACP within their working environment there was a need to adjust 'normal' working practice within the nursing home. One element required to drive this change was that all staff needed to have sufficient motivation and opportunity to enhance their current knowledge and skills. Managers recognised that there was great diversity within

their nursing staff in terms of knowledge and experience, and they acknowledged that additional training would be required to ensure that existing staff members could undertake ACP discussions effectively.

“I have staff here who are long-standing and are very highly skilled but then I’ve newly qualified staff who need to gain experience and it’s sometimes sourcing that training that is difficult” Nursing Home Manager #26.

“I think we could do better but where do you get the time and how do you get everybody on board?” Nursing Home Manager #1.

Feasibility – Experience and capabilities of nurse to fulfil the ACP role

There was a clear recognition that having experience in working with residents and their families was an essential element in undertaking ACP. Managers acknowledged that some staff members were more comfortable in undertaking these discussions than others, and that ACP was a sensitive subject which needed to be tailored to the needs of each individual situation.

“It’s very important that you [understand] the illness and the caring of the dementia [resident]” (ACP Facilitator).

The managers also believed that the timing of discussions was extremely important in encouraging family members to engage in the ACP process. Although educating family members on the likely trajectory of the disease was essential, managers had a variety of opinions as to when the ACP discussions should take place with family members.

“Some nurses...through experience are much more comfortable with doing it [end-of-life discussions] so it’s sort of trying to get everybody up to that

level...How do you say to somebody on their first day ...how are we going to bury them?" Nursing Home Manager #20.

"The resuscitation bit, we don't usually discuss it right there and then on admission, it takes a couple of days or months, even years sometimes!"
Nursing Home Manager #5.

"I think on admission or soon after admission, you know? To meet them and discuss, I know it's hard especially when somebody is walking and minimal care is needed, nobody's thinking, 'Oh they're going to die', but ... it's better to have a discussion with the relatives after the admission, probably after a couple of weeks or a couple of months" Nursing Home Manager #19.

Feasibility – Communication and Shared Decision Making

Nursing Home Managers recognised that it was important for an ACP facilitator to be able to build a trusting relationship with the resident's family, and stressed the importance of listening to family members during the ACP discussion. Again, managers felt that some members of staff potentially could find this aspect of the facilitator's role easier than others. Nonetheless, it was felt to be essential in order to facilitate shared decision making and ensuring that family members recognised their contribution to the decision making process.

"Every client you met had a story to tell and yes, you listened to it and it's sad...so although your family conference was only an hour...then you did another follow up with them to make sure that what I had written in the care plan they were happy with" (ACP Facilitator).

"The documentation was excellent that was provided. It was excellent for families to take part as well, it opened their mind-set up to – this is what is going to happen in the future and we have very clearly been able to our wishes and views for what we want for our family" Nursing Home Manager #26.

Feasibility – Resourcing constraints

Although respondents were positive about ACP they recognised that implementing this intervention in a nursing home setting could be challenging due to resource constraints. Managers reported that staffing levels were stretched and, with staff attending to the day-to-day care of residents, there was little spare capacity to undertake ACP discussions. Managers also recognised that the model of ACP intervention employed in this study could be time consuming and it could potentially be difficult to release staff from their normal routine. Furthermore, nursing home managers reported that often, ACP would be carried out in combination with colleagues in General Practice and again, due to their workload, it was not always possible for GPs to participate in ACP discussions.

“The way Advanced Care Planning was being done [in this nursing home] was GP led so it was. Our difficulty is that our GPs don’t have time to do ACP” (Nursing Home Manager #26).

“...adding this stuff to the nurses workload would be too much” (Nursing Home Manager #5).

“The way our staffing levels are at the minute and time constraints? I don’t know like...everywhere’s the same. You’re working on limited staff. You’re up against it with staff absences and stuff and, with the best will in the world and the best staff in the world...would it ever be done? I think you need to have one person focusing on it all the time” (Nursing Home Manager #1).

DISCUSSION

Quantitative findings

Our study evaluated an ACP model with five elements identified as essential to successful care planning; a trained ACP facilitator; family education; family meetings; documentation of ACP decisions; and, orientation of GPs and nursing home staff to the intervention.

In this mixed-methods cluster randomized trial, the ACP intervention significantly reduced family carer uncertainty in decision-making concerning the care of the family member and improved family carer satisfaction in nursing home care. However the intervention did not have a detectable impact on family carer psychological distress; the number of completed DNRs; reduced hospitalisations; or, number of deaths in a hospital.

Flo et al (2016) conducted a review of ACP in nursing homes and reported that most studies had tested different interventions, with staff education being the most common (learning courses and practical training). While most studies targeted nursing home staff for education, some interventions similar to ours, focused on providing information and education to family carers regarding the terminal nature of dementia. As was the case in our study, most previous studies did not use nursing home residents as study informants. Those studies that did include residents excluded those with advanced dementia.

The challenge of recruiting family carers in this type of research is noteworthy. In our case, the cross-sectional approach to recruitment generated low initial response from family carers. This observation highlights what is recognized in the literature, that successful ACP engagement, is predicated on the initiation of a health care provider who is engaged in a trusting relationship and who recognizes the importance of timing when to initiate ACP discussions (Mullick,et al, 2013).

The booklet that we used for family carer education 'Comfort care at the end of life for persons with Alzheimer's Disease or other Degenerative Diseases of the Brain' has been shown through multi-country studies to have high levels of acceptability among family carers, nurses and physicians (van der Steen et al, 2011b; Arcand et al, 2013; van der Steen et al, 2012) and the WHO has identified the booklet as a best practice instrument (World Health Organisation, 2011). The tools used in previous ACP intervention studies have been diverse. However, it was commonly viewed across studies, as in our work, that ACP is a decision-making process. Flo et al (2016) further noted variation across studies on the level of formalization of the ACP conversation and its documentation. In our study, family meetings were implemented using a standardized approach based on clinical practice guidelines (Hudson et al, 2009). Embedded in this structure the ACP facilitator employed therapeutic communication that included empathy and active listening. Furthermore, advance care plan documentation was also standardized.

A recent systematic review by Robinson et al (2012) identified four ACP intervention studies for patients with cognitive impairment or dementia. All of these were completed in nursing homes with the focus of the intervention on end-of-life decisions made by family carers. Unlike Hanson et al (2005) who reported a significant increase in DNR orders, our study did not have an impact on DNR completion. In the Molloy et al study (1996) advance directives were completed more often in the intervention group compared with the control group however, the level of statistical significance was not reported. Morrison et al (2005) reported significant increases in the intervention group in documentation of preferences of care, which included resuscitation, artificial nutrition, intravenous antibiotics and hospitalisation. Unlike our study, two studies (Sampson et al, 2011a; Caplan et al, 2006) reported statistical significant reductions in hospitalisations. The heterogeneity of outcome measures used in these studies prevented further comparison with our study and those reported by Robinson et al (2012).

In an attempt to extend autonomy for the person living with dementia who does not have decisional capacity to determine goals of care, current practice is to rely on family carers as best interest decision makers. Despite the widespread acceptance of this practice, the presence of family carer stress and conflict around the 'right' decision makes the decision-making process challenging (Shalowitz et al, 2006). A further concern is the accuracy of the best interest decision makers in predicting the decisions patients would have made if they still had decisional capacity (e.g. Shalowitz et al, 2006; Ditto et al, 2001; Perkins 2007; Vig et al, 2007). A systematic

review on the accuracy of Best Interest Decision Makers predicting patient treatment preferences revealed an overall 68% accuracy, decreasing to 58% when the patient's health state was dementia (Shalowitz et al, 2006). The concerns regarding accuracy in decision-making shifts the importance of ACP as a means to support best-interest decision-making, where consideration is whether a decision is the least restrictive of a person's right or freedom (Vig et al, 2007). Despite these concerns, family carers acting as Best Interest Decision Makers remains the best method for implementing substituted judgement. These observations encourage the use of strategies by clinicians to support the decision maker before, during and after decision-making that can facilitate the patient's best-interests, thereby reducing stress and conflict (Vig et al, 2007).

The quantitative component of our study has both strength and limitations. We showed that the intervention was successful for the target population. An important feature of our study was that participants were offered a standardized ACP approach allowing for generation of a detailed description of the intervention and its implementation. Explicit details on the model and its operation facilitates the opportunity to disseminate the model to other nursing home settings. Another important strength of our study is the use of cluster randomization of nursing homes to avoid contamination between participants in the intervention and control groups. The paired nature of our design also allowed the balancing of potential confounding variables to ensure similarity between groups. We also utilised internationally recognized and widely used outcome instruments.

Our study has some limitations. One limitation was the inability to blind the allocation between randomization and data collection. Nursing homes had to be randomized before we collected baseline data, which reduced the internal validity of the study, as did the lack of blinding for follow-up data. This complex intervention also had the potential to be influenced by local cultural and systematic factors. The accuracy of nursing home reports of DNR, hospitalisations and location of death was dependent on nursing home manager access to records and also thorough routine record keeping. However, despite this we believe that our model of ACP is likely to be generalizable to other nursing homes and has international importance given the emerging agenda for ACP in the nursing home setting. While the study did not include an economic analysis it did record time spent by the ACP facilitator on a family case basis. This information can be used to estimate manpower costs and inform the commissioning of business cases.

Qualitative Findings – the views of family carers

The findings of this study provide insights into the transitions and experiences of family carers responsible for decision making on behalf of a relative living with advanced dementia within a nursing home. We were also able to interview Nursing Home Managers to discuss the acceptability and feasibility of implementing this model of ACP in a nursing home environment. These insights provide key messages which can inform practice, family carer and formal carer education, and further research.

Impact of caring for someone living with dementia

Similar to previous international research, with other family carers in end of life care, participants in this study had experienced carer burden which appeared to affect them on a whole person level (Hudson and Hayman-White 2006, Payne, Hudson et al. 2010, Hudson, Thomas et al. 2011). This indicates the need for family carers of people with dementia to equally be offered holistic care and support including that within the nursing home setting. At a European level this holistic support required by family carers is a key recommendation within a European Association of Palliative Care White Paper which defines best practice in palliative care for people with dementia (van der Steen, Radbruch et al. 2014). In this study carer burden was generated by family members being unable to get away from the constant stress and responsibility of caring for their relative with dementia, resulting in them having to find their own and sometimes adverse ways of coping such as using alcohol. Central to this carer burden, stress was one key experience reported by participants. This was the feeling of premature loss which they experienced as their family member with dementia irreversibly changed, due to cognitive impairment, and was no longer the person that they had previously known and loved. This finding has implications for nursing home staff caring for and supporting people on a dementia trajectory, and their families. It highlights that this family carer population may be exposed to loss and bereavement in perhaps a different and earlier way than family carers of people on other end of life disease trajectories (e.g. Garand et al, 2012; Holley and Mast, 2009)

Caring for someone living with dementia also meant making decisions on their behalf and this added to the stress and responsibility which participants felt. A recent systematic review focusing on proxy decision making by family carers of people with dementia reveals the distress which this family caregiving population can experience in making decisions for their relative, and the need for increased support from health care professionals to facilitate this process (Lord, Livingston et al. 2015). Some participants in this study felt isolated due to a lack of other family members with whom they could share decisions, whilst others felt that their family members relied on them to make the right decisions due to their nursing knowledge. It was also apparent that there was a lack of previous discussion around end of life issues and decisions on goals of care with family members, which suggests a need for on-going training of professionals and also more preparedness and education of family members of people with dementia. The findings of this study suggest that 'best interest decisions' made by family carers of people with dementia can start with the decision for their relative to be transferred to a nursing home. Whilst this decision was a challenging one which could generate guilt, sadness and anxiety (Lord, Livingston et al. 2015) for some participants this was a decision based on a safety rationale and as something which was for the benefit of the person with dementia and in their best interests.

Differing levels and sources of support

Participants reported different levels of support and help which they had experienced. Some participants talked about a supportive family network which they drew solace from whilst difficult family dynamics were experienced by other family carers. It was obvious that strong peer support could naturally occur with family members of residents within the nursing home. These friendships were valued, but could also cause pain through a sharing of loss between family carers of different residents within a nursing home when a death of a resident occurred, and family carers from the home took part in death rituals such as attending the funeral. Nonetheless, the concept of family forums within nursing homes was thought by participants to be something which could be valuable and this resonates with the peer support from other family carers which participants experienced. This naturally developed peer support experienced and articulated by family carers of people with dementia has implications for the mode of delivery of family carer palliative care psychoeducational care within nursing homes. A systematic review of family carer interventions in a palliative care context highlights the need for more robust empirical work to determine novel and carefully designed strategies which best support and help family carers in different contexts (Hudson et al, 2010). The findings of this study suggest that for family carers of people with dementia residing in nursing homes psychoeducational care interventions, containing facilitated peer support, should be designed and evaluated. Given the complex, distressing and challenging best interest decision making which these family carers are required to partake in,

this concept of facilitated peer support embedded within group psychoeducational care could be of value.

Partnership working between family carers and nursing home staff was appreciated by most participants who felt that their role as a carer of a resident with dementia was validated and recognised in that they were consulted and informed about what was happening. Shared decision making with family carers, and with the person with dementia where possible, is a key aspect of recognised international practice in palliative care provision for this population (van der Steen et al, 2014). Whilst there were also positive accounts of support received from formal carers prior to their relative's admission to the nursing home, some participants reported a lack of support and information and were unsure where to obtain help. They also reported anxieties which had arisen when formal carers were not familiar with them or the wishes of their relative.

Knowledge and understanding

There was diversity in the level of knowledge and understanding of the dementia disease trajectory and how to care for someone with this condition. A few participants talked about transferable knowledge and skills from previous experience of caring for someone with dementia or from being able to draw from nurse training and experience. Overall amongst participants an apparent lack of knowledge and dementia awareness emerged, highlighting again a need for family carer education and the provision of anticipatory guidance to promote a better sense of

preparedness for this caring role and for the best interest decision making which had to take place. In particular the need for family carer education in relation to the disease progression and appropriate, non-aggressive treatment options for people with dementia has been recognised (van der Steen et al, 2014). A recent ethnographic study in the United Kingdom evidences that both family carer and formal carer education on dementia disease progression is needed to promote conversations about end of life (Saini, Sampson et al. 2016). There is also a responsibility for formal carers to sensitively normalise discussions about dying to enable appropriate care planning and decision making (Black, Fogarty et al. 2009).

There was also a perceived lack of dementia knowledge and skills around caring for people with dementia amongst nursing home staff. Participants in this study felt that more education and training needed to be targeted at formal carers within the nursing home setting to develop their competence in caring for this population. This requires education underpinned by recognised domains of best practice in palliative care provision for people with dementia and their family carers (van der Steen, Radbruch et al. 2014). There is evidence from a Canadian study that health care professionals who are able to demonstrate knowledge and expertise can more effectively initiate discussion and facilitate decision making with family carers of people with dementia (Torke, Schwartz et al. 2013). It is also known that family carers need a whole family approach to consult with and be reassured following a best interest decision (Livingston, Leavey et al. 2010). Some participants commented that no staff from the nursing home had engaged in an end of life care

discussion with them in relation to their family member which further supports the need for palliative and end of life training in nursing home settings, both for formal and informal carers. However, it is noteworthy that the high turnover and attrition of nursing home staff makes palliative and end of life care competency acquisition for formal carers challenging in this setting.

Participants perceived a lack of discussion and openness about end of life issues among family carers themselves and also with the resident prior to their nursing home admission. Being able to have an early discussion with their relative about end of life issues made things easier and meant that their relative's wishes and preferences were known. However, best interest decisions were mostly required as an early end of life care discussion with the family member living with dementia had not taken place or had not been successful.

Experience of health care environment

Family carers who took part in this study talked about their experience of care for their relative in the hospital and in the nursing home environment. Unscheduled hospital admissions were perceived to cause distress and anxiety to the person with dementia and their family carers, due to the unfamiliar environment, and the perceived lack of preparedness and dementia awareness, of formal carers in this setting (Alzheimer's Society 2009, Guijarro, San Roman et al. 2010, Sampson 2010). This highlights the need for nursing home staff to develop known evidence based anticipating care strategies to reduce the risk of unscheduled hospital admissions of

people with dementia from nursing homes (Brumley, Enguidanos et al. 2007, Wright, Zhang et al. 2008, Schweitzer, Blankenstein et al. 2009, Wowchuk, Wilson et al. 2009).

Examples of good practice were heralded in the nursing home setting relating to person centred quality care, but concerns were raised about staff attrition causing a lack of continuity of care and affecting the quality of care, as perceived by family carers. Family carers expressed a desire for better interaction between formal carers in the nursing home and residents. However, they also recognised that here challenges could exist given that many of the staff in nursing homes do not have the national language as their first language.

Qualitative Findings – the views of Nursing Home Managers.

In this study we interviewed Nursing Home Managers to establish their views on the practice of providing ACP for residents with dementia. The issues identified provide some insight into the acceptability and feasibility of implementing ACP within nursing homes and illustrate the changes to working culture and practices that may be required to improve the acceptability of ACP initiatives and ensure their successful implementation.

Managers recognised that a barrier to successfully implementing ACP was the lack of understanding about the nature of dementia demonstrated by both nursing home

staff and carers. A failure to recognise the chronic and progressive nature of the disease led to complacency regarding planning end-of-life care. Nursing Home Managers felt this contributed to difficulties in timing ACP discussions as to do so when someone appeared well was potentially upsetting for family members and leaving discussions too late resulted in residents being unable to participate due to cognitive decline. This study demonstrates both the feasibility and potential benefits of having open communication between healthcare professionals and family members regarding end-of-life care. Where possible, these discussions should take place at an early time point and be incorporated into policy and practice within the home as an extension of routine person-centred care.

Similar to previous studies, managers believed that many family members preferred to live in denial of the disease and did not want to face the reality of their family member's illness (Flo et al, 2016; Gilissen et al, 2017). Managers reported that the Comfort Care Booklet, was a useful resource to inform family members about dementia although, they recognised that for many carers, the information provided may be upsetting. Managers believed that providing information about dementia would help family members to engage in the ACP process as it would be viewed as a necessary process to help ensure the adherence of care preferences at the end-of-life. Our findings highlight the value of the Comfort Care Booklet and the ACP process however, this information should be provided to family members in the context of ongoing education and emotional support designed to help prepare them for the potential changes that will occur with advanced dementia.

This study, similar to previous research (e.g. Gilissen et al, 2017) illustrates that to facilitate ACP discussions, nursing home staff need to be knowledgeable, have good communication skills and have the confidence to undertake this process. There was recognition that current variation in knowledge and skills within nursing staff would impact on the consistent practice of providing ACP. Managers also believed that many staff members were reluctant to initiate ACP conversations as they felt ACP was contrary to normal routine therapeutic practices and that this process may place an undue burden on the family member. Overcoming this barrier requires a change in the way people view ACP and, similar to previous studies, managers recognised that to initiate a change of culture within nursing homes required a knowledgeable staff team who acknowledge the importance and potential benefits of ACP, and the importance of integrating this into the culture of the home as an extension of routine care (Harrison Dening et al, 2016; Gilissen et al, 2017).

Limitations

Those who completed the individual interviews were a self-selected sample, 12 of which were exposed to an Advance Care Planning intervention which may have guided the respondents thinking. However, their specific responses to this intervention were not incorporated in the reported results.

CONCLUSIONS

This paired cluster randomized trial indicates that it is feasible to implement an ACP intervention in dementia care nursing homes with effective outcomes. Implications for clinicians and policy makers include recognizing the importance of improving communication between family carers and formal care providers who are involved in resident nursing home care. Secondly, family carer education is essential to enable family carers to weigh the burden or benefit of treatment options when the family member enters the late stages of dementia. Furthermore, ACP needs to become part of the usual nursing home care involving various formal care providers such as the resident's GP and nursing home staff. In conclusion, it should be recognized that the approach pursued in cultivating and supporting sustainable ACP expertise will be shaped by broader nursing home conditions and should be accounted for in practice and policy deliberations. The qualitative element of the study aimed to explore the experiences of family carers responsible for decision making on behalf of a relative living with advanced dementia and Nursing Home Managers views on implementing an ACP intervention. Findings have implications for practice and education and suggest the development of family carer psychoeducational care interventions, with embedded facilitated peer support, to help prepare this population for best interest decisions. Given the global impact of dementia (World Health Organisation 2012), and the fact that most people with dementia receive end of life care in nursing homes (NICE, 2006; Mitchell et al, 2004), the findings of this study have international applicability for the nursing home setting across the world.

Key findings for further investigation are to hold goals of care decision-making earlier in the dementia disease trajectory; recognise influence of family dynamics; improve knowledge to facilitate informed decision-making, and communication with and between staff.

Pathways to Impact

Despite the importance afforded to ACP in policy documents, there is currently limited UK-based evidence to guide policy makers and service planners on the provision of ACP for people with dementia living in nursing homes and their families (Exley et al, 2009; Robinson et al, 2010). While many nursing homes have policies encouraging the development of advanced care plans, practice appears to be variable, particularly in relation to residents with dementia (Stewart et al, 2011).

We engaged in a collaborative research process where Patient and Public Involvement and consultation with a major provider of private nursing home care was key to formulating the research questions and developing the intervention. This process was undertaken to ensure the relevance of the project to policy makers, service providers, residents with dementia and their families, both locally and further afield.

To ensure our findings reach an appropriate audience we have engaged on a series of knowledge translation activities including: reporting findings to participants (see Appendix six); providing summary findings to nursing home managers and staff; publishing papers summarising the study in academic journals (Brazil et al, 2017a; Carter et al, 2017; Brazil et al, 2017b; Carter et al, 2016; Brazil et al, 2015); and, to promote collaboration between the research team and the policy and practitioner community.

We were also mindful of the national and international significance of our study and engaged in a series of conference presentations to disseminate our findings widely amongst academics and professionals (see below).

In addition, as a direct result of this study and our dissemination activities, staff in the Belfast Health and Social Care Trust are engaging with the research team with a view to using the 'Comfort Care at the end of life for persons with Alzheimer's disease or other degenerative diseases of the brain – a guide for carers' booklet as a decision aid to help family carers make best interest decisions for older people with dementia.

Knowledge Exchange Activities

Publications

BRAZIL, K., CARTER, G., CARDWELL, C., CLARKE, M., HUDSON, P., FROGGATT, K., McLAUGHLIN, D., PASSMORE, P., KERNOHAN, W.G. (2018). Effectiveness of Advance Care Planning with Family Carers in Dementia Nursing Homes: A Paired Cluster Randomized Controlled Trial, *Palliative Medicine*, 32(3); pp 603-612.

CARTER, G., McLAUGHLIN, D., KERNOHAN, G., HUDSON, P., CLARKE, M., FROGGATT, K., PASSMORE, P., BRAZIL, K. (2017). The experiences and preparedness of family carers for best interest decision-making of a relative living with advanced dementia: A qualitative study. *Journal of Advanced Nursing*, (accepted for publication, March 2018).

BRAZIL, K., SCOTT, D. and CARTER, G. (2017a) Identifying the triggers of ethical conflict in the initiation of advance care planning for persons living with dementia in nursing homes. (Paper in preparation).

CARTER G, MCLAUGHLIN D, KERNOHAN G, HUDSON P, CLARKE M, FROGGATT K, PASSMORE A, BRAZIL K. (2016). Transitions experienced by carers on the living-dying journey of a relative with dementia. *Palliative Medicine*, Vol. **30**(6) pp. 201.

BRAZIL K, CARTER G, CLARKE M, FROGGATT K, HUDSON P, KERNOHAN G, MCLAUGHLIN D, PASSMORE A. (2015). Promoting informed decision making on goals of care at the end of life: A study update. *The Journal of Nursing Home Research*, **1** pp. 22

Conferences

BRAZIL K, CARTER G, SCOTT, D. (2017). Identifying *the Triggers of Ethical Conflict in the Initiation of Advanced Care Planning for Persons with Dementia in Nursing Homes*. Paper accepted for oral presentation at International Ethics in Care Conference, Leuven, Belgium. September 15th-16th.

BRAZIL K, CARTER G, CARDWELL, C, CLARKE M, HUDSON P, FROGGATT K, MCLAUGHLIN D, PASSMORE P, AND KERNOHAN G. (2017). *Assessing the Impact of Advance Care Planning in Dementia Nursing Homes*. Oral presentation at EAPC conference, Madrid. May 18th – 20th.

BRAZIL K, CARTER G, MCLAUGHLIN D, KERNOHAN G, HUDSON P, CLARKE M, FROGGATT K, PASSMORE A, & CARDWELL C. (2016). *Considerations on the feasibility & acceptability of an Advance Care Planning intervention for dementia residents in UK care homes*. Poster. 4th Annual Symposium of the Palliative Care Research Network, All Ireland Institute of Hospice and Palliative Care, Dublin, Republic of Ireland. December 7th

BRAZIL K. (2016). *Integrating palliative care into the care for people with advanced dementia*. Paper. Oral presentation. 35th Anniversary Distinguished Lecture Series, Faculty of Medicine, The Chinese University of Hong Kong, Hong Kong. November 16th.

BRAZIL K, CARTER G, MCLAUGHLIN D, KERNOHAN G, HUDSON P, CLARKE M, PASSMORE P. & FROGGATT K. (2016). *Evaluation of an advance care planning intervention in dementia care homes: aspects of feasibility and acceptability*. Poster. Nursing home research international working group, Barcelona, Spain. November 9th – 10th.

BRAZIL K, CARTER G, MCLAUGHLIN D, KERNOHAN G, HUDSON P, CLARKE M, PASSMORE P. & FROGGART K. (2016). *Considerations on the feasibility and acceptability of an advance care planning intervention for dementia residents in UK care homes*. Poster. 12th International congress of the European Union Geriatric Medicine Society, Lisbon, Portugal. November 5th – 7th.

BRAZIL K, CARTER G, MCLAUGHLIN D, KERNOHAN G, HUDSON P, CLARKE M, PASSMORE P. & FROGGART K. (2016). *Overview on an advance care planning (ACP) model for care home residents living with dementia*. Oral presentation. 26th Alzheimer Europe Conference, Copenhagen, Denmark. November 2nd – 3rd.

BRAZIL K, CARTER G, MCLAUGHLIN D, KERNOHAN G, HUDSON P, CLARKE M, FROGGART K, PASSMORE A, & CARDWELL C. (2016) *Overview of an Advance Care Planning (ACP) model for care home residents living with dementia*. Poster. 21st International congress on Palliative Care, Montreal, Canada. October 18th – 21st.

CARTER G, MCLAUGHLIN D, KERNOHAN G, HUDSON P, CLARKE M, FROGGATT K, PASSMORE P & BRAZIL, K. (2016). *Transitions experienced by carers travelling on the journey of a relative with dementia*. Poster. Alzheimer's Society Research Conference, Bristol UK. June 30th

CARTER G, MCLAUGHLIN D, KERNOHAN G, HUDSON P, CLARKE M, FROGGATT K, PASSMORE P, & BRAZIL, K. (2016). *Transitions experienced by carers on the living-dying journey of a relative with dementia*. Poster. 9th World Research Congress of the European Association for Palliative Care (EAPC) Dublin. June 9th – 11th.

Recommendations for Practice and Policy

- Dementia should be recognised as a terminal illness. People diagnosed with dementia will either die with the illness or die from it and this should inform the development of all policies relating to dementia care.
- There is a need to increase awareness about ACP among the general population. This will facilitate the timely completion of care plans when people

continue to have the capacity to contribute to decisions about their end-of-life care.

- Many people with dementia would prefer a homely and peaceful death.
- There is a pressing need to improve knowledge about ACP among health care professionals who work outside acute hospitals and palliative care.
- There is a need for policies which will help to facilitate the development of effective partnerships between staff based in the community, primary care, palliative care and the nursing home sector.
- Nursing homes should have an explicit policy to guide the provision of end-of-life care for residents with dementia.
- Where possible, nursing home residents with a diagnosis of dementia should not be moved at a crucial point in their care. Nursing home staff, who know the resident best, should be supported and guided in providing appropriate care.
- Nursing home staff report having little formal education in ACP and lack the skills and confidence to engage in end-of-life discussions. There is evidence to suggest that providing structured training to nursing home staff will help them to initiate and complete ACPs with residents who have dementia.
- ACP discussions should be sufficiently detailed to allow a person with dementia and/or their family to communicate clearly their end-of-life care preferences. Any ACP intervention should provide guidance in how to initiate and engage in ACP discussions, how to systematically document this process and, how to share this information with all relevant stakeholders.

- A range of education programmes and tools have been developed to help nursing homes deliver improved end-of-life care. However, these programmes need to be evaluated, particularly in relation to people with dementia and their families.
- Family carers value transparency and good communication. It is important that family members are kept informed and, where appropriate, be included in the ACP process.
- Care home managers should examine patient records for evidence of an ACP. Where none exists, residents should be offered the opportunity to complete an ACP discussion and have their wishes recorded. Not all residents will want to take part and participation should be left to the discretion of the resident and/or their family.
- Nursing home managers should recognise that engaging in ACP discussions with residents may have a psychological impact on their staff. There is a need to provide adequate training and ensure that supports are in place to help staff in this task.

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Declaration of conflicting interests

All authors declare: no support from any organization for the submitted work; no financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

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Tables and Figures

Table 1 Study Objectives, Measures and Timing of Data Collection

Study Objectives	Measures	Timing
Improved satisfaction in decision making	Decisional Conflict Scale (DCS)	Completed by family member on baseline, 6 weeks
Reduced family carer anxiety and depression	General Health Questionnaire (GHQ-12)	Completed by family member on baseline, 6 weeks
Quality of the dying experience for the resident at the end of life - assessed by staff and family member	Quality of Dying in Long-Term Care (QOD-LTC)	Completed by care staff within one week retrospective of resident death Mailed to family member 4 weeks retrospective of resident death
Assess the intervention's ability to increase family satisfaction with nursing home care.	Family Perception of Care Scale (FPCS)	Completed by family member on baseline, 6 weeks
Health care utilization (hospitalizations, transfers to A&E, ambulance calls)	Facility administrative records	6 months post-intervention
Examine feasibility of implementing and sustaining the intervention in nursing homes Explore family carers experience as SDM	Individual interviews with health care providers and family carers	12 months
Record of ACP nurse facilitator direct and indirect intervention activities	ACP Nurse facilitator log	Maintained by ACP nurse during the intervention period.
ACP facilitator journal of experience	ACP Nurse facilitator's reflections on her experience of delivering the intervention	Maintained by ACP nurse during the intervention period.

Table 2. Respondents' characteristics at baseline. Values are numbers (percentages).

Characteristics	As randomised		Included in main analysis	
	Intervention (n = 79)	Usual Care (n = 117)	Intervention (n = 51)	Usual Care (n = 91)
Gender				
Male	15 (19.0)	45 (38.5)	8(15.7)	34(37.4)
Female	64 (81.0)	72 (61.5)	43(84.3)	57(62.6)
Age				
Mean (SD)	61.6 (11.8)	59.9 (10.6)	61.6(11.6)	60.3(11.0)
Range n(%)				
18-30	1 (1.3)	0 (0.0)	1(2.0)	0(0.0)
31-40	2 (2.5)	3 (2.6)	1(2.0)	3(3.3)
41-50	9 (11.4)	17(14.5)	5(9.8)	12(13.2)
51-60	21 (26.6)	39 (33.3)	15(29.4)	33(36.3)
61-70	26 (32.9)	24 (20.5)	17(33.3)	17(18.7)
71-80	8 (10.1)	18 (15.4)	3(5.9)	17(18.7)
81-90	5 (6.3)	2 (1.7)	4(7.8)	2(2.2)
Relationship of care home resident				
Parent	44 (55.7)	70 (59.8)	28(54.9)	53(58.2)
Spouse	12 (15.2)	20 (17.1)	7(13.7)	16(17.6)
Sibling	5 (6.3)	6 (5.1)	4(7.8)	6(6.6)
Extended family	18 (22.8)	20 (17.1)	12(23.5)	15(16.5)
FAST Score				
Mild dementia	2(2.5)	2(1.7)	1(2.0)	2(2.2)
Moderate dementia	2(2.5)	4(3.4)	1(2.0)	3(3.3)
Moderately severe dementia	49 (62.0)	54 (46.2)	34(66.7)	45(49.5)
Severe dementia	26 (32.9)	57 (48.7)	15(28.4)	41(45.1)

FAST: Functional Assessment Staging Tool.

Table 3. Comparison of primary outcome decisional conflict scale (DCS) between the control and intervention group.

Primary Outcomes	Time	Control		Intervention		Difference in mean ^b (95% CI)	P	I ² (hetero P)
		n ^a	mean (SD)	n ^a	mean (SD)			
Total DCS Score	T1 ^c	91	34.7(21.0)	51	28.3(22.3)			
	T2 ^d	91	30.7(20.5)	51	18.3(19.7)	-10.5(-16.4, -4.7)	<0.001	58% (0.01)
DCS Subscore: Informed	T1	94	39.5(26.2)	56	33.8(26.0)			
	T2	94	37.4(25.7)	56	20.2(22.7)	-15.0(-22.0, -8.0)	<0.001	58% (0.01)
DCS Subscore: Values clarity	T1	94	36.2(24.8)	55	33.2(28.3)			
	T2	94	32.5(24.0)	55	21.2(25.2)	-12.8(-24.1, -1.6)	0.03	75% (<0.01)
DCS Subscore: Support	T1	95	31.6(21.5)	55	26.8(24.2)			
	T2	95	27.4(20.9)	55	17.1(19.5)	-7.7(-12.9, -2.5)	<0.001	16% (0.29)
DCS Subscore: Uncertainty	T1	94	38.2(22.2)	54	34.4(27.5)			
	T2	94	31.8(21.2)	54	21.6(21.6)	-8.3(-14.5, -2.2)	0.01	34% (0.13)
DCS Subscore: Effective decision	T1	94	29.6(21.7)	54	24.4(22.1)			
	T2	94	25.8(19.7)	54	16.8(21.0)	-7.3(-11.5, -3.0)	<0.001	1% (0.44)

^aNumbers only include those who contribute at both time points.

^bPooled difference in mean adjusting for baseline, summarized at pair home level and pooled across homes using meta-analysis.

^cTime 1 baseline.

^dTime 2 follow-up.

Table 4. Comparison of secondary outcomes General Health Questionnaire (GHQ) and Family Perception of Care Scale (FPCS) between intervention and control group.

Secondary outcomes	Time	Control		Intervention		Difference in mean ^b (95% CI)	P	I ² (hetero P)
		n ^a	mean (SD)	n ^a	mean (SD)			
Total GHQ Score	T1 ^c	88	12.6(6.1)	55	11.4(5.3)			
	T2 ^d	88	11.6(5.4)	55	9.9(6.1)	-0.5(-1.9, 0.8)	0.44	26% (0.19)
Total FPCS Score	T1	88	131.0(22.9)	42	138.0(21.4)			
	T2	88	133.6(23.8)	42	144.6(25.6)	8.6(2.3, 14.8)	0.01	14% (0.31)
FPCS Subscale: Resident Care	T1	91	59.1(11.3)	46	61.6(10.6)			
	T2	91	60.1(11.4)	46	63.6(12.3)	2.1(-0.5, 4.7)	0.11	9% (0.36)
FPCS Subscale: Family Support	T1	91	26.8(7.1)	45	28.7(7.1)			
	T2	91	28.2(7.3)	45	32.7(7.2)	3.9(1.7, 6.1)	<0.001	16% (0.29)
FPCS Subscale: Communication	T1	96	33.1(5.2)	52	34.3(6.9)			
	T2	96	33.2(5.4)	52	35.6(6.9)	2.2(0.8, 3.6)	<0.001	27% (0.19)
FPCS Subscale: Rooming	T1	95	12.2(1.8)	56	12.9(1.2)			
	T2	95	12.2(1.9)	56	12.7(1.9)	0.3(-0.2, 0.9)	0.21	31% (0.15)

^a Numbers only include those who contribute at both time points.

^b Pooled difference in mean adjusting for baseline, summarized at pair home level and pooled across homes using meta-analysis.

^c Time 1 baseline.

^d Time 2 follow-up.

Table 5. Do Not Resuscitate orders (DNRs), hospitalizations and location of death.

	Usual Care	Intervention	P ^a
No. of completed DNRs ^b	23 (42%) ^c	21 (51%)	0.18
Hospital admissions ^b	17 (18%)	5 (7%)	0.12
Location of death ^b :			
Nursing home	24 (80%)	12 (86%)	
Hospital	6 (20%)	2 (14%)	0.94

DNR: Do Not Resuscitate.

^aP-value based upon a Wilcoxon sign rank comparison of paired home proportions.

^bDuring 6 months after last point of contact with study.

^cOut of people on whom DNR information was available and were know not to have a DNR at the start of the study.

Table 6 .Underpinning themes and categories.

Underpinning Themes	Categories
1. Impact of caring for someone living with dementia	<ul style="list-style-type: none">▪ Impact on health and well-being of carer▪ Experience of being a substitute decision-maker▪ Best interest decision-making
2. Differing levels and sources of support	<ul style="list-style-type: none">▪ Family and friends▪ Nursing home partnership working with families▪ Other Healthcare Professionals▪ Outside resources
3. Knowledge and understanding	<ul style="list-style-type: none">▪ Characteristics of the illness▪ Education and training▪ Systems and processes for end of life care discussions
4. Experience of health care environment	<ul style="list-style-type: none">▪ Hospital environment▪ Nursing home environment

Figure 1. CONSORT flow diagram

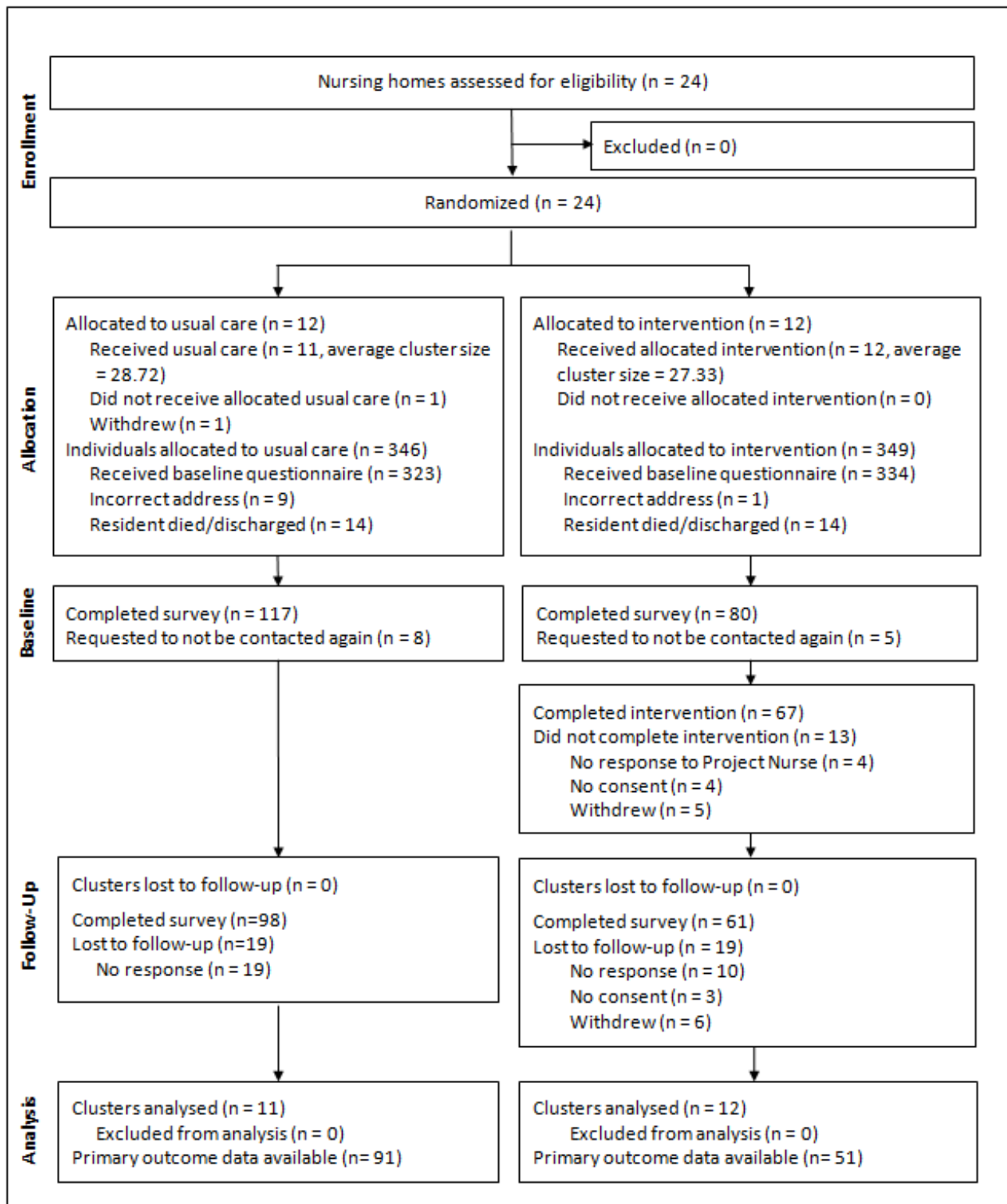
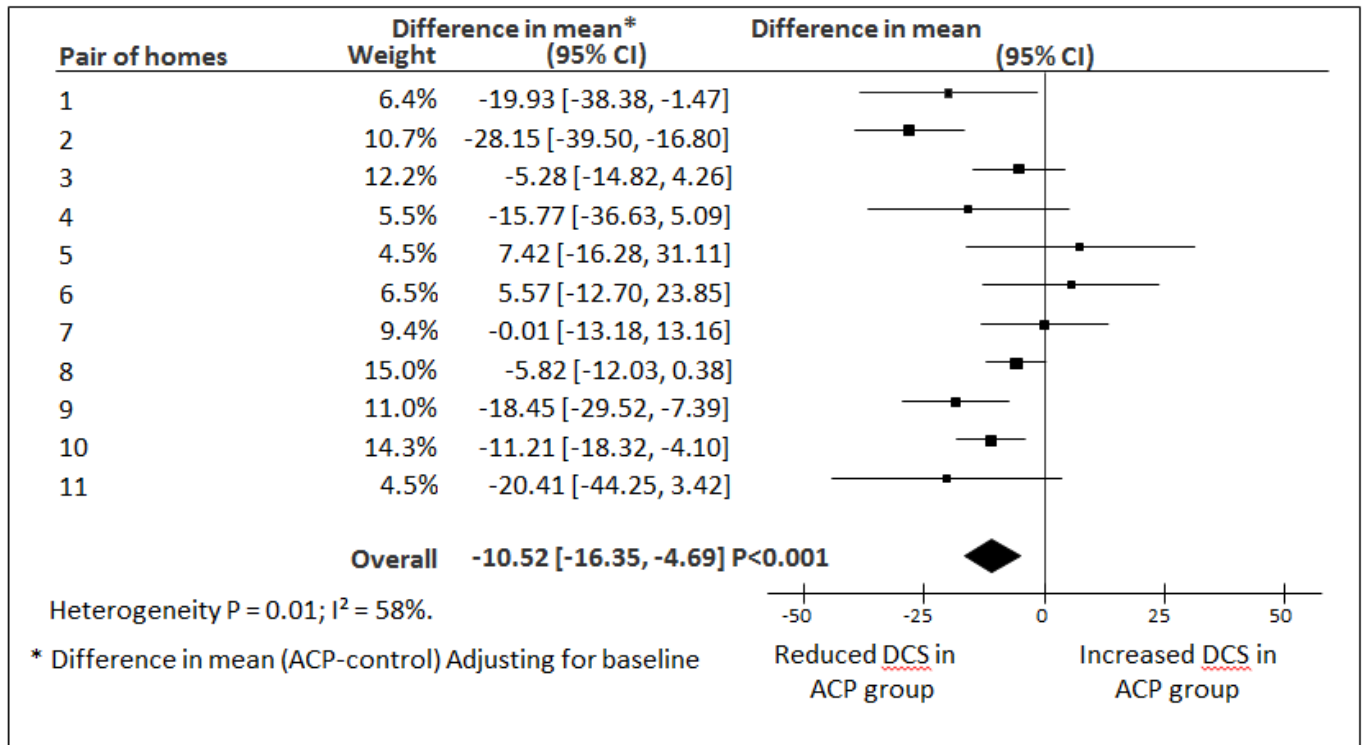


Figure 2. Comparison of Decision Conflict Scale (DCS) by pairs of homes
DCS: Decision Conflict Scale



Appendices

Appendix One

ACP Nurse Facilitator Job Specification



Job Details

Position:	Nurse Facilitator for Advance Care Planning (ACP)
School/Department:	School of Nursing and Midwifery
Reference:	TBC
Closing Date:	TBC
Salary:	£22,900 – £26,000 Depending on experience
Anticipated Interview Date:	TBC
Duration:	14 months

JOB PURPOSE:

The Nurse Facilitator for ACP will be engaged in an experimental trial which will assess the implementation and impact of an advance care planning intervention for people living with dementia residing in nursing homes in Northern Ireland. It is anticipated that the study will provide evidence towards the development of practice in nursing homes that will support family carers in decisions that will promote person-centred care for individuals living with dementia.

Informal Enquiries may be directed to Prof Kevin Brazil (k.brazil@qub.ac.uk).

MAJOR DUTIES:

1. Complete online training in the 'Respecting Choices Facilitator Curriculum' – a program consisting of a series of six critical thinking modules designed for healthcare professionals to enhance ACP facilitation skills
2. Conduct family conferences to review contents of a booklet 'Comfort Care at the End of Life for persons with Alzheimer's Disease or other Degenerative Diseases of the Brain'
3. Assist participants at family conferences to reflect on resident goals, values and beliefs
4. Discuss and document end of life care options including life prolonging treatments and cardiopulmonary resuscitation
5. Documentation of ACP decisions generated from family conferences
6. Conduct follow-up meetings/telephone interviews with designated family carers
7. Provide orientation and education opportunities for nursing home administrators, GPs and nursing staff on the role of the ACP family meeting
8. Maintain a journal of direct and indirect intervention activities, including a narrative of the experience of delivering the intervention
9. Provide on-going maintenance and storage of secure research documentation
10. Carry out routine administrative activities as requested
11. Present regular progress reports on research to members of the research group

12. Such other duties as may be reasonably required, within the remit of the post.

Planning and Organising:

1. Plan own day-to-day activity within the framework of the agreed research programme.

Resource Management Responsibilities:

1. Ensure research resources are used in an effective and efficient manner
2. Provide guidance as required to support staff and any students who may assist in the research.

Internal and External Relationships:

1. Liaise with research colleagues and support staff on routine matters
2. Work collaboratively with community partners
3. Attend and contribute to relevant meetings.

ESSENTIAL CRITERIA:

1. Band 5 or 6 Registered Nurse
2. Minimum of three years post registration experience
3. Minimum of two years working in a field relative to palliative care
4. Ability to demonstrate good knowledge and skills in communicating sensitively and supportively with families and patients in a palliative care context
5. Have training or willingness to undertake training in Advanced Communication Skills and Advance Care Planning
6. Ability to communicate complex information clearly
7. Ability to work as a team member
8. Demonstrates intellectual ability and ability to manage resources
9. Good IT skills in particular using online resources, and Microsoft Office Word and PowerPoint
10. Ability to facilitate group discussions
11. Experience of planning, delivering and evaluating information
12. Oral and written presentation skills
13. The ability and willingness to travel locally.

DESIRABLE CRITERIA:

1. Experience working within a nursing home environment.

Appendix Two

The Comfort Care Booklet (Northern Ireland Version)

Comfort Care AT THE END OF LIFE FOR PERSONS WITH DEMENTIA



A Guide for Caregivers
(Northern Ireland Version)



THIS GUIDE IS INTENDED FOR CAREGIVERS OF A PERSON WHOSE HEALTH HAS BEEN SEVERELY AFFECTED BY DEMENTIA.

A COMMON ELEMENT IN THIS DISEASE IS THAT THE PERSON INCREASINGLY HAS DIFFICULTY SPEAKING AND UNDERSTANDING REALITY IN TERMS OF WHAT IS HAPPENING AROUND THEM, THUS MAKING IT DIFFICULT FOR THE INDIVIDUAL TO PARTICIPATE IN MEDICAL DECISIONS THAT CONCERN THEM. CONSEQUENTLY, WHEN A COMPLICATION OR A NEW HEALTH PROBLEM OCCURS, EITHER THE SPOUSE, CHILD OR SOMEONE CLOSE TO THE SICK PERSON MUST REPRESENT THEM DURING DISCUSSIONS WITH THE CAREGIVING TEAM WHEN DECISIONS ARE MADE ABOUT HOW MUCH CARE SHOULD BE PROVIDED. THIS IS A SENSITIVE TASK FOR WHICH YOU, AND MOST FAMILY MEMBERS OR NEXT OF KIN MAY NOT BE PREPARED.

THE PURPOSE OF THIS GUIDE IS TO PROVIDE YOU WITH BASIC INFORMATION SO THAT YOU CAN HAVE A BETTER UNDERSTANDING OF HOW THE ILLNESS PROGRESSES TOWARD THE FINAL STAGES OF LIFE. AS WELL, IT PROVIDES YOU WITH INFORMATION ABOUT AN APPROACH TO CARE WHICH ENSURES ABOVE ALL A COMFORTABLE END OF LIFE. WE HOPE THAT THIS INFORMATION WILL BE HELPFUL AND GIVE YOU PEACE OF MIND DURING THIS DIFFICULT PERIOD.



Natural

Evolution of dementia

WHAT IS THE PATH LEADING TO THE END OF LIFE LIKE FOR THOSE SUFFERING FROM DEMENTIA?

In the later stages of life, the two main medical problems connected to this illness is trouble eating and repeated infections.

The most frequent cause of death is pneumonia, for which there are multiple causes. First, most of these illnesses are accompanied by increasing eating problems. Affected persons often choke on their food because it enters the wrong passage. More particularly, saliva or food enters the lungs instead of the stomach, leading to coughing spells and trouble breathing. Some people who are very ill may not have the strength to cough and will have tremendous difficulty breathing. Eventually, most patients will develop what is called aspiration pneumonia. Even if the pneumonia is treated successfully, it will likely re-occur if the individual continues to have difficulty swallowing.

At the same time, the individual will lose weight and become increasingly dehydrated, meaning that the body will have a lower volume of liquid because of difficulty swallowing. As a result, the individual will become weaker and increase their likelihood of developing further complications such as pneumonia or urinary tract infections.

WHAT CAN CAREGIVERS DO WHEN THE SICK PERSON CAN NO LONGER EAT OR DRINK?

The first thing that nursing and medical staff do is trace the cause of the eating problem and attempt to correct it. In some cases, the individual can be helped (i.e., when there is a mouth infection or a problem with a medication). However, in the later stages of life, some individuals refuse to swallow for a number of reasons. They may not be hungry or their food might not taste very good. They may also be afraid of choking, may simply be unable to open their mouths, or may have lost the ability to swallow.

The caregiving team uses a number of approaches when dealing with eating problems. The most frequent strategy is to provide food in a thickened form, such as purées (food that has been mashed up or put through a blender) and thickened liquids, which are easier to swallow. To enrich the diet or simply to meet hunger needs, food supplements are also provided (i.e., Ensure, Resource, and so on). These supplements are usually accepted by patients and can replace a portion of the meal.

However, as the illness progresses, these strategies become less and less effective. The question then arises as to whether the patient should continue to be fed and hydrated (provided liquids) orally or through a feeding tube inserted directly into their stomach. A feeding tube is helpful for people who are lucid and who still enjoy a certain quality of life or who hope to recover their normal eating habits after a period of rehabilitation.

WHAT CAN CAREGIVERS DO WHEN THE SICK PERSON CAN NO LONGER EAT OR DRINK?

... continued

This approach, however, is not recommended for individuals who are at the advanced stages of dementia for the following reasons:

- ◇ The process of inserting a tube into the stomach is uncomfortable and can cause distress;
- ◇ Feedings with a feeding tube can lead to severe diarrhoea;
- ◇ The feeding tube can become blocked and therefore have to be changed regularly;
- ◇ Individuals who are confused will often try to pull out the feeding tube;
- ◇ The pleasure of tasting food provided through a feeding tube is eliminated, and the individual misses out on the social contact that they normally would have with the caregiver at mealtime;
- ◇ Moreover, the use of a feeding tube has not been found to lead to a longer life in the advanced stage of dementia. This is because aspiration pneumonia frequently occurs at this stage, even among people with feeding tubes.

For the above-mentioned reasons, it is not recommended that doctors insert a feeding tube in an individual with a degenerative illness, whose condition realistically is not expected to improve, or for whom this procedure is likely to cause more discomfort than relief.

WHAT CAN THE CAREGIVING TEAM DO WHEN THE PATIENT DEVELOPS PNEUMONIA?

When a person develops respiratory problems and food or saliva enters the respiratory tract, it is necessary to clear the back of the throat and the breathing passages. To make the person feel more comfortable, it also helps to provide them with oxygen. The doctor can prescribe an antibiotic if the individual develops a fever and if it is judged, from a medical standpoint, that they have pneumonia. However, as mentioned earlier, the chance of recovering from pneumonia in the advanced stages of these types of neurological diseases is limited, and the possibility of this problem re-occurring shortly thereafter is elevated.

Each situation is evaluated on a case-by-case basis. The doctor and the patient's representative must decide whether a curative or palliative care approach such as described further on in this document, is to be taken, keeping in mind the patient's best interest.

SHOULD THE INDIVIDUAL WITH THIS PROBLEM BE TRANSFERRED TO A HOSPITAL?

Transferring a person in an advanced stage of dementia to a hospital may, at times, cause them a great deal of distress. A transfer to an acute care hospital should only be made when it is absolutely necessary, and only for the shortest possible time period. A short hospitalization period is justified under some circumstances, such as for painful fractures that can be stabilized through surgery. Nevertheless, it is generally preferred not to transfer the patient if the problem can be dealt with in the long-term care home with a palliative care approach and good symptom control.



DO DOCTORS ALWAYS CARRY OUT CARDIOPULMONARY RESUSCITATION (A PROCEDURE TO GET THE HEART BEATING AGAIN)?

Most long-term care settings are not equipped for cardiopulmonary resuscitation (CPR), raising the question of whether to carry out this procedure. However, for argument's sake, let's assume that the individual is in a facility that is equipped to carry out this procedure. Would CPR be appropriate under such circumstances? The majority of doctors are of the opinion that more harm than good results from this procedure. First, the likelihood of successfully resuscitating a person in a poor state of health, such as we have described, is extremely limited. On the other hand, the risk of causing injury to the patient is quite elevated (i.e., fracturing the ribs). The likelihood of the person remaining in a coma for the rest of their life is extremely elevated after conducting such a procedure if they were unconscious for a long period of time. These are some of the reasons why it is not recommended that resuscitation procedures be carried out on individuals who are at the advanced stages of brain deterioration.



Decisions

about the end of life

WHO MAKES MEDICAL DECISIONS AT THE END OF LIFE, THE DOCTOR OR THE PATIENT'S REPRESENTATIVE?

It is common practice for caregivers to be faced with the dilemma of preserving life (curative treatment) or ensuring a comfortable end of life (palliative care). It is recommended to take the necessary time to have an open discussion with the doctor and the family. The question that needs to be considered is: "What is the most appropriate thing to do for this person at this time in his or her life?". The ideal situation is one in which everybody agrees on the appropriate course of action for the patient. The family should not be left alone with the burden of having to make such a difficult decision. Ideally, positive relations have been established between the family and the caregiving team well before the last days of life stage. Family members tend to feel more confident when they have been well informed and that their point of view has been respected on past occasions.

WHAT IS THE ROLE OF THE PATIENT'S REPRESENTATIVE IN THE DECISION MAKING PROCESS?

The role of the patient representative is essentially to accept or to refuse the doctor's advice. The person who is the representative must act according to what they

believe is in the patient's best interest. Consent must be informed and provided voluntarily and without constraint; the patient's representative must be informed of treatment options and must not feel that any choice is being imposed upon them.

You should never hesitate to share your questions with staff! When questions or concerns are not expressed, family members are left with unnecessary distress.

WHAT TO DO IN CASE OF CONFLICT OR DOUBT?

Family members occasionally disagree with the doctor's advice or among themselves on deciding upon the appropriate course of action for the patient. The doctor does not have the power to impose a solution upon the family. At the same time, the preferred choice of the patient's representatives can also be contested if it is not in the patient's best interest. What can be done under such circumstances? It is sometimes necessary to arrive at a compromise. For example, one can try out a treatment and evaluate its effects. One can also get a second opinion from another doctor, hold a case conference, use local mediation services or involve an independent advocate. Fortunately, differing points of view between the medical team and the family are rarely settled in court. It is much preferable to find a friendly solution before resorting to tribunals.

IF IT IS DECIDED NOT TO RESORT TO CURATIVE TREATMENT, DOES THIS MEAN THAT THE PATIENT IS LEFT ON THEIR OWN?

In the past, doctors would often tell the family that “nothing more can be done” during the end stage of the illness. Family members often considered this as abandoning the patient, and in spite of good nursing care, viewed it as a very uncomfortable or painful period at the end of life. This way of thinking no longer exists. Inspired by the success of palliative care teams working with patients with cancer, today’s caregiving team plays an important role in providing maximum physical and psychological comfort to the dying person and their family. A number of ways are now available to make this possible, as will be described herein.



UNDER SUCH CIRCUMSTANCES, ARE RELIGIOUS
AUTHORITIES IN AGREEMENT WITH THE
DECISION TO WITHDRAW OR NOT PROVIDE LIFE-
PROLONGING TREATMENT?

To the best of our knowledge, all religious authorities who have addressed these questions consider it morally acceptable to refrain from using life-prolonging measures if there is little or no significant hope of improving the patient's quality of life. If questions should arise, it is recommended that family members take the necessary time to discuss this matter with a representative of their religious or spiritual denomination. Priests, ministers or spiritual counsellors, who are all aware of the patients' problems and the concerns of the caregiving teams, are available in most long-term care facilities and hospitals to address family concerns.



WHAT ARE THE MOST FREQUENT SYMPTOMS AT THE END OF LIFE?

The most frequent symptoms at the end of life are dyspnoea (breathlessness) and pain. Other symptoms include anxiety, agitation and vomiting.

HOW DOES THE CAREGIVING TEAM LOOK AFTER BREATHING PROBLEMS?

Breathing difficulties can have many causes (lung infections, cardiac failure, aspiration of food into the lungs, and so on). Treatment will vary according to the cause of the problem. Morphine is the drug that is generally used to reduce the patient's distress. Certain medications, which can be inhaled through a pump, an inhaler or a mask, can reduce spasms of the breathing tubes or bronchi. This type of breathing problem is similar to an asthmatic reaction. Diuretics (medication to increase the volume of urine produced) may also be necessary when there is heart failure or to eliminate excess water that has accumulated in the lungs.

SHOULD THE PATIENT BE GIVEN ANTIBIOTICS WHEN THEY HAVE AN INFECTION?

In the case of pneumonia, it may be necessary to administer antibiotics if the patient has high fever and purulent secretions (with pus). The dilemma that then arises is deciding whether the pneumonia should be treated or whether the focus should be on ensuring a comfortable end of life. Through discussions with the family, the patient's wishes need to be identified in order to decide upon the most appropriate care to administer. In case of doubt, or when the next of kin cannot be located, some doctors may decide to implement a treatment, and then stop it if it is not effective or if it is no longer desirable.

On the other hand, in the case of certain infections which result in discomfort (i.e., bladder infection), antibiotic therapy may be the best way to provide the patient with rapid relief.



HOW ARE SECRETIONS CONTROLLED WHEN **THEY CAUSE DIFFICULT AND NOISY BREATHING?**

When there is a large quantity of secretions at the back of the throat, caregivers position the patient correctly and administer medications to decrease the formation of new secretions. The medications are usually helpful at the beginning; however, the secretions often become too plentiful or thick, and the patient continues to have noisy respirations. To those near the patient, this type of respiration may seem uncomfortable; however, if the patient is in a coma or if they are receiving enough medication to keep them comfortable, they are unlikely to be aware of the way they are breathing. It may sometimes be necessary to use a suction machine to remove large quantities of secretions from the mouth. Since this can be an unpleasant procedure, it is only carried out when necessary.

IS IT HELPFUL TO PROVIDE OXYGEN?

When the patient has difficulty breathing, oxygen may help reduce certain muscular pains and breathing problems. However, when the end of life is near or if the patient is in a coma, it is reasonable to remove the oxygen so as not to prolong life with the use of technology.

WHAT ARE THE SIGNS OF PAIN IN SOMEONE WHO IS UNABLE TO EXPRESS THEMSELF?

Pain is often difficult to evaluate in someone who is unable to express themselves. Thus one has to observe facial expressions, vocal sounds and the way the patient moves. Do not hesitate to inform nursing staff if you feel that the patient has not received enough pain killers.

HOW CAN PAIN BE RELIEVED?

There are many possible causes of pain, thus it is important to identify the right one. It is especially important that the patient be properly positioned in a comfortable bed. Various medications are available for different types of pain, and sometimes they have to be combined in different ways to be effective. Analgesics i.e. opioids, such as morphine, are definitely the most effective medications to relieve moderate to severe pain. In order to effectively control pain at this stage of the illness, it is preferable to regularly administer analgesia (i.e., every four hours). Additional doses are occasionally prescribed by doctors within the four-hour period so that the patient doesn't wait too long to receive adequate pain relief. Because the body becomes accustomed to certain doses of morphine, the dose has to be increased by the doctor in order to keep it effective.



CAN MORPHINE KILL THE PATIENT?

Many people wrongly believe that it is the last dose of morphine that the patient receives that causes breathing to stop, especially if it is stronger than the others. Patients can tolerate heavier doses of morphine if the strength is gradually adjusted. It is possible that high doses can sometimes lead to death prematurely. Under such circumstances, it is generally understood that if the intent was to provide relief and not to end life, it is morally acceptable to administer the necessary doses. Failing to respond to the patient's needs would ultimately be immoral.

HOW CAN ANXIETY OR AGITATION BE RELIEVED?

It is not always easy to distinguish pain from anxiety when an individual is agitated or unable to rest. That's why experts in palliative care prefer to administer, in addition to morphine, medications for anxiety or hallucinations. These medications, which are highly effective in providing a more comfortable end of life, are usually administered at regular intervals.

I S IT NECESSARY TO ADMINISTER OTHER
MEDICATIONS OR TO VERIFY BLOOD PRESSURE,
TEMPERATURE, BLOOD SUGAR LEVELS, AND SO ON?

The caregiving team also has decisions to make regarding other types of care and treatments for the patient. Towards the end of life, when swallowing difficulties become problematic, it is often preferred and even necessary to stop taking medications orally. Instead, necessary treatments are administered through injections or suppositories. In order to reduce the discomfort of repeated injections, nursing staff insert small catheters under the skin attached to a syringe pump which patients can easily tolerate.

It becomes less relevant to take the patient's temperature and pressure or to verify blood sugar levels as they approach the end of their life, especially when the interventions disturb the person who is sleeping peacefully. On the other hand, nursing care, aimed at maintaining hygiene and care of the skin (to prevent skin breakdown) and mouth, needs to be carried out until the end of life because this contributes to the comfort and the dignity of the dying person.



HOW DOES THE PATIENT FEEL WHEN HE OR SHE IS NO LONGER DRINKING OR EATING?

People who are lucid and who are suffering from cancer or degenerative, neurological diseases say that the feeling of thirst and hunger is not prevalent near the end of life. Most patients refuse all or even small amounts of food that are offered to them and say that they feel a sensation of dryness in the mouth. That's why experts in palliative care have developed products that are effective for treating dryness of the mouth, lips and throat. In terms of nursing care, management of this symptom is given high priority.

On the other hand, an overall lowering of body-fluid levels (dehydration of the body) is not painful in itself. The blood becomes more concentrated and the kidneys gradually operate less and less, eventually stopping their function. All these changes are generally positive for the patient because the perception of pain is lowered as well. In addition, having a lower volume of fluids in the body also means a reduction in the quantity of secretions, thereby making it easier to breathe.

SHOULD INTRAVENOUS FLUIDS BE STARTED?

Some families believe that the patient would be more comfortable with intravenous (IV) fluids known as a 'drip'. Our experience is the total opposite, as IV fluids can result in more secretions in the breathing passages, puts off the onset of the coma, and prolongs the duration of the discomfort.

WHAT TO DO IF THE PERSON ALREADY HAS A FEEDING TUBE?

Even though some might have trouble understanding this concept, experts in the field of ethics consider that the decision to stop tube feedings is essentially the same as not inserting a feeding tube. Thus, after discussing with the family representative, it is possible to stop the tube feeding at any time that it is judged to be in the best interest of the patient. The tube does not need to be removed because the procedure is usually uncomfortable. Although this may seem inhumane, as ethics experts point out, why should people suffer for a longer time than before the advent of current technological advances?

HOW LONG WILL A PERSON WHO IS NO LONGER DRINKING OR EATING LIVE?

When a person is no longer eating or drinking, they will usually keep on living for a few days. However, people who are physically stronger or ingesting liquids when they are receiving mouth care, may live one or two additional weeks. Each case is different, and it may be difficult for the caregiving team to calculate the amount of time remaining at the onset of the end of life phase.



The final

moments

HOW SHOULD YOU BEHAVE WITH SOMEONE WHO APPEARS TO BE UNCONSCIOUS?

The kinds of interventions which appear to help the person who is dying are simple. Touching and holding the person, speaking with a soft voice, or playing music that the individual enjoyed are some of the ways in which the person can be comforted and helped to feel more secure. Whenever possible, family members should make arrangements so that the person is not left alone during the last days of their life. Institutions are increasingly helpful in accommodating family members so that they can spend the night with their loved one. When the family member is elderly or unwell, or if only a few family members are available, talking to the care home staff may identify alternative services such as volunteers in the community who can stay with the dying individual and inform nursing staff if the patient appears to be uncomfortable.

WHAT ARE THE FINAL MOMENTS LIKE?

When the dying person receives comfort care, as described in this guide, death is usually peaceful. Breathing becomes more shallow and irregular. The pauses between breaths become longer and longer. Eventually, the unconscious patient will take one or two deep breaths before exhaling the final one. Many family members and friends who have been present at this time have said that these final moments were much less difficult or upsetting than they had anticipated, and in turn they became reassured about their own eventual death. Most were content to have been with their loved one right up to the end.





After the death


WHAT HAPPENS AFTER DEATH?

A doctor will confirm the death and nursing staff will then prepare the body before the body is taken to the funeral parlour in accordance with the family's wishes. The doctor may seek your approval for a post-mortem, although this will usually have been discussed prior to the death.

The results of the post-mortem could be of significant importance if the patient had an illness that can be traced to their relatives, especially if a treatment becomes available for the disease.

After the death of the person for whom you have cared, you will experience grief in various forms. These reactions can be very different from one person to another. Some people will be surprised to find that they feel more relieved than grief-stricken. This is a normal reaction when death is "timely" after a long illness. You may also feel angry, alone, exhausted and even guilty and need to give yourself some time or to obtain support during this period. If you need counselling or support, certain community services can be of assistance, such as the local Alzheimer's society.





IN THIS GUIDE WE HAVE TRIED TO PROVIDE SOME ANSWERS TO THE SENSITIVE QUESTIONS THAT ARISE AT THE END OF LIFE OF PEOPLE SUFFERING FROM DEMENTIA. IN ORDER FOR THIS STAGE OF THE ILLNESS TO TAKE PLACE IN A SERENE MANNER, IT IS IMPORTANT THAT FAMILY MEMBERS AND NEXT OF KIN HAVE A GOOD UNDERSTANDING OF WHAT THE CAREGIVING TEAM MUST DO. IT IS ALSO ESSENTIAL THAT THE DOCTOR AND NURSING STAFF BE AVAILABLE TO PROVIDE THE NECESSARY INFORMATION AND TAKE THE TIME TO AGREE ABOUT THE TREATMENT THAT SERVES THE BEST INTEREST OF THE PERSON AND RESPECTS THEIR WISHES. GIVEN THAT THE WISHES OF THE PATIENT ARE NOT ALWAYS CLEARLY EXPRESSED ORALLY OR IN WRITING, WE HAVE RECOMMENDED THAT IN CASE OF DOUBT, PALLIATIVE CARE APPROACH, BASED ON PHYSICAL AND PSYCHOLOGICAL COMFORT, BE ORGANISED. THAT'S BECAUSE THE MAJORITY OF PEOPLE PERCEIVE THAT ADVANCED AND PROLONGED DEMENTIA IS WORSE THAN DEATH.

Notes

Developed by Arcand and Caron (2005) *Comfort Care at the End of Life for Persons with Alzheimer's Disease or Other Degenerative Diseases of the Brain—A Guide for Caregivers*: Centre de santé et de services sociaux—institut universitaire de gériatrie de Sherbrooke.

Northern Ireland version adapted by Professor Kevin Brazil and Dr Gillian Carter, Queen's University Belfast, School of Nursing and Midwifery.



Based on the results of a research project sponsored by the Alzheimer Society of Canada.

A Guide for Caregivers



Photographs: www.sxc.hu







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Appendix Three

**Advance Care Plan Documentation:
Example of telephone interview and family
conference template scripts, and
documentation used to record ACP
decisions**

TELEPHONE CONVERSATION

Hello can I speak to *NAME* my name is Violet Graham I am from the School of Nursing & Midwifery at Queens University. I am ringing in connection to you completing the questionnaire that was mailed to you from *NAME OF CARE HOME*. Is it ok to have a quick discussion with you now about this study and the next stage of it?

RESPONSE

Firstly thank you for taking the time to complete the questionnaire it is much appreciated. Just to give you a brief understanding of my role, I am trained to help and assist you in creating an advance care plan for *NAME OF RESIDENT*, to do this I would like to organise a family conference – which is private meeting with myself. At this meeting would you like any other people there? For example *NAME OF RESIDENT GP*, any other health care professionals or family members? It is completely your choice who does or doesn't attend.

RESPONSE

IF YES (THEY DO WANT OTHER(S) TO ATTEND):

Ok I will contact *NAME(S)*, would you like me to contact *NAME OF FAMILY MEMBER/FRIEND* on your behalf as well? Could you give me their contact details?

IF NO (THEY DON'T WANT ANYONE ELSE TO ATTEND):

OK what would be the best day/time of day to suit you to arrange a family conference which will be held in *NAME OF CARE HOME*? In your information sheet it states that the meeting should last for no more than 60 minutes.

IF NOT SURE OF TIMES ARRANGE TO CALL BACK AND DISCUSS TIMINGS

As part of preparing for this discussion I am going to mail you a booklet that explains questions and answers about end of life care for people living with dementia. If you are not happy to read this booklet on your own you are more than welcome to chat to me about the contents of it at the meeting.

RESPONSE

With this booklet there is a blank sheet that if you want to, you can note down any queries or main concerns that you have at the moment about NAME OF RESIDENT future care. Feel free to post this to me before the meeting in the stamped addressed envelope that I'll provide, or if you prefer bring it with you on the day to discuss. Again don't feel that you have to complete this it is just there as an aid to help with any thoughts that you want to write down.

Do you have anything that you would like to ask me at the moment?

RESPONSE

My contact details will be issued with the booklet and feel free to contact me if you have any concerns. But I look forward to meeting you, thank you for your time

Take care

Good bye etc

FAMILY CONFERENCE

Introductions

Hello, my name is Violet Graham it is nice to meet you (all) in person. Today at this meeting I will assist you in making out an advance care plan in relation to how NAME OF RESIDENT would like to be cared for when they are nearing the end stages of life. I will be focusing on how to assist them to live well when they are approaching the end of life.

In general the purpose of a family conference like this is to share information and concerns regarding, for example, a resident's future care, to clarify their goals of care, to discuss their diagnosis, treatment and future health, and ultimately to develop TOGETHER a plan of care for them. As I previously mentioned this meeting can last up to 60 minutes but if you feel that you would like to stop the discussion at any stage just let me know and if you prefer we can arrange another time.

So in this meeting we will discuss a plan of care for NAME OF RESIDENT to live as well as possible as they approach end of life and I will be asking you to discuss NAME OF RESIDENT wishes /preferences taking into account how their previously known wishes. We will therefore be making best interest decisions for the NAME OF RESIDENT regarding their future care

How this meeting will be structured is flexible but the main areas will be for you tell me about NAME OF RESIDENT, to review the Comfort Care Booklet and what parts of this you would like to discuss in detail and chat about, and also we will talk about any concerns/thoughts that you have noted on the issues sheet. During the meeting I will be writing down brief notes and key words, so that nothing is

missed and I can recap on any key issues that may have been overlooked. The ultimate aim is to create together an Advance Care Plan what we call an ACP which will be a written account of what we discuss and that you like to be recorded for further reference.

Just so you are aware you will keep a copy of the ACP (*show a blank version of the document*), one will be placed in the NAME OF RESIDENT nursing home medical notes and one will be provided to their GP.

I have to stress that the ACP is NOT a legal document however it is a plan of care for the healthcare professional to follow. It will be reviewed as necessary or as condition dictates or if you have any concerns.

Please be aware any issues not related to Advance Care Planning will be passed if necessary to the NAME NURSING HOME MANAGER.

Are you happy to continue with this discussion? – verbal consent to continue

RESPONSE

SUGGESTED FAMILY CONFERENCE SCHEDULE:

1. Tell me about NAME OF RESIDENT

- How would you describe NAME OF RESIDENT
- What were their main interests?
- Did they at any time ever express any strong beliefs about their life?
- How long have they been a resident here?

2. How has NAME OF RESIDENT been keeping?

- Have there been any recent hospital admissions/ GP visits?
- Reasoning for admissions/ visit
- Treatment received – would you considered it to have been beneficial or a burden?
- What was your experience of NAME OF RESIDENT going to hospital
- Explore family member's understanding of the complication associated with dementia/Alzheimer's

3. Let's talk about the Comfort Care Booklet

- Did you have an opportunity to read it?
- Is there anything/any area you would like to discuss?

4. Can I clarify any issues?

- Check the 'Issues Sheet'

5. Have you ever discussed ACP / end-of-life care plans before?

- Who did you discuss this with?
- What were the outcomes?
- Were they documented and if so who has the record?

6. Have you ever discussed DNR (Do Not Resuscitate)?

- What is your understanding of this?
 - ?hospitalisations

7. Did NAME OF RESIDENT ever discuss ADRT (Advance Decision to Refuse Treatment)

- Living will/ Advance Directive

8. What would living well mean as they approach the end stages of life to the NAME OF RESIDENT?

- What activities?
- Spiritual/ Religious beliefs?

9. How would you like NAME OF RESIDENT to be cared for? (specifics of care)

- If they stop eating and drinking would you want artificial nutrition and hydration?
 - ?difficulties in swallowing; aspiration pneumonia
- If they had repeat infections how would you want these to be monitored and treated?
 - Hospitalisation/ GP visit
 - ?antibiotics

10. What would your goals be for NAME OF RESIDENT?

- How do you think we can achieve this?

11. What would you feel the NAME OF RESIDENT would NOT like to happen?

- Fears, concerns
- Medical interventions?

12. RECAP MAIN GOALS AND HOW TO ACHIEVE

- WHAT WILL BE DOCUMENTED

13. Do you have any other questions for me?

POTENTIAL QUESTIONS THAT MAY BE ASKED BEFORE/ DURING THE FAMILY CONFERENCE

- 1. What is the family member's role when making the ACP**
 - Willing to accept the role
 - Willing to discuss understand goals values and beliefs
 - Able to make difficult choices
 - Willingness to honour or follow the ACP

- 2. Do we need to have an ACP for the resident?**
 - To have an ACP in place means that the family members know what type of care the resident wishes for without putting a burden onto one person to make decisions. It is good to have ACP in place before the person becomes ill and then the family is not left to make decisions about their care within a stressful situation.

- 3. Can the resident be present at the family conference?**
 - Take on case per case basis

- 4. Have you got any information that I (the participant) could have about further support?**
 - MacMillan book, support sheet

- 5. Will the home be able to meet the goals in the ACP**
 - If the goals are realistic at the time of making the ACP then the home should be able to achieve the goals.
 - If the residents care needs changed then the ACP would need to be reviewed and ACP rewritten

- 6. What happens to the ACP once completed**
 - A copy will be kept in the nursing home records
 - Copy given to the GP
 - Copy to any other relevant healthcare professional involved in the resident's care home
 - Notify out of hours and GP

- 7. Will the ACP be reviewed, how often and by who**
 - Yes by the named nurse, Doctor
 - As condition dictates

8. What is Advance Decision to Refuse Treatment (also known as Living Will/ Advance Directive)?

- Legal document
- Is a statement of the person's wish to refuse a particular type of medical treatment or care in a predefined potential future situation, if they lose sufficient mental capacity.

9. What is a DNR?

10. What is an Enduring Power of Attorney

EPA is a legal document, it allows you to choose other people to make decisions on your behalf about your property and financial affairs

11. What is a Lasting Power of Attorney?

It exists in England and Wales and allows an individual to appoint someone to make decisions about their welfare

FOLLOW-UP PHONE CALL

Advance Care Plan

Today's Date:

Next Planned Review Date:

Advance Care Plan Version No.:

Reason for review (*for Version 2 onwards*):

Section 1: Resident's details

Resident Name:

GP Name:

DOB:

GP Address:

Primary Carer:

Primary Carer Tel. No.:

GP Tel. No.:

Section 2: Individuals involved in family conference

Family member(s)/carer(s)

Name	Role/ Relationship	Tel. no	Date	Signature

Healthcare Professional(s)

Name	Role	Tel. No.	Date	Signature

Section 3: Documentation already held

Document	Completed Y/N	Document Date	Who has a copy?
Advance Decision to Refuse Treatment (ADRT)	Yes <input type="checkbox"/> No <input type="checkbox"/>		
Do Not Resuscitate (DNR)	Yes <input type="checkbox"/> No <input type="checkbox"/>		
Living Will	Yes <input type="checkbox"/> No <input type="checkbox"/>		
Legal Advance Directive	Yes <input type="checkbox"/> No <input type="checkbox"/>		

Section 5: Proxy/ Next of Kin details

Contact 1

Name: Address: Tel. No.:

.....

.....

Contact 2

Name: Address: Tel. No.:

.....

.....

Section 5: Declaration

This Advance Care Plan summary is a true reflection of my/ our wishes:

Name (*in capitals*): Date: Signature:

Name (*in capitals*): Date: Signature:

Name (*in capitals*): Date: Signature:

Name (*in capitals*): Date: Signature:

Section 6: Copies

Place to be kept	Y/N	Date completed
Copy in Nursing Homes Records`	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Copy to GP clinical record	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Copy to any other relevant Healthcare professional involved in the resident's care	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Notify out of hours and GP systems of existence of ACP	Yes <input type="checkbox"/> No <input type="checkbox"/>	

Appendix Four

Advisory Committee Members

NAME	ROLE
Lorraine Kirkpatrick	Regional Manager Four Seasons Health Care
Richard Orr	GP Medical Advisor (Rtrd)
Bernadine McCrory	Director Alzheimer's Society Northern Ireland
Ray Elder	Strategic Lead Strategic Lead for Palliative Care, South Eastern Health and Social Care Trust
Rema Borland	Oncology and Palliative Care Facilitator
Rosemary	PPI representative who was a past carer

Appendix Five

Engagement Documentation: Information Sheet for Study Awareness Raising Events



Queen's University
Belfast

Research *study*

Promoting informed decision making and effective communication through Advance Care Planning for people living with dementia and their family carers

Four Seasons Health Care is collaborating with the School of Nursing & Midwifery at Queen's University Belfast on a study investigating the value of establishing goals of future care for when individuals living with dementia and residing in nursing homes approach end of life.

What is the purpose of the study?

More people are living with dementia and residing in nursing homes. The primary aim of this study is to assess the value of establishing goals of care at the end of life for people living with dementia residing in nursing homes.

An Advance Care Planning (ACP) document is a written or verbal record of a person's choices about their future medical care. Regrettably, given the relative importance of ACP for people living with dementia, the available research demonstrates that the provision of ACP for persons living with dementia is poor.

A substantial number of individuals living with dementia

are admitted to a Nursing Home before death and are often transferred to hospitals where aggressive and overly burdensome treatments are provided. In this situation family carers are often required to make many difficult and emotionally burdensome decisions about whether or not to proceed with life sustaining treatments when they are not prepared to make such decisions.

The purpose of this study is to evaluate the application of a best practice ACP process for individuals living with dementia in a sample of nursing homes in Northern Ireland.



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How are Four Seasons Health Care Involved?



Working in collaboration with FSHC, 6 of the their care homes within the Belfast and Greater Belfast area have been identified to take part in this study.



What are the next steps?

After the nursing home manager has identified residents with the diagnosis of dementia and who no longer have decision-making capacity, their primary carer or Next of Kin will be invited to participate in the study.

Questionnaire packages will be mailed from your care home to you—the primary carer/ Next of Kin of the resident identified as no longer having decision-making capacity and with the diagnosis of dementia. A few weeks later all respondents to the first package will receive the second questionnaire package to complete.

At the end of the study in each nursing home all respondents will be invited to complete an individual interview with either Gillian or Kevin to openly discuss their lived experience of being a carer for someone living with dementia and residing in a nursing home. This will help to give a greater understanding of the impact of acting as a decision-maker for a family member.

What are the possible benefits of taking part?

By providing your views you will contribute to the greater understanding of the impact on family carers when involved in the decision-making process on goals of care at the end of life of a family member.

Your participation can contribute towards recognising how, if any, enhancements can be made to the family carer experience and to the comfort of the nursing home resident towards their end of life.

Any questions?

If you have any questions please feel free to contact Kevin or Gillian for further information.

Contact details are provided at the beginning of this information sheet.



Funding has been received from the Health and Social Care Public Health Agency, and The Atlantic Philanthropies to undertake this study.

Appendix Six

Feedback Sheet Mailed to Participants at Conclusion of the Study

Research *study* Feedback

Promoting informed decision making and effective communication through Advance Care Planning for people living with dementia and their family carers

At some point during 2014/2015 you kindly participated in our study which investigated the value of establishing goals of future care for individuals living with dementia and residing in nursing homes. We would like to express our *sincere gratitude* for you taking part in this research. Your contribution has made a significant difference and we would like to share with you the results of the study to date.

What was the purpose of the study?

An Advance Care Plan (ACP) is a written or verbal record of a person's choices about their future medical care. In this study we were assessing the value of establishing goals of care at the end of life for people living with dementia residing in nursing homes. This was done by evaluating a particular ACP intervention in a sample of nursing homes in Northern Ireland.

How were participants involved?

Nursing homes were randomly assigned to either receive an ACP intervention or continue their care as usual. Depending on which home you were connected to you would have either completed two questionnaire packages, or completed these with the opportunity of participating in a family conference with an ACP Facilitator to produce an ACP for your relative.

What was the ACP intervention?

- ◆ A nurse facilitator trained in Advance Care Planning
- ◆ Education of family members using the Comfort Care Booklet
- ◆ Family meeting with the facilitator
- ◆ Production of an ACP

How many people took part?

23 Nursing Homes completed the study— 12 of these received the ACP intervention

	USUAL CARE GROUP	ACP INTERVENTION GROUP
Number of participants who completed their 1st questionnaire	117 out of 346 (34%)	80 out of 349 (23%)
Number of these participants who also completed their 2nd questionnaire	98 (84%)	61 (76%)
Number of ACPs produced	N/a	67

What were the results?

The ACP intervention:

- ◆ Significantly reduced family carer uncertainty in decision-making concerning the care of their family member
- ◆ Improved family carer satisfaction in nursing home care.

From 20 interviews held after the study, family carers highlighted:

- ◆ The differing levels & sources of support available to them, but not all were easily accessible or beneficial
- ◆ The individual experiences of caring for someone living with dementia including the impact it had on their health & wellbeing and on younger relatives
- ◆ The challenges of being a decision-maker
- ◆ The differing levels of knowledge & understanding of dementia both with family carers and health care staff
- ◆ The positive & negative experiences of the nursing home & hospital environments
- ◆ The impact of moving into a nursing home.

What does this mean?

Implications for clinicians & policy makers include:

- ◆ Recognizing the importance of improving communication between family carers & formal care providers
- ◆ The need for ACP to become part of usual nursing home care involving GPs, nursing home staff and including a trained ACP facilitator
- ◆ Family carer education is essential to enable family carers to weigh the burden or benefit of treatment options when the family member enters the late stages of dementia.

Further investigation is needed to include:

- ◆ Holding goals of care and decision-making earlier in the dementia disease trajectory
- ◆ Recognition of family dynamics
- ◆ The need for improved knowledge of family carers and nursing home staff to facilitate informed decision-making
- ◆ Improving communication with and between staff.

Where can I access a copy of the Comfort Care Booklet?

This booklet was provided to those participants in the intervention group to help aid their understanding of comfort care at the end of life for individuals living with dementia. It contains five sections:

Section 1: The Natural Evolution of Dementia

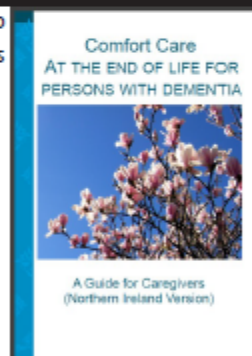
Section 2: Decisions About the End of Life

Section 3: Relief of Symptoms

Section 4: The Final Moments

Section 5: After the Death

If you would like a copy of the booklet it is available here <http://bit.ly/2ixMZLn>



Any questions?

If you have any questions please feel free to contact Kevin Brazil.



Professor Kevin Brazil
Professor of Palliative Care
Chief Investigator of study k.brazil@qub.ac.uk
02890 975782

Appendix Seven

Functional Assessment

Staging Test (FAST)



Functional Assessment Staging Test

The Functional Assessment Staging Test (FAST) is the most well validated measure of the course of AD in the published, scientific literature.

The stages of Alzheimer’s disease as defined by FAST are:

Stage	Stage Name	Characteristic	Expected Untreated AD Duration (months)	Mental Age (years)	MMSE (score)
1	Normal Aging	No deficits whatsoever	--	Adult	29-30
2	Possible Mild Cognitive Impairment	Subjective functional deficit	--		28-29
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person’s most complex tasks	84	12+	24-28
4	Mild Dementia	IADLs become affected, such as bill paying, cooking, cleaning, traveling	24	8-12	19-20
5	Moderate Dementia	Needs help selecting proper attire	18	5-7	15
6a	Moderately Severe Dementia	Needs help putting on clothes	4.8	5	9
6b	Moderately Severe Dementia	Needs help bathing	4.8	4	8
6c	Moderately Severe Dementia	Needs help toileting	4.8	4	5
6d	Moderately Severe Dementia	Urinary incontinence	3.6	3-4	3
6e	Moderately Severe Dementia	Fecal incontinence	9.6	2-3	1
7a	Severe Dementia	Speaks 5-6 words during day	12	1.25	0
7b	Severe Dementia	Speaks only 1 word clearly	18	1	0
7c	Severe Dementia	Can no longer walk	12	1	0
7d	Severe Dementia	Can no longer sit up	12	0.5-0.8	0
7e	Severe Dementia	Can no longer smile	18	0.2-0.4	0
7f	Severe Dementia	Can no longer hold up head	12+	0-0.2	0



A simple to use, electronic version of FAST is included in Medical Care Corporation’s system.

Medical Care Corporation
 Simple and Accurate Memory Assessment
 www.mccare.com • (888)565-5535



Functional Assessment Staging Test

Differential Diagnosis

Use the FAST tool to determine if changes in a patient's condition are due to Alzheimer's disease or another condition. If the change is due to AD progression, then any changes on the FAST scale will be in sequence—**AD-related changes do not skip FAST stages.**

Example: a patient is mildly demented (FAST stage 4), and loses the ability to bathe (FAST 6b) but can still pick out their clothes (FAST 5) and dress themselves (FAST 6a), then they skipped FAST stages 5 and 6a and went directly to FAST stage 6b. These changes are not due to AD progression. It could be that the diagnosis of AD is wrong or that the patient has a second dementing disorder in addition to AD. Alternatively, the patient may have an exacerbation of an existing medical problem, developed a new medical problem, or had some other change in their care or living situation that caused the difficulty bathing.

Measurement of delay in AD

Use the FAST tool at each office visit to measure treatment effect in each patient. The longitudinal view of the FAST shows how long a patient has spent in each FAST stage, plus its average expected untreated duration. The difference, which appears in the column, "Actual minus Expected Untreated AD Duration", indicates whether treatment has delayed AD progression.

Example: you have been treating an AD patient for four years and staging them at each office visit. The FAST longitudinal view shows that the patient has spent 46 months in stage 4 (e.g., difficulty managing finances). The average, expected untreated duration of stage 4 is 24 months, and the difference shown is 22 months. This indicates that treatment has delayed AD progression by approximately 22 months. Without treatment, they would have progressed to FAST stage 6b and would be unable to dress or bathe.

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Medical Care Corporation
Simple and Accurate Memory Assessment
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Appendix Eight

Pre-notification Recruitment Letter and Baseline Questionnaire Cover Letter



Four Seasons
Health Care

Dear

**Re: Research Project:
Promoting informed decision making and effective communication through advance care planning (ACP) for people living with dementia and their family carers**

at which your family member resides, is taking part in the above research project funded by the Health and Social Care Public Health Agency, and The Atlantic Philanthropies. Professor Kevin Brazil is the Chief Investigator for the project and works in the School of Nursing and Midwifery at Queen's University Belfast and I would like to take this opportunity to briefly inform you about the research.

The aim of the study is to assess the value of establishing goals of care at the end of life for people living with dementia within a care home. Four Seasons Health Care supports this study as the findings will contribute towards improving the end of life care of our residents. Your participation is *voluntary* and within the next seven days you will receive a questionnaire and information pack providing more details.

If you would like to find out more information about the study you are invited to a Study Awareness Raising Event at – please see enclosed advert for more details. But feel free to contact me or Kevin (details provided below) if you have any questions at this stage.

It is completely your choice whether you participate, but I want to assure you that if you choose to not take part in this study *this will not affect* the care that your family member receives.

Thank you.
Yours sincerely,

Professor Kevin Brazil
Queen's University Belfast
School of Nursing & Midwifery
97 Lisburn Road, BT9 7BL
02890 975782
k.brazil@qub.ac.uk

Page 156 of 195

Enclosures: Study Awareness Raising Event advertisement



Dear

**Re: Research Project:
Promoting informed decision making and effective communication through advance care planning (ACP) for people living with dementia and their family carers**

In a previous letter you were informed about the above study. As a reminder _____ at which your family member resides, is taking part in this research project funded by the Health and Social Care Public Health Agency, and The Atlantic Philanthropies. Professor Kevin Brazil is the Chief Investigator for the project and works in the School of Nursing and Midwifery at Queen's University Belfast.

The aim of the study is to assess the value of establishing goals of care at the end of life for people living with dementia within a care home. Four Seasons Health Care supports this study as the findings will contribute towards improving the end of life care of our residents. Your participation is *voluntary*, but if you are interested please read the attached documentation, then **sign the enclosed consent form, complete the questionnaire booklet, and return both in the stamped addressed envelope provided.**

If you do choose to participate in the research, at the end of the study in order to gain a greater understanding of the experiences of family carers, you will be invited to complete an interview with either Professor Kevin Brazil or Dr Gillian Carter.

I want to assure you that if you choose to not take part in this study *this will not affect* the care that your family member receives. If you have any questions please don't hesitate to contact Kevin or Gillian (details provided in the participant information sheet).

Over the next couple of weeks you will receive a reminder postcard and then a replacement baseline questionnaire package, but please ignore these if you have already responded or choose not to participate.

Thank you.
Yours sincerely,

Enclosures: Participant information sheet; questionnaire booklet; two copies of the consent form (one to be kept by you); support sheet; stamped addressed envelope.

Appendix Nine

Baseline Questionnaire

QUESTIONNAIRE BOOKLET



INSTRUCTIONS

After you have read the accompanying participant information sheet, please provide your open and honest answers to the following survey questions found in Sections A,B and C.

On completion of the survey please mail it, ***along with a signed consent form***, back to the research team in the stamped addressed envelope provided.

Next you will be contacted by the Project Nurse to arrange a time to hold a family conference. A few weeks after this you will be asked to complete this survey again.

On completion of both questionnaires and the family conference you will be entered into a raffle for £100 in recognition of your commitment to the study.

**THANK YOU FOR YOUR TIME AND SUPPORT WITH PARTICIPATING IN
THIS STUDY**

Please complete the following:

Your gender: Male Female

Your age: _____

Relationship of the Nursing Home resident **to you**:

Mother	<input type="checkbox"/>	Father	<input type="checkbox"/>	Husband	<input type="checkbox"/>
Wife	<input type="checkbox"/>	Sister	<input type="checkbox"/>	Brother	<input type="checkbox"/>
Aunt	<input type="checkbox"/>	Uncle	<input type="checkbox"/>		
Other	<input type="checkbox"/> (Please specify)			

SECTION A

When determining the preferences of future care at the end of life for your family member who is residing at a nursing home, the options of future care available may include being prescribed antibiotics if they develop an infection; their preferred place of care and of death; resuscitation if their heart stops; provision of other comforts of care, and other potential sources of future care important to them. When considering your family member’s preferences of future care, please answer the following questions:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. I know which options of care are available to my family member.	0	1	2	3	4
2. I know the benefits of each option.	0	1	2	3	4
3. I know the risks and side effects of each option.	0	1	2	3	4
4. I am clear about which benefits matter most to my family member.	0	1	2	3	4
5. I am clear about which risks and side effects matter most to my family member.	0	1	2	3	4
6. I am clear about which is more important to my family member (the benefits or the risks and side effects).	0	1	2	3	4
7. I have enough support from others to make a choice.	0	1	2	3	4
8. I am choosing without pressure from others.	0	1	2	3	4
9. I have enough advice to make a choice.	0	1	2	3	4
10. I am clear about the best choice for my family member.	0	1	2	3	4
11. I feel sure about what to choose.	0	1	2	3	4
12. This decision is easy for me to make.	0	1	2	3	4
13. I feel I have made an informed choice.	0	1	2	3	4

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
14. My decision shows what is important to my family member.	0	1	2	3	4
15. I expect to stick with my decision.	0	1	2	3	4
16. I am satisfied with my decision.	0	1	2	3	4

SECTION B

We should like to know if you have had any medical complaints, and how your health has been in general, over the past few weeks. Please answer ALL the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you had in the past. It is very important that you try to answer ALL the questions. Thank you very much for your co-operation.

Have you recently:

1. - been able to concentrate on what you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2. - lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3. - felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less than usual
4. - felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
5. - felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
6. - felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
7. - been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8. - been able to face up to your problems?	More so than usual	Same as usual	Less able than usual	Much less able

9. - been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10. - been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11. - been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12. - been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual

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SECTION C

Please circle the number that best describes how you feel about the care given to your family member to date and what has been explained about their future care. There are no right answers to any of these questions. Please circle only one response. In the survey, “staff” refers to anyone who is providing care for your family member at the nursing home.

	Strongly Disagree	Disagree	Mildly Disagree	Neutral	Mildly Agree	Agree	Strongly Agree
1. The staff are friendly to me.	1	2	3	4	5	6	7
2. The staff treat my family member with dignity.	1	2	3	4	5	6	7
3. The staff spend enough time with my family member.	1	2	3	4	5	6	7
4. The staff provide comfort to my family member.	1	2	3	4	5	6	7
5. The staff are sensitive to the needs of my family member.	1	2	3	4	5	6	7
6. The staff keep me informed about my family member’s health.	1	2	3	4	5	6	7
7. The staff keep me updated based on what I want to know.	1	2	3	4	5	6	7
8. The staff speak to me in a way that is easy to grasp.	1	2	3	4	5	6	7
9. The staff have described what to expect in the future as my family member comes closer to death.	1	2	3	4	5	6	7

	Strongly Disagree	Disagree	Mildly Disagree	Neutral	Mildly Agree	Agree	Strongly Agree
10. The staff have informed me about care options available when my family member will be in his/her last few days.	1	2	3	4	5	6	7
11. The staff involve me in the planning of care.	1	2	3	4	5	6	7
12. There has been a plan of care tailored specifically to the needs of my family member.	1	2	3	4	5	6	7
13. The staff put decisions I make into action quickly, in regards to my family member's care.	1	2	3	4	5	6	7
14. My family member's pain has been eased to the greatest extent possible.	1	2	3	4	5	6	7
15. Other symptoms are eased to the greatest extent possible. (E.g. difficulty breathing, coughing, swelling or weakness)	1	2	3	4	5	6	7
16. In the future the staff will inform me when they believe that death is at hand.	1	2	3	4	5	6	7
17. In the future the staff will welcome me to stay with my family member during his/her last few days.	1	2	3	4	5	6	7
18. The staff help me to be involved in the care of my family member.	1	2	3	4	5	6	7

	Strongly Disagree	Disagree	Mildly Disagree	Neutral	Mildly Agree	Agree	Strongly Agree
19. My family member is placed on an appropriate floor/unit.	1	2	3	4	5	6	7
20. My family member's room offers privacy.	1	2	3	4	5	6	7
21. Chaplaincy services are at hand for my family member.	1	2	3	4	5	6	7
22. The staff have asked about the rites and rituals of my family.	1	2	3	4	5	6	7
23. There is someone there for my family member to talk to.	1	2	3	4	5	6	7
24. There are enough staff to deal with my concerns.	1	2	3	4	5	6	7
25. Overall, I am satisfied with the current and future care that is available for my family member.	1	2	3	4	5	6	7

26. Please list, in order, the three questions in this Section C that you think are the most important for excellent end of life care.

1. Question # _____
2. Question # _____
3. Question # _____

If you feel that there are factors that are important to end of life care that are not covered on this survey, please print them, along with any additional comments on the next page.

DATE OF COMPLETION _____

**THANK YOU FOR TAKING THE TIME TO
COMPLETE THIS SURVEY.**

Appendix Ten

ACP Nurse Facilitator Log of Activities

	2014			2015									
	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Nov
Care Home Code(s)													
Number of phonecalls [total time]		0hrs 50mins		0hrs 20mins	1hr 20mins	0hrs 40mins	0hrs 30mins	1hr 40mins	1hr 50mins	1hr 40mins	3hrs 20mins	1hr 30mins	
Family meeting preparation time		2hrs 0mins	0hrs 30mins		2hrs 30mins	2hrs 30mins	1hr 0mins		8hrs 0mins	5hrs 30mins	5hrs 30mins	6hrs 0mins	0hrs 30mins
Number of family meetings [total time]		5hrs 0mins	1hr 15mins		8hrs 45mins	8hrs 45 mins	2hrs 30mins		20hrs 0mins	13hrs 45mins	13hrs 45mins	15hrs 0mins	1hr 15mins
Number of follow-up meetings [total time]		0hrs 45mins	0hrs 15mins		1hr 45mins	1hr 30mins	0hrs 30mins	0hrs 30mins	3hrs 15mins	3hrs 30mins	2hrs 45mins	2hrs 45mins	0hrs 30mins
Total contact time		8hrs 35mins	2hrs 0mins	0hrs 20mins	14hrs 20mins	13hrs 25mins	4hrs 30mins	2hrs 10mins	33hrs 05mins	24hrs 25mins	25hrs 20mins	25hrs 15mins	2hrs 15mins
Number of ACPs created		3	1	0	7	6	2	2	14	12	11	12	2
Average time for production of an ACP		2hrs 51mins	2hrs 0mins		2hrs 03mins	2hrs 14mins	2hrs 15mins	1hr 05mins	2hrs 21mins	2hrs 02mins	2hrs 18mins	2hrs 6mins	1hr 08mins
Total handover time to nursing home staff		0hrs 45mins	0hrs 15mins		1hr 45mins	1hr 30mins	0hrs 30mins	0hrs 30mins	3hrs 30mins	3hrs 0mins	2hrs 45mins	3hrs 0mins	0hrs 30mins
Time to complete journal				6hrs 40mins	13hrs 20mins	8hrs 20mins	6hrs 40mins	6hrs 40mins	10hrs 0mins	4hrs 0mins	8hrs 20mins	41hrs 40mins	2hrs 0mins
External training													
Respecting choices ACP Facilitator Online Curriculum [time to complete]		8hrs 0mins											
e-ELCA (End of Life Care for All) – online training for Health and Social Care staff – communication skills modules: 1. The importance of good communication 2. Principles of communication 3. Communication with Ill people 4. Talking with ill people 5. Culture and language in communication [time to complete]		10hrs 0mins											
Sage & Thyme ACP - Considering Wishes at End of Life [time to complete]		4hrs 0mins											
ACP training with Sue Foster , Lecturer in Palliative Care , Head of Education Department NI Hospice [time to complete]		2hrs 0mins											
Introduction to Good Clinical Practice (GCP) e-learning course [time to complete]		8hrs 0mins											
Reading preparation materials - academic journals and resources		80hrs 0mins											
Total training time required		112hrs 0mins											

Appendix Eleven

Individual Interviews Invitation Letter and Documentation for Family Carers (Intervention Version)



The School of Nursing and Midwifery

Queen's University Belfast

Medical Biology Centre

97 Lisburn Road

BELFAST

Dear NAME OF FAMILY CARER,

Re: Research Project:

Promoting informed decision making and effective communication through advance care planning (ACP) for people living with dementia and their family carers

You recently completed two questionnaire packages and a family conference as part of the above study and I would like to thank you for your time and support with the research. As mentioned in previous correspondence, in order to gain a greater understanding of the experiences of family carers, you are invited to complete an interview with me, Professor Kevin Brazil, or with Dr Gillian Carter. Participation is voluntary but, if you would like to do this please complete the response slip enclosed and mail in the prepaid envelope to the Research Team who will contact you to arrange a suitable time and location.

The aim for this interview is to openly discuss your lived experience of being a carer for someone living with dementia and residing in a nursing home. You will also help to give a greater understanding of the impact of acting as a decision-maker for a family member. The interview will take approximately 60 minutes and will be arranged at a location and at a time that is the most convenient to you. At the start of the interview you will be asked to sign a consent form to record that you have agreed to be involved.

If you have any questions please feel free to contact me or Dr. Gillian Carter (Research Fellow) for further information (contact details on reverse of this letter).

Thank you for your time.

Yours sincerely,

Kevin Brazil

Chief Investigator

ADDITIONAL CONTACT DETAILS:

Professor Kevin Brazil

Professor of Palliative Care

Queen's University Belfast

School of Nursing & Midwifery

97 Lisburn Road, BT9 7BL

02890 975782 k.brazil@qub.ac.uk

Dr Gillian Carter

Research Fellow in Palliative Care

Queen's University Belfast

School of Nursing & Midwifery

97 Lisburn Road, BT9 7BL

02890 975762 g.carter@qub.ac.uk

Enclosures: Participant information sheet, stamped addressed envelope, response slip



**PROMOTING INFORMED DECISION MAKING AND EFFECTIVE
COMMUNICATION THROUGH ADVANCE CARE PLANNING (ACP) FOR
PEOPLE LIVING WITH DEMENTIA AND THEIR FAMILY CARERS**

PARTICIPANT INFORMATION SHEET FOR FAMILY CARERS

SPONSORS: HSC Public Health Agency & The Atlantic Philanthropies

CHIEF INVESTIGATOR: Professor Kevin Brazil

CONTACT DETAILS:

Professor Kevin Brazil
Professor of Palliative Care
Queen's University Belfast
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Dr Gillian Carter
Research Fellow in Palliative Care
Queen's University Belfast
School of Nursing & Midwifery
97 Lisburn Road, BT9 7BL
02890 975762 g.carter@qub.ac.uk

You are being invited to participate in a research project that seeks to assess the value of establishing goals of care at the end of life for people living with dementia and residing in nursing homes.

Why is the study being done?

More people are living with dementia and residing in nursing homes. The purpose of this study is to assess the value of establishing goals of care at the end of life for people living with dementia residing in nursing homes.

Who is organising and funding the research?

Kevin Brazil the Chief Investigator works in the School of Nursing and Midwifery at Queen's University Belfast and we have received funding from the Health and Social Care Public Health Agency, and The Atlantic Philanthropies to undertake this study.

Why have I been chosen?

You have been chosen because you have been identified by a Four Season Health Care Nursing Home to be the primary carer/ family member for one of their residents living with dementia.

What is the purpose of the study?

- The primary aim of this study is to assess the value of establishing goals of care at the end of life for people living with dementia within a nursing home.
- We are particularly interested in your perceptions of nursing home care and the impact on you at establishing these goals of care.

Do I have to take part?

- No. Your participation in this study is entirely voluntary. It is up to you to decide whether to take part or not. If you choose to not take part *this will not affect* the care that your family member receives.

- If you decide to take part, you are also free to withdraw at any time without giving a reason.
- If you withdraw, any information you have given us will be destroyed if you wish.

What will I have to do and what kind of information will I have to provide if I take part?

Should you agree to take part in this study:

- First you will be asked to complete the attached questionnaire booklet, sign the consent form and mail back in the stamped addressed envelope.
- At a later date you will take part in a family conference with a Project Nurse:
 - A family conference is a private meeting run by the Project Nurse which will be held between you and chosen health care professionals.
 - The aim for this meeting is to openly discuss care decisions for your family member, in particular to highlight their goals, values and beliefs.
 - These discussions of life care options will be recorded and placed in your family member's personal nursing home record and shared in full with their GP.
 - The meeting will take approximately 60 minutes and will be arranged in your family member's nursing home at a time that is the most convenient to you.
 - If you desire, you can also choose to invite other family members/significant others to join the meeting.
 - At the start of the meeting you will be asked to sign a consent form to record that you have agreed to be involved.

- As a follow-up for our project, a few weeks after the meeting, the questionnaire booklet will be sent to you to complete for a second time.
- Please be aware that *you can change anything* completed in the Family Conference by contacting the Nursing Home Manager or Project Nurse at any time.

Who attends the family conference?

- It is completely *your choice* who attends – e.g. other attendees could be family members, close friends, the resident’s GP or key healthcare workers etc. Whoever you would like to attend will be invited.

What if an Advance Care Plan (ACP) has already been completed?

- If you have already completed an ACP you are still very welcome to take part in the study.
- The Project Nurse may be able to provide further information to assist in the decision-making process, so the opportunity will still be available for you to hold a family meeting with the Nurse and to revisit these choices as necessary.
- You are under no obligation to participate in a meeting, please be reassured that this document will remain unchanged.

What if my family member dies during the study?

- In the exceptional circumstance that your family member dies during the study you will be offered the opportunity of continuing your participation in the study by completing a bereavement questionnaire.

What are the possible benefits of taking part?

- By providing your views you will contribute to the greater understanding of the impact on family carers when involved in the decision-making process on goals of care at the end of life for a family member.
- Your participation can contribute towards recognising how, if any, enhancements can be made to the family carer experience and to the comfort of the nursing home resident towards their end of life.

Are there any risks to me if I take part?

- It is possible that you may feel emotional when discussing or thinking about your family member's care.
- If this does happen, you have the choice to stop your involvement in the study at any point.
- You have been provided with an advice slip in this package directing you to appropriate support and counselling networks.
- If needed, you can also be supported with further advice by the Project Nurse during the family meeting.

What if I have questions with my involvement in the study?

- You can ask questions or receive advice about any aspect of the study from either Kevin Brazil or Gillian Carter – contact details at the start of this leaflet.

Will my taking part in the study be kept confidential?

- Whatever information you offer is between you and the researcher and will be kept private. However, if something arises that requires someone to intervene for example where there is risk to a patient or

yourself, appropriate procedures will be followed. However, what you say will not be made public.

- No individual person will ever be identified and no connections will be made between any individuals.
- Consent forms and completed questionnaires will be stored separately and at no point will any comparisons/links be made between them.
- Your name is not required anywhere on the questionnaire booklet and responses will be stored securely in a locked filing cabinet in Queen's University Belfast.
- Only the code on returned questionnaires will be provided to the associated nursing home so the Project Nurse can contact you, and also if necessary so a single reminder postcard and replacement questionnaire can be sent to those who have not yet responded.
- At no point will the research team have access to the list of codes and names; these will be retained by the nursing home only.
- All information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998.

What will happen to the results of the research study?

- All the information collected will be examined to give a general summary picture.
- For research purposes data content of the family conference will be analysed in combination with all other family conferences held across the study.
- We hope this will identify strategies to improve quality of care for individuals living with dementia in nursing homes.

Who has reviewed the study?

The study has been approved by the Queen's University Belfast Research Ethics Committee and the Office for Research Ethics Committee N. Ireland.

**PLEASE KEEP THIS INFORMATION SHEET FOR REFERENCE
ABOUT THE STUDY.**

Participants who complete both questionnaires and the family conference will be entered into a raffle for £100 to recognise your commitment to the study.

THANK YOU for taking time to read this sheet and giving consideration to taking part in our study.

**PROMOTING INFORMED DECISION MAKING AND EFFECTIVE
COMMUNICATION THROUGH ADVANCE CARE PLANNING (ACP) FOR PEOPLE
LIVING WITH DEMENTIA AND THEIR FAMILY CARERS**

This research project seeks to assess the value of establishing goals of care at the end of life for people living with dementia and residing in nursing homes. In order to gain a greater understanding of the impact this has on family carers, you are being invited to participate in the final stage of this project in which you will have the opportunity to voice your experiences.

INDIVIDUAL INTERVIEWS FOR CARERS: RESPONSE SLIP

Yes I am interested in taking part in an interview. Please contact me to discuss my participation.

Print name:

Signature:

Date:

If you have any queries before returning the slip, please feel free to make contact with Professor Kevin Brazil (02890 975782) or Dr Gillian Carter (02890 975762). Full contact details are provided at the start of the Participant Information Sheet -Family Carers.

Please return the completed and signed slip in the stamped addressed envelope. **Thank you.**

Appendix Twelve

Family Carer Interview Schedule

Family Carer – Individual Interview Schedule (I)

Thank you for agreeing to participate in this interview. This interview will give you the opportunity to elaborate on the lived experience of being a family carer who has been required to act as a decision maker on planning the goals of care for a family member who no longer has the capacity to make decisions.

As a recap the Advance Care Planning (ACP) intervention in the study included five elements: a trained nurse facilitator – the Project Nurse; family education on comfort care at the end of life for individuals with dementia; a family meeting with a follow-up meeting; documentation of ACP decisions; and orientation and education directed towards GPs and nursing home staff about the intervention.

1. How would you describe the experience of being a carer for your _____ in _____?
 - Responsibility?
 - Pressure?
2. What has the experience of making decisions about your _____ goals of care been like?
 - Had your _____ previously chosen an individual who would act in their best interest when they no longer had capacity to decide on goals of care?
 - Did they previously communicate their wishes concerning goals of care?
 - How has this experience affected you?
3. Can you tell me about the circumstances that led you to decide to be involved in this study to participating in a family conference, to discuss the goals of care at the end of life for your _____ ?
4. How well did this conference help you understand the choices and decisions that needed to be made?
 - Did you feel that you understood all the options that were available for your _____ including all the benefits and risks?
 - Did the conference meet your needs?
 - Were there things that comforted you?
 - Is there anything that continues to bother you today?

5. In your role as a decision maker for your _____ care planning, how much conflict including disagreements and negative feelings, has there been between you and the healthcare staff e.g. GPs nursing home staff etc. regarding your current and future care needs?
6. How well do you feel your GP and the nursing home staff recognize, value and understand your role as the primary carer and as a decision maker for your goals of care?
7. Do you think there are things that could be changed or added in your nursing home to improve the experience of a carer who is also the decision maker for a family member's goals of care?
8. Are there any other comments you would like to make that we have not covered?

Appendix Thirteen

Support Resources for Family Carers

SUPPORT SHEET FOR FAMILY CARERS

If you have any queries or concerns arising from your participation in this study or from contact with the researcher, or feel you would like alternative support following the death of your relative, there are a number of people and organisations who would be happy to help you. They can provide information and support to you and clarify any issues which might have arisen. You can contact them at any time, days later or even weeks after your participation in the study or following the death of your relative.

Cruse Bereavement Care Northern Ireland

Cruse Bereavement Care is there to support you after the death of someone close. Their mission is to offer support, advice and information to children, young people and adults when someone dies and to enhance society's care of bereaved people. There are seven areas located throughout Northern Ireland: Armagh and Dungannon Belfast, Foyle, Newry and Mourne Branch, Northern, North Down and Ards, Omagh and Fermanagh.

Helpline: 0844 477 9400

Email: helpline@cruse.org.uk

Website: www.cruse.org.uk/northern-ireland

Alzheimer's Society Northern Ireland

The Alzheimer's Society Northern Ireland is a membership organization which works to improve the quality of life of people affected by dementia in Northern Ireland. Many of their members have personal experience of dementia, as carers, health professionals or people with dementia themselves, and their experiences help to inform the work of the Alzheimer's Society.

Helpline: 0300 222 11 22

**Address: Alzheimer's Society, Unit 4 Balmoral Business Park, Boucher Crescent,
Belfast, BT12 6HU**

Telephone: 028 90664100

Email: nir@alzheimers.org.uk

Website:

<http://www.alzheimers.org.uk/northernireland/>

The National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales and Northern Ireland.

Tel: 020 7697 1520

Website: www.ncpc.org.uk

Dying Matters

Dying Matters is a broad based and inclusive national coalition of 30,000 members; they are committed to supporting changing knowledge, attitudes and behaviours around death and dying. Joining is free and they're there for people in the last years of life, their families, carers and friends and offer links to local services, information and a supportive online community.

Website: <http://www.dyingmatters.org/>

<http://dyingmatters.org/page/coping-bereavement>

Local Hospices in Northern Ireland

The Northern Ireland Hospice, Marie Curie Hospice Belfast, Foyle Derry Hospice, and the Southern Area Hospice Newry are charities all providing information and support for local people.

<p>N.I. Hospice, Adult Services, Whiteabbey Hospital Grounds, Doagh Road, Newtownabbey, BT37 9RH Tel: 02890 781 836 Website: http://www.nihospicecare.com/ Email: information@nihospice.org</p>	<p>Marie Curie Hospice, Kensington Road Belfast, BT5 6NF Tel: 028 9088 2000 Website: http://www.mariecurie.org.uk/en-GB/nurses-hospices/our-hospices/belfast/ Email: belfast.hospice@mariecurie.org.uk</p>
<p>Foyle Hospice, 61 Culmore Road, BT48 8JE Website: http://foylehospice.com/ 24 Hour Tel Advice Line - (028) 71351010</p>	<p>Southern Area Hospice Southern Area Hospice Services, St John's House, Courtney Hill, Newry, Co. Down, BT34 2EB Tel: (028) 3026 7711 Website: http://www.southernareahospiceservices.org/ Email: info@southernareahospiceservices.org</p>

CARERS Northern Ireland

Carers Northern Ireland is a charity set up to support people who care for an elderly relative, a sick friend or a disabled family member. They are part of Carers UK and they support carers and provide information and advice about caring, and help carers get the best for the person they care for; make the most of their income; stay in paid work; juggle their busy lives; keep healthy; find a listening ear; and campaign for change.

Address: Carers Northern Ireland, 58 Howard Street, Belfast BT1 6PJ

Tel: 02890 439 843

Website: <http://www.carersuk.org/northernireland> Advice email: advice@carersni.org

Complaints about the Research

If you are not satisfied with the manner in which this study was conducted, or if you have any concerns, complaints, or general questions about the research as a research participant, please contact Professor Kevin Brazil:

Address: Queen's University Belfast, School of Nursing & Midwifery, 97 Lisburn Road, BT9 7BL

Tel: 02890 975782 Email: k.brazil@qub.ac.uk

If you wish to speak to someone other than a member of the research team please contact Research Governance Office:

Address: Queen's University Belfast, Research & Enterprise, 63 University Road, Belfast BT7 1NF

Tel: 028 90 97 2568 E-mail: researchgovernance@qub.ac.uk

Appendix Fourteen

Ethical Approval Documentation

Customer Care & Performance Directorate

Office Suite 3
Lisburn Square House
Haslem's Lane
Lisburn
Co. Antrim BT28 1TW
Tel: +44 (0) 28 9260 3107
www.orecni.hscni.net

HSC REC A

03 July 2014

Professor Kevin Brazil
Queen's University Belfast
Medical Biology Centre
97 Lisburn Road
Belfast
BT9 7BL

Dear Professor Brazil

Study title: Promoting Informed decision making and effective communication through advance care planning for people living with dementia and their family carers

REC reference: 14/NI/0082

IRAS project ID: 150085

Thank you for your letter dated 27 May 2014, received 30 May 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Lead Reviewer in correspondence.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Kathryn Taylor, RECA@hscni.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- the existing 'Participant Information Sheet –Family Carer: Version 2 (Intervention) – 19/06/14' should be amended to state what a family conference is.



Customer Care & Performance Directorate

Office Suite 3
Lisburn Square House
Haslem's Lane
Lisburn
Co. Antrim BT28 1TW
Tel: +44 (0) 28 9260 3107
www.orecni.hscni.net
HSC REC A

04 June 2014

Professor Kevin Brazil
Queen's University Belfast
Medical Biology Centre
97 Lisburn Road
Belfast
BT9 7BL

Dear Professor Brazil

Study Title: Promoting informed decision making and effective communication through advance care planning for people living with dementia and their family carers

REC reference: 14/NI/0082

IRAS project ID: 150085

The Research Ethics Committee reviewed the above application at the meeting held on 27 May 2014. Thank you for attending to discuss the application, with Dr Gillian Carter.

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair and the Lead Reviewer, acting in correspondence.

Further information or clarification required

The Committee would be content to give a favourable opinion of the application, subject to receiving a complete response to the request for the following information:

1. Please address the following in a covering letter, providing any revised study documents, e.g. protocol as appropriate:
 - a. Are there any "checks" to ascertain if any advance care planning discussions have taken place between carer and resident to determine wishes
 - b. No consent is taken from NH residents or assent from family caregivers that personal information can be accessed from confidential records to ascertain diagnosis, access carer details or review health care utilisation for research purposes.
 - c. There is no prior warning this research is happening and then caregivers will receive a recruitment pack with cover letter from the home, about their relative, which will also



