

2013 Commissioned Research on Dementia Care

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

Abstract: The patient's right to self-determination has become a key ethical principle in dementia care. Advance Care Planning (ACP) 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. 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.

In Western countries 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 which may lead to death when they are not prepared to make such decisions.

The purpose of this study is to evaluate the application of a best-practice ACP model for individuals living with dementia in a sample of nursing homes in Northern Ireland. Specific outcomes examined will include family carer satisfaction in decision making regarding options for care; family carer's overall satisfaction with nursing home care; assessment of comfort care in nursing homes for persons living with dementia; and, impact the ACP model has on the use of acute care services. As part of this study, the lived experience of family carers required to make treatment decisions on behalf of a family member living with dementia will be explored.

It is anticipated that this 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