# Dementia, Decision-Making and Advance Care Planning: A Review

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## Word Count:

## Key Words:

## Abstract

Background

Dementia and Alzheimer’s disease are the leading cause of death in England and Wales (ONS, 2017); despite this, dementia is not viewed as terminal or life limiting (Sampson & Harrison Dening 2013) resulting in little significance being placed on the completion of an Advance Care Plan (ACP). Within clinical practice it has been observed that most patients with advanced dementia have never been given the opportunity to complete an ACP and equally had not had conversations with family regarding their wishes and preferences at end of life (Harrison Dening et al, 2011; Hirschman et al, 2008).

Aim

To explore the evidence on the introduction of ACP for those with a dementia diagnosis.

Methods

A review of the literature pertaining to ACP for patients with a dementia diagnosis.

Results

The overall results demonstrated ACP discussions to be beneficial, however, there were identified factors that can either facilitate or hinder such discussions. Carers reported feeling unprepared, lacking in knowledge and felt that there was an absence of emotional support when they faced such decision-making (Barker et al, 2017). These factors impact on whether a person with dementia achieves their preferred place of care and death (Barker et al, 2017; Harrison Dening et al, 2011).

Conclusion

Patients with dementia, and their family, need to plan for the end of life (EOL). They can be supported to do so by the completion of an ACP, a document which increases the likelihood of them achieving their preferred place of care and death and also reduces decisional burden for carers.

## Introduction

The number of people living with dementia in the UK is rising, with an estimated 850, 000 currently living with a dementia diagnosis (Alzheimer’s Society, 2018). Over a decade ago, dementia was recognised as a highly prevalent and life-limiting disease with increasing complex needs (Harris, 2007). Yet despite this, Sampson & Harrison Dening (2013) assert that dementia is still not traditionally thought to be terminal or life-limiting. There are a large number of people living with and dying from dementia (Alzheimer’s Society, 2018); indeed, dementia and Alzheimer’s disease are now identified as the leading cause of death in England and Wales (ONS, 2017), with a median survival range from symptoms to death being between 3.5 years (Rait et al, 2010) and 4.5 years (Xie et al, 2008) following diagnosis. However, such distressing demographics do not highlight the fractional amount of time a person with dementia will retain their mental capacity and decision-making abilities due to the progressive nature of the condition which are essential in ACP.

## Planning for end-of-life

The End-of-Life Care Strategy (DH, 2008) recognised the importance of having open discussions regarding death and dying for people with a life-limiting condition, including the person with dementia. The strategy identified a number of potential risks to not having an open dialogue which included; a person becoming needlessly afraid as they approach their end-of-life (EOL); close relatives making decisions (for a person who lacks mental capacity) without having any knowledge of their wishes and a person potentially receiving inappropriate treatments and interventions. In relation to dementia, both The EOL Care Strategy (DH, 2008a) and The National Dementia Strategy (DH, 2009) acknowledged the importance of early EOL planning for this group of people, to allow a person with dementia to be involved in discussing and documenting their wishes and preferences for EOL care whilst they retain capacity to make decisions. However, there still appears to be little urgency or consistency in the support offered on EOL care and ACP planning to people living with dementia or their families.

## Advance Care Planning

Advance care planning (ACP) has been defined as a process of discussing and/or recording the wishes, values, and preferences for future care and treatment held between an individual, family members and their care provider(s) (Sudamore et al. 2013) (see box 1). ACP can only involve the person with dementia whilst they have the capacity to do so (HMSO 2005) and becomes a complex matter or may even no longer possible when the person loses capacity (Teixeira et al. 2013). ACP differs from general care planning in that it is usually used in the context of progressive illness and anticipated deterioration. However, ACP is an umbrella term for several aspects of future planning, including advance decisions to refuse treatment, advance statements, lasting power of attorney. Each varies in complexity and legal standing (NHSE (2018).

*Box 1 approximately here*

The National Institute for Health and Care Excellence (NICE) (2018), recommended that people living with dementia should be offered needs-based palliative care from the point of diagnosis that takes into account how unpredictable dementia progression can be. NICE (2018) also recommended that people with dementia be offered the opportunity to undertake advance care planning whist still having the capacity to do so, in order to maximise the control they can achieve over their EOL care.

## Mental Capacity

In the UK, the Mental Capacity Act (HMSO 2005) supports people making decisions for themselves and protects individuals who lack capacity by providing a framework for such decision making. The Act is underpinned by five key principles; the most relevant here are that a person assessed as lacking capacity must be treated in their best interests (principle 4), with the least restrictive option (principle 5). An appointed Lasting Power of Attorney (LPA) for health and welfare can legally make decisions on the person’s behalf if they lack capacity. However, if there is no appointed LPA, the closest relative will be consulted regarding any decision making; however, their views could be disregarded if deemed not to be in the person’s best interests.

The Office of the Public Guardian provided the Alzheimer’s Society (2012) with data on the numbers and types of LPA’s registered from 2007 – 2012 in a freedom of information request. Interestingly, 80% of registered LPA’s were for financial and property and only 20% of registered LPA’s were for health and welfare which would also encompass an ACP. From this the Alzheimer’s Society concluded that there is a poor understanding of the benefits of having a health and welfare LPA and people with dementia are being denied the opportunity of having their preferences legally represented by an appointee (Alzheimer’s Society 2012).

## Proxy Decision Making

There is a wealth of literature on family involvement in decision making in health care (Livingston et al. 2010; Lord et al. 2015; Kenny 2019). Terms vary between studies with ‘family decision maker’, ‘surrogate decision maker’ and ‘proxy’ used almost interchangeably (Harrison Dening et al. 2017). The Alzheimer’s Society (2012) report recognised the difficulties of being a proxy decision maker for a person with dementia, whether the person has been legally appointed to do so or are contributing to the decision-making process informally. In Wendler & Rid’s (2011) review of surrogate decision-making the researchers found that one third of participants reported experiencing ‘negative emotional burden’ when making EOL decisions for a relative who lacked the capacity to make their own. EOL decisions can be especially difficult and complex when caring for a person with dementia, particularly if there is any existing family conflict (Livingston et al. 2010). Using data from focus groups and interviews, families were asked about the decisions they had made, concentrating on common, difficult decisions and facilitators/barriers to decision making. Livingstone et al. (2010) identified accessing help, decisions around permanent placements, legal matters and EOL decisions as being particularly difficult. On the other hand, knowing the views of the person living with dementia, having clear prognostic information, knowledge about future quality of life and family support were identified as facilitators to decision making. Such findings demonstrate the importance of documenting an individual’s wishes and preferences whilst they have mental capacity to articulate them.

This literature review explores decision making for people with advanced dementia and aims to address whether the development of an ACP can help people with dementia to achieve their preferred place of care or death and the potential impact this can have on carers.

## Methods

A PICO approach (Richardson et al. 1995) was applied to frame the clinical question(s) for the review. This is a technique to support the researcher to focus on the Population, Intervention, Comparison and Outcome (PICO). For the purpose of the review, the following were identified;

* P (patient population) - Patients with advanced dementia.
* I (intervention) - ACP.
* C (comparison) - No ACP in place.
* O (outcome) - Achieving preferred place of care or death and reducing carer burden.

The PICO provided the following question: For patients with advanced dementia, does having an ACP in place ensure that a preferred place of death is achieved and reduce carer burden?

A systematic search of health databases was undertaken using a range of nursing, medicine and psychology databases, including AMED, BNI, CINAHL, EMBASE, PsycINFO, HBE, HMIC, Medline and PubMed. A range of search terms were applied (see table 1).

*Table 1 approximately here*

### Inclusion criteria

Articles selected for inclusion were determined by the PICO (Richardson et al. 1995) criteria. Papers included in the review had research participants over the age of 18. All subjects with a formal dementia diagnosis, regardless of type, were included. Only research articles published in the last 10 years were included (total of 3 excluded), as the benefits of ACP in dementia care is a relatively new concept and dementia, until recently, has not been recognised as a life-limiting condition (Marie Curie, 2014; Alzheimer’s Society, 2014). All articles included were written in English (total of 3 excluded) due to lack of resources available for translation. Additionally, quantitative, qualitative and mixed methods studies were included.

### Exclusion criteria

Position papers offering guidance on feeding and antimicrobial use in dementia were excluded. Position papers are known to examine the evidence of a controversial issue in depth, analyse the findings and formulate a viewpoint (Maimon et al, 2005), however, when examined they were thought to be very focussed on one issue and not broad enough to offer anything to the review. Finally, a chapter of a book was identified in the results and excluded as these are not robustly peer reviewed (n=1) and an article detailing a research proposal as this did not include any findings (n=1).

## Results

A total of 32 papers were identified (see figure 1). Records were kept of numbers of titles and abstracts screened, papers retrieved, papers rejected at this point and studies suitable for inclusion (see table 1). A screening of the 32 articles titles, abstracts and full texts against the inclusion/exclusion criteria was undertaken by (WM & JG) and with the removal of duplicates resulted in **five** articles included for review. Full details are included in PRISMA (Moher et al, 2009) flow chart (see figure 1).

*Figure 1 approximately here*

Each of the five studies (see table 2) were examined individually applying the appropriate Critical Appraisal Skills Program (CASP) () appraisal tool (Public Health Resource Unit, 2006) to ensure a critical approach to the review. The findings are outlined below.

*Table 2 approximately here*

Each paper identified in Table 2 has been examined individually due to the small amount of results yielded.

In 2017, Barker and colleagues undertook a scoping review to explore decision making for people living with dementia undertaken by their carers’ at EOL. Scoping reviews differ from a systematic review as they allow for broader topics and questions to be asked (Peterson et al. 2017) resulting in less depth but a wider conceptual breadth (Arksey & O’Malley, 2005). As a research method, scoping reviews are considered higher (in the evidence pyramid) than a literature review but not as detailed as a systematic review (Arksey & O’Malley, 2005). However, with limited research available and varied methodologies a systematic review was not deemed to be feasible by the authors.

Barker et al (2017) undertook a comprehensive search of relevant peer-reviewed papers from health databases and a total of 40 papers were reviewed. Thematic analysis revealed five themes which included; influential factors in carer decision making, the scope of carer decision making, the conflicts and problems in carer decision making, the resources carers need to make decisions and the impact of carer decision making. Barker et al. (2017) suggest that a proactive ACP may lead to reduced care costs (namely reduced hospital attendance and invasive treatments), however, this is stated with caution as the evidence base is limited and of poor methodological quality (Martin et al, 2016). The paper recommends that ideally EOL conversations should be initiated earlier in the dementia journey in order to reduce carer decisional burden; this is as advocated in the NICE (2018) dementia guidelines.

An interesting outcome of the Barker et al. (2017) review was that carers expressed a wish to be involved in decision making but Gjerberg et al. (2015) found carers to prefer health care professionals to make the final EOL decisions. However, Gjerberg et al. (2015) study was a small, qualitative study conducted in one Norwegian nursing home therefore results need to be treated with caution as this may not be transferrable in the UK. Generally, Barker et al. (2017) provide a useful insight into the benefits of ACP and the decision support needs of carers, albeit their study population lacked generalisability in failing to include ethnic minority groups, early onset or rarer forms of dementia which would invariably impact on the support needed by informal carers.

In 2017, Schellinger et al. undertook a qualitative analysis of self-defined goals in serious illness and formed part of a larger four-year study. Overall a total of 160 patients with advanced heart failure (68%), cancer (16%) and dementia (17%), all who were expected to die within 2 – 3 years, were interviewed. Through the use of deductive analysis and coding, four broad themes were identified; medical goals (40%), non-medical goals (40%), multiple domain goals (16%) and global statements (4%). Schellinger et al (2017) concluded that disease-specific guidelines had as their focus physical goals. But the results of their study found they accounted for only 40% of patient self-defined (medical) goals. Therefore, guidelines may well overlook other goals that are of importance to patients with a serious illness. Thus, leading to a failure to provide individualised assessments and care plans (Della & Bernstein, 2004) and dementia patient centred care (Kitwood, 1997). Reference to consent was made but how this was obtained, or the procedures applied if subjects did not have capacity, were not described and indeed the sample size was small; in view of this, any results should be treated with caution. Similarly, the results did not identify any differences between the three disease groups in terms of outlining the goals that were most important to each group. Importantly, this paper gave no consideration to non-medical goals for both the person with dementia and their carers which enable holistic care.

In 2011, Harrison Dening, Jones & Sampson undertook a review of ‘Advance Care Planning for People with Dementia’. Due to the limited information available on ACP and dementia at the time of publication, Harrison Dening et al (2011) undertook a literature review which included a combination of quantitative, qualitative and mixed research methodologies. The findings from the seventeen studies were synthesised to produce a narrative review. Narrative reviews tend to be interpretive and qualitative in nature. They offer insight by summarising and offering comments about a collection of studies (Rumrill & Fitzgerald, 2008).

The heterogeneity of the 17 included studies was not analysed, however several limitations were highlighted including variable inclusion and exclusion criteria, unclear study dates or duration and reasons for attrition. In view of these limitations any conclusions have to be examined with caution. The findings of the review were across six themes including cognitive impairment and mental capacity; ACP and decisions about life-sustaining treatment; ACP in dementia compared to other groups; family carers and decision making; professional attitudes and education of professionals and relatives.

Harrison Dening et al (2011) concluded that a screening tool, such as the Mini Mental State Examination (Folstein et al, 1975) tool were not designed to assess mental capacity in an individual with dementia for determining ability to undertake ACP. Furthermore, patients with mild to moderate stage dementia should be assisted to complete an advance care plan whilst they retain capacity. However, the purpose of these plans, the review reveals, are not always adequately discussed by health care professionals. Family members need the emotional support and information to make confident decisions which includes support when opting to forgo treatments as opposed to consenting to treatments. However, it appears that this would require additional training for health care professionals as they disclosed that they are uncomfortable when making withholding or withdrawing treatment decisions.

Of the 17 reviewed studies, only three were conducted in the UK compared to 12 studies from the United States of America (USA). Additionally, only nine studies directly involved a person with dementia, eight studies had the involvement of family carers and the studies covered those with mild cognitive impairment rather than those with severe dementia. Consequently, it is with extreme caution that any results are applied to the local population. The literature review did acknowledge a limited international evidence base for ACP in dementia and urged more research in this area.

In 2008, Hirschman, Kapo & Karlawish undertook semi structured interviews to identify the factors that facilitate or hinder ACP in people with dementia. This was to obtain qualitative data by the use of open-ended questions (Grove et al, 2013). A total of 30 family members caring for a person with advanced dementia were interviewed. The published findings were divided into themes that either facilitated or hindered planning. Interestingly, they found that 50% of subjects interviewed had made an effort to put their ‘affairs in order’, although most of these conversations had been initiated by a lawyer or accountant (50%), as opposed to a health care professional (30%) and they tended to be in response to a specific event (57%), such as, a medical event or a change of care environment.

Not surprisingly, the identified barriers included families not recognising the importance (60%) or what topics to cover (33%) for ACP. Patient’s personality (50%) and denial of dementia diagnosis (17%) were other related factors. Hirschman et al (2008) concluded that ACP discussions do happen in families, when caring for a person with dementia, but they are usually in response to an event. Furthermore, families require educational strategies, so they are aware of the importance of ACP early enough, but this requires future research. In addition, there is a need for educational materials for non-health care professionals, for example lawyers or accountants who may be assisting families with initial conversations.

The authors highlighted some limitations to the study as predominantly, subjects were white, well-educated and came from higher economic backgrounds. The study did not comment on potential researcher bias, any contradictory data or whether subjects needed to be signposted to appropriate services if any concerns or issues were raised. Interestingly, these results are similar to experiences in clinical practice. The unanticipated result was around the role of non-health care professionals who may be initiating ACP discussions and the need for further research in this area.

In 2015, Brazil, Carter, Galway, Watson & van der Steen undertook a cross-sectional survey to determine General Practitioners (GP’s) perceptions of ACP for dementia patients. GP’s in Northern Ireland were asked to complete a questionnaire to obtain views on palliative care in dementia. This method of data collection allowed them to self-report their views. Survey methods have been criticised as being ‘shallow’ and offering little to ‘scientific knowledge’ (Grove et al, 2013) although, in this publication this method of data collection appeared the most appropriate.

They received a total of 138 responses which represented almost 61% of surveyed practices. From the use of a 5-point Likert scale (strongly disagree, moderately disagree, neither agree nor disagree; moderately agree, and strongly agree) a range of results were obtained including that; 69% of GP’s agreed that early discussions would help prepare families and aid decision making in the advanced stages of dementia. While 31% held reservations about having these conversations at diagnosis, almost 80% of surveyed GP’s identified the need for education and increased knowledge to successfully involve families in caring for dementia patients at end of life.

The limitations of the study included that; only GP’s from Northern Ireland were included in the sample, GP’s who were deemed to have experience of dementia care were selected and the possibility of non-response bias (Berg 2005). The findings were interesting and could prompt further research particularly in addressing barriers, identifying methods that could facilitate ACP and ascertaining as to who the most appropriate individual is to initiate ACP conversations.

## Conclusion

All the studies demonstrate the benefits of having ACP discussions but recommend that conversations happen early in the dementia pathway whilst the person living with dementia retains mental capacity. Health care professionals are well placed to introduce and promote ACP, but notably 50% of conversations happen with non-health professionals, for example legal representatives who may not be best placed to discuss personal or disease prognostic issues.

The literature suggests that informal and formal conversations take place, but this is most often following a critical event which may not be the most appropriate time to embark on ACP. Family carers want to be involved in decision making but tend to do so with a limited knowledge base and ultimately prefer health care professionals to lead or make any final decisions. Some professionals, such as GP’s, were divided on whether they should make the final decision on a patient needs, but felt particularly uneasy when making decisions to forgo treatments.

To assist decision making, carers need emotional support, information and education. Similarly, health care professionals identified the need for additional training and an agreed format for ACP to assist in their conversations and documentation. The known economic benefits of ACP include; a reduction in emergency calls, fewer hospital admissions or interventions, reduced mortality rates and an influence on place of care/death.

The gold standard for ACP will always be to have conversations with the person diagnosed with dementia, so it is imperative that researchers and health and social care practitioners do all they can to ensure that these conversations take place.

Future Research

* Do early conversations in the dementia pathway facilitate the PLWD achieving their preferred place of care/death?
* Does having an ACP reduces decisional burden for carers?
* Is there an emphasis on physical and financial needs when completing an ACP and little stated on social, ethical, family, psychological and bereavement needs (whole person)?
* Are ACP’s reviewed? If so, when, how and by whom? What kinds of changes are made and why?
* Do carers and professionals receive formal training on ACP conversations and formats? If so, what is the impact?
* Are there any differences in BAME communities regarding ACP?
* Does the relationship of the carer have an influence on ACP discussions?
* Does the premorbid personality of the PLWD have an impact on ACP discussions?

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**Box 1: The international consensus definition for Advance Care Plan** (Sudmore et al. 2017, p. 826)

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| --- |
| 1. …… a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care.
2. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.
3. For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions.
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**Table 1: Search terms and search yields**

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| --- | --- | --- |
|  | **Term** | **Yield** |
| 1 | Dementia | 527 519 |
| And 2 | Advanced Dementia |  8 554 |
| Or 3 | Severe Dementia |  24 845 |
| Or 4 | End Stage Dementia |  25 770 |
| Or 5 | Neurodegenerative Disorder |  34 569 |
| And 6 | Advanced Care Plan\* |  464 |
| Or 7 | Care Plan\* |  898 |
| Or 8 | Anticipatory Care Plan\* |  898 |
| Or 9 | Ceilings of Care |  899 |
| Or 10 | Escalation Plan |  899 |
| And 11 | Patient Wishes |  32 |
| Or 12 | Patient Preferences |  64 |
| Or 13 | Preferred Place of Care |  67 |
| Or 14 | Preferred Place of Death |  67 |
| And 15 | Carer Burden |  3 |
| Or 16 | Carer Stress |  4 |
| Or 17 | Surrogate Decision Maker |  8 |
| Or 18 | Family Preferences |  33 |
| Or 19 | Proxy Decision Maker |  33 |

**Figure 1: PRISMA flowchart – Stages of article selection**



| **Table 2: Review papers included** |
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| **Paper** | **Aims** | **Methodology** | **Tools used in recruitment** | **Sample size** | **Study date and duration** | **Intervention** | **Tools used in methods** | **Study Setting** | **Outcomes measured** |
| Barker et al (2017) | To explore the evidence on the decisional support needs of informal carers of people with end-stage Dementia | Scoping review – mixed methodologies | Data base searches; BNI, CINAHL, EMBASE, MEDLINE, PsychINFO, Web of Science  | 40 studies | Between 2000 - 2016 | Thematic analysis |  | UK (16)USA (10)Canada (5)Other (9) | 5 identified ThemesInfluential factors in decision-making (DM)The scope of carer DMConflicts in DMResources carers need to make decisionsImpact of carer DM |
| Schellinger et al (2017) | Descriptive qualitative analysis of self-defined serious illness goals | Qualitative analysis | Part of a larger 4-year late life supportive care study | 160 participants | 14 months(Nov 2012 – March 2014) | Interview | Deductive analysis and coding | USA | 4 identified themesMedical goals (40%)Non-medical goals (40%)Multiple goals (16%)Global goals (4%) |
| Harrison-Dening et al (2011) | What are the facilitators/ inhibitors to ACP for people with Dementia?Key themes. | Mixed methods | Data base searches; BNI, CINAHL, EMBASE, PubMed, AMED, PsychINFO | 17 studies | 1991 - 2008 | Narrative review |  | Nursing homesPrimary careCommunity teams (psych)Memory teamsOld age psych teams Research teamSupport group | 6 identified ThemesCognitive impairment and mental capacityACP and decisions re: life-sustaining treatmentsACP in Dementia compared to other groupsFamily carers and DMProfessional attitudesEducation of professionals and relatives. |
| Hirschman et al (2008) | Experiences of family members of patients with advanced Dementia in planning for the future with their relative. | Mixed methods | Purposive sampling  | 30 participants | Not stated | Semi-structured interviews | Statistical software package and coding | Alzheimer’s Disease center and care facility | 2 identified ThemesPrompting planning – active/reactiveBarriers – passive/ active avoidance |
| Brazil et al (2015) | Describe the attitudes and practice preferences of GP’s working within the NHS regarding communication and decision-making for patients with Dementia and their families. | Quantitative | Purposive clustering sampling approach | 138/340 (40.6%) participants | 2011 - 2012 | Cross-sectional postal survey | Care for Dementia patients at the EOL survey instrument | GP’s in Northern Ireland | 3 identified ThemesInforming patients and relativesACPDecision-making |