

Advance care planning in dementia: recommendations for healthcare professionals

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Abstract: The process of advance care planning in dementia is far from straightforward; as dementia progresses, the ability to consider future thoughts and actions becomes compromised, thus affecting decision-making abilities. Family carers find themselves increasingly in a position where they need to inform, or directly make, decisions on behalf of the person with dementia. This article discusses the context and importance of a palliative care approach and recommends rationales and strategies for healthcare professionals to support families affected by dementia to better plan for their future care.

Keywords: advance care planning, decision-making, dementia, healthcare practice

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An ageing population

People aged 60 years and over make up the most rapidly expanding segment of the population. Between 2000 and 2050, the proportion of the world's population aged over 60 years will more than treble from 605 million to 2 billion.¹ More people are surviving into old age and tending to live longer; over the next 50 years, global life expectancy at age 60 is expected to increase from 18.8 years during 2000–2005 to 22.2 years in 2050.¹ These changes to the age structure of the population will influence both the prevalence and incidence of age-related conditions such as dementia.^{2,3}

Dementia

It is estimated that there are currently 44.4 million people worldwide with dementia, and (if mortality, prevention and treatment remain the same) this number will increase to an estimated 75.6 million in 2030 and 135.5 million in 2050.⁴ Dementia is a term used to describe a syndrome, a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily living activities. These symptoms are caused by structural and chemical changes within the brain as a result of neurodegenerative changes

and as such dementia is the end-stage manifestation of numerous brain disorders.⁵

Increasing numbers of people will die with (or from) dementia. Estimates from the UK Medical Research Council–Cognitive Function and Ageing Studies (MRC–CFAS), a large multicentre research programme examining the health and cognitive function of 13,000 older people, suggest that people who died between the ages of 65 and 69 years had a 6% risk of dying with or from dementia, rising to a 58% risk in those over 95 years. This means that, in the United Kingdom, one in three people over the age of 65 will die with or from dementia.⁶ Dementia is the commonest cause of death in men and women over the age of 80 years,⁷ with the number of related deaths forecast to increase from around 59,000 per year (2014) to around 220,000 per year by 2040.⁸ Many people with dementia die of a medical complication, such as pneumonia or another infection, but dementia itself can be the cause of death, for example, through frailty, malnutrition and dehydration when a person with dementia can no longer eat safely and move independently. There are many challenges in providing palliative and end-of-life care to this group of people, some of which may be amenable to advance care planning (ACP) to support people with dementia to

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have a greater influence on their care at end of life.

Palliative care in dementia

Historically, dementia has not been recognized as a life-limiting condition that may benefit from a palliative care approach. It is now recognized and accepted, particularly in developed countries, that an integral part of care coordination and case management pathways for people with dementia should include end-of-life care.⁹ The European Association of Palliative Care (EAPC) published a consensus statement attempting to define the principles of practice, which are to take a holistic approach, valuing autonomy of patients and their families, with a focus on dignity, a collaborative relationship between healthcare professionals, patients and their families, good communication, and to maintain the quality of life.¹⁰ More recently, and in a further EAPC-sponsored project, van der Steen and colleagues¹¹ used a Delphi consensus process involving 64 experts from 23 European countries, including the United Kingdom, to provide the first definition of palliative care in dementia. A total of 57 recommendations resulted covering 11 domains, with the aim of providing guidance for clinical practice, policy and research. Domain 3 was specifically dedicated to setting care goals and ACP, endorsed by Prince and colleagues⁹ (see Box 1).

The EAPC White paper¹¹ presents healthcare professionals with a more tangible template for supporting ACP development in people with dementia, whereas national guidance has still not moved beyond the nebulous recommendation to offer ACP to people diagnosed with dementia.¹²

Advance care planning

ACP is an important part of palliative care and has been present in the clinical literature since the latter half of the 20th century.¹³ ACP has been defined as a process of discussing and recording of wishes, values and preferences for future care and treatment held between an individual, family members and their care provider(s)¹⁴ that takes effect when the person loses capacity.¹⁵ ACP differs from general care planning in that it is usually used in the context of progressive illness and anticipated deterioration.

ACP supports an individual who has capacity to anticipate how their condition may affect them in the future. If the person wishes, they can set on record choices about their care and treatment and/or an advance decision to refuse a treatment in specific circumstances, the premise being that such plans can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to make decisions as their illness progresses.

However, many people with a life-limiting illness, especially dementia, are not routinely consulted about their wishes and preferences for future care. Berrio and Levesque¹⁶ gave detail to several potential barriers that may contribute to this, all of which remain applicable 20 years on (see Box 2).

Harrison Denning¹⁷ extended this list concerning people with dementia suggesting that there are several additional barriers to initiating ACP in dementia care. These include the following: failure in acknowledging dementia is a terminal/life-limiting illness; the potential for loss of decision-making capacity early on in the disease trajectory;

Box 1. EAPC white paper: palliative care in dementia – Domain 3.¹¹

- 3.1. Prioritizing of explicit global care goals helps guide care and evaluate its appropriateness.
- 3.2. Anticipating progression of the disease, ACP is proactive. This implies that it should start as soon as the diagnosis is made, when the patient can still be actively involved and patient preferences, values, needs and beliefs can be elicited.
- 3.3. Formats of advance care plans may vary in terms of preferences, the amount of detail required, and what is available in the specific setting for the individual.
- 3.4. In mild dementia, people need support in planning for the future.
- 3.5. In more severe dementia and when death approaches, the patient's best interest may be increasingly served with a primary goal of maximization of comfort.
- 3.6. ACP is a process, and plans should be revisited with patient and family on a regular basis and following any significant change in health condition.
- 3.7. Care plans should be documented and stored in a way that permits access to all disciplines involved in any stage and through transfers.

Box 2. Barriers to completing an ACP [16].

- Procrastination, or waiting to do it later
- Dependence on family for decision-making
- Lack of knowledge about ACP
- Difficulty of talking about the subject
- Waiting for the healthcare professional to initiate a discussion by the patient
- for the patient to initiate discussion by the health professional
- Believing a lawyer is needed to fill out the forms
- Fatalism or acceptance of the 'will of God'
- Fear of 'signing my life away'
- Fear of not being treated

a lack of knowledge of the course of dementia (prognostication) in families; lack of confidence in care professionals in starting discussions with people diagnosed with dementia and finally the failure to identify a care manager or lead to facilitate ongoing ACP as the illness progresses.

Decision-making and capacity in dementia

As dementia progresses, the ability to consider future thoughts and actions becomes compromised,¹⁸ thus affecting decision-making abilities.⁵ Historically, people with dementia were rendered powerless, with decisions being made 'for' them by professionals rather than 'with' them or 'by' them. Participation in decision-making is now viewed as essential to the delivery of individualized and person-centred dementia care.⁹ The concept of shared decision-making is emerging in dementia care.^{19,20} People with dementia want to be involved in decisions about their care²¹ and, while dementia does not automatically render someone incapable of making decisions, shared decision-making with family carers is their preference. For such shared decision-making, mutuality must be established.²⁰ However, in the context of ACP, participation of the person with dementia is sometimes little more than lip service paid to an ideal and the issues around decision-making for this group of people become more complex as the disease progresses.

In the United Kingdom, the Mental Capacity Act 2005 (MCA)²² protects and supports people who do not have the ability to make decisions, affirming the rights of people with impaired decision-making capacity caused by illnesses such as dementia. The act changed the legal concept of

capacity, from one which regarded decision-making capacity as 'all or nothing' to one which recognizes capacity as being decision specific, relating to the time when a decision or action needs to be taken. Capacity must be assumed unless evidence suggests the contrary. If there is doubt about an individual's capacity, a capacity assessment must be made to ensure that any decision is valid. The person must be able to understand the information relevant to the decision, retain the information long enough to be able to make the decision, weigh up the information available to make the decision and communicate their decision by any possible means. The MCA encompasses the right of the person with dementia to exercise their autonomy as far as possible and requires others to support them to do so. The general legal and ethical rule is that people without capacity are treated in their 'best interests' which must also take into account their own wishes and preferences as well as what is clinically viewed as the most appropriate action. Where individuals lack capacity, a fundamental consideration is their past wishes and preferences. If these are not recorded or known, relatives are asked about what the person would or would not have wanted. If there is no lasting power of attorney, the closest relative must be consulted and his or her views only disregarded for a very good reason, such as if they do not seem to be in the patient's best interest or are impossible.

Despite people with dementia having many years' experience of making decisions for themselves before the onset of the disease, family carers are often assumed to know what decisions they would have made had they not lost capacity. Consequently, decisions about end-of-life care for people with dementia are typically made by family member surrogates.^{23–28}

Successful decision-making for a family affected by dementia involves sharing knowledge, experience and wishes and preferences for care across all stakeholders: the person with dementia, the family carers(s) and professionals. In practice, this might mean a balance between considering the perspectives and wishes of the person with dementia and those of the carer. It can be challenging to support this balance of interests and needs in end-of-life care as effective support of shared decision-making requires professional confidence, advocacy for the person with dementia and support for family members in understanding their own wishes and preferences in any care situation.²⁹ Professionals must strive to make

the wishes and preferences of the person with dementia influence delivery of care when they may well become at odds with what is in the best interests of the carer.

Kelly and colleagues³⁰ asked older people what was most important to them should they lose capacity with the majority wanting a close family member to act as their decision-maker in such an event. There was the commonly held belief that their family member would know the treatments they would want or not. Making decisions about end-of-life care and treatment on behalf of a family member is not straightforward and can at times be extremely difficult. It will often involve complex issues around whether to treat or whether to withhold treatment. There may be several treatment options to choose from, and in certain contexts the decision will also be important (e.g. in a crisis as compared to states of chronic ill health). Overlaid on this are the perspectives, preferences and wishes for future care of the person for whom decisions are to be made. For clinicians, it may often be difficult to know whether proxy decision-making and treatment choices are consistent with the previously expressed wishes of the person with dementia.

Challenges for family caregivers

Family carers can often experience increasing demands in making decisions as the dementia progresses and studies have reported on certain emotional and practical issues, including the following:

- Difficulties in deciding what to do about day-to-day care;^{31,32}
- Distress in making health-related decisions;
- Having insufficient information about any possible alternatives and their effects;³²
- Negative emotional effects, such as, stress, guilt and self-doubt.²⁸

In the general population, Shalowitz and colleagues³³ found that family carers were able to predict patients' treatment preferences with moderate accuracy. A recent study by de Vries and Drury-Ruddlesden²³ found that family members confidently made decisions about end-of-life care based on many years of previously held conversations about death and dying within the family. However, Harrison Denning

and colleagues³⁴ interviewed 60 dyads (a person with dementia and their family carer) to examine the accuracy of family carers in predicting the wishes and preferences for end-of-life care and treatments of the person with dementia for whom they cared. None of those interviewed held an ACP. Using a modified version of the Life Support Preference Questionnaire (LSPQ),³⁵ participants were presented with three illness scenarios, including the nature of the impairment, its prognosis and level of pain: advanced cancer, severe stroke and 'as you are today' (with a diagnosis of dementia). They were asked to consider themselves in each scenario and indicate their preference using a five-point Likert-type scale from 'definitely would want' to 'definitely would not want' for receiving three life-sustaining medical treatments: antibiotics, cardiopulmonary resuscitation and tube feeding. Carers were interviewed separately and asked to indicate what treatment preference the person with dementia, for whom they care, was likely to have chosen. Results revealed that a carers' ability to accurately predict the person with dementia's treatment preferences (in the absence of previous discussions or an ACP) was no better than chance (lower than 35% accuracy), thus questioning the professional reliance on family members in decision-making.

ACP that promotes the wishes and preferences of the person with dementia may, at times, mean a balance to also consider the wishes and preferences of the carer as these may be in conflict. It can be a challenge to support this balance of interests and needs in end-of-life care. In more complex cases, this may require the input of skilled professionals, such as Admiral Nurse case managers (see Box 3), to support families affected by dementia and in balancing the needs of each family member.³⁶

Research suggests that the most difficult decisions families have to make are those for end-of-life care; these are made more difficult in the presence of family disharmony³⁷ and families in conflict, with poor interrelational dynamics, were more likely to opt for aggressive care at end of life.^{38,39} In the absence of family cohesion, the role of the surrogate decision-maker becomes isolated and even more difficult, and Caron and colleagues⁴⁰ state that professionals, such as Admiral Nurses, by promoting trust in their therapeutic relationships with family carers can counter this to some degree.

Box 3. Admiral Nurse case management.

Admiral Nurses focus on the needs of the whole family affected by dementia, including psychological support to help the person with dementia and family carers to understand and deal with their thoughts, feelings and behaviour, and to adapt to the changing situation. Caregiving involves a change in ongoing patterns of exchange between the caregiver and care recipient. Both the caregiver and recipient have to adjust to the transformation of their relationship into a caregiving relationship; this includes a change in the balance of roles, as the caregiver takes more responsibility for the welfare of the recipient.

Admiral Nurses use a range of specialist interventions that help people live well with the condition and develop skills to improve communication and maintain relationships.

Admiral Nurses work with families at particular points of difficulty in the dementia journey, including diagnosis, when the condition progresses, or when tough decisions need to be made, such as moving a family member into residential care. Anticipated problems are misdiagnosis, delayed diagnosis and lack of information and services for people with dementia and their families, which give rise to the risk for inappropriate management, crises, poor psychological adjustment to the diagnosis, reduced coping capacity and the ability to forward plan.

Admiral Nurses help families cope with feelings of loss and bereavement as the condition progresses.

There is an acknowledgement that family care does not end once 'hands-on' caregiving ceases.

Admiral Nurses care coordinate and manage referrals to other appropriate services and liaise with other health professionals on behalf of the family. (www.dementiauk.org)

Confidence and knowledge of professionals

ACPs are not only about the paperwork and documentation of wishes; they are also not meant to be a one-off conversation but are concerned with the opportunity for professionals to instigate and conduct ongoing conversations related to death, dying, bereavement and anticipatory loss.⁴¹ In people with dementia, cognitive activity and abstract thinking, abilities that are needed to think about the future, can become difficult. Piers and colleagues⁴² argue that although this can make such conversations difficult, it does not preclude them. However, the literature reveals that professionals often lack the confidence and the skills in breaking bad news and in initiating the process of ACP with sensitivity and empathy.^{43–45}

Facilitation of ACP requires advanced communication skills central.⁴⁶ ACP research from the United Kingdom has found that earlier discussions in a life-limiting illness can help reduce anxiety about death^{47,48} and lead to an increase in feelings of autonomy,⁴⁹ maintenance of a sense of control,⁵⁰ increased patient satisfaction,⁵¹ and a range of improved outcomes for family carers, such as reduced depression, stress and anxiety⁵² and reduced decisional uncertainty.⁵³ Yet people with dementia are still not routinely consulted about their wishes and preferences for future care³⁴ with many of the barriers identified by Berrio and Levesque¹⁶ still existing.

Conversation models

Several models have been developed to support the initiation of these difficult discussions (see Box 4). As Russell⁴¹ argues, one size does not fit all, from either the perspective of the patient or indeed that of the professional. However, such models have a formulaic approach that includes preparation, person-centred, empathy and acknowledgment of emotions and concerns and in eliciting wishes and preferences. Older people want to be treated in a manner consistent with their own wishes and preferences⁵⁶ and often want to keep the burden of decision-making upon their family to a minimum and they are often willing to be helped to make decisions in consultation with their doctor.⁵⁷ Often the reluctance to initiate such discussions is largely felt by the professional and in reality families affected by dementia are only too ready to hold them.³² However, although healthcare professionals may aspire to support with people with dementia in making decisions about their health and social care, in practice attention is often diverted to family carers who wish to pursue proxy decision-making.

In addition, Piers and colleagues⁴² followed Belgian Centre for Evidence-Based Medicine's¹ procedures to examine studies relating to ACP in dementia and graded the studies' quality and level of evidence to develop recommendations for practice. However, this process developed an unwieldy number of recommendations that, rather than support practice, may inhibit or

Box 4. Communication models and resources.

- **AFIRM**
AFIRM is an acronym which provides professional carers with a framework to guide informal conversations and uses these as opportunities to pick up on any underlying apprehensions or queries the person with dementia (and/or their family member) may have (<https://www.hse.ie/eng/about/Who/ONMSD/eductraining/dementiaeducation>).
- **SAGE & THYME⁵⁴**
SAGE & THYME is a mnemonic that acts as an aide-memoire for a structured conversation with a person in distress or with concerns. 'SAGE' gets the user into the conversation and 'THYME' gets them out (<http://www.sageandthymetraining.org.uk/sage-thyme-model-and-benefits-1>).
- **SPIKES⁵⁵**
SPIKES is a six-step protocol for delivering bad news and to holding a difficult conversation: setting up the **I**nterview (1), assessing the patient's **P**erception (2), obtaining the patient's **I**nvitation (3), giving **K**nowledge (4) and **I**nformation, addressing the patient's **E**motions (5) with empathic responses and **S**ummarizing (6).
- **Talking Mats⁻**
Talking Mats is a communication symbols tool that uses unique, specially designed picture communication symbols as an interactive resource to enhance communication in people where this is compromised
- (<https://www.talkingmats.com/thinking-ahead-supporting-people-to-plan-for-the-future/>).

Box 5. Recommendations for ACP conversations.⁴²

- Start ACP as early as possible and integrate ACP into the daily care of people living with dementia.
- Always assume mental capacity; consider capacity as a fluctuating rather than static condition; stay alert for signs of loss of capacity; judge mental capacity task-specifically, that is, for a certain decision at a particular moment in time.
- Adjust conversation style and content to the person's level and rhythm.
- Lead the conversation but do not force it to become too formulaic or phased.
- Try to understand the whole person living with dementia; explore their life story, important values, norms, beliefs and preferences.
- ACP conversations are not one-off occurrences and are best held on several occasions and over a longer period of time.
- Explore the person's current experiences; their fears and concerns for the future and for the end of life.
- Evaluate their disease awareness and inform them about the expected disease trajectory and possible end-of-life decisions.
- Keep connected with the person with dementia to ensure their maximum participation; respond to their emotions; attend to nonverbal communication; observe their behaviour.

indeed paralyse it. All of the recommendations were gleaned from the previous literature that has thus far failed to improve the implementation of ACP for people with dementia (see Box 5 for a selection of the recommendations).

When is the best time to initiate ACP in dementia?

There is much debate on when the best time is to offer ACP to people with dementia; many professionals feel that entering into discussions about ACP for end-of-life care is both too soon and insensitive within the initial diagnostic process. However, in dementia, end-of-life care planning needs to take place early, while the person has sufficient mental capacity to consider their

preferences and make decisions for their future. However, there are various transition points (see Table 1), where carers find themselves increasingly called upon to inform, or directly make, decisions on behalf of the person with dementia.

The place for case management in supporting ACP

People with dementia do not exist in isolation and, while there has been a strong thrust to identify the needs of people with dementia against a background of person-centred care, they live within relational contexts, whether that be with family members or with professional carers but often, both. Case management has a long history in supporting people with long-term conditions

Table 1. Milestones which can act as triggers to engage in ACP.⁵⁸

Transition points	Healthcare events
<ul style="list-style-type: none"> • Time of diagnosis of dementia • When undertaking a Lasting Power of Attorney for finance and/or personal welfare • Care plan/package review for community home care • Changes to setting of care; transfer to acute care or residential care setting and so on. • Changes to the health status of the family carer (illness, death, etc.) 	<ul style="list-style-type: none"> • Deterioration or decline in the PWD condition • PWD presenting with complex symptoms • PWD presenting problems with nutrition and hydration • Decreasing response to antibiotic treatment • When the question of a need for further medical investigations of treatments arise • Discussions about attempting cardiopulmonary resuscitation
ACP, advance care planning; PWD, person with dementia.	

and mental illness. In a meta-analysis, Reilly and colleagues⁵⁹ found evidence to suggest that there were benefits to adopting a case management approach in dementia, reducing or delaying admission to care homes and reducing admissions to and length of stay in hospital and reduction in behaviour disturbance. Harrison Dening and colleagues⁶⁰ suggest that the benefits to case management in dementia span the entire trajectory of dementia and specifically in supporting decision-making from the point of diagnosis through the introduction of ACP to better influence end-of-life care.⁶⁰ In discussing the improvement and coverage of healthcare for people living with dementia, Prince and colleagues⁹ in the World Alzheimer Report support the call for case management. They state that the healthcare team in its entirety needs to have adequate skills in applying a palliative care approach to dementia with all members being able to provide at least a baseline palliative care approach and that care plans, including ACPs, should be stored and accessible to all stakeholders involved in the persons care. Harrison Dening and colleagues⁶⁰ argue that care of people with dementia and their families is best managed by a case manager with specialist knowledge of dementia who can effectively coordinate the input of other disciplines and specialities based upon families' specific needs, thus not requiring the wider care team members to have expert knowledge in dementia. The refreshed National Institute for Health Care Excellence (NICE) dementia guideline¹² acknowledges that there is evidence that case management is an effective intervention for people living with dementia. However, NICE states that the effectiveness and cost effectiveness of high-intensity case management have not been fully tested in the United Kingdom. There is

some evidence from settings outside the United Kingdom⁶¹ that it may reduce the use of other services, leading to cost savings across the whole system. Because of the cost, robust evidence of effectiveness and cost effectiveness from a UK setting is needed.

Conclusion

There will be large number of people with dementia as the population continues to age. Dementia is a progressive, irreversible neurodegenerative condition that greatly reduces life with one in three of the population expected to die with or from dementia. People with dementia (and their families) are much in need of a palliative approach to their care, especially through ACP and support with decision-making in preparation for end of life.

The process of ACP in dementia is far from straightforward; as dementia progresses, the ability to consider future thoughts and actions becomes compromised, thus affecting decision-making abilities. Family carers find themselves increasingly in a position whereby they are called on to inform, or directly make, decisions on behalf of the person with dementia. It is often assumed that they know what might have been the decisions of a person with dementia when capacity is lost even though wishes and preferences may not have been previously articulated. We need to have greater confidence to initiate ACP conversations to directly involve the person with dementia themselves if we are to ensure that their wishes and preferences are realized at a time where they have lost capacity to make these themselves in real time. This article makes recommendations in enabling more focused communication with the

person with dementia that will enable ACP discussions. Of equal importance is for professionals, in the form of a case manager or care coordinator, to support family carers to make decisions on behalf of the person with dementia and to enable them to effectively navigate the various transition points along the trajectory of dementia, such as seeking a diagnosis, facilitation to develop ACP, gain access to support services, admission to a care home and end-of-life care options.

Recommendations for practice

- ACP discussions need to be initiated as early after the diagnosis of dementia as decision-making capacity may be lost early on in the disease trajectory.
- Facilitation of ACP requires specific skills and competencies of the professional responsible, such as advanced communication skills, expert knowledge of dementia, its course and prognosis, complications of comorbidity, coordination of the dissemination and sharing of the plan.
- A case management approach in supporting families affected by dementia, such as Admiral Nursing, can support ACP discussions throughout the trajectory of dementia to adapt to changing needs within the relationship.
- Support ACP within the context of family relationships embracing shared decision-making with the ability to involve all family stakeholders but not assuming family members will always know the wishes and preferences of the person with dementia.
- For professionals to confidently facilitate ACP in dementia requires specific training and development to counter the demands of the role.

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