

PRIORITY BRIEFING

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. They were compiled in 2-3 days.

At what stage of the Dementia diagnostic process should advanced care planning be raised?

Question ID: 17

Question type: Intervention

Question: At what stage of the Dementia diagnostic process should advanced care planning (ACP) be raised?

Population: Patients attending a local Memory Clinic who are given a diagnosis of Dementia (or Mild Cognitive Impairment – MCI).

Intervention: Have a specific interview/contact session with the patient (and carer) some time (within months) following a diagnosis of Dementia (or MCI), to discuss End of Life decisions and Advanced Care Planning (wills, Power of Attorney etc) in addition to the initial diagnostic interview (and information pack). The deliverer of the session may/may not need training but does not need to be a consultant or clinical specialist.

Control: Patients who have also been given a diagnosis of dementia at a local Memory clinic and received the information pack but not had the additional interview/contact session about Advanced Care Planning.

Outcome: Patients to have greater knowledge around Advanced Care Planning, be comfortable with the notion of needing future care and hopefully will have undertaken the process of preparing Lasting Power of Attorney and Advanced Care Plans. It would also be important to measure the patient/carer's experience of the additional session as it may be too distressing and have a negative impact on the patient/carer and their future relationship with dementia services. In the future ACP may reduce distress for both carers and patients and avoid medical interventions at end of life. This would add to the current knowledge of this issue and help develop a local care pathway for Advanced Care Planning as part of everyday practice in the management of Dementia.

Dementia:

Dementia is a common condition characterised by loss of cognitive functions such as memory and problem solving beyond what would be expected from normal ageing. The diagnosis of dementia also requires that the person's cognitive functions have declined to the extent that it interferes with their work, social activities, self-care or relationships with others. Treatment options that are currently available are largely limited to treating symptoms such as difficulties in maintaining attention. For the majority of people with dementia there is currently no treatment that will alter the course of the disease.

Advanced care planning (ACP):

ACP is a process of discussion between an individual and their care providers. If the individual wishes, their family and friends may be included. With the

individual's agreement, discussions should be documented, regularly reviewed and communicated to key persons involved in their care.

Examples of what an ACP discussion might include are:

- the individual's concerns
- their important values or personal goals for care
- their understanding about their illness and prognosis
- particular preferences for types of care or treatment that may be beneficial in the future and the availability of these.

The difference between ACP and care planning more generally is that the process of ACP will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.

The Health Problem:

The National Dementia Strategy states that there are over 700,000 people with dementia in the UK (1 in 20 over the age of 65 years and 1 in 5 in the over 80s) which costs the economy roughly £17 billion per year. In the next 30 years it is predicted that the number of people with dementia will double to 1.4 million and the cost will treble to around £50 billion per year (DoH, 2009). There is also a wider cost to the quality of life and the health needs of those caring for people with dementia.

In Cornwall there are around 8000 people with dementia and in Devon there are more than 12,000. This is and will be a considerable burden on health resources. There are also numerous sufferers admitted to Acute Care Settings at end stage because their wishes have not been explored or documented appropriately. At the diagnostic interview the clinician imparts a lot of information around the diagnosis and has limited time to discuss other areas, it can also seem inappropriate to discuss future planning in too much detail at this time, when they are only just becoming aware of the implications of the diagnosis.

Guidelines:

The NICE Guidelines Dementia: supporting people with dementia and their carers in health and social care (2006) recommend that advanced statements of care, treatment and Power of Attorney should be discussed whilst the person with dementia still has the mental capacity to make decisions.

Dementia Care and Diagnosis is one of the Government's key priorities. Objective 12 of the National Dementia Strategy is to improve end of life care for people with dementia. It goes on to suggest setting up pilot studies in this area as there is limited evidence and evaluation of the best care pathways. This should be linked into the Department of Health End of Life Care Strategy. Objective 3 of the National Dementia Strategy is for good quality information for those with diagnosed dementia and their carers. This information could then be shared in the 'Good Practice Compendium', which is being developed by the Department

of Health and which is aimed at bringing together examples of good practice in improving dementia care from across the regions.

The End of Life Care Strategy (DoH, 2008) also recommends that all people approaching the end of life should be involved in their care planning, though it does not suggest a particular or structured format for doing this or for ensuring it is completed as part of a care package.

NHS Priority:

Regional

SW SHA Priorities framework 2008-11

- full implementation of the End of Life Care Strategy in all PCTs
- all health communities will be able by 31 March 2011 to identify the number of people with a plan for their death and to report the percentage of cases where the preference about place of death has been delivered
- responding to individual preferences will lead to a 10% reduction year-on-year in adult deaths in acute hospital

The QIPP agenda advocates for reducing procedures of limited clinical benefit and adopting best-practice care pathways for long term conditions.

Local

- help to address variability in community and primary care
- CIO SPCT has a particular priorities surrounding dementia due to the potential burden on health and social care resources

Existing Research:

Published research

No systematic reviews on this topic were identified during the searches conducted for this priority briefing. No studies were identified that specifically answered this question though there were studies carried out in the UK, US, France and the Netherlands that have implications for the delivery or implementation of ACP. Three studies investigate the importance of the content of ACP^{5,8,11}. These studies highlight the issue of euthanasia as a potential option as part of an ACP⁵ particularly in the Netherlands, the use of differing tools which allow different options for patients and the importance of capturing patient preferences⁸, and the use of different methods of presentation of information during the ACP¹¹. The research suggests use of a video-decision support tool to influences initial ACP preferences and makes initial decisions more stable at later review points. Four studies suggest that concern regarding general implementation of ACP is justified as potentially at first referral only a fifth of patients with dementia were competent enough to complete ACP¹. Cognitive competence affects ACP preferences^{2,3} with those more capable of making decisions more likely to choose non-intervention in end of life treatment. Also, people with dementia suffer different losses at different stages and therefore accurate assessment of abilities and losses is critical to assist in planning for

their future care needs¹⁰. Research suggests that many people at risk of becoming mentally impaired are still not completing ACP⁹ and indicates that even where ACP is implemented many trainee physicians in the UK choose a level of care different from that in the ACP⁷ and in some cases the physician is unaware that it exists⁴. Confusion also exists among doctors about the legal status of advance directives, which may limit their usefulness⁷. One study has suggested a structured process for conducting ACP discussions, though it has not been tested⁴ and one theory paper argues the balance between ACP and Best Interest Standard which aims to be a more 'flexible' approach to end of life care decision making⁶.

Ongoing research

No registered ongoing research was identified. However, the abstract written by Robinson¹³ and the article written by Exley et al (2010)¹² (see references section) suggests a project may be ongoing in Newcastle to determine the effectiveness of ACP and to develop tools to aid implementation in practice. A systematic review has been completed and a paper is expected to be submitted for publication by the end of the year. Initial results from this review suggest little/no research has been done on this area in the UK and only five studies internationally were able to be included in the review (three in USA, one in Australia and one in Canada). The review highlights the need for high quality UK based studies to investigate effectiveness of ACP and optimum conditions for implementation.

Feasibility:

In Cornwall there is a newly commissioned Memory Service and an expanding ageing population with expected huge increases in numbers of Dementia Sufferers. A local community matron has been investigating the use of ACP in nursing homes at which time it is believed that patients have lost the mental capacity necessary to communicate their wishes.

References:

1) Fazel, S., T. Hope, et al. (1999). "Dementia, intelligence, and the competence to complete advance directives." Lancet **354**(9172): 48.

At referral, a fifth of patients with dementia were competent to complete advance directives. Competence was significantly related to higher premorbid IQ estimated by the National Adult Reading Test. Oxford.

2) Fazel, S., T. Hope, et al. (2000). "Effect of cognitive impairment and premorbid intelligence on treatment preferences for life-sustaining medical therapy." American Journal of Psychiatry **157**(6): 1009-11.

OBJECTIVE: This study examines the influence of cognitive impairment, premorbid intelligence, and decision-making capacity to complete advance directives on the treatment preferences for life-sustaining medical therapy in the elderly. **METHOD:** One hundred elderly individuals were recruited. Fifty were first referrals to specialist services with a DSM-IV diagnosis of dementia, and 50 were

volunteers. Each person was asked about treatment preferences in three clinical vignettes. RESULTS: Elderly individuals who had cognitive impairment and were incapable of completing advance directives were significantly more likely to opt for life-sustaining interventions. There was no association between premorbid intelligence and treatment preferences. CONCLUSIONS: Cognitive impairment appears to influence treatment preferences for life-sustaining medical therapy. With increasing cognitive impairment, elderly individuals tend to opt for treatment interventions. Oxford.

3) Rempusheski, V. F. and A. C. Hurley (2000). "Advance directives and dementia." Journal of Gerontological Nursing **26**(10): 27-34.

Since the 1990 Patient Self-Determination Act, increasing numbers of adults are completing advance directives (ADs), but unfortunately many adults seen in a dementia evaluation program have not completed an AD. This article discusses the issue of individuals with dementia completing ADs. Situational factors that frame this issue are the stage of dementia, degree of certainty of an individual's wishes for end-of-life care, the decision-making act required by care providers, and the degree of contentment or distress experienced by an individual with dementia. Several investigators have demonstrated successful completion of ADs by individuals with mild and moderate dementia. A nurse's knowledge about the stages of dementia is essential to helping an individual through the AD decision-making process. Nurses caring for individuals with dementia should assess decision-making context; recognize the emotions of family, friends, and staff; understand the substance and logic of AD requests; and support individuals and their decisions.

4) Kass-Bartelmes, B. L. and R. Hughes (2004). "Advance care planning: preferences for care at the end of life." Journal of Pain & Palliative Care Pharmacotherapy **18**(1): 87-109.

Predictors of patient wishes and influence of family and clinicians are discussed. Research findings on patient decision-making relating to preferences in end-of-life care are described. Advance directives and durable powers of attorney are defined and differentiated. Most patients have not participated in advance care planning and the need for more effective planning is documented. Appropriate times for discussions of such planning are described. Scenarios discussed include terminal cancer, chronic obstructive pulmonary disease, AIDS, stroke, and dementia. Patient satisfaction is discussed, as is a structured process for discussions about patient preferences. Results of patient responses to hypothetical scenarios are described. Invasiveness of interventions, prognosis and other factors that favor or discourage patient preferences for treatment are discussed. Findings resulting from research funded by the Agency for Healthcare Research and Quality (AHRQ) are discussed. This research can help providers offer end-of-life care based on preferences held by the majority of patients under similar circumstances.

5) Rurup, M. L., B. D. Onwuteaka-Philipsen, et al. (2005). "Physicians' experiences with demented patients with advance euthanasia directives in the Netherlands." Journal of the American Geriatrics Society **53**(7): 1138-44.
OBJECTIVES: To estimate the incidence of (compliance with) advance euthanasia directives of patients suffering from dementia in the Netherlands and to gain knowledge about the experiences of physicians. DESIGN: Retrospective interview study. SETTING: Physicians in the Netherlands. PARTICIPANTS: Four hundred ten physicians. MEASUREMENTS: Physicians were interviewed about their demented patients who had an advance euthanasia directive. Nursing home physicians were interviewed more extensively. RESULTS: Approximately 2,200 demented patients with an advance euthanasia directive die annually after being treated by a physician who knows about this directive. In 76% of such cases, compliance with the directive was discussed, but euthanasia was seldom performed. In two-thirds of the cases of demented nursing home patients with an advance euthanasia directive, the physician was able to identify during the course of the disease a situation for which the patient had intended the directive. One-quarter of the nursing home physicians thought that their most recent patient suffered unbearably to a (very) high degree, and half of them thought that the patient suffered hopelessly to a (very) high degree. In three-quarters of the cases, the relatives did not want the nursing home physician to comply with the directive, but they did want to respect the patient's wishes by forgoing life-prolonging treatment, which occurred in approximately 90% of cases. CONCLUSION: Most nursing home physicians think that the suffering of patients with dementia can be unbearable and hopeless as a consequence of dementia, but most physicians do not consider dementia to be grounds for euthanasia, unless perhaps the patient has an additional illness. NL.

6) Harvey, M. (2006). "Advance directives and the severely demented." Journal of Medicine & Philosophy **31**(1): 47-64.
Should advance directives (ADs) such as living wills be employed to direct the care of the severely demented? In considering this question, I focus primarily on the claims of Rebecca Dresser who objects in principle to the use of ADs in this context. Dresser has persuasively argued that ADs are both theoretically incoherent and ethically dangerous. She proceeds to advocate a Best Interest Standard as the best way for deciding when and how the demented ought to be treated. I put forth a compromise position: both ADs and the Best Interest Standard have roles to play in guiding the care of the severely demented.

7) Toller, C. A. S. and M. M. Budge (2006). "Compliance with and understanding of advance directives among trainee doctors in the United Kingdom." Journal of Palliative Care **22**(3): 141-6.
AIM: To investigate doctors' response to and understanding of the legal status of advance directives. METHODS: A vignette-based study administered at palliative medicine, oncology, general practice, and geriatric medicine specialist registrar meetings (United Kingdom). Respondents determined the treatment to provide for a patient presenting with a myocardial infarction with or without an advance

directive requesting maximum therapy. RESULTS: Response rate 77% (43/56). Twenty-five percent (10/40) of respondents increased the care that they would provide in response to the advance directive ($p = 0.004$); 77% (33/43) support/strongly support use of advance directives; 51% (22/43) did not know the legal status of advance directives; 44% found that their medical school education was not an important influence on their decision making. CONCLUSIONS: Advance directives requesting treatment can increase the level of care provided by the physician, however, most trainees chose a level of care different from that in the advance directive. Confusion exists among doctors about the legal status of advance directives, which limits their usefulness. Medical education needs to be improved to train doctors to deal with advance directives. UK.

8) Abbo, E. D., S. Sobotka, et al. (2008). "Patient preferences in instructional advance directives." Journal of Palliative Medicine **11**(4): 555-62. BACKGROUND: Instructional advance directives (ADs) are traditionally written to apply in terminal illness. As such, they do not readily capture patient preferences for care in acute and chronic illness. OBJECTIVE: To test whether patients prefer a modified AD that includes preferences to limit life-sustaining therapy (LST) for critical illness and advanced dementia over a traditional AD. METHODS: A convenience sample of medically stable, hospitalized general medical patients were presented a traditional AD (the recommended Illinois statutory living will that limits LST in terminal illness) and a modified AD. The modified AD presents four conditional options: (1) to limit LST in terminal illness, (2) to limit LST in critical illness to a reasonable trial, (3) to refuse LST in advanced dementia (described in lay language), and (4) to refuse artificial hydration and nutrition (AHN) in advanced dementia. The primary outcome was the preferred AD to present to patients. Secondary outcomes included the AD choice of those who executed an AD and the options chosen by those executing the modified AD. RESULTS: Seventy-two patients completed the survey. Eighty-six percent (95% confidence interval [CI], 76%-93%), preferred that the modified AD be presented to patients over the traditional AD. Twenty-one patients chose to execute an AD. Eighteen (86%; 95% CI, 64%-97%), executed the modified AD. Twelve executed all four options. CONCLUSIONS: Traditional instructional ADs fail to capture important patient preferences. Future research should further validate these preferences and explore whether including these specific options in ADs can improve their efficacy. US.

9) Lingler, J. H., K. B. Hirschman, et al. (2008). "Frequency and correlates of advance planning among cognitively impaired older adults." American Journal of Geriatric Psychiatry **16**(8): 643-9. OBJECTIVE: To examine the prevalence and sociodemographic correlates of written advance planning among patients with or at risk for dementia-imposed decisional incapacity. DESIGN: Retrospective, cross-sectional. SETTING: University-based memory disorders clinic. PARTICIPANTS: Persons with a consensus-based diagnosis of mild cognitive impairment (N = 112), probable or possible Alzheimer disease (AD; N = 549), and nondemented comparison

subjects (N = 84). INTERVENTION: N/A. MEASUREMENTS: Semistructured interviews to assess durable power of attorney (DPOA) and living will (LW) status upon initial presentation for a dementia evaluation. RESULTS: Sixty-five percent of participants had a DPOA and 56% had a LW. Planning rates did not vary by diagnosis. European Americans (adjusted odds ratio = 4.75; 95% CI, 2.40-9.38), older adults (adjusted odds ratio = 1.05; 95% CI, 1.03-1.07) and college graduates (adjusted odds ratio = 2.06; 95% CI, 1.33-3.20) were most likely to have a DPOA. Findings were similar for LW rates. CONCLUSIONS: Although a majority of persons with and at risk for the sustained and progressive decisional incapacity of AD are formally planning for the future, a substantial minority are not. US.

10) Nourhashemi, F., S. Gillette Guyonnet, et al. (2008). "A randomized trial of the impact of a specific care plan in 1120 Alzheimer's patients (PLASA Study) over a two-year period: design and baseline data." SO: The journal of nutrition, health & aging(4): 263-71.

OBJECTIVE: To describe the design and baseline patient characteristics of a multicomponent specific care and assistance plan (PLASA) study in Alzheimer's Disease (AD). The study is designed to evaluate the effect of PLASA in AD primarily looking at change in functional capacity. DESIGN: Two-years prospective cluster randomized controlled trial comparing PLASA and usual care. SETTING: Forty-nine hospitals in France. PARTICIPANTS: 1120 community-dwelling AD. INTERVENTION: Patients in the intervention group are evaluated biannually using a standardized comprehensive global assessment. In the case of decline in any one domain a standardized study protocol recommends specific physician directed intervention in addition to information and training for the caregiver. MEASUREMENTS: Alzheimer Disease Cooperative Study-Activities of Daily Living scale, Resource Utilization in Dementia scale, Clinical Global Impression of Change. RESULTS: At baseline, the two groups were similar regarding patient and caregiver characteristics. The mean patient age was 79.61±5.72 years and the mean MMSE 19.73±4.01 for the whole cohort. Time since dementia diagnosis was about 1.37±1.65 years in the whole cohort. Almost a third of the patients lived alone at baseline. Mean monthly time spent in caregiving in the whole cohort was 52.70±71.83 hours for instrumental activities and 17.73±51.38 hours for basic activities. CONCLUSION: Persons with dementia suffer different losses at different stages of the disease and therefore accurate assessment of abilities and losses is critical to assist the person in planning for their future and for care needs. The PLASA intervention study is ongoing with 2 year follow-up to be completed in 2007. France.

11) Volandes, A. E., M. K. Paasche Orloff, et al. (2009). "Video decision support tool for advance care planning in dementia: randomised controlled trial." SO: BMJ (Clinical research ed.): b2159.

OBJECTIVE: To evaluate the effect of a video decision support tool on the preferences for future medical care in older people if they develop advanced dementia, and the stability of those preferences after six weeks. DESIGN:

Randomised controlled trial conducted between 1 September 2007 and 30 May 2008. Setting Four primary care clinics (two geriatric and two adult medicine) affiliated with three academic medical centres in Boston. PARTICIPANTS: Convenience sample of 200 older people (≥ 65 years) living in the community with previously scheduled appointments at one of the clinics. Mean age was 75 and 58% were women. INTERVENTION: Verbal narrative alone ($n=106$) or with a video decision support tool ($n=94$). MAIN OUTCOME MEASURES: Preferred goal of care: life prolonging care (cardiopulmonary resuscitation, mechanical ventilation), limited care (admission to hospital, antibiotics, but not cardiopulmonary resuscitation), or comfort care (treatment only to relieve symptoms). Preferences after six weeks. The principal category for analysis was the difference in proportions of participants in each group who preferred comfort care. RESULTS: Among participants receiving the verbal narrative alone, 68 (64%) chose comfort care, 20 (19%) chose limited care, 15 (14%) chose life prolonging care, and three (3%) were uncertain. In the video group, 81 (86%) chose comfort care, eight (9%) chose limited care, four (4%) chose life prolonging care, and one (1%) was uncertain ($\chi^2=13.0$, $df=3$, $P=0.003$). Among all participants the factors associated with a greater likelihood of opting for comfort care were being a college graduate or higher, good or better health status, greater health literacy, white race, and randomisation to the video arm. In multivariable analysis, participants in the video group were more likely to prefer comfort care than those in the verbal group (adjusted odds ratio 3.9, 95% confidence interval 1.8 to 8.6). Participants were re-interviewed after six weeks. Among the 94/106 (89%) participants re-interviewed in the verbal group, 27 (29%) changed their preferences ($\kappa=0.35$). Among the 84/94 (89%) participants re-interviewed in the video group, five (6%) changed their preferences ($\kappa=0.79$) ($P<0.001$ for difference). CONCLUSION: Older people who view a video depiction of a patient with advanced dementia after hearing a verbal description of the condition are more likely to opt for comfort as their goal of care compared with those who solely listen to a verbal description. They also have more stable preferences over time. US.

12) Exley, C. (2010). Advance Care Planning: an opportunity for person-centred care for people living with dementia

- * address the current gaps in the evidence base of ACP.
- * synthesise existing evidence from a range of countries on ACP in dementia care
- * identify the factors which facilitate/inhibit the process of ACP within the NHS
- * identify the professional competencies and training required to implement ACP
- * explore how ACP can be implemented in the context of loss of mental capacity, specifically focusing on people with dementia
- * To develop guidance for healthcare professionals, patients and carers regarding the process of ACP in dementia care.

13) Robinson, L., C. Bamford, et al. "Patient preferences for future care--how can Advance Care Planning become embedded into dementia care: a study protocol." BMC Geriatrics **10**: 2.

BACKGROUND: People living with a long term condition may wish to be able to plan ahead, so that if in future they cannot make decisions, their wishes about their care will be known; this process is termed Advance Care Planning (ACP). In dementia, guidance stipulates that ACP discussions should take place whilst the person still has capacity to make decisions. However there is a lack of evidence on the effectiveness of ACP in influencing patient choice and resource use. The aims of this study are to determine the effectiveness of ACP in dementia care, identify the factors which facilitate the process in practice and provide a better understanding of the views and experiences of key stakeholders in order to inform clinical practice. **METHODS/DESIGN:** The four phase project comprises a systematic review (Phase 1) and a series of qualitative studies (Phases 2 and 3), with data collection via focus groups and individual interviews with relevant stakeholders including people with dementia and their carers, health and social care professionals and representatives from voluntary organisations and the legal profession. The conduct of the systematic review will follow current best practice guidance. In phases 2 and 3, focus groups will be employed to seek the perspectives of the professionals; individual interviews will be carried out with people with dementia and their carers. Data from Phases 1, 2 and 3 will be synthesised in a series of team workshops to develop draft guidance and educational tools for implementing ACP in practice (Phase 4). **DISCUSSION:** In the UK, there is little published research on the effectiveness of ACP, despite its introduction into policy. This study was designed to explore in greater depth how ACP can best be carried out in routine practice. It affords the opportunity to develop both a theoretical and practical understanding of an area which both patients and professionals may find emotionally challenging. Importantly the study will also develop practical tools, which are grounded in practice, for all relevant stakeholders to enable the facilitation of timely and sensitive ACP discussions.