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NHS
Health Education England

Advance Care Planning for Dementia Care

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Developing people
for health and
healthcare

www.hee.nhs.uk

Overview of this session

- Why do we need education for Advance Care Planning (ACP) in dementia care?
- Pilot course in ACP for dementia care for health and social care workers developed by the University of Northampton with funding from HEE Thames Valley
- Results from the pilot course
- Using the course materials

What plans have we made?

Do you feel confident that your wishes will be respected

- if you lose capacity?
- when you die?

What have you put in place to ensure this?

Advance Care Planning (1)

- provides the basis for delivering person-centred end-of-life care in line with the wishes and preferences of the individual;
- enables a record of the individual's wishes and preferences, which guides the person's care when they have lost mental capacity and provides crucial support for families and carers; and
- offers ongoing vital opportunities to enhance the choice and control an individual has over their treatment and care needs / preferences throughout their care journey.

My Future Wishes, NHS 2018

NHS
Health Education England

Department of Health

End of Life Care Strategy

Promoting high quality care for all adults at the end of life

'How people die remains in the memory of those who live on'

Dame Cicely Saunders
Founder of the Modern Hospice Movement

July 2008

NHS

Healthier Northamptonshire

A Strategy for End of Life Care across Northamptonshire

2014 - 19

Date	12th December, 2014
Version	V1.0
Status	Final

COMMITMENT STATEMENTS

ONE CHANCE TO GET IT RIGHT

Improving people's experience of care in the last few days and hours of life

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CareQuality Commission

A different ending

Addressing inequalities in end of life care

Overview report

MAY 2016

NICE National Institute for Health and Care Excellence

NICE guideline

Care of dying adults in the last days of life

NICE guideline
Published: 16 December 2015
nice.org.uk/guidance/ng31

NHS England

My future wishes

Advance Care Planning (ACP) for people with dementia in all care settings

tide

Department of Health

Prime Minister's challenge on dementia 2020

Advance Care Planning (2)

a **voluntary process** of discussion & review

… to help an individual who has **capacity**

… to anticipate how their condition may affect them in the **future**

&, if they wish

set on **record** choices or decisions relating to their care & treatment

…so that these can then be referred to by their carers (whether professional or family carers)

… in the event that they **lose capacity** to decide once their illness progresses

(NEoLCP, 2011)

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ACP and older people research

- a survey of approx 2,000 older people in the East Midlands revealed that although a third would like to have anticipatory discussions, only 17% had actively engaged in such conversations (Musa et al. 2014)
- ACP tends to **decrease** inappropriate hospital admissions of frail elderly residents with palliative care needs (Beynon et al, 2011; Shanley et al, 2011).

ACP and Dementia research (1)

- people with dementia are interested in ACP discussions (Brechling et al. 1993: Lynn et al 1999; Marin et al. 1999; Rempusheski & Hurley 2000)
- people with mild to moderate dementia can feel reluctant to talk about ACP because of lack of knowledge and awareness, difficulty finding the right time, and lack of support to make choices about their future healthcare (Dickinson et al 2013)
- professionals need to take the initiative to start these discussions (Lawrence et al 2011, Samsi & Manthorpe 2011)
- 39.6% of people with dementia die in hospital (Sleemanet et al 2014)

ACP and Dementia research (2)

- **Service evaluation in Boston, Lincolnshire, with 7 care homes:** ACP conducted with people with dementia to avoid hospital admissions. 250 staff trained by 2 RGNS with experience of dementia & frailty. By the third year had achieved 55% reduction in inappropriate hospital admissions - and all but one PWD died in their preferred place (Garden et al 2016)
- **Structured ACP training approaches** with people with mild dementia following diagnosis can be helpful both to people with dementia and their family / carers. For example:
  - Advanced Care Planning in Early Dementia tool (ACP-ED) (Maudsley): carers “found it helpful to know the patient’s wishes in case they had to make a decision on behalf of the patient in the future” (Poppe et al 2013)
  - Let Me Decide (Canada, Eire): after implementing training programme > 50% of residents had some end-of-life care plan in place, and nurses drove the process (McGlade et al 2017)

The ACP in dementia care pilot course

Aim: To develop the skills, knowledge and behaviours to enable and support people with dementia to think about, discuss and record their advance care wishes in a timely way

Format: one-day pilot course for 12 participants and two facilitators.

A programme outline and a set of Powerpoint slides were developed.

Facilitators should be experienced in Dementia or End of Life Care at a senior clinical level, or an experienced educator / facilitator with experience of dementia/ end of life care topics.

Objectives of the ACP course

- Appreciate the evidence base supporting the use of ACP for people with dementia and carers
- Understand ACP under the terms of the Mental Capacity Act (2005)
- Understand one's role with regard to ACP and people with dementia and carers
- Recognise the potential trigger points for initiating ACP with people with dementia and carers
- Explore how to support the end of life wishes of people with dementia and their carers
- Demonstrate the communication skills required to help initiate ACP with people with dementia and their carers

ACP: what carers say

No professional offered ACP

No end of life matters raised by clinicians

I wish somebody had explained the importance of both the power of attorney docs

Ought to be more signposting from the Memory Clinic

No medical follow-up at all

Alzheimer's Society were empathetic on the phone, but no solid advice

I would be lost without the support group

It felt like falling off a cliff

ACP: what staff say (1)

Short survey conducted with healthcare staff in one NHS trust in the Midlands.

Concerns expressed include:

- Bringing up the topic would be distressing for service users and families.
- Feeling de-skilled in how to approach the topic.
- Potential conflicting views between service users and families could lead to further distress.
- Not knowing the right time to introduce documentation.
- Not having enough time to complete documentation during appointments.
- Not all service users/families are willing to discuss or consider topic.
- No specific place for ACP documentation to be kept.

ACP: what staff say (2)

Perceived benefits of implementing ACP:

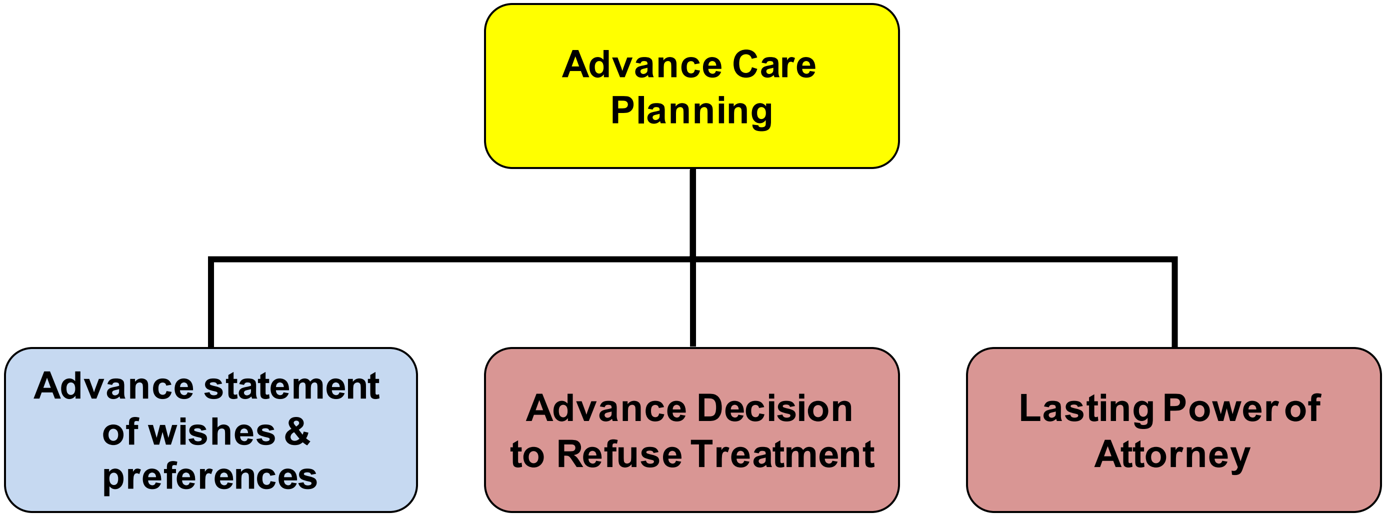
- Sense of empowering service users to be involved in discussions and plan for their future care.
- Allows them to have their voices heard.
- Person-centred approach.
- Having these wishes written down helps to formalise their hopes for future care.
- Improves communication between service users and families.
- Creates a space for people to think about diagnosis and begin to come to terms with this.
- Reduces pressure on families as ACP documentation allows them to know service users' preferences.
- Discussing early on allows service users and families time to plan out care for the future.

Decision-making

- People with dementia have said that they want to have personal control and choice over the decisions that affect them. (DoH 2012)
- Ideally, receiving an early diagnosis enables the person with dementia to plan for the future while they still have capacity to do so.
- The Care Act 2014 states that people with dementia must be involved in decisions about their own care.

No decision about me, without me!

ACP & Mental Capacity Act



Advance Care Planning

Advance statement of wishes & preferences

Advance Decision to Refuse Treatment

Lasting Power of Attorney

blue = advisory; red = legally binding

Advance statement of wishes & preferences

- Covers an individual's wishes, preferences, beliefs & values about future care
- It is **not** legally binding but must be taken into account when acting in an individual's best interests (MCA 2005)
- Can be changed at any time whilst person has capacity

Advance Decision to Refuse Treatment (1)

An ADRT enables someone to refuse specific medical treatment for a time in the future when they may lack capacity to consent to, or refuse treatment

An advance decision to refuse life sustaining treatment is legally binding if:

- The person is over 18yrs with capacity
- It is clear, specific & states that the decision applies **'even if my life is at risk as a result'**
- It is valid & applicable to the current situation
- It is in writing, signed, witnessed & dated

Advance Decision to Refuse Treatment (2)

NB. An ADRT can be cancelled or changed any time, whilst the person still has the capacity to do so. Changes must be signed & witnessed.

If a disagreement exists about an ADRT, a senior clinician must consider all the available evidence (serious disagreement may only be resolved by the Court of Protection)

ADRT example

My decisions

I do not want to receive the specific treatments shown below; **my directions apply even if my life is at risk as a result.**

Specific treatment I want to refuse	**Circumstances I want to refuse the treatment in**
Intravenous antibiotics	Chest infection
Cardio-pulmonary resuscitation	If my heart and breathing stop

Lasting Power of Attorney

Appointing someone to make decisions on your behalf, should capacity be lost in the future. There are 2 types:

- **Health & Welfare:** you appoint one or more persons to make decisions about your future health needs (specific authority is required for the refusal of a life sustaining treatment)
- **Property & Financial Affairs:** you appoint one or more persons to make decisions about your financial affairs

You can choose to make one type of LPA or both.

When to have the conversation

- How soon after a diagnosis of dementia can you talk with the person and their family or carer about ACP?
- When is too late?

When to have the conversation (2)

"…it should be done shortly after diagnosis so that we are not also carrying that burden of stress of what's going to happen to us later on. I also think that to do it early would give us time for modifications to be made and ensure that you're still capable of adding the things you'd like or not like before they have been forgotten…"

https://dementiadiaries.org/entry/4810/advanced-care-planning-is-very-important-the-burden-of-my-future-is-not-put-on-my-family

When to have the conversation (3)

“ACP is not a ‘one-off’ plan-making session. It is an inclusive, personalised, proactive and transparent process that cuts across health, social and community care settings.”

(My Future Wishes, NHS England 2018)

NHS England

My future wishes

Advance Care Planning (ACP) for people with dementia in all care settings

tide

Northants ACP booklet

https://www.nhft.nhs.uk/download.cfm?doc=docm93jijm4n1158.pdf&ver=23318

#weareNHFT

NHS
Northamptonshire Healthcare
NHS Foundation Trust

ADVANCE CARE PLANNING

PLANNING FOR YOUR FUTURE CARE

Preparing for the future

Helping with practical arrangements

Allowing the right care to be given at the right time

"No decision about me, without me"
Department of Health, 2010

Version three - 2018

MAKING A DIFFERENCE FOR YOU, WITH YOU

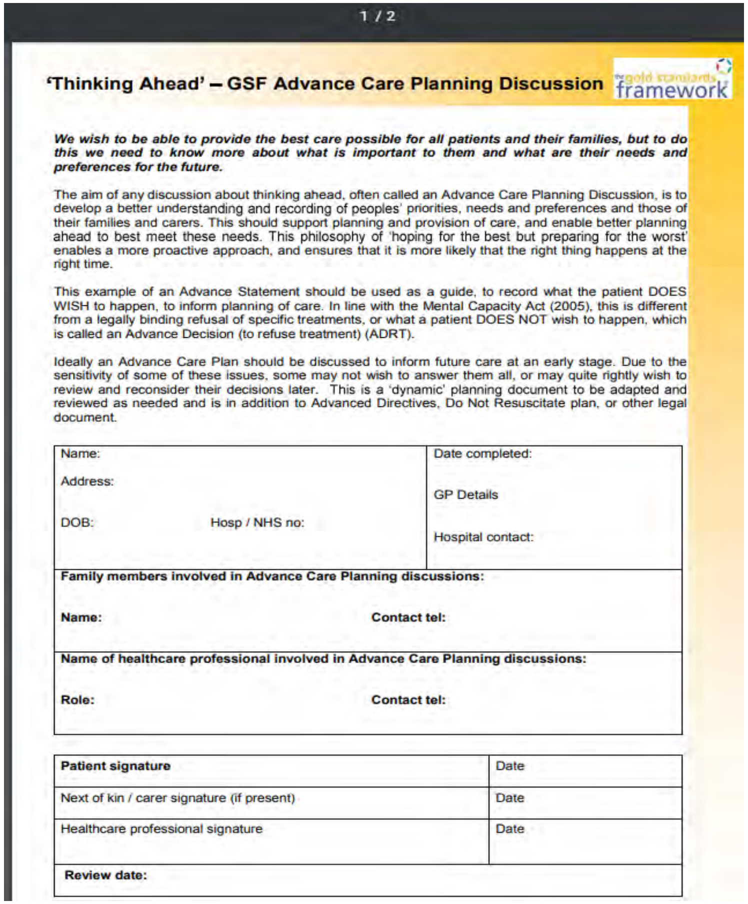
Gold Standards Framework

The GSF Thinking Ahead Advance Statement includes these questions:

- At this time in your life, what is important to you?
- What elements of care are important to you?
- What WOULD you like to happen in future?
- What would you NOT want to happen? Is there anything that you worry about or fear happening?
- Who would speak for you - your nominated proxy spokesperson or Lasting Power of Attorney?

What adaptations to this process might be needed when someone has dementia?

http://www.goldstandardsframework.org.uk/advance-care-planning



1 / 2

'Thinking Ahead' – GSF Advance Care Planning Discussion

We wish to be able to provide the best care possible for all patients and their families, but to do this we need to know more about what is important to them and what are their needs and preferences for the future.

The aim of any discussion about thinking ahead, often called an Advance Care Planning Discussion, is to develop a better understanding and recording of peoples' priorities, needs and preferences and those of their families and carers. This should support planning and provision of care, and enable better planning ahead to best meet these needs. This philosophy of 'hoping for the best but preparing for the worst' enables a more proactive approach, and ensures that it is more likely that the right thing happens at the right time.

This example of an Advance Statement should be used as a guide, to record what the patient DOES WISH to happen, to inform planning of care. In line with the Mental Capacity Act (2005), this is different from a legally binding refusal of specific treatments, or what a patient DOES NOT wish to happen, which is called an Advance Decision (to refuse treatment) (ADRT).

Ideally an Advance Care Plan should be discussed to inform future care at an early stage. Due to the sensitivity of some of these issues, some may not wish to answer them all, or may quite rightly wish to review and reconsider their decisions later. This is a 'dynamic' planning document to be adapted and reviewed as needed and is in addition to Advanced Directives, Do Not Resuscitate plan, or other legal document.

Name: Address: DOB: Hosp / NHS no:	Date completed: GP Details Hospital contact:
Family members involved in Advance Care Planning discussions: **Name:** **Contact tel:**	
Name of healthcare professional involved in Advance Care Planning discussions: **Role:** **Contact tel:**	

Patient signature	Date
Next of kin / carer signature (if present)	Date
Healthcare professional signature	Date
Review date:	

Initiate, assess, check

- **Initiate** – around time of diagnosis
- **Assess** – after an increase in care needs
- **Check** – advanced dementia, diminished capacity and end of life

(My Future Wishes, NHS 2018)

What is the process in your organisation?

Communicating well

General points about conversations with people with dementia:

- Ensure the family member/carer is present
- Speak slowly and clearly
- Maintain relaxed body language and sit at their level
- Use repetition and gentle reminders
- Avoid questions which require any memory recall
- Be patient, wait for the answer
- Don’t contradict

Forum theatre

"…is a form of theatre that encourages audience interaction and explores different options for dealing with a problem or issue."
https://www.involve.org.uk/resources/methods/forum-theatre

Forum theatre is used in the ACP training to enable trainees to rehearse how to have an ACP conversation

Scenario 1

Annie is 57 and has been married to James for 30 years and they they have 2 grown-up sons. Annie has been concerned about recurrent problems with her memory – although she has long periods of capacity.

You first met Annie and James at the beginning of January 2019, when after test, she was given a diagnosis of early onset dementia. At that time Annie and James were given an information pack which included a leaflet regarding ACP – it did not feel the right time to discuss this with them.

On your second meeting (with just Annie) you want to include ACP within the conversation. How do you start this conversation ?

Participants learning needs before the pilot

Participants expressed a range of training needs, including:

- wanting to improve skills in communication for ACP and end of life care;
- removing anxiety and gaining confidence in ACP and end of life care;
- better understanding of what patients and families really want and dealing with challenging family situations;
- more knowledge about dementia care; and
- better understanding of ACP decision making in dementia.

Feedback from participants after the pilot

All participants (n=15) felt more confident to support a person with dementia and family through the ACP process after the course.

- post-course general satisfaction = 96%
- many positive comments
- 9 participants responded that they would be able to deliver the ACP training in their workplace, although some had limited support to do so.

"very interactive and informative"

"very beneficial for my practice"

"made everything more human"

"knowledgeable presenters"

"should be made available to more staff"

"excellent delivery of a difficult topic; removed all the mystery from an ACP""

Any questions?

Please leave your email if you would like a copy of the materials – I will send a link to download them.

Or email me: r.riachi@brookes.ac.uk

Thank you for participating today

Resources and useful links

- Ann Craft Trust, Six Principles of Adult Safeguarding - https://www.anncrafttrust.org/resources/six-principles-adult-safeguarding/
- Department of Health, The Care Act - https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/365345/Making_Sure_the_Care_Act_Works_EASY_READ.pdf
- Gov.uk, Deputies: make decisions for someone who lacks capacity - https://www.gov.uk/become-deputy
- Gov.uk, Make, register or end a lasting power of attorney - https://www.gov.uk/power-of-attorney
- Health Education England, Dementia training resources - https://www.hee.nhs.uk/our-work/dementia-awareness/resources-tier-one-two-three
- Health Education England, *Dementia guide for carers and care providers* e-book, available from: iBooks, the Kindle Store, and Smashwords. It is also available as a standalone app through the Apple App Store.

Resources and useful links

- Care Quality Commission (CQC) (2014) ‘Monitoring the use of the Mental Capacity Act Deprivation of Liberty Safeguards in 2012/2013’, London: CQC
- Dementia UK (2018) *Tips for Better Communication* http://www.dementiauk.org/wp-content/uploads/2018/10/Tips-for-communication-WEB-Oct.pdf
- Department for Constitutional Affairs (2007) ‘Mental Capacity Act 2005: Code of Practice’, London: The Stationery Office.
- House of Lords (2014) ‘Select Committee on the Mental Capacity Act 2005, 2014: Post-legislative scrutiny’, summary, p 1, London: The Stationery Office.
- Law Commission, Mental Capacity and Deprivation of Liberty - https://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/
- Legislation.gov.uk, Care Act 2014: - http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted
- Legislation.gov.uk, Mental Capacity Act 2005 - https://www.legislation.gov.uk/ukpga/2005/9/contents
- Ministry of Justice (2008) ‘Mental Capacity Act 2005: Deprivation of Liberty Safeguards - Code of practice to supplement the main Mental Capacity Act 2005 Code of Practice’ London: The Stationery Office.

Resources and useful links

- SCAS (2016) *Communicating with people living with dementia* (video) https://www.youtube.com/watch?v=jhSFA_ib48U
- Social Care Institute for Excellence (SCIE) (2015) Dementia and decision making https://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/
- Social Care Institute for Excellence (SCIE) (2013) 'Report 66: Deprivation of Liberty Safeguards: Putting them into practice', London: SCIE.
- Social Care Institute for Excellence, Advance care planning in dementia - https://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/advance-care-planning.asp
- Social Care Institute for Excellence (2014), ACP in dementia in a care home using GSF https://www.scie.org.uk/dementia/advanced-dementia-and-end-of-life-care/end-of-life-care/
- Social Care Institute for Excellence, Deprivation of Liberty Safeguards (DoLS) - https://www.scie.org.uk/mca/dols/at-a-glance
- Social Care Institute for Excellence, Mental Capacity Act - https://www.scie.org.uk/mca/introduction/mental-capacity-act-2005-at-a-glance
- University of Nottingham, Improving Dementia Education and Awareness (IDEA) - https://idea.nottingham.ac.uk/resources

References

- Ann Craft Trust (2018) Six Principles of Adult Safeguarding. https://www.anncrafttrust.org/resources/six-principles-adult-safeguarding/
- Brechling B, Schneider C. (1993) Preserving Autonomy in Early Stage Dementia. *Journal of Gerontological Social Work*; 20(1-2):17-33.
- Brooker, D. & Latham, I (2015) Person-centred Dementia Care: (2nd Edition) Making Services better with the VIPs Framework. London, Jessica Kingsley Publishers
- Dening K, Jones L, Sampson E. Preferences for end-of-life care: A nominal group study of people with dementia and their family carers. *Palliative Medicine.* 2012;27(5):409-17.
- Department of Health (2013). A state of the nation report on dementia care and support in England. London: Department of Health,
- Department of Health (2014) The Care Act. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/365345/Making_Sure_the_Care_Act_Works_EASY_READ.pdf
- Department of Health (2012) Health and Social Care Act. London, The Stationery Office
- Department of Health (2013) The NHS Constitution: the NHS belongs to us all. London, The Stationery Office.
- Department of Health (2013a) Patients First and Foremost: The initial Government Response to the Mid Staffordshire NHS Foundation Trust Public Inquiry, London, The Stationery Office.

References

- Dickinson C, Bamford C, Exley C, Emmett C, Hughes J, Robinson L. (2013) Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. *International Psychogeriatrics.* 25(12):2011-21.
- Engel SE, Kiely DK, Mitchell SL (2006). Satisfaction with end-of-life care for nursing home residents with advanced dementia. *Journal of the American Geriatric Society*; 54:1567-72.
- Fazel S, Hope T. (1999) Assessment of competence to complete advance directives: validation of a patient centered approach. *British Medical Journal*; 318(7182):493-7.
- Hirschman K, Kapo J, Karlawish J. Identifying the factors that facilitate or hinder advance planning by persons with dementia. Alzheimer Disease and Associated Disorders 2008;22(3):293-98.
- Kitwood, T. (1997) Dementia Reconsidered: People Come First.. Buckingham, Open University Press
- Karel M, Moye J, Bank A, Azar A (2007). Three methods of assessing values for advance care planning: comparing persons with and without dementia. *Journal of Ageing and Health.* 7;19(1):123-51.
- Lawrence V, Sampsi K, Murray J, Harari D, Banerjee S (2011) Dying well with dementia: a qualitative examination of good end of life care for people with dementia. *British Journal of Psychiatry* 199: 417–22
- Legislation.gov.uk (2014) Care Act 2014. http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted
- Legislation.gov.uk (2005) Mental Capacity Act 2005. https://www.legislation.gov.uk/ukpga/2005/9/contents
- Lynn J, Teno J, Dresser R, Brock D, Nelson H, Nelson J, et al.(1999) Dementia and advance-care planning: perspectives from three countries on ethics and epidemiology. *Journal of Clinical Ethics*; 10(4):271-85.

References

- Marin D, Rudin E, Fox B, Neugroschl J, Brickman A, Northrop J, et al.(1999) Feasibility of a healthcare proxy counselling program for patients with Alzheimer's disease. *Journal of Palliative Medicine*; 2(3):323-29.
- Mezey M, Mitty E, Bottrell M, Ramsey G, Fisher T.(2000) Advance directives: older adults with dementia. *Clinical Geriatric Medicine.*16(2):255-68.
- Musa I, Seymour J, Conroy S. (2014) A Survey Of Older Peoples' Attitudes Towards Advance Care Planning. *Age and Ageing*. 44(3):371-6.
- Nicholas LH, Bynum JPW, Iwashyna TJ, Weir DR, Langa K. (2014) Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. *Health Affairs*; 33:667- 674.
- Poppe M, Burleigh S, Banerjee S. (2013) Qualitative Evaluation of Advanced Care Planning in Early Dementia (ACP-ED). *PLOS One*; 8(4):60412.
- Rempusheski V, Hurley A (2000). Advance directives and dementia. *Journal of Gerontological Nursing*; 26(10):27-34.
- Robinson L, Dickinson C, Rousseau N, Beyer F, Clark A, Hughes J, et al.(2012) A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age and Ageing.*41(2):263-69.
- Ryan T, Gardiner C, Bellamy G, Gott M, Ingleton C. (2012) Barriers and facilitators to the receipt of palliative care for people with dementia: The views of medical and nursing staff. Palliative Medicine, 2;26:879.
- Sampson EL, Gould V, Lee D, Blanchard MR. (2006) Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Ageing*; 35(2):187-9.

References

- Sampson E, Jones L, Thune-Boyle I, Kukkastenvehmas R, King M, Leurent B, et al. (2011) Palliative assessment and advance care planning in severe dementia: an exploratory randomized controlled trial of a complex intervention. *Palliative Medicine*; 25(3):197-209.
- Samsi K and Manthorpe J (2011) 'I live for today': a qualitative study investigating older people's attitudes to advance planning. *Health and Social Care in the Community* 19(1), 52–59.
- Social Care Institute for Excellence (2056), Advance care planning in dementia. https://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/advance-care-planning.asp
- Social Care Institute for Excellence (2016), Mental Capacity Act (MCA). https://www.scie.org.uk/mca/introduction/mental-capacity-act-2005-at-a-glance
- Social Care Institute for Excellence (2017), Deprivation of Liberty Safeguards (DoLS). https://www.scie.org.uk/mca/dols/at-a-glance
- van der Steen JT, van Soest-Poortvliet MC, Hallie-Heierman M, Onwuteaka-Philipsen BD, Deliens L, de Boer ME, et al. (2014) Factors Associated with Initiation of Advance Care Planning in Dementia: A Systematic Review. *Journal of Alzheimer's Disease*. 40(3):743-57.
- Volandes A, Paasche-Orlow M, Barry M, Gillick M, Minaker K, Chang Y, et al.(2009) Video decision support tool for advance care planning in dementia: randomised controlled trial. *British Medical Journal*. 338: b2159.