



# SILENCE WISHES:

**THE EXPERIENCES OF ADVANCE CARE  
PLANNING IN PEOPLE WITH DEMENTIA**

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# DEMENTIA

- By 2050, more than 35.6 million people are expected to be affected (WHO, 2018).

**Cognitive**



**Behavioral**



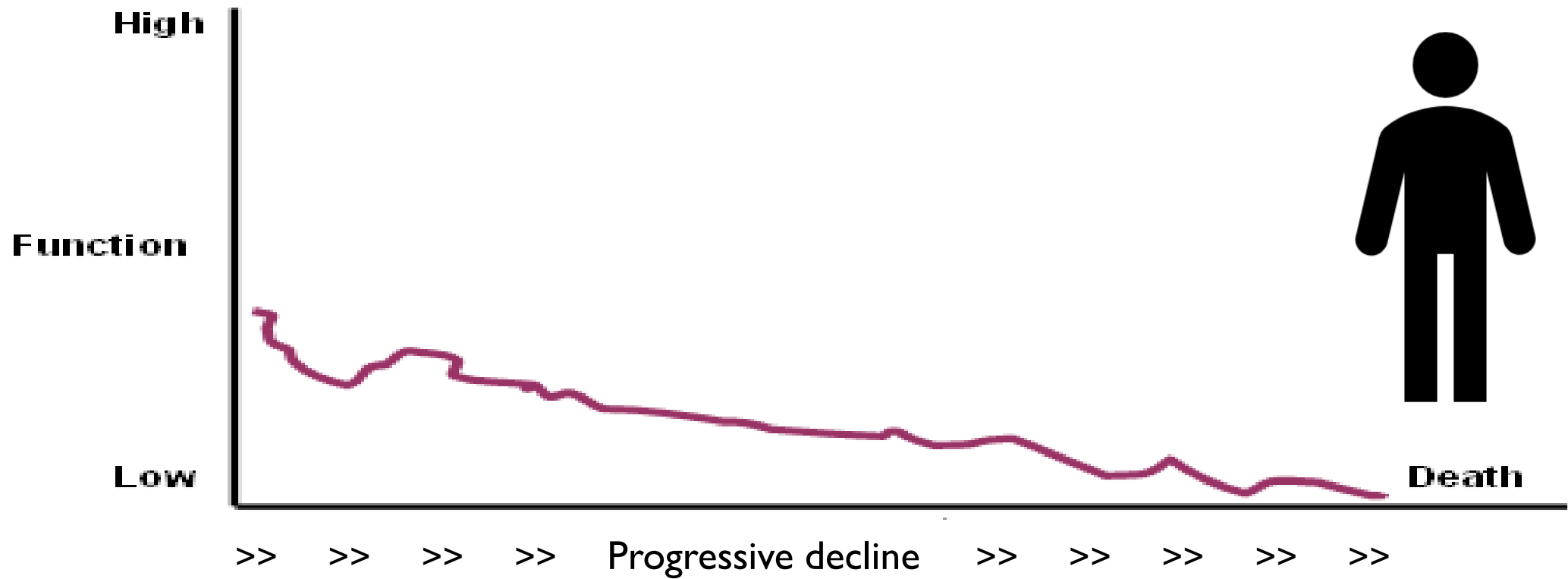
**Functional**





Cognitive	Behavioral and psychological	Functional
Memory loss	Personality changes	Difficulty in performing activities of daily living (e.g. feeding, toileting, grooming and even walking)
Communication barriers ( e.g. aphasia)	Psychiatric symptoms (e.g. anxiety, depression, hallucinations and delusions)	
	Behavior problems such as restlessness/ wandering	

# PROLONGED & PROGRESSIVE...





# UNIQUE END-OF-LIFE EXPERIENCE

- To examine the end-of-life experience of individual with dementia and dying from cancer.

## Semi-structured interviews

- Participants:
  - ◆ 17 Bereaved Family Caregivers
  - ◆ 4 Professionals caregivers

# GUILT AND REGRET SURROUNDING PAST DECISION-MAKING

Sometimes I asked my mother in law, did we make a wrong decision of sending him to OAH? This is my regret.  
(Iris; Daughter-in-law)

My regret is...he has many wishes and things that he wanted to do, but he couldn't tell!  
(Grace; Daughter-in-law)

It's a heartache...inserting feeding tube!...If I could choose one more time, I won't choose tube feeding. I would let it be.  
(Diana; Daughter)



# GUILT AND REGRET SURROUNDING PAST DECISION-MAKING

Living  
arrangement

Tube feeding

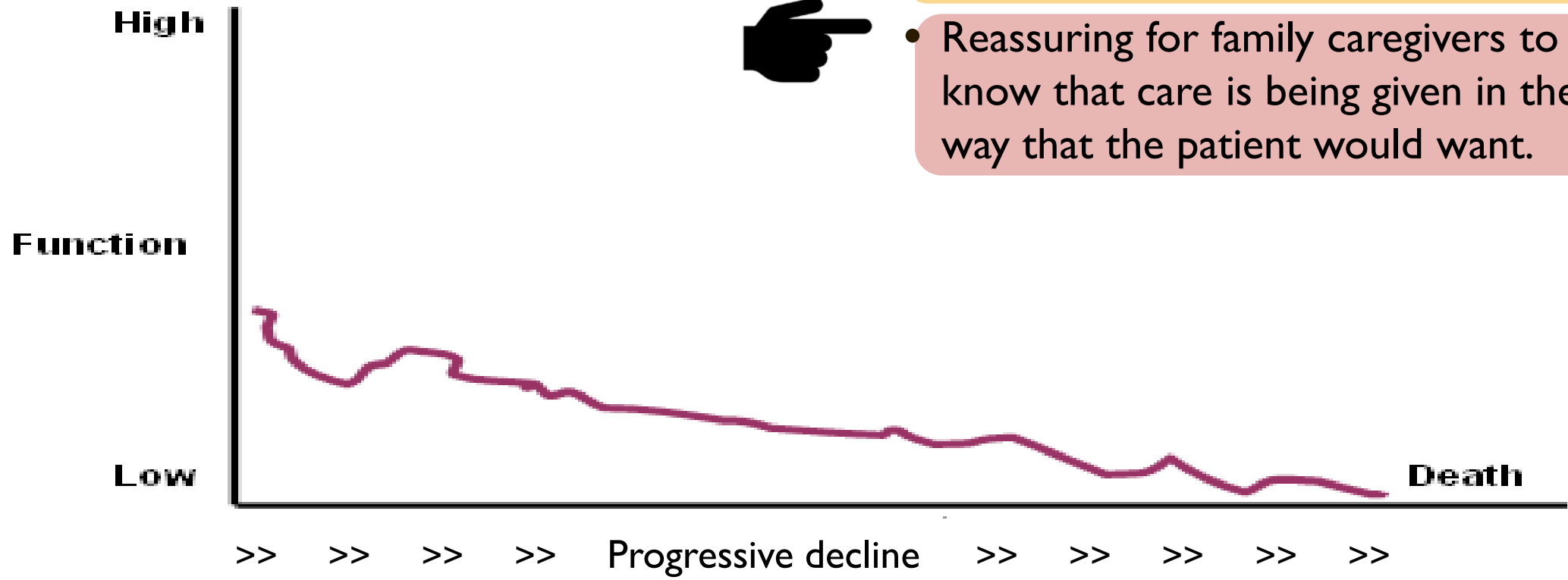
Treatment  
options

# WHY IS PLANNING AHEAD IMPORTANT IN PEOPLE WITH DEMENTIA?

## Planning ahead

- Allowing patient to share their views on future care and what is important.

- Reassuring for family caregivers to know that care is being given in the way that the patient would want.





*Review Article*

The Effectiveness of Advance Care Planning in Improving  
End-of-Life Outcomes for People With Dementia and Their  
Carers: A Systematic Review and Critical Discussion



Josie Dixon, MSc, Maria Karagiannidou, MSc, and Martin Knapp, PhD  
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# BENEFITS OF ACP FOR PEOPLE WITH DEMENTIA

*Abstract*

**Context.** End-of-life care for people with dementia can be poor, involving emergency hospital admissions, burdensome treatments of uncertain value, and undertreatment of pain and other symptoms. Advance care planning (ACP) is identified, in England and elsewhere, as a means of improving end-of-life outcomes for people with dementia and their carers.

**Objective.** To systematically and critically review empirical evidence concerning the effectiveness of ACP in improving end-of-life outcomes for people with dementia and their carers.

**Methods.** Systematic searches of academic databases (CINAHL Plus with full text, PsycINFO, SocINDEX with full text, and PubMed) were conducted to identify research studies, published between January 2000–January 2017 and involving statistical methods, in which ACP is an intervention or independent variable, and in which end-of-life outcomes for people with dementia and/or their carers are reported.

# BENEFITS OF ACP FOR PEOPLE WITH DEMENTIA



Decreased hospital admission



Died in preferred place



Improved carer satisfaction



Decreased emotional distresses



Decreased physical distresses



Consistent end-of-life care



Improved satisfaction of end-of-life care



# ADVANCED CARE PLANNING FOR PEOPLE WITH DEMENTIA

- Increased focus on the benefits of ACP for people with dementia (Beck et al., 2017; Brazil et al., 2016)
- Low completion among people with dementia.

## Uptake of a newly implemented advance care planning program in a dementia diagnostic service

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### Abstract

**Background:** advance care planning (ACP) provides a framework for discussion and documentation of future care preferences when a person loses cognitive capacity. It can assist people in the early stages of dementia to document their preferences for care at later stages of the illness.

**Method:** a three-stage project introduced ACP to clients with mild cognitive impairment (MCI) or recently diagnosed dementia and their families through a specialist memory clinic. Over 8 months, all English-speaking clients ( $n = 97$ ) and carers ( $n = 122$ ) were mailed a survey assessing completed documentation for future care; understanding of the principles of ACP (Stage 1). Participants wanting further information about ACP (Stage 2). Participants wanting to complete ACP documentation could make an appointment with the ACP clinicians (Stage 3).

Forty-eight (52.2%) carers and 34 clients (35.1%) responded to the survey. Most clients (62.1%) and carers (78.6%) were interested in ACP, and 78.6% of clients and 63.6% of carers believed that clients should be involved in their care decisions. Nine clients (26.5%; diagnoses: MCI = 5; AD = 3; mixed dementia = 1) and 9 carers (18.8%) attended the ACP program. Of 48 (49%) carers and 34 (35%) clients (diagnoses: MCI = 2; AD = 1) completed ACP.

**Conclusion:** Although there is interest, ACP completion was low. The reasons for this need to be determined. Any barriers to ACP completion among people with dementia and their carers are discussed.

*Keywords:* dementia, mild cognitive impairment, Respecting Patient Choices, older people

### for dem

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### out this topic

Advanced care planning (ACP) is a process of documenting a patient's preferences for future care in the event of loss of cognitive capacity. There is limited evidence to suggest that ACP leads to better health outcomes for people with dementia. However, uptake of ACP is low among people with dementia.

### ids

as between  
and

The uptake of advance care planning (ACP) is particularly low among people with dementia. This may reflect barriers to communication between professionals, patients and families in the face of lack of consensus about the process. This study aimed to methodically investigate consensus views of how ACP should be explained and carried out with people with dementia. A three-round Delphi study explored views of how and when ACP should be addressed, what should be covered, who should be involved and why rates of ACP are low.

Seventeen participants took part comprising family members, old age psychiatrists and policy makers. Thirty-two items reached consensus. The panel agreed on 11 different areas for discussion. They concurred that ACP was best addressed after the person has come to terms with the diagnosis when the individual feels ready to do so. There was a consensus view that the process should be couched in terms of 'certain possibilities'. Consensus items emphasised personal choice and autonomy, while also prioritising the need to discuss financial aspects and to include spouses. There was no consensus that professionals should be involved, although the panel viewed them as carrying some responsibility for low uptake. It is suggested that ACP should include financial aspects and to include spouses. There was no consensus that professionals should be involved, although the panel viewed them as carrying some responsibility for low uptake. It is suggested that ACP should include



DEMENTIA PRESENTS  
PARTICULAR CHALLENGES  
FOR  
ADVANCE CARE PLANNING

(Sampson & Burns, 2013)

# CHALLENGES:

The nature of the illness

Current service configuration

Problems relating to professionals

Challenges relating to patients & families



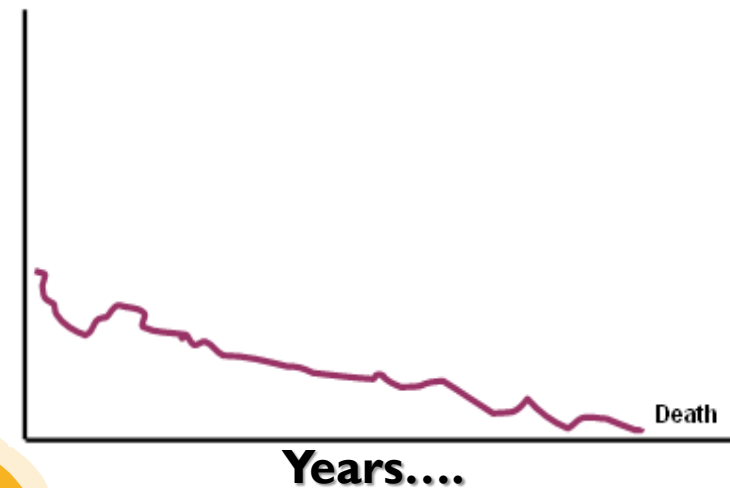


# THE NATURE OF THE ILLNESS

# THE NATURE OF THE ILLNESS

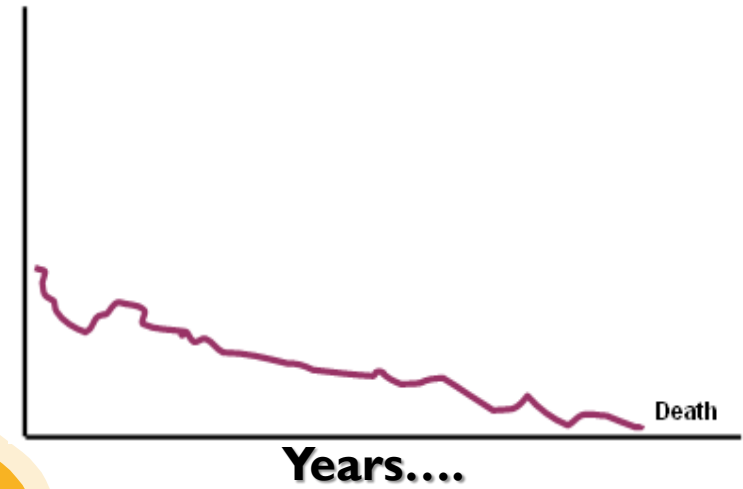
- Loss of capacity
- Protracted decline

Discussion about end-of-life care will be in reference to events that happen many years thereafter.



# THE NATURE OF THE ILLNESS

- Multimorbidity → an accelerated decline in people with dementia
- Difficult to: Understanding a prognosis & Making advance care decision



Are we talking  
about 2022 ?

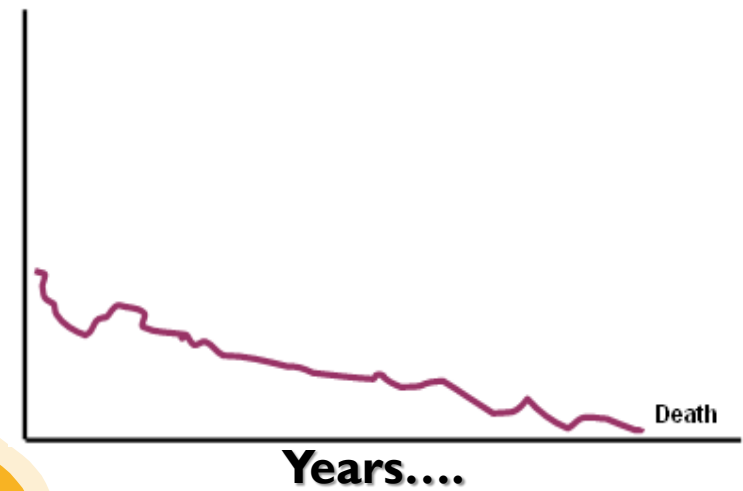




# THE NATURE OF THE ILLNESS

- The ability to consider future thoughts and actions becomes compromised as dementia progresses → thus affecting decision-making abilities (Fratiglioni & Qiu, 2013).
  - Possible to develop plans (Poppe *et al.*, 2013)
  - Difficult to think about themselves in the future (Dening *et al.*, 2012).

(Dening, 2015)



# CURRENT SERVICE CONFIGURATION



# CURRENT SERVICE CONFIGURATION

Natural of  
Dementia ?

Options in ?  
end-of-life care



- A fragmented set of interactions with different health-care services
- Day-to-day management of the condition relies on families and communities.
- Coordinated support through the course of the illness is lacking

Lack of a broader public understanding

(Brown, 2015)



PROBLEMS  
RELATED TO  
PROFESSIONALS

# PROBLEMS RELATED TO PROFESSIONALS

The anxiety that health and social care professionals can often feel in initiating ACP :

- A lack of understanding of the options for later-life care
- A lack of confidence in discussing end-of-life care
- A lack of time
- Language and communication difficulties

(Brown, 2015; Thomas & Lobo, 2011; Beck et al., 2017)

## Health care professionals' perspectives of advance care planning for people with dementia living in long-term care settings: A narrative review of the literature

Abstract  
This paper provides an overview of the evidence on the perspectives of health care professionals (HCPs) in relation to advance care planning (ACP) for people with dementia living in long-term care settings. A narrative approach was adopted to provide a synthesis of the recently published literature in the area. A systematic literature search was conducted to identify relevant studies. Following review of the studies four themes were identified: HCPs' views on and planning for palliative care in dementia; HCPs' views on ACP; Communication challenges when interacting with people with dementia and their families and HCPs need for education and training. Despite the potential benefits of ACP, they struggle with its implementation due to their limited understanding of dementia and the concept of ACP, and a lack of time and resources in practice. Synthesising the existing evidence will allow for the identification of key issues, potentially resulting in improved implementation.

Abstract

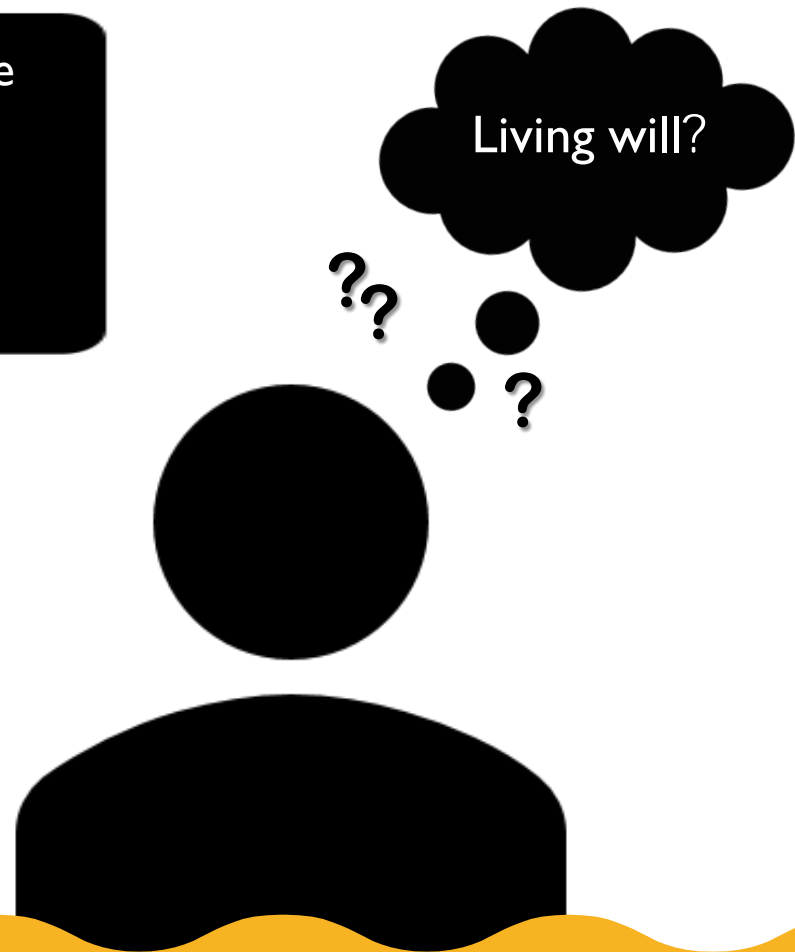
This paper provides an overview of the evidence on the perspectives

CHALLENGES  
RELATING TO  
PATIENTS &  
FAMILIES






I suppose it was just the financial side that that they talked about. I didn't realize there was two different ones.  
(Carer, Wife)



- Lack of knowledge and awareness



... we're just sort of ignoring it for a while because it's not really affecting us in any great detail, so we're just plodding on... (Person with Dementia)



**When?**

Discussions of ACP mostly initiated when patient was admitted to the long term care facilities (Robinson et al., 2011; Froggatt et al., 2015).  
Often too late → resulting in anxiety for proxy decision makers (Happ et al, 2002; Robinson et al., 2011; Beck et al., 2017)

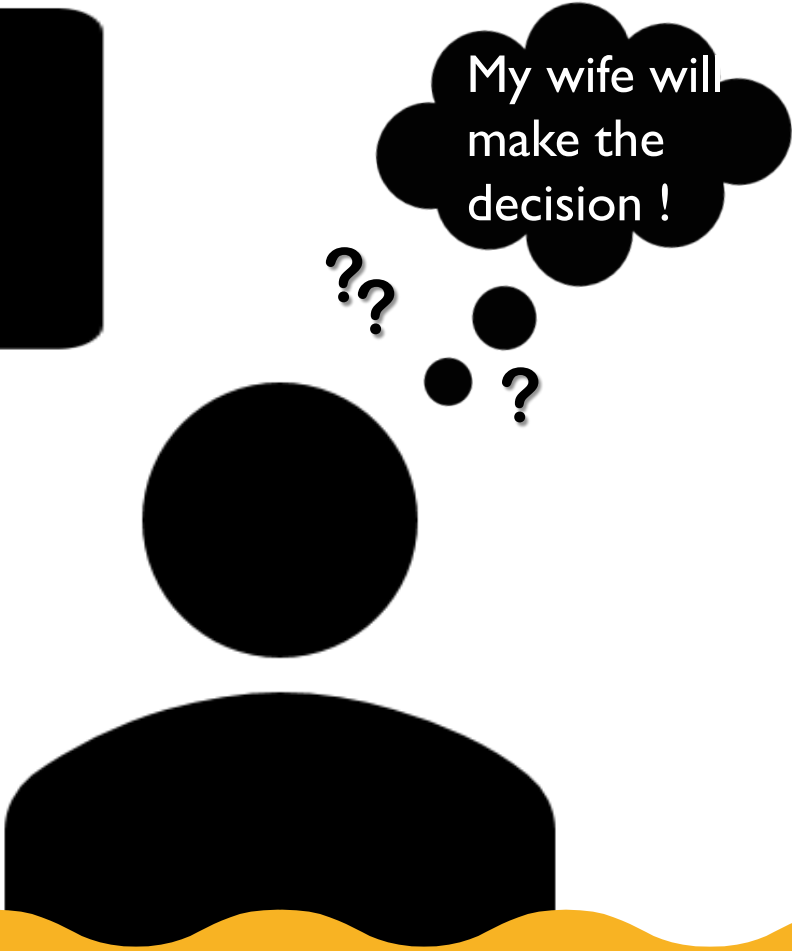
- Finding the right time

(Dickinson et al., 2013)





Yeah, I know she would do the right thing and she knows I would do the right thing you know so it's not a problem. (Person with Dementia)



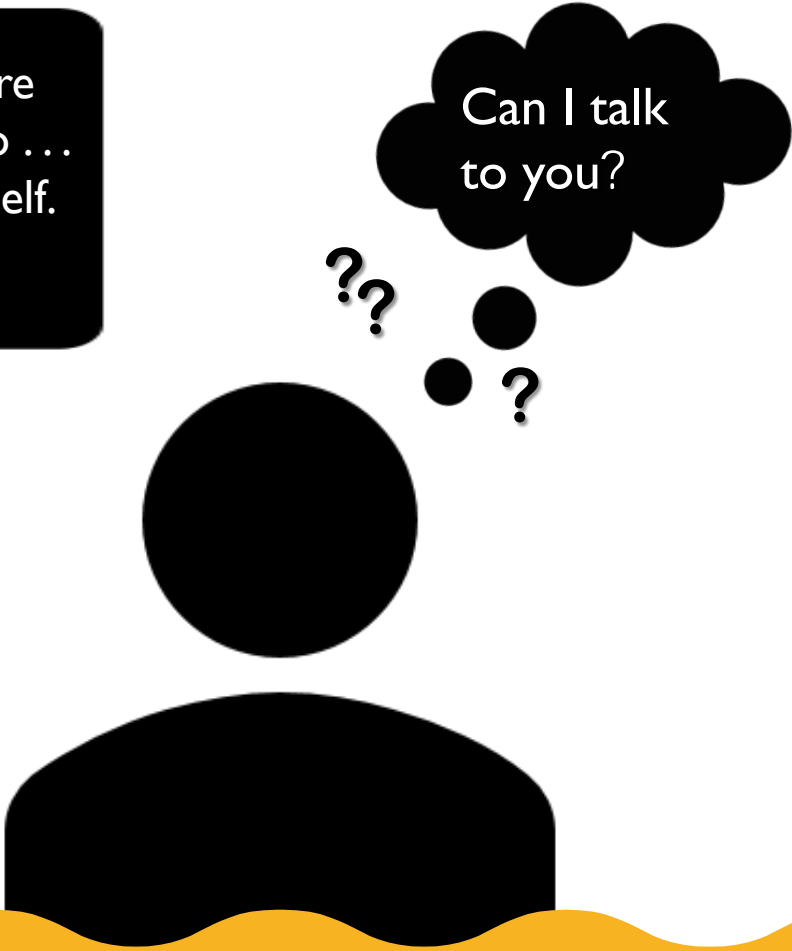
• Preference for informal discussions

# Do family caregivers know the treatment preferences of people with early dementia?

- Family caregivers had a low to moderate agreement on preferences for end of life treatment
- even when the caregivers and person with dementia perceive the care-giving/receiving relationship is good.



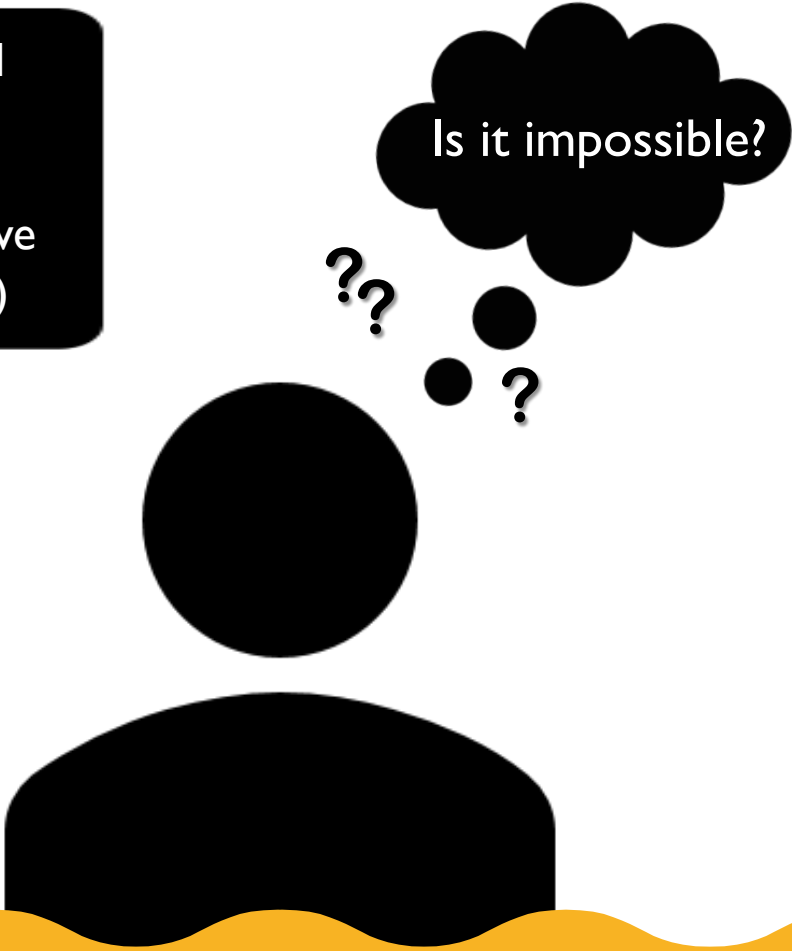
Oh you've got to have the doctor there to explain it all. It's too complicated to ... it's not a decision you can make yourself.  
(Carer, Wife)



- Lack of support to make choices about future healthcare



Actually talking about going into care, I have no thoughts of going into care but . . . . I know that there's every possibility like other people I could have to go into care (Person with dementia)



- Constraints on choice around future care options

## 'False Promise'



Limited resources + the practicalities of caring for a person

(Sampson & Burns, 2013)

- not possible to support their advance wishes
- may unfortunately face conflict with what their loved ones had previously expressed

(Livingston et al., 2010)

- persistent feelings of guilt that have extended into her post-caregiving life

(Corey & McCurry, 2017)

(Dickinson et al., 2013)

# ADVANCE CARE PLANNING (ACP)



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WHAT CAN WE DO?

# WHAT CAN WE DO?

- To bring together the expertise of dementia care practitioners and palliative care specialists in responding to advanced dementia



# WHAT CAN WE DO?

- To share information on the course of the illness.

# WHAT CAN WE DO?

- To gain support of the wider media

# WHAT CAN WE DO?

- To empower those closest to the person to make decisions with education and support.

# LOSS & GRIEF PERSONHOOD

- Loss and grief are fundamental parts of the dementia experience.
- Promote personhood throughout the person's journey.



**PAST**



**PRESENT**

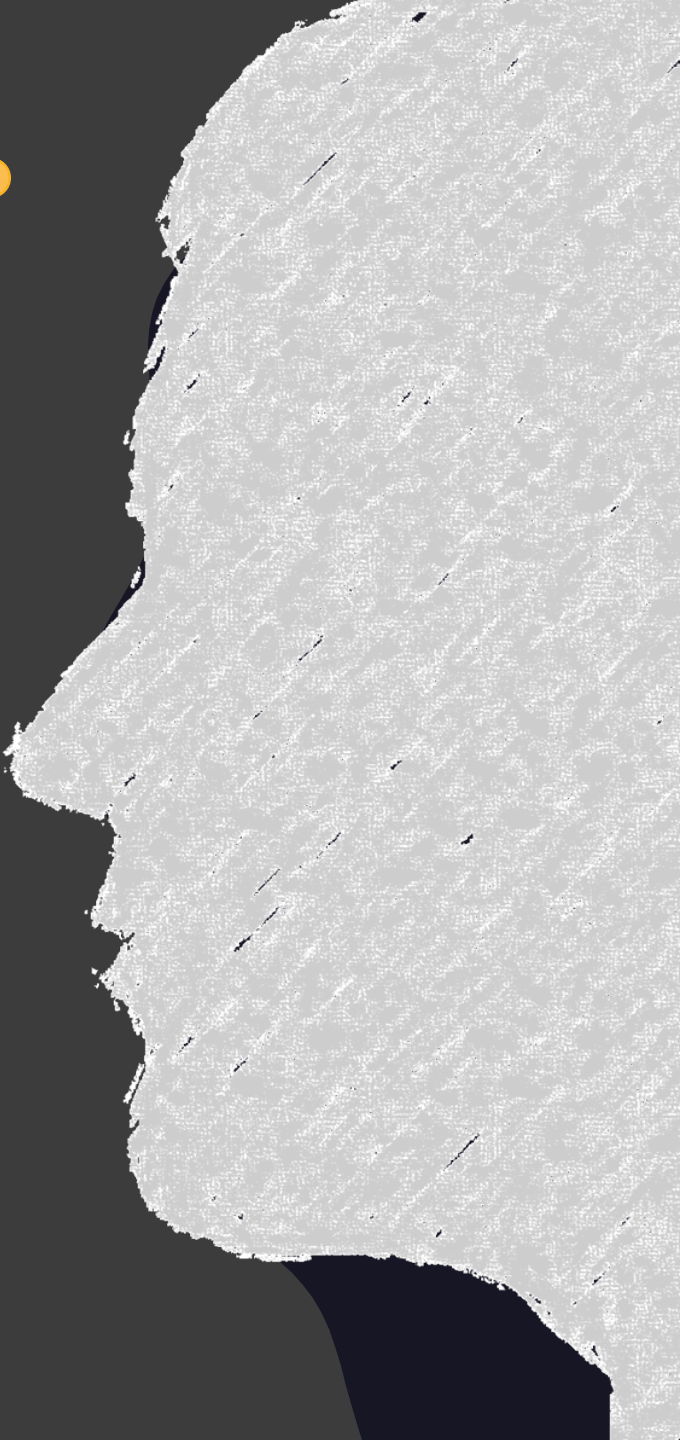


**FUTURE**





WISHES  
COME TRUE



# REFERENCES:

- Beck, E. R., McIlfratrick, S., Hasson, F., & Leavey, G. (2017). Health care professionals' perspectives of advance care planning for people with dementia living in long-term care settings: A narrative review of the literature. *Dementia*, 16(4), 486-512.
- Brown, J. (2015). Advance care planning in dementia. *The Lancet Psychiatry*, 2(9), 774-775.
- Corey, K. L., & McCurry, M. K. (2017). When caregiving ends: The experiences of former family caregivers of people with dementia. *The Gerontologist*, gnw205.
- Dempsey, D. (2013). Advance care planning for people with dementia: benefits and challenges. *International journal of palliative nursing*, 19(5), 227-234.
- Dempsey, L., Dowling, M., Larkin, P., & Murphy, K. (2018). Providing care for a person with late-stage dementia at home: What are carers' experiences?. *Dementia*, 1471301218774937.
- Dening, K. H. (2015). Advance care planning in dementia. *Nursing Standard (2014+)*, 29(51), 41.
- Dening, K. H., Jones, L., & Sampson, E. L. (2011). Advance care planning for people with dementia: a review. *International Psychogeriatrics*, 23(10), 1535-1551.
- Dening, K. H., King, M., Jones, L., Vickestaff, V., & Sampson, E. L. (2016). Advance care planning in dementia: do family carers know the treatment preferences of people with early dementia?. *PloS one*, 11(7), e0159056.
- 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), 2011-2021.
- Dixon, J., Karagiannidou, M., & Knapp, M. (2018). The Effectiveness of Advance Care Planning in Improving End-of-Life Outcomes for People With Dementia and Their Carers: A Systematic Review and Critical Discussion. *Journal of pain and symptom management*, 55(1), 132-150
- Flo, E., Husebo, B. S., Bruusgaard, P., Gjerberg, E., Thoresen, L., Lillemoen, L., & Pedersen, R. (2016). A review of the implementation and research strategies of advance care planning in nursing homes. *BMC geriatrics*, 16(1), 24.
- Poole, M., Bamford, C., McLellan, E., Lee, R. P., Exley, C., Hughes, J. C., ... & Robinson, L. (2018). End-of-life care: A qualitative study comparing the views of people with dementia and family carers. *Palliative medicine*, 32(3), 631-642.
- Robinson, L., Dickinson, C., Bamford, C., Clark, A., Hughes, J., & Exley, C. (2013). A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but...'. *Palliative medicine*, 27(5), 401-408.
- Robinson, L., Dickinson, C., Rousseau, N., Beyer, F., Clark, A., Hughes, J., ... & Exley, C. (2011). A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age and ageing*, 41(2), 263-269.
- Sampson, E. L., & Burns, A. (2013). Planning a personalised future with dementia: 'the misleading simplicity of advance directives'. *Palliative Medicine*; 27(5):387 – 388
- Sinclair, J. B., Oyebode, J. R., & Owens, R. G. (2016). Consensus views on advance care planning for dementia: a Delphi study. *Health & social care in the community*, 24(2), 165-174.
- van der Steen, J. T., van Soest-Poortvliet, M. C., Hallie-Heierman, M., Onwuteaka-Philipsen, B. D., Deliëns, L., de Boer, M. E., ... & de Vet, H. C. (2014). Factors associated with initiation of advance care planning in dementia: a systematic review. *Journal of Alzheimer's Disease*, 40(3), 743-757.



**THANK YOU!**