

# Advance directives in dementia care

-  
*from the perspective of people with dementia*

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Research Programme >

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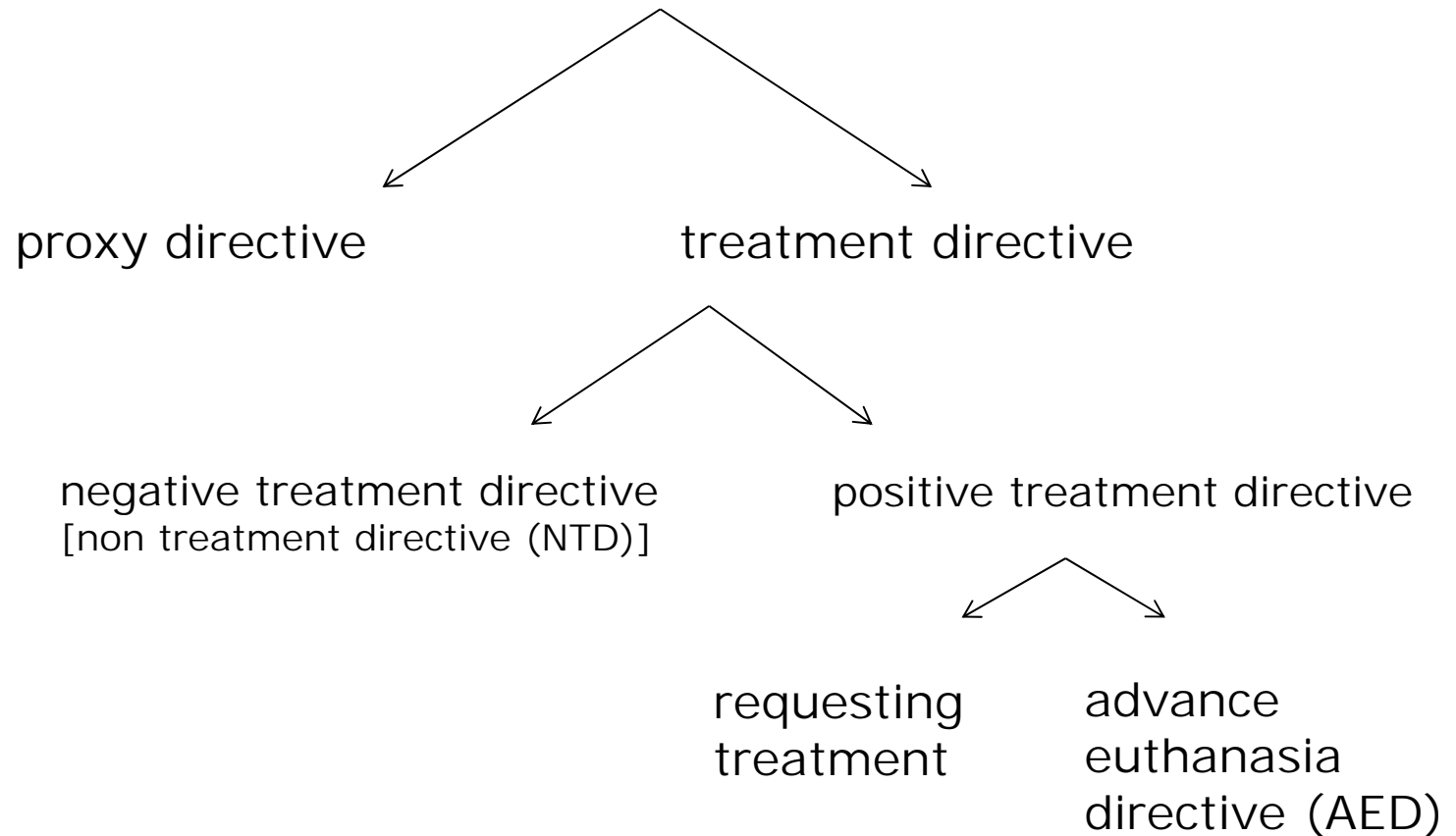
# Content

- Overview AD's
- Ethical considerations
- Empirical data patient's perspective
- Changing preferences over time
  
- Conclusions

# Advance directives (1)

## Types:

oral advance directives ↔ written advance directives



# Advance directives (2)

## Legal status:

- Negative treatment directives

Legally binding - Medical treatment Contract Act 1995 (Wet op geneeskundige Behandelings-overeenkomst, WGBO)

- Positive treatment directives

Not legally binding

### - Advance Euthanasia Directive

Criminal offence, unless .....- Euthanasia legislation (Termination of Life on Request and Assisted Suicide Act, 2002)

# Advance directives (3)

## Requirements of due care in the Dutch Euthanasia Legislation

1. The physician is convinced that the patient has made a voluntary and well considered request
2. The physician is convinced that the patient's suffering is unbearable, and that there is no prospect of improvement
3. The physician has informed the patient about his or her situation and prospects
4. The physician has come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation
5. The physician has consulted at least one other physician, who must have seen the patient and given a written opinion on the due care criteria referred to above, and
6. The physician has terminated the patient's life or provided assistance with suicide with due medical care

# Advance directives (4)

## Formal requirements:

No requirements by law, but

- Discussed with physician
- Clear and unambiguous text
- Known to family, representative, GP, other physician(s)
- Dated and signed
- Preferably renewed
- Adapted when necessary

# Ethical considerations

## 'Complicating' factors of dementia

- slowly diminishing competence
- lacking capacity, but still alert, involved and interactive
- remaining subjective experiences + wishes and preferences

current wishes ↔ former wishes  
[person with dementia]                      [advance directive]

# Ethical debate

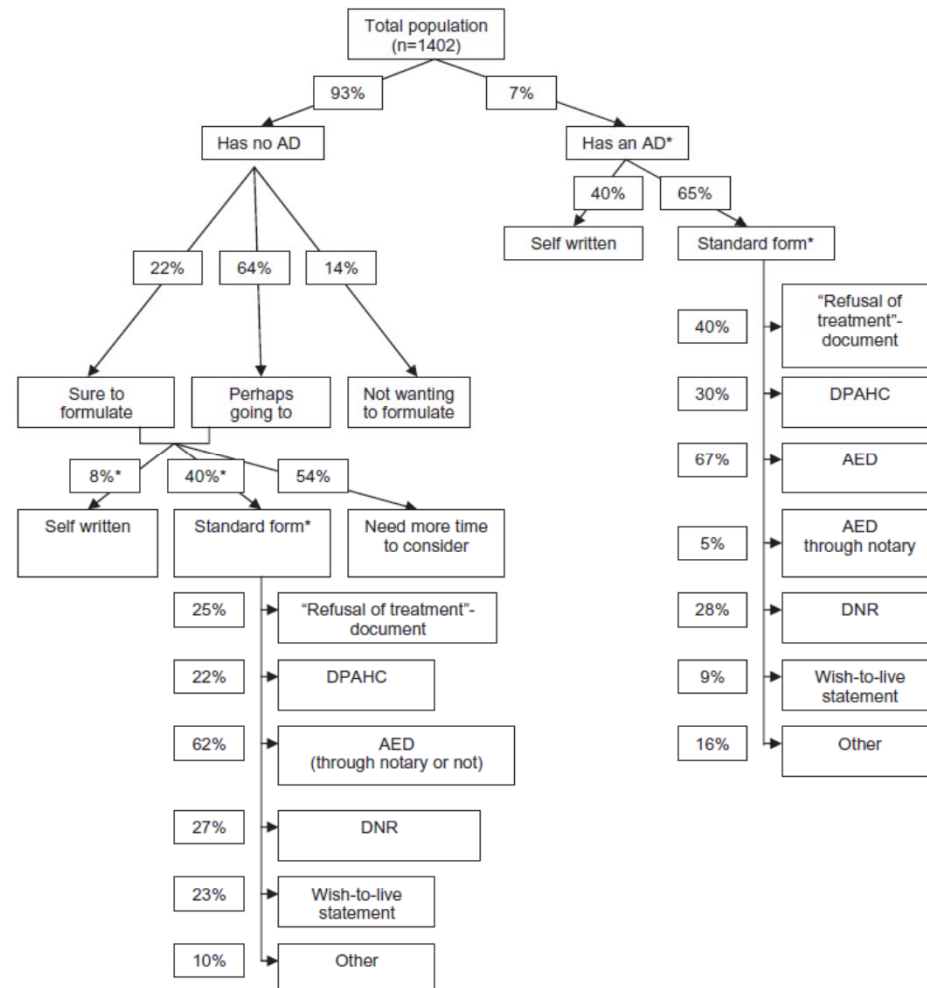
- Parfit
  - loss of identity
- Dworkin
  - different 'selves'
  - critical- and experiential interests
  - 'precedent autonomy'
- Dresser
  - essence of experiential experiences
  - 'moral paternalism' justified
- Jaworska
  - capacity to value
  - overriding an AD is possible



# Actual practice

Advance Directives in the Netherlands

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## Advance directives in the Netherlands:

### 7% has an AD

- Mostly standard forms (65%)
- Majority Advance Euthanasia Directives (67%)

### 93% does NOT have an AD

- 22% was sure to draw one up in the future
- 64% maybe wanted to formulate an AD

\*Van Wijmen et al. *Bioethics* 2010, 24(3): p121

# Dementia – the patient's perspective

## I. Dementia – the patient's perspective

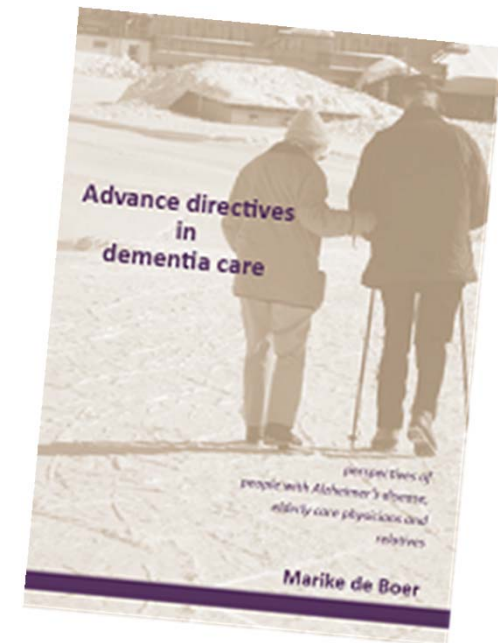
→ Review international literature

Experiences on living through dementia

→ Interviews with 24 elderly diagnosed with Alzheimer's disease

Experiences with regard to:

- *their situation and their illness*
- *their vision with regard to the future and future care*



## Results (1) – dementia: the patient's perspective

### Widespread assumption: dementia = suffering

→ impact of dementia is huge – many negative experiences

But:

- experiences of people with dementia seem more varied and nuanced
- gradual deterioration leaves room for adaptive processes

→ *actual experiences can deviate from earlier values and anticipatory beliefs*

## Results (2) – dementia: the patient's perspective

### Interviews

#### Losses

*'I feel like, 'you don't belong anymore, you can't live that life anymore, how can I put it'*

*'...at the moment I feel I simply don't..how can I put it.. someone who is in the closet'  
....'someone who observes life from afar'*

#### Suffering

*'no, that is overstating it a little...suffering...ehm, but annoying is what I think it is...'*

#### Coping

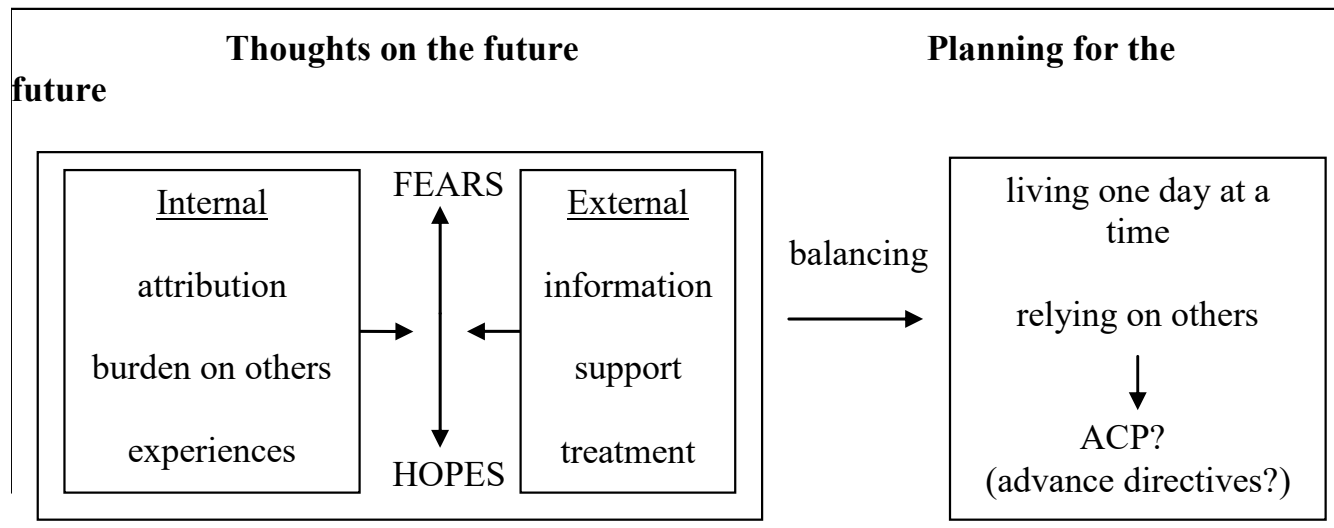
*'...if you look at it at it from a distance, then you dread it, but once you are faced with it, it's not too bad.'*

*Well, then then, you view it as an outsider and then you think, well it must be terrible to have that. And now that it's an everyday thing, I don't see it as a big problem anymore,'*

→ actual experiences can deviate from earlier values and anticipatory beliefs

# Results (3) – dementia: the patient's perspective

*Figure 1 The process of thinking about and planning for the future*



## Results (4) – dementia: the patient's perspective

### Thoughts on the future

- thinking about the future is limited – live by the day
- planning future care – upon own initiative – hardly present
- adaptation to changing situation; change in experiences

*'It contains a whole story about me, eh, not really wanting to go through this. You know. And that I would want then, eh yeah, to get an injection'...*

*Well, I think it is still a little premature. Because I still feel quite good.'*

# Dementia: the patient's perspective

Television program: Zembra\*:

***'If I am demented, I want to die'***

*Example Frans Nuijts, 77 jr*

How are you?

*'Great, I could live another 20 years'*

In the past you have mentioned that you would then want to die

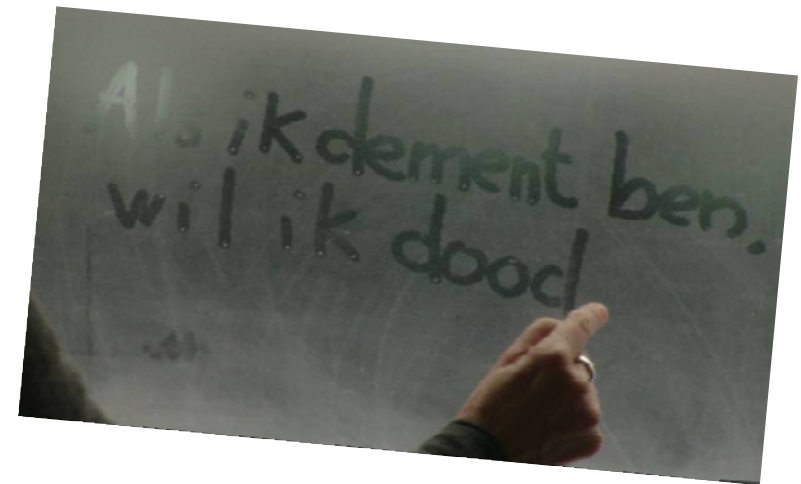
*'Are you serious?'*

It is stated in your advance directive

*'Everybody makes a mistake every now and then'*

So, you don't want to die?

*'Die? Now? No, out of the question'*



- ▶ People with dementia adapt to their changing situation
- ▶ Possible difference between current wishes/preferences and previous wishes as written in an advance directive

# Changing preferences

PAPER

## The implausibility of response shifts in dementia patients

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### ABSTRACT

Dementia patients may express wishes that do not conform to or contradict earlier expressed preferences. Our understanding of the difference between their prior preferences and current wishes has important consequences for the way we deal with advance directives. Some bioethicists and gerontologists have argued that dementia patients change because they undergo a 'response shift'. In this paper we question this assumption. We will show that proponents of the response shift use the term imprecisely and that response shift is not the right model to explain what happens to dementia patients. We propose a different explanation for the changed wishes of dementia patients and conclude that advance directives of dementia patients cannot be simply put aside.

### INTRODUCTION

Frank has been suffering from Alzheimer's disease for at least 5 years. He barely reacts to questions asked by his physician and is only interested in sleeping and smoking cigarettes. For a couple of weeks he has been living in a special nursing facil-

ity. His prior preferences do not matter anymore for dementia patients<sup>1-3</sup> because dementia is a gradually progressive condition and psychological coping strategies will contribute to 'coming to terms' with the disease.<sup>1</sup> Furthermore, so it is argued, what patients find important may change as dementia progresses; what was important in the early stages may seem unimportant in the late stages.<sup>4,5</sup> Because this adaptation process is regarded by some as a 'response shift', we should not hold dementia patients to their previously expressed preferences.<sup>3,4</sup> This view has far-reaching implications, namely that we can disregard prior preferences even when we can disregard advance directives.

The aim of this paper is to show the flaws in expressed conflicting preferences and wishes of dementia patients as a response shift. The main questions we will answer are: (1) What is a response shift? (2) How is the term 'response shift' used for dementia patients? (3) Does the response shift accurately describe the experience of patients with dementia?

We will argue that dementia patients' capacities required to measure a response shift are intact.

Clinical ethics

## Treatment decisions and changing selves

Rebecca Dresser

Commentary

Treatment decisions are difficult when outcomes are highly uncertain. Many life-saving interventions produce a variety of outcomes and no one can predict precisely where a particular patient will end up. It is also impossible to predict exactly how patients will evaluate outcomes that leave them with fewer abilities than they once had.

In *Long-term survival with unfavourable outcome: a qualitative and ethical analysis*, Stephen Honeybul and colleagues present some surprising information about patients' adaptive capacities.<sup>1</sup> The analysis describes the results of semistructured interviews with patients who had life-saving surgery (decompressive craniectomy) following severe brain trauma. Patients suffering traumatic brain injury are incapacitated, and so the surgery decision must be made by clinicians and family members.

Decompressive craniectomy yields a

broader message is that treatment preferences can change over time. The personal values, beliefs and emotions that shape medical choices are not necessarily fixed; instead, they can shift with changing circumstances. One research group examining the treatment preferences of elderly individuals before, soon after and months after a hospitalisation concluded that 'Preferences for life-sustaining treatment are dependent on the context in which they are made, and thus individuals may express different treatment preferences when they are healthy than when they are ill.'<sup>3</sup> This phenomenon has impli-

People make mistakes in forecasting how they will respond to different treatment alternatives. A growing body of research reveals that these sorts of mistakes occur whenever people make choices about what would be good and bad for them in the future. Empirical data suggest that people generally underestimate the extent to which their preferences and values will change in the future.<sup>5</sup> People also tend to predict that 'bad events will be worse than they turn out to be.'<sup>6</sup>

These flaws in human reasoning present particular problems for people preparing advance treatment directives. Patients who remain competent often have opportunities to revise an initial choice based on a questionable prediction. Clinicians and loved ones may challenge patients' initial decisions, contending that patients are overestimating the burdens that treatment would impose. In my own case, that process led to just such a revision. But such opportunities are absent in the context of advance medical decision-making. Consider someone who refuses all life-sustaining interventions if she becomes cognitively impaired due to dementia. Suppose that she later finds life-

- People generally underestimate the extent to which their preferences and values will change in the future.
- Biases that affect one's thinking should be recognized!

## Response shift

Change in self-evaluation of QoL as a result of a change in:

- 1) Internal standards
- 2) Values
- 3) Meaning of QoL



# Stability of preferences

## From Advance Euthanasia Directive to Euthanasia: Stable Preference in Older People?

Eva E. Bolt, MSc,\* H. Roeline W. Pasman, PhD,\* Dorly J. H. Deeg, PhD,<sup>†</sup> and Bregje D. Onwuteaka-Philipsen, PhD\*

**OBJECTIVES:** To determine whether older people with advance directive for euthanasia (ADEs) are stable in their frequently older people with an ADE eventually request euthanasia, and what factors determine this.

**DESIGN:** Mortality follow-back study nested in a cohort study.

**SETTING:** The Netherlands.

**PARTICIPANTS:** Proxies of deceased members of a cohort representative of Dutch older people (n = 168) and a cohort of people with advance directives (n = 154).

**MEASUREMENTS:** Data from cohort members (possession of ADE) combined with after-death proxy information on cohort members' last 3 months of life. Multiple logistic regression analysis was performed on determinants of a euthanasia request in individuals with an ADE.

**RESULTS:** Response rate was 65%. One hundred forty-two cohort members had an ADE at baseline. Three

**Key words:** end-of-life care; advance care planning; advance directives; physician-assisted dying; euthanasia

In advance directives, people describe their future preferences for end-of-life care. In the Netherlands, advance directives for euthanasia (ADEs) are the most popular advance directives; approximately 6% of older adults have an ADE.<sup>1,2</sup> In ADEs, people describe an advance desire for euthanasia and the circumstances under which they want euthanasia. Most people discuss their ADE with their family physician at the time of writing.<sup>3</sup> If they develop an active desire for euthanasia because of unbearable suffering, they can request euthanasia. However, ADE is not required for euthanasia, and people without an ADE can also request euthanasia. After a n

## Original Investigation

## Stability of End-of-Life Preferences: A Systematic Review of the Evidence

Catherine L. Auriemma, MD; Christina A. Nguyen; Rachel Bronheim; Saïda Kent, BS; Shrivatsa Nadiger, MD; Dustin Pardo, MD; Scott D. Halpern, MD, PhD

**IMPORTANCE** Policies and practices that promote advance care planning and advance directive completion implicitly assume that patients' choices for end-of-life (EOL) care are stable over time, even with changes in health status.

**OBJECTIVE** To systematically evaluate the evidence on the stability of EOL preferences over time and with changes in health status.

**EVIDENCE REVIEW** We searched for longitudinal studies of patients' preferences for EOL care in PubMed, EMBASE, and using citation review. Studies restricted to preferences regarding the place of care at the EOL were excluded.

**FINDINGS** A total of 296 articles were assessed for eligibility, and 59 met inclusion criteria.

Majority of older adults with an ADE will have a stable preference over time

BUT

An advance desire for euthanasia does not necessarily result in a euthanasia request

Stability of EOL preferences suggested; especially among more seriously ill patients and those engaged in ACP

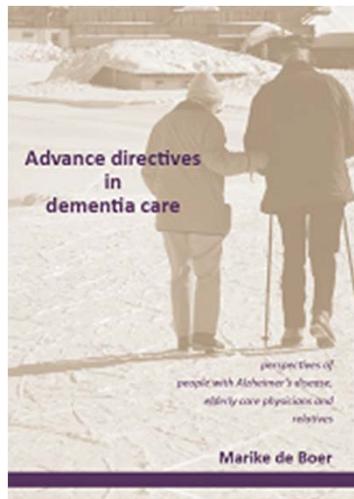
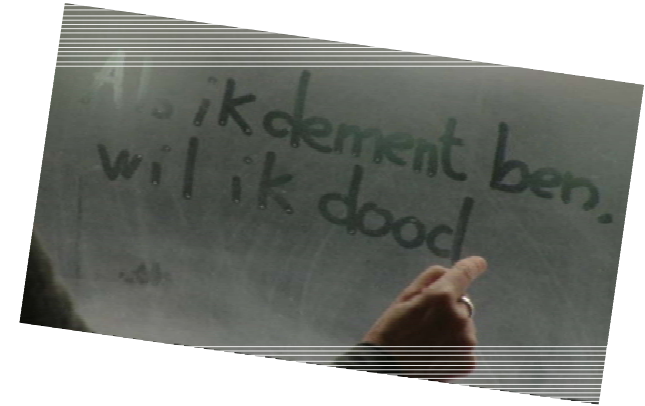
# Summary and conclusions

- Focus on euthanasia in the Netherlands
- AD's in dementia care limited
- Limited 'window of opportunity'
- Thinking about the future + planning ahead is limited
- Changing preferences
- Guidance is needed
- Awareness about dementia + changing preferences
- Development of models of ACP
- Longitudinal research into effects of ACP (incl. AD's)

# Advance directives in dementia care



Thank you for your attention!



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stability of preferences...?

COMMUNICATION

