



Practical and ethical issues related to the use of advance directives by people with dementia

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Overview

- 1. Alzheimer Europe and its work and interest in advance directives**
- 2. About dementia and advance directives**
- 3. Factors affecting advance decision making**
- 4. Issues related to the use and interpretation of advance directives**



1. Alzheimer Europe and its work and interest in advance directives

Alzheimer Europe

Alzheimer Europe: an umbrella organisation with 36 member associations (national Alzheimer societies) throughout Europe



Jean Georges, Executive Director

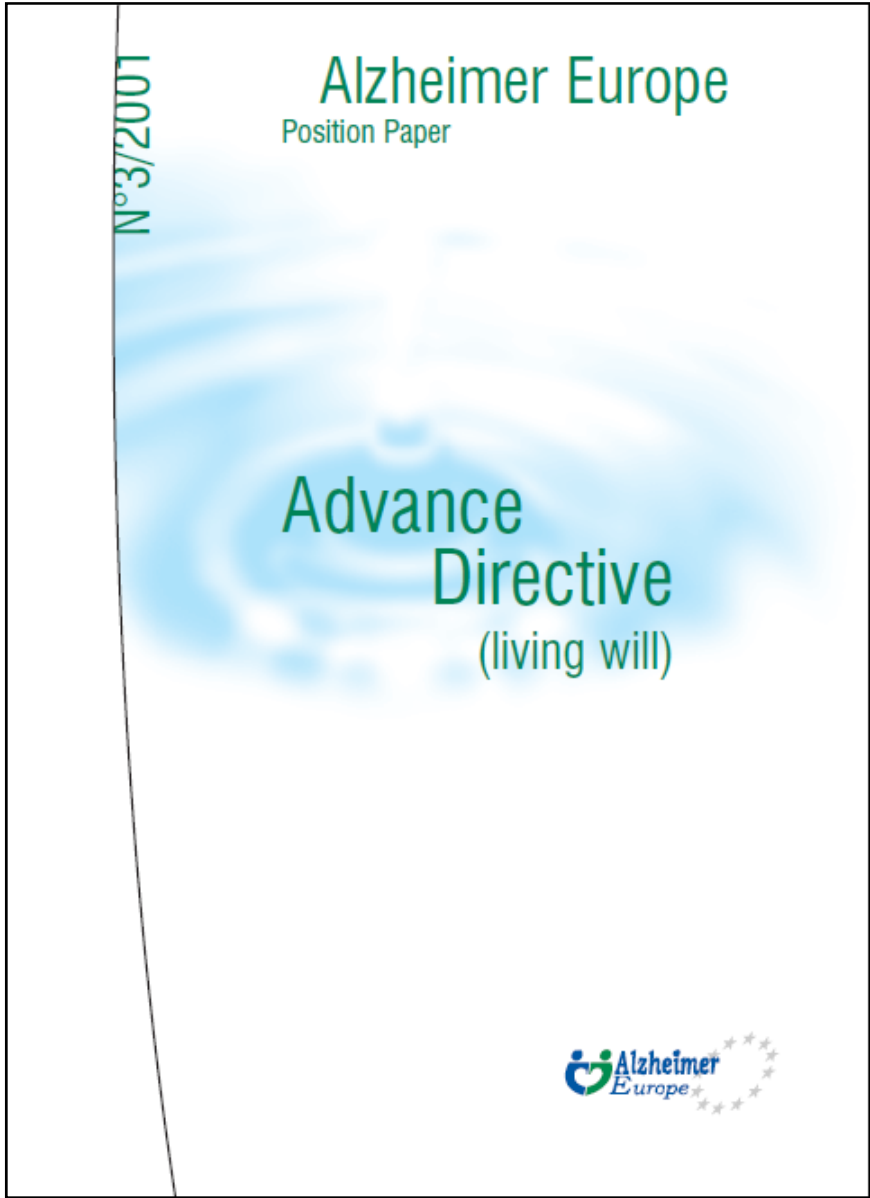
Our members are helping people with dementia and their carers in 31 countries



The board of Alzheimer Europe



The European Working Group of People with Dementia





2. About dementia and advance directives

Dementia and capacity



- People may live with dementia for many years
- Capacity is not an all or nothing matter
- Capacity is decision-specific
- Capacity may fluctuate depending on a range of factors
- It should not be presumed that a person lacks capacity simply because they have dementia or have made an advance directive

Dementia and advance directives



- Advance directives are not just for end-of-life decision making
- A person may have an advance directive but still be able (sometimes with the necessary support) to consent to certain treatment or care
- Advance directives should cover care and treatment decisions in any setting (e.g. in nursing homes, hospices, hospitals and at home).

People with dementia at the end of life



People dying with/from dementia may include:

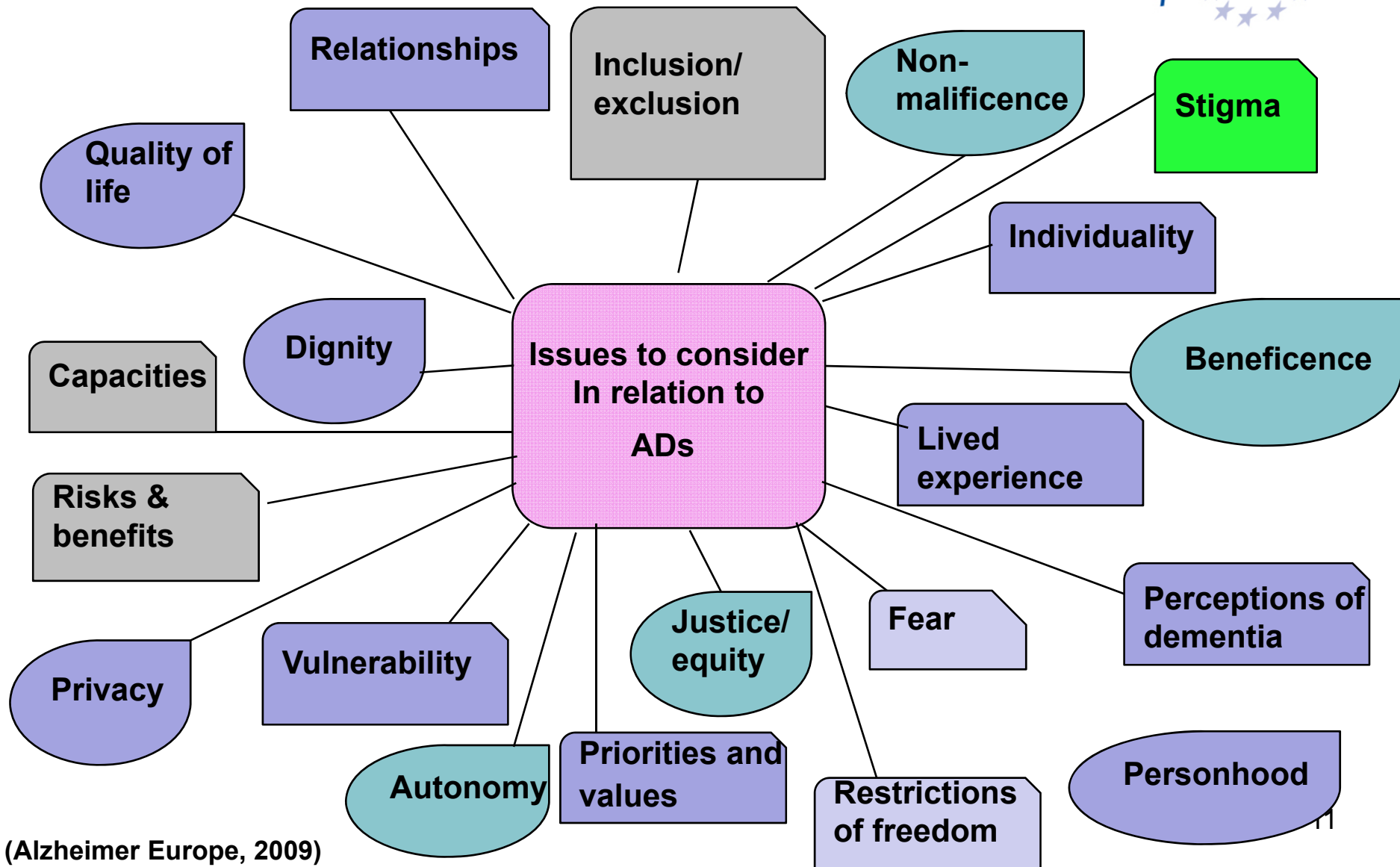
- People who reach the end of life but die from some other identifiable condition, such as cancer, before reaching the final stage of dementia.
- People who reach the end of life with a complex mix of mental and physical problems but where the effect on brain functioning is not as advanced
- People who reach the end of life and die of the complications of dementia, such as end-stage dementia

(Source: Cox and Cook, 2007 - in "Palliative care for older people in care homes")

Respecting autonomy and dignity

Alzheimer Europe feels that it is important that people with dementia are given the opportunity to exercise their right to self-determination and is of the opinion that advance statements and directives are an effective means of preserving the autonomy of people with dementia and reflecting their human dignity.

Ethical issues and related concepts



(Alzheimer Europe, 2009)

3. Issues related to the drafting of an advance directive



- Motivation and state of mind
- Perceptions of dementia and stigma
- Ability to make informed decisions
- Different options

Motivation and state of mind



- To express autonomy
- To benefit from available treatment
- To avoid treatment one does not want
- Concerns about under and over treatment
- Pressure to make decisions
- Emotional reaction to diagnosis of dementia

Perceptions of dementia



“I’ve heard people say “You don’t look like you’ve got dementia”, fancy that! How are we supposed to look?” (Devlin, MacAskill & Stead, 2007, p. 52)

**“A typical stereotype is someone in a rest home, just eh, not doing anything, sat there, looking gormless. When you start talking about dementia, that’s the image people have. They kind of miss out the years before that.”
(Gove, 2012, p.146)**

- no quality of life
- symptoms typical of advanced dementia
- a burden / no value
- focus on deficits
- dangerous
- disturbing behaviour
- vulnerable
- dependent
- lack of reciprocity

Perceptions of dementia



- “It’s as though that’s it, you are dribbling and nodding, and that’s Alzheimer’s. That’s the picture of Alzheimer’s. But we are sitting all here talking perfectly normally. We have got Alzheimer’s of some form, we are not nodding and dribbling.”
- “I don’t think every day, “oh gosh, I have got Alzheimer’s” or something like that, I just carry on.”
- “I am doing all sorts. I can drive. I mow the garden. I can decorate.”

(Alzheimer’s Society, 2008; Hulko, 2009)

The ability to make informed decisions



- Ability to make an informed decision about future situation (even with capacity)
- Medical treatment decisions seldom one-off choices of action
- Change of mind always possible but capacity may have deteriorated

Different options in relation to advance decision making



- **Specific reference to dementia and different healthcare scenarios**
- **Focus on quality of life outcomes or treatment options**
- **Consultation with doctors (re terminology, understanding what one is agreeing to or refusing etc.)**
- **Unlimited duration of the advance directive**

4. Issues related to the use of advance directives

The time factor



- **Importance of timely diagnosis**
- **Need to avoid a time limit on validity**
- **Importance of updating at regular intervals**

Healthcare proxies and trusted persons



- Appointment in the advance directive of a healthcare proxy or “trusted person”
- With or without specific written guidance on the person’s wishes
- Consultation advisable

Issues linked to “person status”



- **Discrepancy between current and previously expressed wishes**
- **Often linked to philosophical and controversial debate about personhood (e.g. is the person who wrote the advance directive the same person or even “a person”?)**

The importance of integrity and continuity



- **Dworkin:** dementia representing one stage of many in a person's life; critical and experiential interests; the latter to take precedence (hence importance of respecting advance directive).
- **Parfit:** varying degrees of continuity between former and later selves. If no relationship between the two, then no moral grounds to respect advance directive.
- **Dresser:** agrees with Parfit about continuity but emphasises importance of the conscious incompetent person's subjective reality.

- **Robertson: competent people may have an interest in controlling their future but advance directives may pose a risk to people with incapacity who clearly have an interest in further life.**
- **Tooley (1983), Buchanan (1988) and Kuhse (1999): call into question the person status of people who lack the capacity for self-consciousness, rationality and purposive agency, and have no conception of themselves existing over time.**

Arguments in favour of personhood



A lay perspective on person status. Sapp (1998), for example, argues that if a person:

“If a person were to retain bodily integrity and vitality but to lose consciousness, rationality and the capacity to make autonomous choices, most people would simply take the commonsense position that of course this is still a human being even if some or even most of these capacities have been lost.”

AE's position



- **Current, competently expressed wishes cannot be overridden**
- **Wishes contained in an advance directive should in principle be respected**
- **Nobody should be subjected to medical treatment or suffer from a lack of medical treatment on the basis of a prior decision when it is obvious that they are currently displaying clear and unambiguous signs or wishes to the contrary.**
- **Importance of considering conflicting past and current wishes when drafting an advance directive**

Thank you for your attention



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