



ALzheimer COoperative Valuation in Europe

The European Joint Action on Dementia
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ALCOVE in cooperation with Alzheimer Europe for Ethics in Dementia

HAS
HAUTE AUTORITE DE SANTÉ



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The main topic

The assessment of competence and the use of advance directives to help promote the autonomy of people with dementia and provide them with protection.

The legal and ethical issues involved.



Advance care planning (ACP)

ACP is a process of communication, discussion, consultation and decision making between an individual, her/his care providers (informal and formal) and other possible relevant persons concerning future care and treatment options for that individual.



Advance directives

- ☆ Written (or oral) statements regarding positive (consent) and negative (refusal) decisions
- ☆ Aim to clarify this person's wishes and will
- ☆ Anticipated decline of the capacity to make decisions
- ☆ Anticipated decline of the ability to express decisions towards others
- ☆ May or may not include end-of-life decisions



Are they legally binding?

They may be legally binding or advisory

Even if advisory, physicians may be legally bound to take wishes into consideration

Physicians may also take into account circumstances not known by the author or that have changed after the drafting of the advance directive

Sometimes validity is limited in time.



Legislation on advance directives

- ☆ Almost all EU countries have in some way recognised the importance of advance directives for ACP.
- ☆ No country has outlawed advance directives drafted by people with dementia.
- ☆ No country has specific legislation on advance directives drafted by people with dementia.



Related ethical issues

- ☆ Recognition of and respect for human dignity, personhood and individuality.
- ☆ Striking the right balance between the autonomy of people with dementia and their protection?
 - Appropriate legal provisions
 - Timely diagnosis
 - Appropriate and good quality care and support



Autonomy and wellbeing through advance directives and advance care planning

- Means to contribute to decision making at a time when the person no longer has the capacity to do so
- Protection against unwanted treatment
- Expression of wishes regarding treatment
- Information about care preferences, values and what is meaningful in life (in statement of values)
- Ongoing discussion with healthcare providers
- Opportunity to involve and inform carers



Autonomy through the appointment in advance of a proxy decision maker

- Expression of autonomy through the choice of a future proxy decision maker
 - who is suitable, willing and familiar with wishes
 - rules out the involvement of certain people
- Measure to address the issue of recent medical advances
- Measure to address ambiguities in the advance directive



Importance of advance directives for carers and healthcare professionals

- For peace of mind
- To provide the means to fulfil the obligation to take into consideration the wishes of the person with dementia.
- To ease the emotional burden of making certain decisions
- To help avoid conflict and dilemmas



Challenges linked to the assessment of capacity

- ☆ Need to ensure that a diagnosis of dementia does not result in a person being automatically considered incompetent.
- ☆ Competence should be assessed on a case by case basis and repeated for every important care or treatment decision.
- ☆ Competence regarding care and treatment should be assessed by qualified and skilled healthcare professionals.
- ☆ Additional research on the development and validation of efficient and practical assessment tools is needed.



Challenges linked to the use of advance directives by people with dementia

- The association with the end of life
- Difficulty broaching the topic
- Time factor
- Awareness of the existence of an advance directive
- Beliefs about personal identity



Resources and recent developments

- ☆ The ALCOVE report on Competence Assessment and Advance Directives (<http://www.kbs-frb.be>)
- ☆ Guidelines on advance directive and a sample form (available in 10 different languages) (info@alzheimer-europe.org)
- ☆ An advance directive and guidance in Finnish and English Finnish Alzheimer Association (toimisto@muistiliitto.fi)
- ☆ Initiatives exist in several EU member states to develop instruments for advance care planning, specifically aimed at people with dementia and their carers in various care settings.

