

Developing evidence-based terminal care for people with dementia

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The Netherlands



Why focus on terminal care?

- The last days of life are (also) very important

**"You matter because you are you,
and you matter to the end of your
life. We will do all we can not only
to help you die peacefully, but also
to live until you die."**

*— Dame Cicely Saunders, nurse, physician
and writer, and founder of hospice
movement (1918 - 2005).*



- No cure; die with or from the dementia

Terminal care - Palliative care?

- Benefits of palliative care as an approach to improve quality of life and dying in the face of incurable illness, evidence also for dementia
- “**Alzheimer Europe** is of the opinion that a palliative care approach should be adopted for people with end-stage dementia”
- **European Association for Palliative Care** (EAPC) white paper expert panel: palliative care is important for people with dementia (although ambiguity about applying it early)



2|2008
Alzheimer Europe Report
End-of-life care for people with dementia
Alzheimer Europe



EAPC
European Association for Palliative Care
Non Governmental Organisation (NGO) recognised by the Council of Europe



PALLIATIVE MEDICINE

White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care

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Palliative care services in the terminal phase

- EAPC white paper not clear on what services are needed at different stages
- “People with end-stage dementia should be guaranteed access to palliative care/geriatric services.”
“Palliative care services and facilities should be provided to people dying with/from dementia” (*Alzheimer Europe report 2008; Gove et al., J Nutr Health Aging 2010*)



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Terminal?

- Terminal =? the last days or weeks of life
- Advanced dementia: “the survivors,” may live on for years
(*Gill et al., NEJM 2010; Mitchell et al., NEJM 2009*)
- Prognostication difficulties: we do not know when that last pneumonia or eating problem develops (*Hendriks et al., under review; DEOLD study*)

→ Developing terminal care services: informed by both prognosis and care needs

How do we develop the best possible terminal care for people with dementia?

In Netherlands:

- great hospices, many staff, volunteers (no dementia)
- more budget with palliative care indication, but not for dementia (without comorbid disease)
- Almost all people with dementia die in a nursing home or residential home (*Houttekier et al., JAGS 2010*)
- Medical care by specialized elderly care physician who is on the staff (*Koopmans et al., JAGS 2010*)
- Poorly educated nursing staff, few volunteers with a feeling for people with dementia or dying people



7

6-May-16

How do we develop the best possible terminal care for people with dementia?

- Small evidence base for best terminal care in dementia
- Approach
 - (1) **evidence** for optimal terminal care: select EAPC white paper recommendations specific for end of life / advanced dementia
 - (2) local patient and family preferences through **focus group** discussions
 - (3) learn from experiences with initiatives elsewhere through **expert interviews**

(1) Evidence for optimal terminal care

EAPC domains and recommendations of particular importance rated by 3 team members, 6 EAPC white paper co-authors from 5 countries

Consider limiting certain treatments and care...

Domain 6. "Avoiding overly aggressive, burdensome, or futile treatment" (6/6)

6.1 Transfer to the hospital and the associated risks and benefits should be considered prudently...taking into account stage of the dementia.

Consider expanding other treatments and care...

Domain 7. "Optimal treatment of symptoms and providing comfort" (4/6)

7.5 Nursing care is very important to ensure comfort in patients near death.

Advance care planning,
education



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(2) Local patient and family preferences

2 focus groups, each 3 discussion sessions

family caregivers of people with dementia in variable stages in the Amsterdam area discussed needs and preferences anticipating or reflecting on the end of life.

Theme 1: communication

Theme 2: familiarity

(2) Local patient and family preferences

2 focus groups, each 3 discussion sessions
family caregivers of people with dementia in variable stages in the Amsterdam area
discussed needs and preferences anticipating or reflecting on the end of life.

Theme 1: communication

“What I think is very important is that in the last stage there is good communication between yourself and the nursing staff. That you know exactly, what is going on? And that you also ask: could we do it differently, could we do it this way, that way? What can I actually do and what should I definitely not do? And that you are being guided in that process.”

(2) Local patient and family preferences

2 focus groups, each 3 discussion sessions
family caregivers of people with dementia in variable stages in the Amsterdam area
discussed needs and preferences anticipating or reflecting on the end of life.

Theme 1: communication

Theme 2: familiarity

“And not to even think about there being different people caring for him. That is confusing. You just cannot do that.”

Both themes related to a desire for continuity in several respects, to continue on familiar grounds as long as possible

(3) Learn from experiences elsewhere

Interviews with 25 experts
about 15 initiatives (7 from dementia care, 8 from palliative care)
Netherlands, Flanders, UK, US, Israel

Theme 1: familiarity

Theme 2: professionalism

Theme 3: stereotyping

(3) Learn from experiences elsewhere

Interviews with 25 experts
about 15 initiatives (7 from dementia care, 8 from palliative care)
Netherlands, Flanders, UK, US, Israel

Theme 1: familiarity

Initially, there has been resistance when the nurse became involved in a team of nurses and GP, with "their patient"
(Flanders, mobile palliative care team)

Attempts to recruit patients with advanced dementia failed mainly because family and nursing staff were not willing to move the patient from a familiar environment
(Netherlands, special unit in nursing home)

(3) Learn from experiences elsewhere

Interviews with 25 experts
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Theme 1: familiarity

Theme 2: professionalism

The right attitude, interest and sensitive awareness to recognize special needs to bring comfort...

Identifying change of needs, symptoms...

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In hospices, volunteers may find that people with dementia disturb the perfect place

Defend against misperceptions such as palliative care meaning you will not get the treatment you need

Theme 3: stereotyping

*Hospice has a good public image
Nursing homes don't*

Service development

Advice...

- Mostly, terminal care is preferred on the place of residence
- Only for a selected group of people and with trained staff, transfer to a (general) hospice is feasible.

Mobile palliative/geriatric/psychogeriatric care teams should be set up in order to provide assistance and advice in people's homes and in residential care settings ([Alzheimer Europe](#))



Service development

Advice...

Continuity of relationships, information, management / care, environment.....

Appealing models:

- empower dementia care staff in nursing homes and in the community to provide high-quality terminal care
- seek multidisciplinary team collaboration between dementia care and palliative care specialists and educate both
- structuring care processes may be helpful to the extent that flexibility is retained to provide terminal care that is person-centred

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