

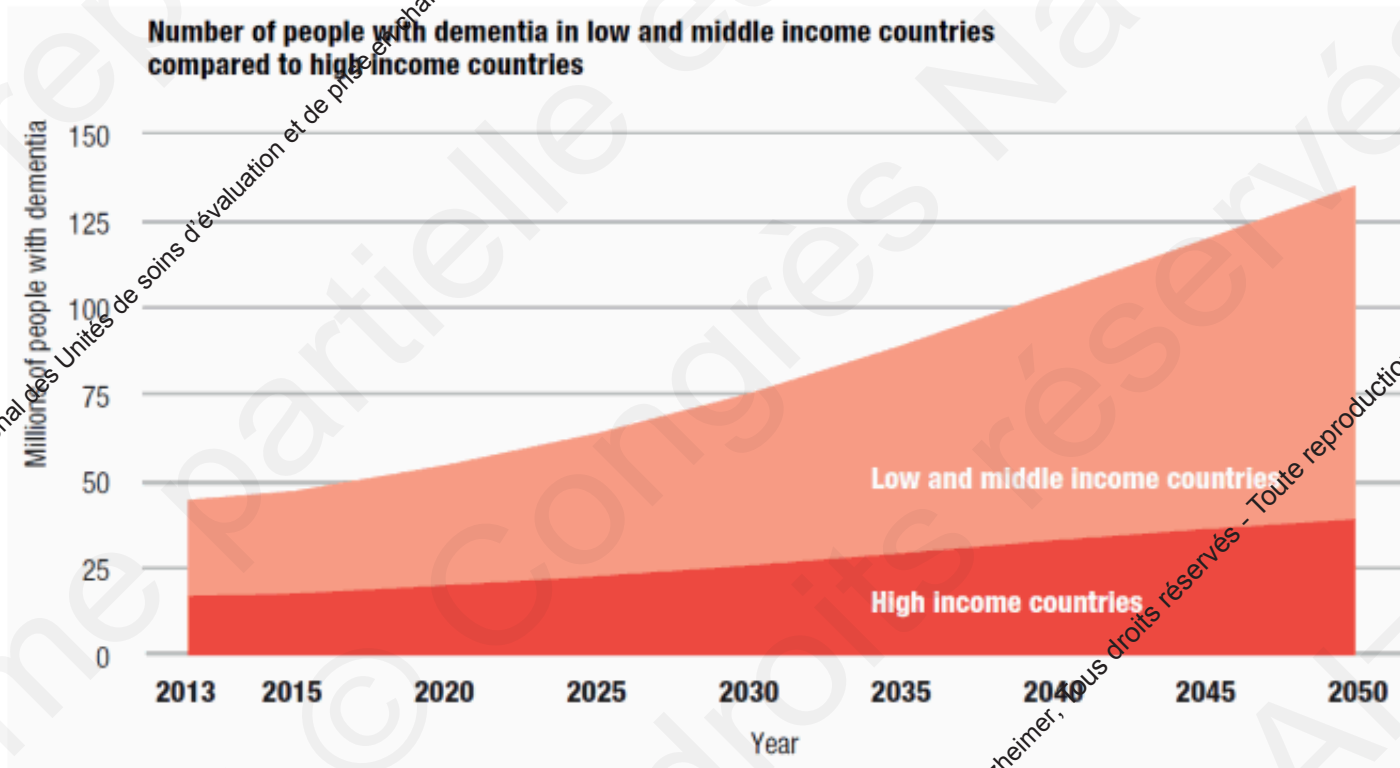
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Fin de vie et démence

F. Nourhashémi

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Contexte



There are 7.7 million new cases of dementia each year, implying that there is a new case of dementia somewhere in the world every four seconds.

Review

Dying with Dementia: What We Know after More than a Decade of Research

Denny T. van der Steen*

VU University Medical Center, EMGO Institute for Health and Care Research, Department of Nursing Home Medicine, and Department of Public and Occupational Health, The Netherlands

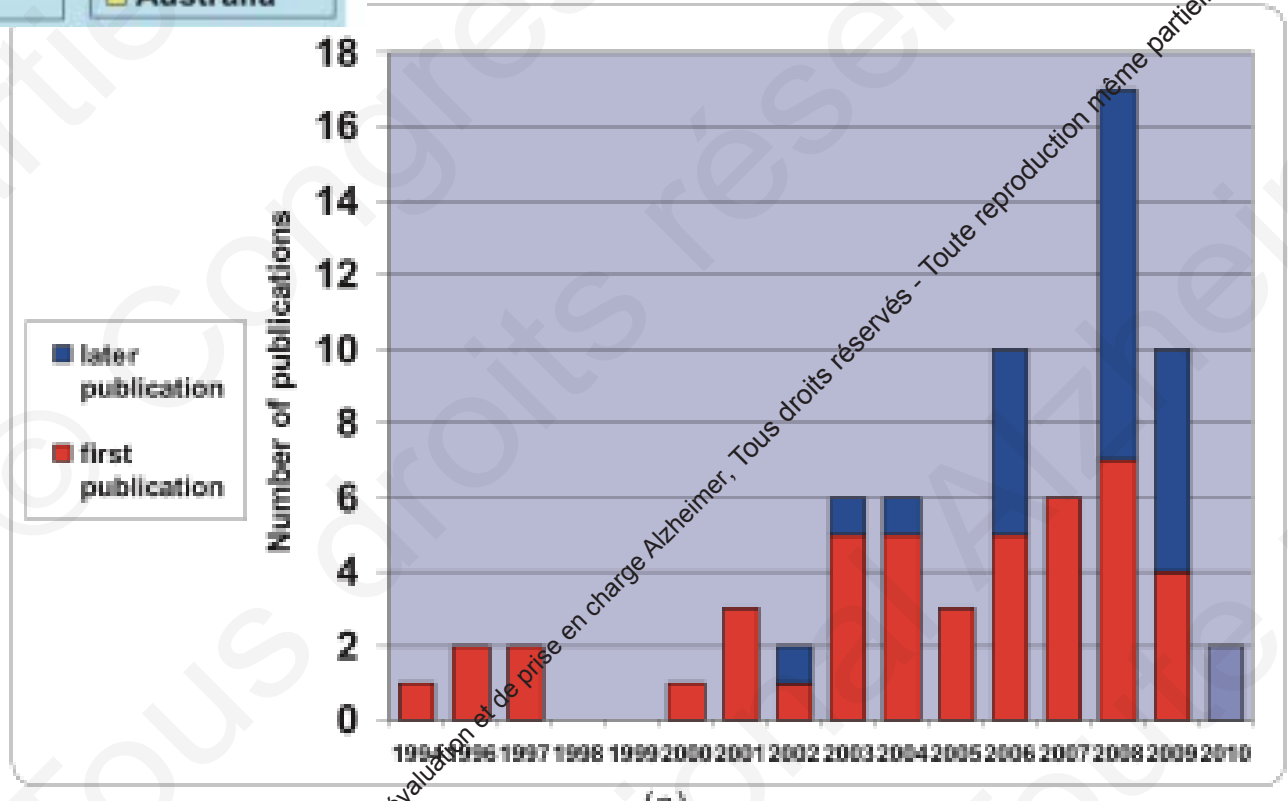
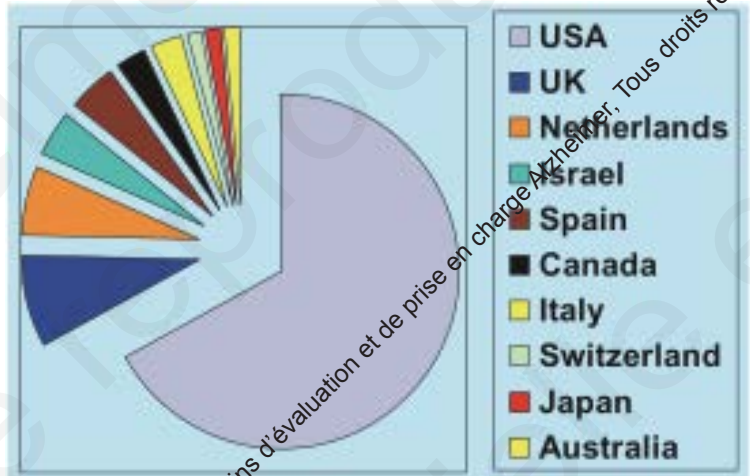
Accepted 16 June 2010

Abstract. Death with dementia is increasingly common. Although prognostication is difficult, it is an incurable, life-limiting illness for which palliative care for the patient is often appropriate. Dementia patients are otherwise at risk of overtreatment with burdensome and possibly non-beneficial interventions and undertreatment of symptoms. Although recent studies indicate encouraging trends of improved palliative care, little evidence supports effectiveness of specific treatments. As of January 2010, at least 45 studies, almost all performed after 2000, have reported on treatment, comfort, symptom burden and families' satisfaction with care. Over half (25; 56%) of these studies were in US settings, and most were small or retrospective. Few randomized trials and prospective observational studies have been performed so far, but several promising studies have been completed recently or are underway in various countries. Guidelines for care and treatment, still mostly consensus-based, support the benefits of advance care planning, continuity of care, and family and practitioner education. Assessment tools for pain, prognosis, and family evaluations of care have been developed and some have been shown to be effective in clinical practice. With increasing numbers of well-designed, large-scale studies, research in the next decade may result in better evidence-based guidelines and practice.

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La période dite « de fin de vie »

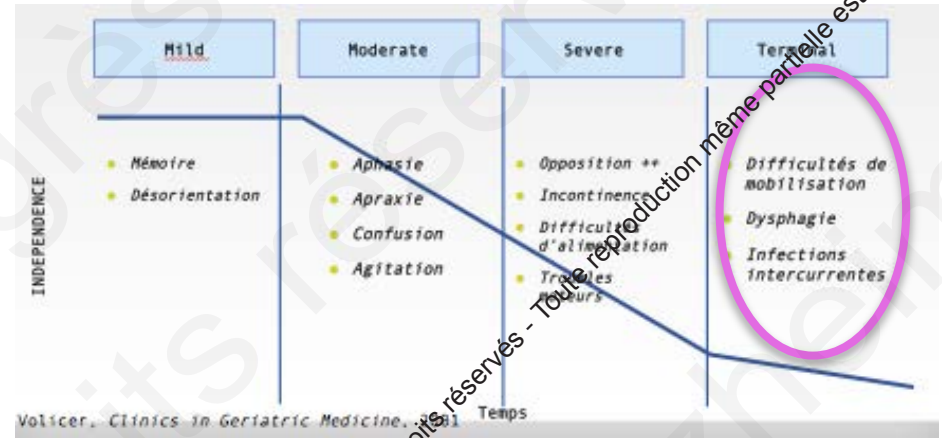
- Constats:
 - Difficile à individualiser
 - Mal reconnue
 - Sous diagnostics et sur diagnostics...
 - Période de « errance » médicale avec dysfonctionnements
 - Peu de personnes atteintes de MA hospitalisées en USP
 - Situations parfois difficiles: demande de mourir

Contexte

Table 1: Seven stages of Alzheimer's

	Memory Loss	Functional Loss
Stage 1	No subjective complaints of memory deficit	Normal function
Stage 2	Very mild decline	Persons may feel as though they are having memory lapses but these are invisible to family and friends.
Stage 3	Mild decline	Trouble remembering names and performing some complex activities. May lose or misplace valuable possessions.
Stage 4	Moderate decline	Greater difficulty with performing complex tasks, such as instrumental activities of daily living (managing finances, shopping). May be becoming moody or withdrawn.
Stage 5	Moderately severe decline	May still be independent with eating and toileting. May forget own address. May require assistance with choosing weather-appropriate clothing.
Stage 6	Severe decline	Personality changes may take place. May need assistance with activities of daily living. Experiences disturbed sleep. May wander and become lost.
Stage 7	Very severe decline	Likely need assistance with all aspects of care. May or may not retain verbal abilities. Muscles may become rigid; swallowing impaired.

(Alzheimer's Association, 2012, and Reisberg, B. et al 1982)



JAMA. 2008 December 10; 300(22): 2608–2610. doi:10.1001/jama.2008.768.

Reporting Dementia on the Death Certificates of Nursing Home Residents Dying With End-Stage Dementia

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Methods. Data were collected between 2003 and 2007 from the Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life study, a prospective study of 323 residents of 22 Boston-area nursing homes with advanced dementia, each followed up for up to 18 months.⁴ Eligibility criteria included age older than 60 years and advanced dementia (based on physician documentation of dementia in chart and Global Deterioration Scale stage 7 determined by a nurse).⁵ The Hebrew SeniorLife institutional review board approved this study. Written consent was provided by participants' health care proxies.

Comment. In this study, dementia, and specifically Alzheimer disease, was underreported on death certificates, raising concerns about the accuracy of mortality statistics based on these documents. Despite the terminal stage of dementia in our cohort, dementia was not recorded on 37% of death certificates. The absence of Alzheimer disease on three-quarters of death certificates of decedents with this premortem diagnosis is a particular problem because among the causes of dementia, NCHS ranks only Alzheimer disease among its leading causes of death.

J Am Med Dir Assoc. 2013 Jul;14(7):485-92. doi: 10.1016/j.jamda.2013.01.016. Epub 2013 Mar 21.



Nursing home residents dying with dementia in Flanders, Belgium: a nationwide postmortem study on clinical characteristics and quality of dying.

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Author information

Abstract

OBJECTIVES: There is a lack of large-scale, nationwide data describing clinical characteristics and quality of dying of nursing home residents dying with dementia. We set out to investigate quality of end-of-life care and quality of dying of nursing home residents with dementia in Flanders, Belgium.

DESIGN/SETTING/PARTICIPANTS: To obtain representativity, we conducted a postmortem study (2010) using random cluster sampling. In selected nursing homes, all deceased residents with dementia in a period of 3 months were reported. For each case, a structured questionnaire was filled in by the nurse most involved in care, the family physician, and the nursing home administrator. We used the Cognitive Performance Scale and Global Deterioration Scale to assess dementia. Main outcome measures were health status, clinical complications, symptoms at the end of life, and quality of dying.

MEASUREMENTS: Health status, clinical complications, symptoms at the end of life, and quality of dying.

RESULTS: We identified 198 deceased residents with dementia in 69 nursing homes (58% response rate). Age distribution was the same as all deceased residents with dementia in Flanders, 2010. Fifty-four percent had advanced dementia. In the last month of life, 95.5% had 1 or more sentinel events (eg, eating/drinking problems, febrile episodes, or pneumonia); most frequently reported symptoms were pain, fear, anxiety, agitation, and resistance to care. In the last week, difficulty swallowing and pain were reported most frequently. Pressure sores were present in 26.9%, incontinence in 89.2%, and cachexia in 45.8%. Physical restraints were used in 21.4% of cases, and 10.0% died outside the home. Comparing stages of dementia revealed few differences between groups regarding clinical complications, symptoms, or quality of dying.

CONCLUSION: Regardless of the dementia stage, many nursing home residents develop serious clinical complications and symptoms in the last phase of life, posing major challenges to the provision of optimum end-of-life care.

J Nutr Health Aging. 2012 May;16(5):457-61.

End-of-life care for persons with advanced Alzheimer disease: design and baseline data from the ALFINE study.

Nourhashémi F¹, Gillette S, Cantet C, Stilmunkes A, Saffron N, Rougé-Bugat ME, Vellas B, Rolland Y.

Author information

Abstract

CONTEXT: Alzheimer disease (AD) is the most common cause of dementia. Most affected individuals survive to an advanced stage of dementia, which is under-recognized as a terminal illness.

OBJECTIVES: Our objectives were to better understand the clinical trajectory of advanced AD and to identify the palliative care needs of these patients.

METHODS: This was an observational prospective study of AD patients in severe stage of disease included after a hospitalization in geriatric wards. They were followed up every three months during 2 years. At each visit, interviews provided data regarding: pain (Elderly Pain Careg Assessment scale), pressure ulcers, eating patterns, daily medications and use of health services. This paper describes the design of the ALFINE study and the characteristics of the recruited cohort.

RESULTS: 112 patients were recruited (mean age: 84.03 + 6.96) years; 76.79% were women. Mean time since diagnosis of AD was 5.28 years. Pressure ulcers were observed in 42 patients. Pain assessment with the EPCA showed a mean score of 8.58. One third of patients with an EPCA score of more than 7 (median) had no analgesics. More than half of patients had been treated with antibiotics during the three months before inclusion in the study and 33 patients were still receiving antibiotics at inclusion. Two third of patients had been hospitalized in the month before inclusion.

CONCLUSION: End-of-life care for individuals with end-stage AD is increasingly important because of the rising number of patients with this disease. Health care systems and clinicians should make efforts to ameliorate the suffering of patients and their caregivers.



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N Engl J Med. 2009 October 15; 361(16): 1529–1538. doi:10.1056/NEJMoa0902234.



The Clinical Course of Advanced Dementia

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Hebrew SeniorLife Institute for Aging Research (S.L.M., D.K.K., R.N.J., J.L.G.); the Department of Medicine, Beth Israel Deaconess Medical Center (S.L.M., R.N.J., J.L.G., M.B.H.); and the Center for Psychosocial Oncology and Palliative Care Research, Dana-Farber Cancer Institute (H.G.P.) — all in Boston; the Center for Gerontology and Health Care Research, Department of Community Health, Alpert Medical School, Brown University, Providence, RI (J.M.T.); Penn State College of Medicine, Hershey, PA (M.L.S.); and the School of Aging Studies, University of Southern Florida, Tampa (L.V.)

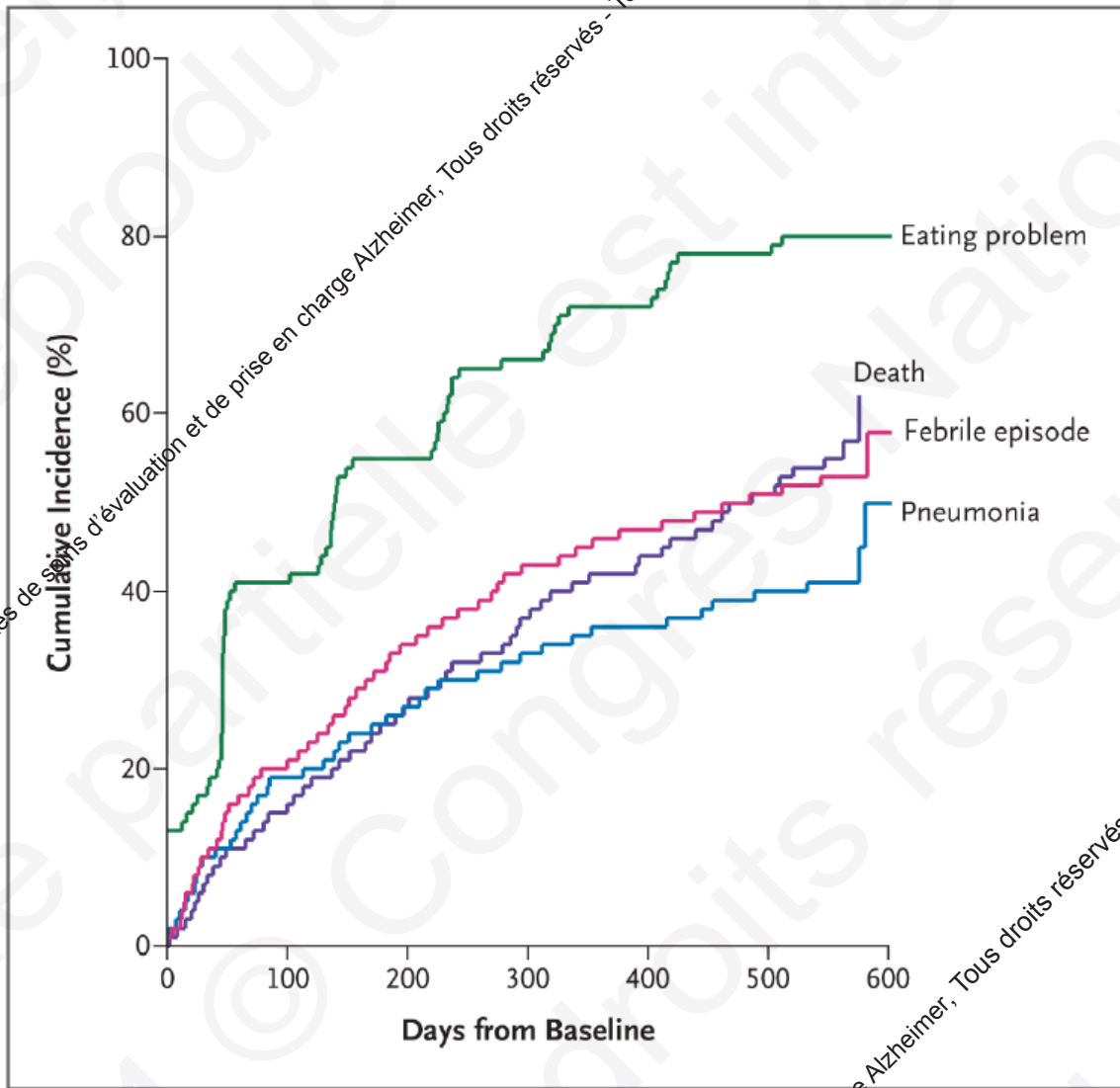


Figure 1. Overall Mortality and the Cumulative Incidences of Pneumonia, Febrile Episodes, and Eating Problems among Nursing Home Residents with Advanced Dementia

Overall mortality for the nursing home residents during the 18-month course of the study is shown. The residents' median age was 86 years, and the median duration of dementia was 6 years; 85.4% of residents were women.

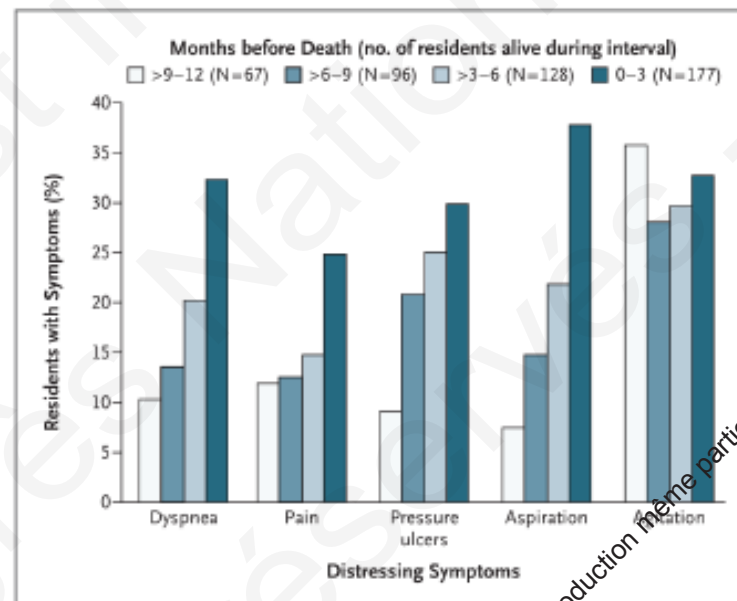
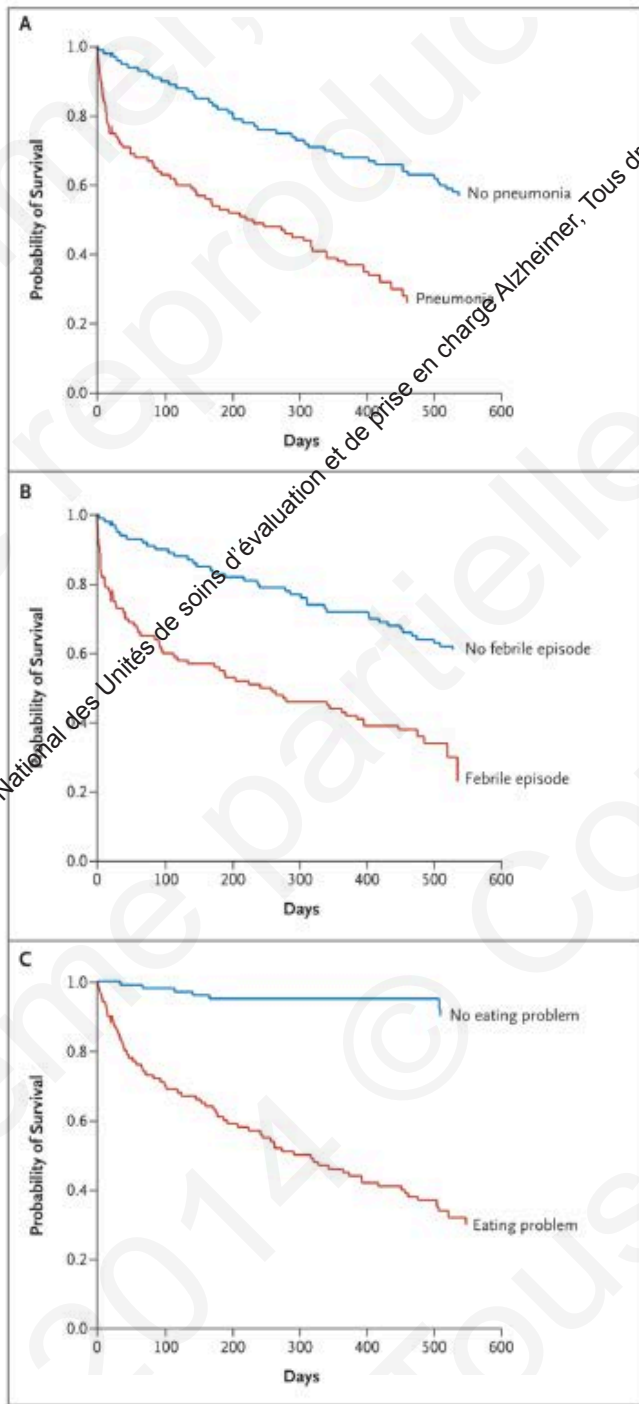


Figure 2. Survival after the First Episode of Pneumonia, the First Febrile Episode, and the Development of an Eating Problem

Panel A shows the results of the survival analysis for pneumonia, Panel B the results for a febrile episode, and Panel C the results for an eating problem. The red line in each panel shows survival after development of these complications. The blue line in each panel shows the estimated survival before the complication developed or in its absence (for residents in whom the complication never developed). All curves are presented for the median age (86 years), median duration of dementia (6 years), and distribution according to sex (85.4% women).

Seven-year hospital and nursing home care use according to age and proximity to death: variations by cause of death and socio-demographic position

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Finland

Background Provision of hospital and long-term care services for the growing number of older people is a major policy concern. The authors estimate hospital and nursing home care use by age and proximity to death for selected causes and by gender, education and marital status.

Methods A 40% random sample of the Finnish population aged 65+ years alive at the end of 1997 was followed to death in 1998–2002. Use of hospital and nursing home care was assessed up to 7 years prior to death for those who died and prior to the end of 2002 for survivors.

Results In the 7-year period, before death total average care days were 294 (95% CI 286 to 301) for men and 430 (95% CI 423 to 438) for women. For surviving men and women, the corresponding figures were 89 (95% CI 86 to 92) and 136 (95% CI 130 to 141) days. Use of hospital and particularly nursing home care increased rapidly with age, while proximity to death was more important for hospital care. The married used less care than the non-married. Care use of those dying from dementia was approximately twice that for all causes combined and was substantial for an extended period before death.

Place of Death of Older Persons with Dementia. A Study in Five European Countries

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 Bregje D. Omwuteaka-Philipsen, PhD,[‡] and Luc Deliens, PhD*[‡]

Table 1. Deaths from Dementia-Related Diseases in People Aged ≥65, Type of Dementia, Sex, Age, Health Resources, and Place of Death in Five European Countries in 2003 (N = 30,281)

Deaths, Type of Dementia, Sex, Age, Health Resources, and Place of Death	Belgium*	Netherlands	England	Wales	Scotland	Total
Deaths from dementia-related diseases, n (%)	2,709 (4.8)	6,964 (6.1)	17,044 (4.1)	1,220 (4.0)	2,324 (5.0)	30,281 (4.6)
Type, %						
Alzheimer's disease	27.8	12.6	26.9	29.3	14.9	22.9
Vascular and other dementia	72.2	87.4	73.1	70.7	85.1	77.1
Sex, %						
Male	31.2	26.9	27.7	27.4	26.3	27.7
Female	68.8	73.1	72.3	72.6	73.7	72.3
Age, %						
65-74	7.4	5.3	5.9	5.8	6.0	5.9
75-84	38.2	33.0	34.3	34.6	34.2	34.4
≥85	54.4	61.7	59.8	59.6	59.4	59.7
Health resources						
Hospital beds/1,000	5.57	3.67	3.05	3.95	4.62	3.52
Nursing home beds/1,000	4.54	10.75	8.37	7.28	7.82	8.24
Place of death, % [†]						
Home	11.4	3.8	3.7	3.2	5.0	4.5
Hospital	22.7	2.8	36.0	46.3	33.9	27.4
Nursing home	65.9	92.3	59.7	50.2	60.8	67.5
Hospice or other palliative care institution [‡]	0.0	0.5		0.1	0.4	0.3

* Flanders and Brussels Capital Region.

[†] Column percentages may not add to 100% because Other was omitted.

[‡] Category concerns hospice in England and Wales, mostly hospice in the Netherlands, and other palliative care institution in Belgium and Scotland.

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

**Jenny T van der Steen¹, Lukas Radbruch², Cees MPM Hertogh¹,
Marike E de Boer¹, Julian C Hughes³, Philip Larkin⁴,
Anneke L Francke^{1,5}, Saskia Jünger⁶, Dianne Gove⁷, Pam Firth⁸,
Raymond TCM Koopmans⁹ and Ladislav Volicer¹⁰ on behalf of the
European Association for Palliative Care (EAPC)**

Palliative Medicine
2014, Vol. 28(3) 197–209
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DOI: 10.1177/0269216313493685
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Van der Steen et al. Palliative Medicine 2014, 28: 197-209

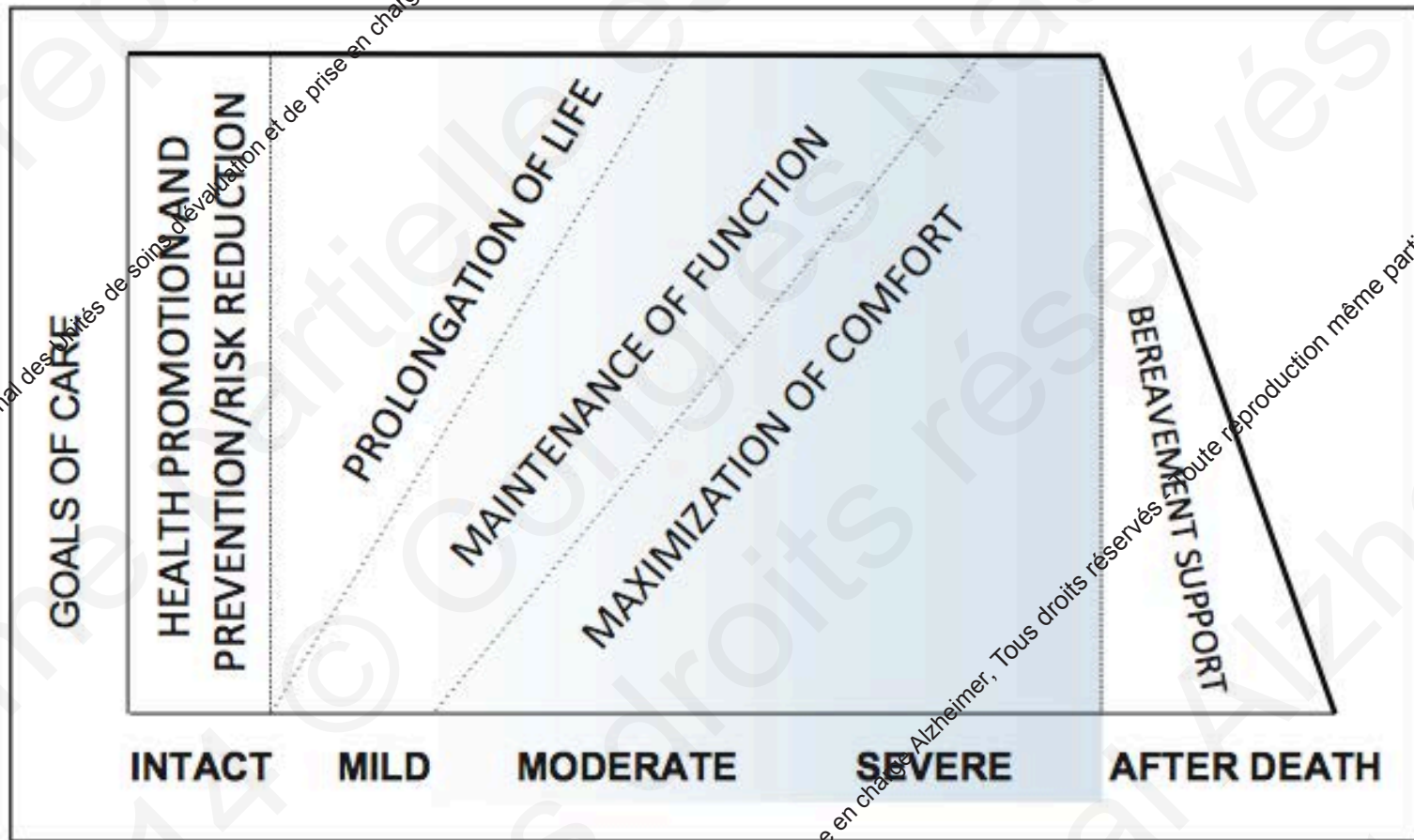
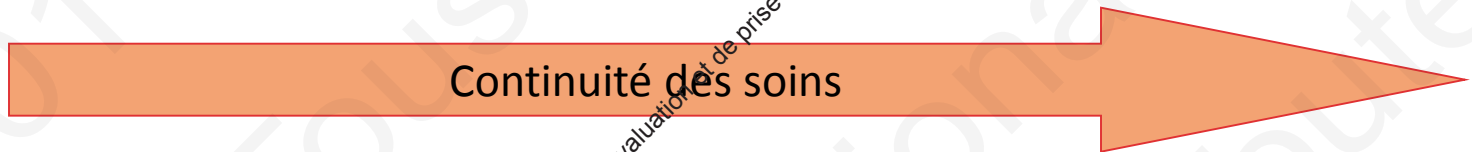
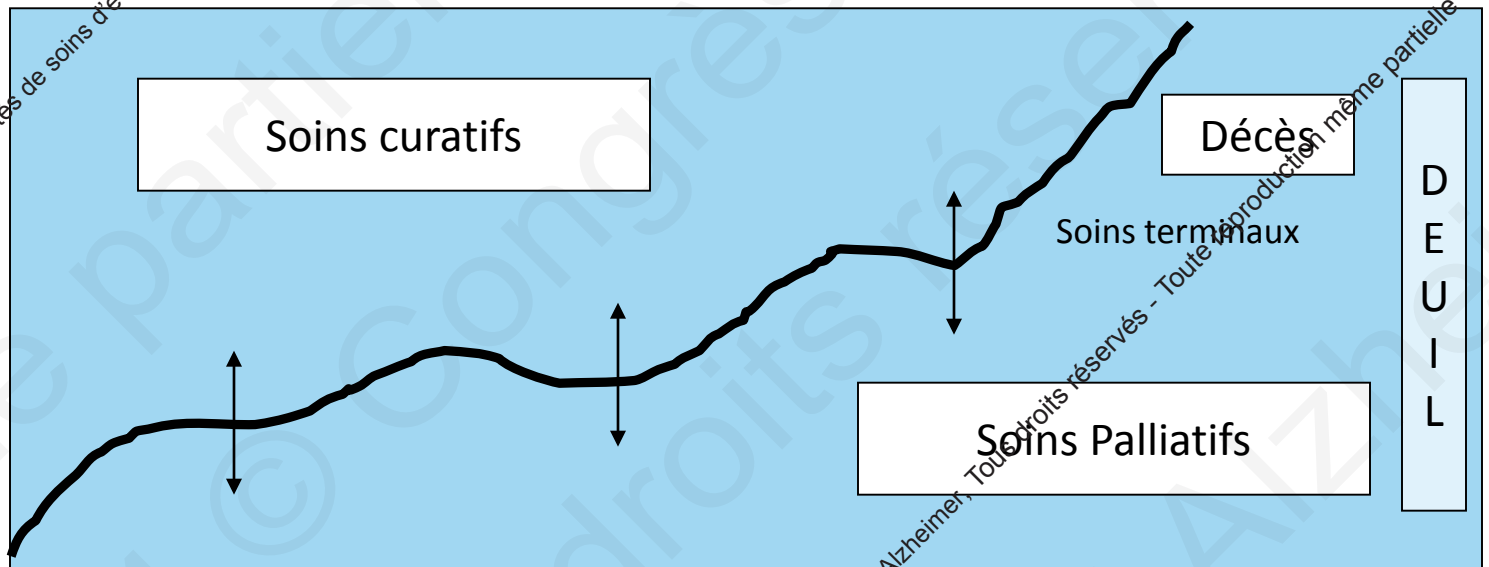


Figure 1. Dementia progression and suggested prioritizing of care goals.

Les soins palliatifs dépassent largement les soins terminaux



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preparing for the end of life

Dementia is a general term for the loss of memory, decision making and other mental abilities serious enough to interfere with daily life. Alzheimer's disease, the most common form of dementia, is a physical and terminal illness.

When a person with late-stage Alzheimer's nears the end of life and is no longer able to make decisions, families must make choices.

Ideally, the person with dementia has put in place advance directives to specify his or her wishes. Without such directives, or if certain issues have not been addressed, families must make decisions based on what they believe the person would want. End-of-life decisions should respect the person's values and wishes while maintaining comfort and dignity.



10 questions about end-of-life care what to ask the doctor

- 1 What is the treatment for?
- 2 How will it help?
- 3 What are the physical risks or discomforts?
- 4 What are the emotional risks or discomforts?
- 5 Does the treatment match what the person would have wanted?
- 6 Are we doing all we can to uphold dignity?
- 7 Are we doing all we can to give the person the best quality of life?
- 8 Is he or she in pain?
- 9 What can be done to ease the pain?
- 10 When is the best time to ask for hospice care?

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