



Journal Club  
**14 Ottobre 2016**  
*Aggiornamenti in geriatria*

# Il Piano Nazionale Demenze

**Marco Trabucchi**



**Il Piano Nazionale Demenze come importante strumento per valorizzare gli interventi più o meno spontanei degli ultimi anni e per renderli omogenei tra le regioni.**

**Il Piano Alzheimer della Regione Lombardia è del 1994!**



**Il Piano Nazionale Demenze come antidoto  
al diffuso disinteresse.**

**Lo “scandalo” del Piano Nazionale Cronicità  
che scorda le demenze.**



**Non è un libro dei sogni, ma una lettura  
delle potenzialità realistiche del sistema.**



**... l'impegno dei governi**



## The Lancet Neurology Commission

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### Defeating Alzheimer's disease and other dementias: a priority for European science and society



*Bengt Winblad, Philippe Amouyel, Sandrine Andrieu, Clive Ballard, Carol Brayne, Henry Brodaty, Angel Cedazo-Minguez, Bruno Dubois, David Edvardsson, Howard Feldman, Laura Fratiglioni, Giovanni B Frisoni, Serge Gauthier, Jean Georges, Caroline Graff, Khalid Iqbal, Frank Jessen, Gunilla Johansson, Linus Jönsson, Miia Kivipelto, Martin Knapp, Francesca Mangialasche, René Melis, Agneta Nordberg, Marcel Olde Rikkert, Chengxuan Qiu, Thomas P Sakmar, Philip Scheltens, Lon S Schneider, Reisa Sperling, Lars O Tjernberg, Gunhild Waldemar, Anders Wimo, Henrik Zetterberg*

**Lancet Neurol 2016; 15: 455–532**

# Piano Nazionale Demenze

Nuovi scenari di cura



# Psicogeriatría

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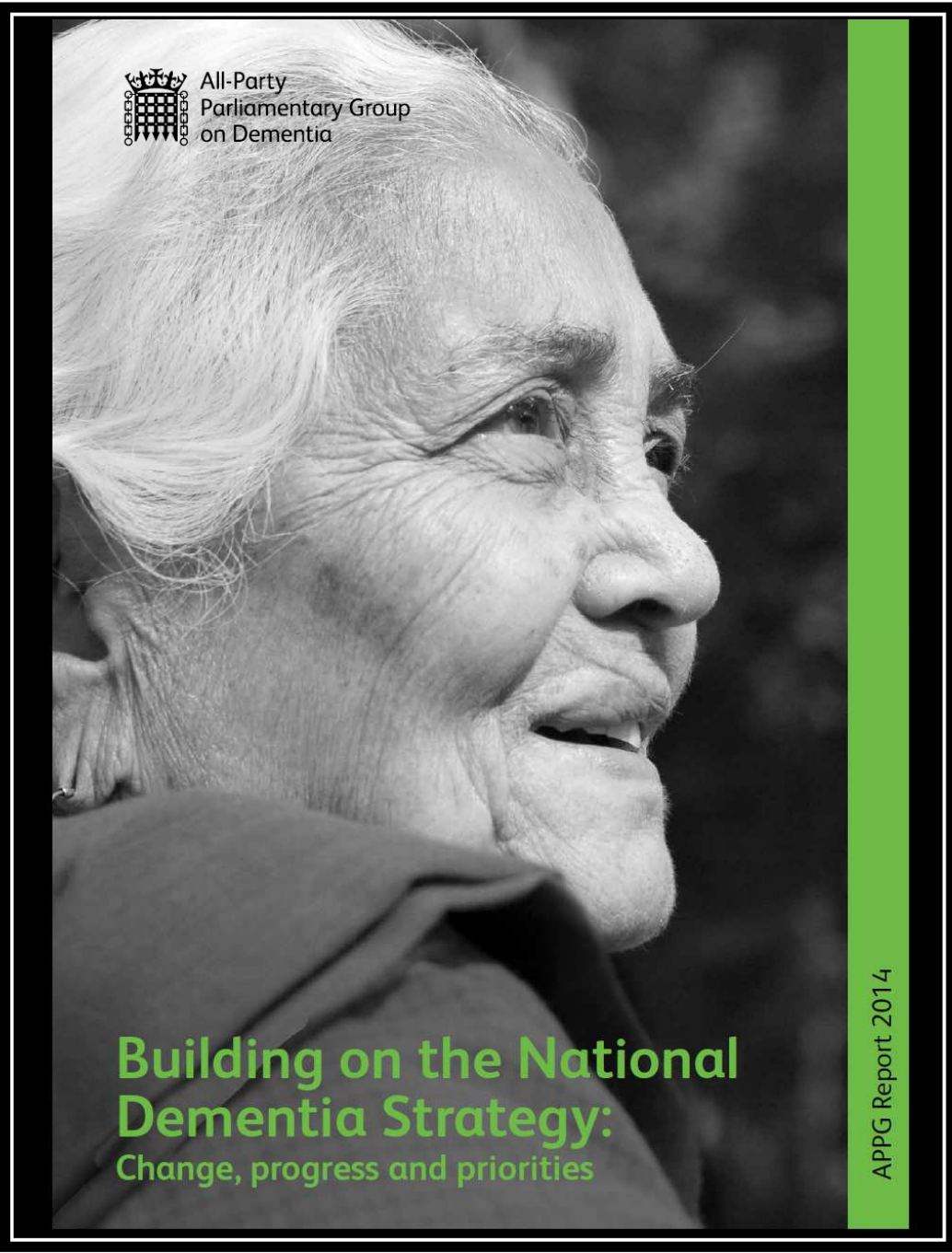
#### SUPPLEMENTO

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#### Rivista ufficiale



ASSOCIAZIONE  
 ITALIANA  
 PSICOGERIATRIA



All-Party  
Parliamentary Group  
on Dementia

**Building on the National  
Dementia Strategy:**  
Change, progress and priorities

APPG Report 2014







**Due percorsi sinergici:  
il Piano Nazionale Demenze, che indica  
alcuni percorsi per l'oggi in Italia e il 2025!**

# Alzheimer's disease

Philip Scheltens, Kaj Blennow, Monique M B Breteler, Bart de Strooper, Giovanni B Frisoni, Stephen Salloway, Wiesje Maria Van der Flier



## Panel 3: Diagnosis and management of early Alzheimer's disease in 2025

To make the postulated changes to the diagnosis and management of Alzheimer's disease a reality by 2025, lots of work is needed. The validity and cost-effectiveness of amyloid and tau imaging need to be shown. Ideally, less invasive and expensive methods will have been developed and become available, such as retinal amyloid imaging or a blood test. Hopefully, more and effective personalised lifestyle recommendations can be provided, perhaps on the basis of individual genetic and environmental characteristics (ie, a personalised risk profile). Effective treatments to reduce Alzheimer's disease burden are urgently needed. An era of discovery is underway to identify drugs targeting the key components of pathogenesis, neuritic plaques, neurofibrillary tangles, inflammation, and neurodegeneration. Open science and a broad alliance of scientific, clinical, public, and private sectors will be needed for treatment breakthroughs. Future treatment will probably involve a combination of two or more drugs with lifestyle and risk-reduction strategies. The development of combination treatments will necessitate adaptive trial designs with early readouts and important safety, dosing, regulatory, and intellectual property challenges will need to be overcome.<sup>141</sup> In 2025, treatment of Alzheimer's disease might have progressed to where some cancer treatments are now—ie, with diagnosis and management based on multimodal information that enables personalised treatment. Research is at a crucial tipping point, and a world in which Alzheimer's disease is a preventable and treatable condition could soon be a possibility.

(Lancet 388:505-517, 2016)

- **La famiglia che non nasconde**
- **MMG**
- **UVA**
- **Centri di alta specializzazione (?)**
- **ADI e centri diurni Alzheimer**
- **Ospedali per acuti**
- **Centri di riabilitazione**
- **Residenze (RSA, centri servizi, case di riposo, ecc.)**
- **Residenze “leggere”**
- **Hospice (?)**

# Servizi per le persone affette da demenza

## Criteri strutturali



- L'indifferibile costruzione di PDTA a livello di ASL (o di provincia) per garantire un supporto organizzativo adeguato
- La costruzione di una rete, in grado di gestire anche le prossime innovazioni cliniche (a cominciare dai nuovi ligandi PET)
- L'assoluta esigenza di defragmenting care
- Nuove esperienze, come il primary nursing, per superare l'attuale inadeguatezza dell'organizzazione degli ospedali e della medicina di famiglia



## **La cura in ospedale:**

**VMD e staging delle malattie, una linea di condotta stabile e la verifica periodica dei risultati, la contenzione, la prevenzione del delirium, l'attenzione alla dimissione.**

# LA PERSONA AFFETTA DA DEMENTIA IN OSPEDALE

Marco Trabucchi

Carocci **Faber** (2007)

LE PROFESSIONI SANITARIE





**La cura nelle residenze per anziani:  
dai nuclei Alzheimer alla sensibilità diffusa  
per una prevalenza di demenza del 60-70%.**

## Prospective Observations of Discomfort, Pain, and Dyspnea in Nursing Home Residents With Dementia and Pneumonia



Tessa van der Maaden MSc<sup>a,b</sup>, Jenny T. van der Steen PhD<sup>a,b,\*</sup>,  
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### ABSTRACT

**Keywords:**

Nursing homes  
dementia  
pneumonia  
discomfort  
suffering  
observation

**Objectives:** To describe observations of suffering in patients with dementia from the diagnosis of pneumonia until cure or death.

**Design:** Prospective observational study between January 2012 and May 2014.

**Setting:** Dutch nursing homes (32).

**Participants:** Nursing home patients with dementia and pneumonia (n = 193).

**Measurements:** Independent observers performed observations of patients with dementia scheduled 13 times within the 15 days following diagnosis of pneumonia; twice daily in the first 2 days— to observe discomfort (Discomfort Scale—Dementia of Alzheimer Type; range 0–27), comfort (End Of Life in Dementia—Comfort Assessment in Dying; range 14–42), pain (Pain Assessment in Advanced Dementia; range 0–10), and dyspnea (Respiratory Distress Observation Scale; range 0–16).

**Results:** Observational data were obtained for 208 cases of pneumonia in 193 patients. In 71.2% of cases, patients received 1 or more treatments to relieve symptoms such as antipyretics, opioids, or oxygen; 89.4% received antibiotics. Discomfort was highest 1 day after diagnosis [mean Discomfort Scale—Dementia of Alzheimer Type score 8.1 (standard deviation, SD 5.8)], then declined, and stabilized around day 10 [mean 4.5 (SD 4.1)], or increased in the days preceding death. Observed pain and dyspnea followed a comparable pattern. Discomfort patterns did not differ much between cases treated with and without antibiotics.

**Conclusions:** Pneumonia in patients with dementia involved elevated levels of suffering during 10 days following diagnosis and in the days preceding death. Overall observed discomfort was low compared with prior Dutch studies, and the number of treatments to relieve symptoms was higher. Future studies should examine whether symptoms of pneumonia can be relieved even more, and what treatments are the most effective.

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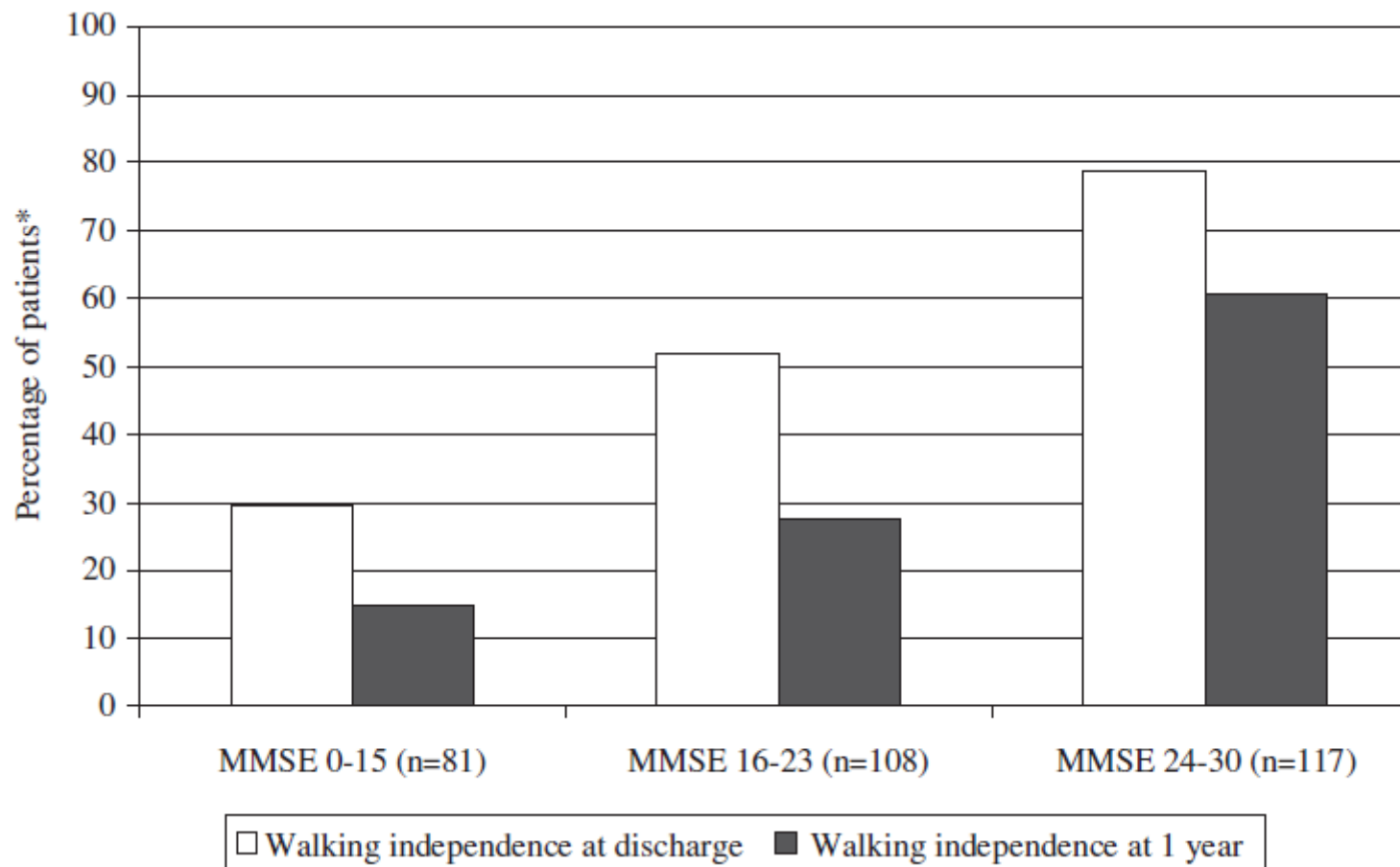


Alzheimer Caffè:  
la **ricchezza**  
di una  
**esperienza** | 2012



**La riabilitazione motoria della persona affetta da demenza: una realtà troppo diffusa di ignoranza e di desolazione.**

## Percentage of participants with walking independence at discharge and at 1 year according to Mini-Mental State Examination (MMSE) score (range 0–30)

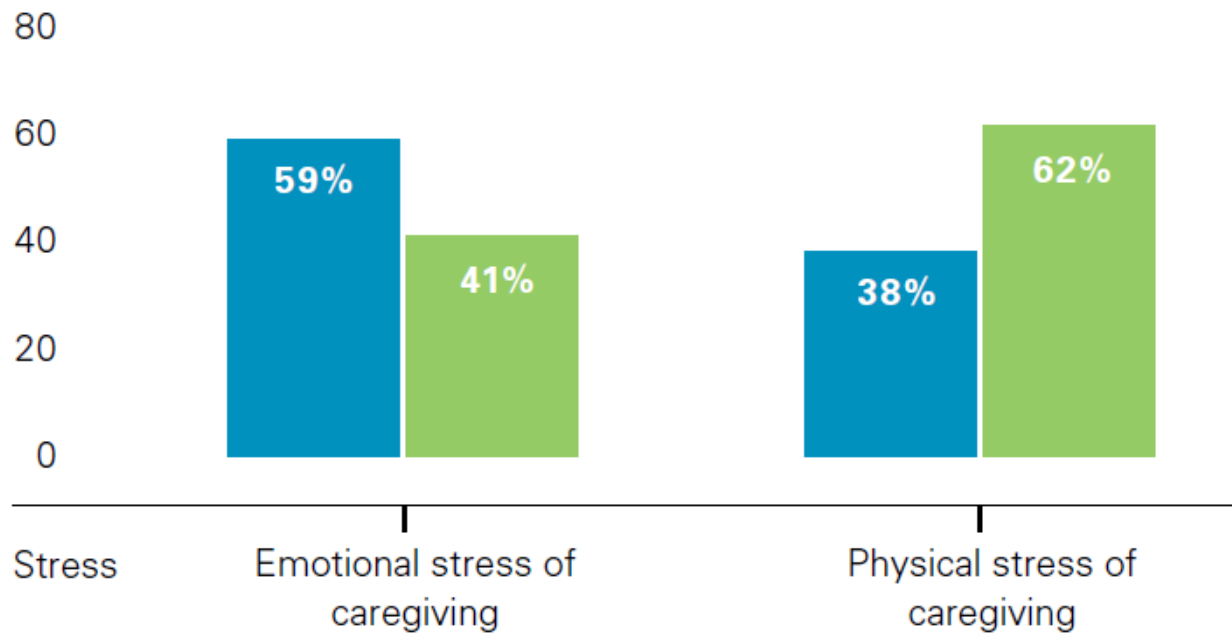




## La centralità del caregiver e l'alleanza con il MMG

## Proportion of Alzheimer's and Dementia Caregivers Who Report High or Very High Emotional and Physical Stress Due to Caregiving

Percentage ■ High to very high ■ Not high to somewhat high



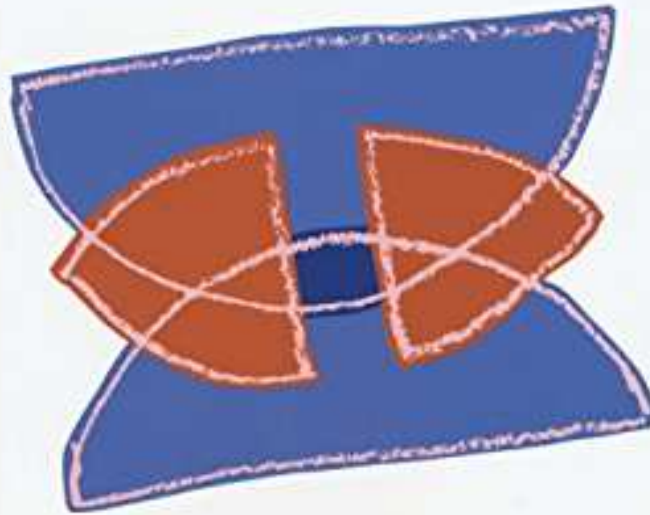
Created from data from the Alzheimer's Association.<sup>A16</sup>



# Le buone pratiche per l'Alzheimer

Strategie assistenziali per operatori coraggiosi

Luisa Bartorelli



Carocci Faber

2015



**Dal 1999 al 2015 l'età media dei malati assistiti a casa è passata da 73,6 anni a 78,8; quella dei loro caregiver da 53,3 anni a 59,2. Inoltre è aumentata la condizione di solitudine della diade paziente-caregiver, che è passata da 23% al 30%.**

(Censis, 2016)



## **The lethality of loneliness**





## **Ruolo del medico di famiglia e le sue risposte a domande angoscianti.**



# Association of Mild Cognitive Impairment With Exposure to General Anesthesia for Surgical and Nonsurgical Procedures: A Population-Based Study



Juraj Sprung, MD, PhD; Rosebud O. Roberts, MB ChB, MS; David S. Knopman, MD; Diana M. Olive, CRNA; Jennie L. Gappa, CRNA; Valerie L. Sifuentes, CRNA; Travis L. Behrend, MD; Joel D. Farmer, MD; Toby N. Weingarten, MD; Andrew C. Hanson, BS; Darrell R. Schroeder, MS; Ronald C. Petersen, MD, PhD; and David O. Warner, MD

## Abstract

**Objective:** To examine whether exposure to general anesthesia for operations and procedures after the age of 40 years is associated with incident mild cognitive impairment (MCI) in elderly patients.

**Patients and Methods:** A population-based, prospective cohort of Olmsted County, Minnesota, residents aged 70 to 89 years at enrollment, underwent baseline and 15-month interval evaluations that included the Clinical Dementia Rating scale, a neurologic evaluation, and neuropsychological testing. Anesthesia records after the age of 40 years until last evaluation for MCI were abstracted. Proportional hazards regression, adjusting for other known MCI risk factors, was used to assess whether exposure to surgical general anesthesia after the age of 40 years is associated with the incidence of MCI.

**Results:** Of 1731 participants (mean age, 79 years), 536 (31.0%) developed MCI during a median follow-up of 4.8 years. Anesthesia exposure was not associated with MCI when analyzed as a dichotomous variable (any vs none; adjusted hazard ratio [HR], 1.07; 95% CI, 0.83-1.37;  $P=.61$ ), the number of exposures (adjusted HR, 1.05; 95% CI, 0.78-1.42; adjusted HR, 1.12; 95% CI, 0.86-1.47; and adjusted HR, 1.02; 95% CI, 0.76-1.34, for 1, 2-3, and  $\geq 4$  exposures compared with no exposure as the reference;  $P=.73$ ), or the total cumulative duration of exposure (adjusted HR, 1.00; 95% CI, 0.98-1.01, per 60-minute increase;  $P=.83$ ). In secondary sensitivity analyses, anesthesia after 60 years of age was associated with incident MCI (adjusted HR, 1.25; 95% CI, 1.02-1.55;  $P=.04$ ), as was exposure in the previous 20 and 10 years.

**Conclusion:** We found no significant association between cumulative exposure to surgical anesthesia after 40 years of age and MCI. However, these data do not exclude the possibility that anesthetic exposures occurring later in life may be associated with an increase in the rate of incident MCI.

## **Corriere.it/salute**

### Vivere con il web

a cura di **Daniela Natali**

#### **Neurologia**

QUANTO PESA L'EREDITARIETÀ  
NELLO SVILUPPO DELL'ALZHEIMER?  
E IL RISCHIO SI PUÒ RIDURRE?



**Le decisioni difficili: la badante, l'allocazione in CdR,  
le decisioni terapeutiche nelle fasi avanzate...  
Centralità del supporto alla famiglia.**

# Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014

Scott Y. H. Kim, MD, PhD; Raymond G. De Vries, PhD; John R. Peteet, MD



**IMPORTANCE** Euthanasia or assisted suicide (EAS) of psychiatric patients is increasing in some jurisdictions such as Belgium and the Netherlands. However, little is known about the practice, and it remains controversial.

**OBJECTIVES** To describe the characteristics of patients receiving EAS for psychiatric conditions and how the practice is regulated in the Netherlands.

**DESIGN, SETTING, AND PARTICIPANTS** This investigation reviewed psychiatric EAS case summaries made available online by the Dutch regional euthanasia review committees as of June 1, 2015. Two senior psychiatrists used directed content analysis to review and code the reports. In total, 66 cases from 2011 to 2014 were reviewed.

**MAIN OUTCOMES AND MEASURES** Clinical and social characteristics of patients, physician review process of the patients' requests, and the euthanasia review committees' assessments of the physicians' actions.

**RESULTS** Of the 66 cases reviewed, 70% (n = 46) were women. In total, 32% (n = 21) were 70 years or older, 44% (n = 29) were 50 to 70 years old, and 24% (n = 16) were 30 to 50 years old. Most had chronic, severe conditions, with histories of attempted suicides and psychiatric hospitalizations. Most had personality disorders and were described as socially isolated or lonely. Depressive disorders were the primary psychiatric issue in 55% (n = 36) of cases. Other conditions represented were psychotic, posttraumatic stress or anxiety, somatoform, neurocognitive, and eating disorders, as well as prolonged grief and autism. Comorbidities with functional impairments were common. Forty-one percent (n = 27) of physicians performing EAS were psychiatrists. Twenty-seven percent (n = 18) of patients received the procedure from physicians new to them, 14 of whom were physicians from the End-of-Life Clinic, a mobile euthanasia clinic. Consultation with other physicians was extensive, but 11% (n = 7) of cases had no independent psychiatric input, and 24% (n = 16) of cases involved disagreement among consultants. The euthanasia review committees found that one case failed to meet legal due care criteria.

**CONCLUSIONS AND RELEVANCE** Persons receiving EAS for psychiatric disorders in the Netherlands are mostly women and of diverse ages, with complex and chronic psychiatric, medical, and psychosocial histories. The granting of their EAS requests appears to involve considerable physician judgment, usually involving multiple physicians who do not always agree (sometimes without independent psychiatric input), but the euthanasia review committees generally defer to the judgments of the physicians performing the EAS.

*JAMA Psychiatry*. doi:10.1001/jamapsychiatry.2015.2887

Published online February 10, 2016.



**... ma anche a domande sulla routine assistenziale di tutti i giorni (alimentazione, idratazione, farmaci, mobilizzazione, prevenzione decubiti, sonno, ecc.).**



## **I problemi economici e le incertezze del futuro**

## Panel 6: Formal resources to include in economic assessments of dementia care

- Formal care
- Living situation (at home or in institutions)
- Respite care
- Home social-care visits
- Home medical-care visits
- Home rehabilitation-care visits
- Visits to clinics: physician specialists
- Visits to clinics: general practitioner specialists (or similar)
- Visits to clinics: registered nurses (or similar)
- Visits to clinics: rehabilitation (similar)
- Hospital care (various specialities and departments)
- Day hospital care (eg, day surgery)
- Day care (special care for dementia)
- Day care (not specifically for dementia)
- Use of drugs
- Technical devices and equipment
- Food support (eg, meals on wheels)
- Transport services

(Winblad B. et al,  
Lancet Neurol 15:455-  
532, 2016)





**Il carattere estremo, forse estremista, di quel che sta avvenendo (l'exasperazione soggettivistica della cura e il pericolo di un blocco finanziario ad essa) ripropongono sotto sotto un problema millenario, quasi di civiltà della vita comune: vale di più l'esistenza di un singolo o l'esigenza di gestire con razionalità e magari con durezza le innovazioni che si vanno imponendo? Non è polemico a tale proposito far notare che un servizio sanitario che dichiara di non potersi far carico di un farmaco pur costosissimo e personalizzato obbedisce in fondo al suo mandato istituzionale quello della "universalizzazione" della cura più che della sua "personalizzazione".**

**E nei fatti esprime anch'esso un valore sociale profondo (la fedeltà a un servizio universale) e non di seconda qualità rispetto alle attese ed ai bisogni di essere dei malati.**

**Inglobare in tale fedeltà istituzionale una personalizzazione di farmaci finanziariamente insostenibili, richiederà una complessa elaborazione culturale che oggi non è ancora matura, e su cui, oltre al confronto fra innovatori industriali e regolatori pubblici, dovrà prendere corpo una continua tensione a decifrare bisogni e interessi da parte di tutto il mondo dei malati, dei loro care-givers, delle famiglie, dell'associazionismo sanitario.**



**Un Piano non è automaticamente sufficiente per rinnovare le cure rivolte alle persone affette da demenza, ma è un punto di partenza di grande significato, perché richiama la responsabilità dei decisori e comunica alle famiglie un impegno diffuso.**



**La demenza non cancella la persona:  
è un'affermazione indispensabile per motivi etici,  
ma anche organizzativi nel tempo della riduzione  
dei finanziamenti alle malattie croniche.**



**La Zeller ha scoperto, cioè, che tutti i gesti incompiuti, le frasi mozze, le incongruenze, le follie di questa sua prediletta ammalata, erano frammenti della sua biografia, riportavano alla mente schegge di episodi remoti, con cui rivelavano di avere una connessione resa quasi invisibile dalla patina del tempo, dai vissuti successivi, dall'affollarsi delle rimozioni. E la Zeller è colpita, fin dagli inizi, da una sorta di rivelazione: crede che sia possibile, con gli strumenti adatti (non solo tecnici, ma soprattutto umani) e con una dedizione passionale, ricostruire il senso e la continuità della storia di sua madre, ricompattare l'unità della sua persona sconvolta (ma non distrutta) dalla malattia, accompagnarla non solo lungo il tragitto della sofferenza, ma fino alle soglie dell'oltre, della vita che non conosce fine” (in *Servitium*, n. 163, p. 144).**

(Farina M., *Psicogeriatrica* 2:28-32, 2016)



**Una storia di piccoli progressi che ha portato negli ultimi 15 anni ad un reale miglioramento delle condizioni di vita delle persone affette da una demenza.**