Calo ponderale e nutrizione nella demenza: la nutrizione artificiale tra etica e necessità

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Dementia – Facts and numbers

• Dementia is a leading cause of death in the US, with mortality affected by aspiration, dehydration, and poor nutritional status.

• In the year 2000 there were approximately 4.5 million people in North America with a diagnosis of dementia, and more than half progressed to the moderate to severe stages of their disease.

• In 2001 there were 24.3 million people in the world with dementia, and by 2040, the number is estimated to increase to over 81 million.

• The prevalence of dementia is estimated to double every 5 years after 65 years old, and at age 85 years, the prevalence is approximately 50%.1,2

Adapted from: Goldberg LS and Altman KW, 2015
Nutritional issues in dementia

- Nutritional problems are part of the disease, putting persons with dementia at high risk of developing malnutrition.

- Malnutrition is clearly associated with poor outcome and contributes to disease progression.

- It also increases caregiver burden, which in turn may aggravate nutritional problems.

Nutritional problems arising in different disease stages.

<table>
<thead>
<tr>
<th>Nutritional problems</th>
<th>Stage of dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Olfactory and taste dysfunction</td>
<td>Preclinical and early stages</td>
</tr>
<tr>
<td>Attention deficit</td>
<td>Mild to moderate</td>
</tr>
<tr>
<td>Executive functions deficit (shopping, preparing food)</td>
<td>Mild to moderate</td>
</tr>
<tr>
<td>Impaired decision-making ability (slowdown in food choice, reduced intake)</td>
<td>Mild to moderate</td>
</tr>
<tr>
<td>Dyspraxia(^a)</td>
<td>Moderate to severe</td>
</tr>
<tr>
<td>Agnosia(^b)</td>
<td>Moderate to severe</td>
</tr>
<tr>
<td>Behavioral problems (wandering, agitation, disturbed eating behavior)</td>
<td>Moderate to severe</td>
</tr>
<tr>
<td>Oropharyngeal dysphagia</td>
<td>Moderate to severe</td>
</tr>
<tr>
<td>Refusal to eat</td>
<td>Severe</td>
</tr>
</tbody>
</table>

\(^a\) Coordination disorder, loss of eating skills.

\(^b\) Loss of ability to recognize objects or comprehend the meaning of objects, which means that food may not be distinguished from non-food and that eating utensils are not recognized as what they are.
Low BMI is a negative prognostic factor in Dementia

- Low BMI is associated with reduced survival and older patients with dementia may benefit from higher BMIs \([1,2]\).

- Higher BMI is associated with a decreased risk of mortality, with all higher BMI categories showing reduced risk relative to patients with BMI 18.5-22.9 and excess risk in those with BMI <18.5 \([3]\)

- In nursing homes residents with advanced dementia, eating problems (which developed in 86% over a period of 18 months) were highly predictive for 6-months mortality \([4]\).

The vicious circle of malnutrition and Dementia

- Frailty
- Sarcopenia
- Dementia
  - Cognitive impairment
- Age-related changes and diseases
- Weight loss
  - Nutritional deficiencies
- Intake ↓
  - Requirements ↑

Dalla alimentazione naturale alla nutrizione artificiale: flow-chart decisionale

**Alimentazione naturale**

Se non sufficiente

**Indicazioni nutrizionali**

Se non sufficienti

**Supplementazione nutrizionale**

Se non possibili la nutrizione per os

**Nutrizione enterale per sonda**

Con apparato digerente non “funzionante”

**Nutrizione parenterale**

**Stato di coscienza conservato**

**Stato di coscienza compromesso o assente**
...dalla capacità di alimentarsi alla necessità di essere nutriti...
La nutrizione artificiale è un complesso di procedure mediante le quali è possibile soddisfare i fabbisogni nutrizionali di pazienti non in grado di alimentarsi sufficientemente per via naturale.

La nutrizione artificiale si differenzia in:

- Nutrizione parenterale
- Nutrizione enterale

In ospedale, a domicilio, nelle residenze asistenziali
Nutrizione artificiale

• Fornisce nutrienti per via artificiale
• Risponde ad esigenze di patologie
• I nutrienti sono i componenti chimici degli alimenti
• Una miscela nutrizionale di norma contiene tutti i nutrienti
• Richiede il consenso informato del paziente e l’intervento del farmacista
INDICAZIONI PIÙ FREQUENTI

• Disordini neurologici (post-CVA, degenerativi)
• Disfagie ostruttive e funzionali
• Sindrome dell’ intestino corto (IICB)
• Pseudo-ostruzione intestinale cronica
• Patologie d’ organo con insufficiente o nullo apporto nutrizionale per os
• Pazienti neoplastici in fase avanzata
Precisazioni in merito alle implicazioni bioetiche della nutrizione artificiale

Documento elaborato dal Consiglio Direttivo* e dalla Commissione di Bioetica** della Società Italiana di Nutrizione Parenterale ed Enterale (SINPE)

Il presente documento è stato approvato all’unanimità dal Consiglio Direttivo SINPE nella seduta del 10 gennaio 2007

* Consiglio Direttivo SINPE 2006-2008 (Presidente: Prof. Maurizio Muscaritoli – Consiglieri: Roberto Biffi, Gianni Biolo, Pietro Carideo, Daniela Crispoldi, Sabrina De Leo, Etta Finocchiaro, Antonello Giannoni, Paolo Orlandoni, Sergio Pastò, Mauro Pittiruti, Danilo Radrizzani, Giancarlo Sandri, Romano Tetamo)

** Commissione di Bioetica (Presidente: Prof. Franco Contaldo; Membri: Federico Bozzetti, Pietro Carideo, Manuela Gambarara, Francesco W. Guglielmi, Agostino Paccagnella, Romano Tetamo, Gabriele Toigo)
Nutrizione Artificiale: “terapia” o “assistenza”? 
La NA può avere un ruolo sia preventivo sia terapeutico (prevenzione della malnutrizione o terapia di una malnutrizione già instaurata).

Come gli altri trattamenti sostitutivi, la NA costituisce un trattamento medico: soltanto il medico può infatti stabilirne in modo corretto indicazioni e controindicazioni.

Come per qualunque trattamento medico l’inizio o l’astensione, così come la continuazione o la sospensione della NA, ricadono nell’ambito decisionale o di responsabilità del medico, fatto salvo quanto riconosciuto dal codice deontologico al malato (o al tutore legale) nell’esercitare il diritto al consenso e all’autodeterminazione.
Artificial Nutrition at the Bioethic cross-road between Treatment and Basic Health Care

- Basic Health Care should never be confused with the prescription of established -Artificial Nutrition-Treatment
- In the difficult bioethical debate, we have to reinforce the scientific and cultural contribution acquired through our clinical practice more than refer to other practices / disciplines for the definition of acceptable ethical conducts

(Contaldo et al., Clin Nutr, 2005)
Ethical and legal issues: practice guidelines

• Legally and ethically, specialized nutrition support (SNS) should be considered a medical therapy. (A)
• Care providers should be familiar with current evidence of the benefits and burdens of SNS. (C)
• Patients should be encouraged to have living wills and/or advance directives and to discuss with their loved ones their wishes in the event of a serious or terminal accident or diseases. (C)
“Da un punto di vista etico e legale, la nutrizione artificiale deve essere considerata un atto medico”
“Fluid or food given by tube enterally or parenterally is legally medical treatment and not basic care”

S. Allison in “ESPEN Basics in Clinical Nutrition, 2005
Since 1990, when the Supreme Court ruled on the Nancy Cruzan case, artificial feeding was deemed to be “medical therapy” and, like any other medical therapy, could be started and stopped based on a person’s wishes and values.¹

¹ Orentlicher D. JAMA 1989
Artificial feeding (nutrition): a medical treatment

Since 1990, when the Supreme Court ruled on the Nancy Cruzan case, artificial feeding was deemed to be “medical therapy” and, like any other medical therapy, could be started and stopped based on a person’s wishes and values.¹

¹Orentlicher D. JAMA 1989
FROM THE ACADEMY
Position Paper

Position of the Academy of Nutrition and Dietetics: Ethical and Legal Issues in Feeding and Hydration

POSITION STATEMENT

It is the position of the Academy of Nutrition and Dietetics that individuals have the right to request or refuse nutrition and hydration as medical treatment. Registered dietitians should work collaboratively as part of the interprofessional team to make recommendations on providing, withdrawing, or withholding nutrition and hydration in individual cases and serve as active members of institutional ethics committees.
La NA non è da considerarsi una terapia eziologica: la NA non è infatti in grado di influire sulle cause di una malattia, ma al più sulle sue conseguenze, ad esempio prevenendo o trattando la malnutrizione oppure riducendo gli effetti negativi dell’ipercretabolismo.

Anche se talvolta in grado di alleviare sintomi quali la fame e la sete la NA non è da considerarsi una terapia sintomatica.
LA NUTRIZIONE ARTIFICIALE E’ UN TRATTAMENTO MEDICO

• La NA è da considerarsi, a tutti gli effetti, un trattamento medico fornito a scopo terapeutico o preventivo.

• La NA non è una misura ordinaria di assistenza (come lavare o imboccare il malato non autosufficiente)
La NA si configura come un trattamento sostitutivo (come ad esempio la ventilazione meccanica o la emodialisi), in altre parole un trattamento che tende a sostituire in modo temporaneo o permanente il deficit di un organo o di un apparato.

In tal senso la NA si sostituisce, in maniera temporanea o permanente al deficit di una funzione complessa come quella della alimentazione naturale, quando questa è compromessa in tutto o in parte da una sottostante condizione di malattia.
• Come per altri trattamenti sostitutivi (ad esempio la ventilazione meccanica) in alcune situazioni cliniche la NA può essere l’unico o uno dei trattamenti necessari per mantenere il malato in vita.

• In questi casi la sospensione (*withdrawing*) o la non attuazione (*withholding*) della NA comporta l’exitus del malato.
Clinical Nutrition

Contents lists available at ScienceDirect

journal homepage: http://www.elsevier.com/locate/clnu

e-SPEN guideline

ESPEN guidelines on nutrition in dementia

Dorothee Volkert a, *, Michael Chourdakis b, Gerd Faxen-Irving c, Thomas Frühwald d, Francesco Landi e, Merja H. Suominen f, Maurits Vandewoude g, Rainer Wirth a, h, Stéphane M. Schneider i
Nutritional recommendations in dementia - 1

1. We recommend screening every person with dementia for malnutrition. In case of positive screening, assessment has to follow. In case of positive assessment, adequate interventions have to follow.

2. We recommend close monitoring and documentation of body weight in every person with dementia.

3. We recommend provision of meals in a pleasant, homelike atmosphere.

4. We recommend provision of adequate food according to individual needs with respect to personal preferences.

5. We recommend to encourage adequate food intake and to provide adequate support.

6. We do not recommend the systematic use of appetite stimulants.

7. We recommend educating caregivers to ensure basic knowledge on nutritional problems related to dementia and possible strategies to intervene.

8. We recommend elimination of potential causes of malnutrition as far as possible.

9. We recommend avoiding dietary restrictions.

10a. We do not recommend the use of omega-3-fatty acid supplements in persons with dementia for correction of cognitive impairment or prevention of further cognitive decline.

10b. We do not recommend the use of vitamin B1 supplements in persons with dementia for prevention or correction of cognitive decline when there is no indication of vitamin B1 deficiency.

10c. We do not recommend the use of vitamin B6, vitamin B12 and/or folic acid supplements in persons with dementia for prevention or correction of cognitive decline when there is no indication of vitamin B6, vitamin B12 and/or folic acid deficiency.

10d. We do not recommend the use of vitamin E supplements in persons with dementia for prevention or correction of cognitive decline.
Nutritional recommendations in dementia - 2

10e. We do not recommend the use of selenium supplements for prevention or correction of cognitive decline.
10f. We do not recommend the use of copper supplements for prevention or correction of cognitive decline.
10g. We do not recommend the use of vitamin D supplements for prevention or correction of cognitive decline.
11. We recommend the use of ONS to improve nutritional status.
12. We do not recommend the use of ONS in persons with dementia to correct cognitive impairment or prevent further cognitive decline.
13. We do not recommend the systematic use of special medical foods for persons with dementia to correct cognitive impairment or prevent further cognitive decline.
14. We do not recommend any other nutritional product for persons with dementia to correct cognitive impairment or prevent further cognitive decline.
15. We recommend that each decision for or against artificial nutrition and hydration for patients with dementia is made on an individual basis with respect to general prognosis and patients' preferences.
16. We suggest tube feeding for a limited period of time in patients with mild or moderate dementia, to overcome a crisis situation with markedly insufficient oral intake, if low nutritional intake is predominantly caused by a potentially reversible condition.
17. We recommend against the initiation of tube feeding in patients with severe dementia.
18. We suggest parenteral nutrition as an alternative if there is an indication for artificial nutrition, as described in recommendation 16, but tube feeding is contraindicated or not tolerated.
19. We suggest parenteral fluids for a limited period of time in periods of insufficient fluid intake to overcome a crisis situation.
20. We recommend against the use of artificial nutrition (enteral nutrition, parenteral nutrition and parenteral fluids) in the terminal phase of life.
Enteral tube feeding in older people with advanced dementia: Findings from a Cochrane systematic review

Bridget Candy, Elizabeth L Sampson, Louise Jones

Abstract

**Aim:** Enteral tube feeding for people with advanced dementia who have difficulty swallowing and poor nutritional intake is common. Potential benefits or harms of this practice are unclear and the authors aimed to evaluate the outcomes of this intervention. **Methods:** A full literature review was undertaken in April 2008. Randomized controlled trials (RCTs), controlled clinical trials, controlled before and after studies, interrupted time series studies and controlled observational studies that evaluated the effectiveness of enteral feeding via a nasogastric tube or via a tube passed by percutaneous endoscopic gastrostomy were selected. The study population comprised adults aged 50 and over with a diagnosis of advanced primary degenerative dementia who had poor nutritional intake and/or developed problems with eating and swallowing. The primary outcomes were survival and quality of life (QOL). **Results:** No RCTs were identified. Seven observational controlled studies were found; six assessed mortality. There was no evidence of increased survival in people with dementia receiving enteral tube feeding. The other study assessed nutritional outcomes. None of the studies examined the effect on QOL and there was no evidence of benefit in terms of nutritional status or the prevalence of pressure ulcers. **Conclusions:** There is insufficient evidence to suggest that enteral tube feeding is beneficial in people with advanced dementia. Data is lacking on the adverse effects of this intervention.

**Key words:** Artificial nutrition ● Dementia ● Feeding ● Nasogastric tube ● Percutaneous endoscopic gastrostomy
Survival Analysis in Patients Affected by Chronic Neurological Disorders in Home Enteral Nutrition (HEN)


Dietetic and Clinical Nutrition, San Giovanni Battista Hospital, Turin, Italy

<table>
<thead>
<tr>
<th>Disease n pt</th>
<th>3 m (%)</th>
<th>6 m (%)</th>
<th>12 m (%)</th>
<th>24 m (%)</th>
<th>36 m (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALS 116</td>
<td>74</td>
<td>61</td>
<td>42</td>
<td>27</td>
<td>14</td>
</tr>
<tr>
<td>CVA 368</td>
<td>60</td>
<td>50</td>
<td>43</td>
<td>29</td>
<td>16</td>
</tr>
<tr>
<td>DEM 155</td>
<td>73</td>
<td>63</td>
<td>52</td>
<td>42</td>
<td>40</td>
</tr>
</tbody>
</table>
Survival in older adults with dementia and eating problems: To PEG or not to PEG?

Andrea Ticinesi a, b, *, Antonio Nouvenne a, b, Fulvio Lauretani b, Beatrice Prati a, b, Nicoletta Cerundolo a, b, Marcello Maggio a, c, Tiziana Meschi a, b

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c Geriatrics Clinic, Geriatric-Rehabilitation Department, Parma University Hospital (Azienda Ospedaliero-Universitaria di Parma), Parma, Italy
Table 1
General characteristics of the study population (n = 184 patients), categorized according to the main outcome (survival vs death) after an average follow-up of 18 months.

<table>
<thead>
<tr>
<th></th>
<th>All (N = 184)</th>
<th>Survivors (N = 94)</th>
<th>Dead (N = 90)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years), mean ± SD</td>
<td>82.2 ± 7.7</td>
<td>80.6 ± 7.6</td>
<td>84.0 ± 7.5</td>
</tr>
<tr>
<td>Women, n (%)</td>
<td>126 (68.5)</td>
<td>60 (64.5)</td>
<td>63 (70.8)</td>
</tr>
<tr>
<td>Types of dementia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer disease, n (%)</td>
<td>102 (55.4)</td>
<td>47 (50.5)</td>
<td>55 (61.8)</td>
</tr>
<tr>
<td>Mixed, n (%)</td>
<td>59 (32.0)</td>
<td>32 (34.3)</td>
<td>26 (28.1)</td>
</tr>
<tr>
<td>Parkinson dementia, n (%)</td>
<td>11 (6.0)</td>
<td>6 (6.5)</td>
<td>5 (5.6)</td>
</tr>
<tr>
<td>Vascular dementia, n (%)</td>
<td>10 (5.4)</td>
<td>6 (6.5)</td>
<td>4 (4.5)</td>
</tr>
<tr>
<td>Lewy body dementia, n (%)</td>
<td>1 (0.6)</td>
<td>1 (1.1)</td>
<td>–</td>
</tr>
<tr>
<td>Other, n (%)</td>
<td>1 (0.6)</td>
<td>1 (1.1)</td>
<td>–</td>
</tr>
<tr>
<td>PEG insertion, n (%)</td>
<td>54 (29.6)</td>
<td>14 (15.0)</td>
<td>36 (40.0)</td>
</tr>
<tr>
<td>Discharged to community, n (%)</td>
<td>88 (48)</td>
<td>53 (56.8)</td>
<td>35 (38.6)</td>
</tr>
<tr>
<td>Discharged to nursing home, n (%)</td>
<td>96 (52)</td>
<td>41 (44.2)</td>
<td>55 (61.4)</td>
</tr>
</tbody>
</table>
Survival Distribution Function

Patients without PEG

Patients with PEG

Log-Rank 17.2590; P = <.0001

Follow-up (years)
<table>
<thead>
<tr>
<th>NE &amp; Demenza - Periodo 2012-2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Totale pazienti</td>
</tr>
<tr>
<td>Età media all’attivazione</td>
</tr>
<tr>
<td>Età range</td>
</tr>
<tr>
<td>Media gg trattamento</td>
</tr>
<tr>
<td>Mediana gg trattamento</td>
</tr>
<tr>
<td>Range gg trattamento</td>
</tr>
<tr>
<td>Deceduti</td>
</tr>
<tr>
<td>Sopravviventi</td>
</tr>
</tbody>
</table>

Nutrizione Clinica Policlinico Umberto I Roma
Conclusioni

• Tutte le forme di demenza hanno un impatto negativo sullo stato di idratazione e nutrizione
• La sorveglianza nutrizionale va effettuata in tutti i pazienti ed in tutte le fasi della demenza
• Le alterazioni nutrizionali hanno un effetto negativo sulla sopravvivenza
• La nutrizione artificiale (NA) è un trattamento medico mediante il quale possono essere soddisfatti i fabbisogni metabolici e nutrizionali nella demenza
• L’utilità o futilità della NA nei pazienti affetti da demenza è motivo di discussione e suscita non pochi interrogativi medici ed etici, tuttora senza risposta.