

WHICH HYDRATION AND NUTRITION FOR ADVANCED DEMENTIA PATIENTS? REASONS FOR CONSIDERING PEG AN OVER TREATMENT FOLLOWING THE OVER DIAGNOSIS OF MALNUTRITION

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Data are controversial and evidence is insufficient to suggest PEG (percutaneous endoscopic gastrostomy) as beneficial in dementia patients¹. In clinical trials adverse effects are not regularly reported though they are various and affect patients' quality of life². The lack of beneficial effects could be attributed to disease progression itself³ and the usual trial outcome (survival days) may not be considered coincident with the patients' main interest⁴.

In Choosing Wisely⁵ the recommendation for avoiding PEG in advanced dementia patients is reported by three different medical societies: the American Academy of Hospice and Palliative Medicine, the American Geriatrics Society and the AMDA – Dedicated to Long Term Care Medicine™.

In the Italian protocol "Fare di più non significa fare meglio" (Doing more does not mean doing better)⁶, the recommendation to avoid PEG lacking evidence-based advantages has been proposed by the Italian Association of Dietetics and Clinical Nutrition (ADI, *Associazione Italiana di Dietetica e Nutrizione Clinica*), considering advanced dementia and cancer in the terminal phase paradigmatic conditions.

The same recommendation in advanced dementia is reported by the Cochrane Neurological Field, suggesting that oral feeding could be a better choice for patient comfort⁷.

Non prescrivere la nutrizione artificiale enterale (PEG, Percutaneous Endoscopic Gastrostomy, o sonda naso-gastrica) ai pazienti affetti da demenza in fase avanzata, ma contribuire a favorire l'alimentazione fisiologica assistita.

(Translated from the American Academy of Hospice and Palliative Medicine, American Geriatrics Society, AMDA – Dedicated to Long Term Care Medicine™)

Don't recommend Enteral Artificial Nutrition through Percutaneous Endoscopic Gastrostomy (PEG) or nasogastric tube in patients with advanced dementia; instead, offer oral assisted feeding.

The following issues have been the object of discussion among different specialty physicians and bioethics scholars involved in this recommendation; a clear identification of these issues may be useful in discussing options with the patient during the early phase of disease (i.e. considering advance directives) or with the family and the proxy in the advanced phase.

1. Is the care-giver aware of dysphagia for liquid intake that is common in the advanced phase of dementia?

In our clinical experience this is not a common subject of information for the care-giver. Thickening food is a usual way to help in reducing dysphagia but, with no information, changes in food preparation may be introduced too late and *ab ingestis* pneumonia reported.

In the case of risk of malnutrition in elderly people with dysphagia, oral supplementations may be effective for weight regain and mortality rate reduction^{8,9}.

2. Is it possible to demonstrate a condition of malnutrition in dementia patients?

Malnutrition (or undernutrition) is defined in different ways. We consider the Allison definition of this state as a condition of energy, protein or other specific nutrient deficiencies, producing measurable changes in body function, associated with

worsening illness outcome; the condition could be specifically reversed by nutritional support¹⁰.

Body weight reduction is reported in dementia, however, the condition may not be reversed by food intake. Weight loss is a common symptom in advanced Alzheimer's disease itself even though possible comorbidity can cause the same effect; it may be reported, even with adequate food intake³.

3. Is the patient thirsty?

In palliative care water intake could be reduced to lower suffering in end of life. Avoiding inappropriate nutrition and hydration lowers the risk of lung edema, ascites and respiratory distress, that are frequent in patients parenterally hydrated⁴. Evidence directly concerning dementia patients should be produced.

4. What purpose in tube-feeding in advanced dementia patients?

PEG aims in dementia patients are various:

- *ab ingestis* pneumonia prevention,
- prevention of malnutrition,
- relief or prevention of pressure sores,
- risk reduction of other infections,
- best functional state and comfort,
- prolonging survival,

None of the trials considered prove that these aims could be achievable by tube feeding^{11,1}.

5. Could advance directives be a useful tool for deciding about PEG use?

Advanced directives are related to early disclosure of diagnosis because patients' competence is impaired or lost in advanced dementia; in Italy a law concerning this subject has never been licenced from the Parliament.

Commonly, family, caregiver or surrogate decision makers choose for incompetent patients, possibly based on the living will or proxy directives. Lacking the previous direct expression of personal will, a substitute judgment could be proposed, or the best interest of the patient considered¹². An open discussion of this issue in early phase of dementia is uncommon.

6. Could PEG be preferred to oral feeding because easier to manage?

Reduction in the time necessary to feed patients with PEG may be considered critical in this decision⁴, especially in PEG positioning and nursing homes or for domestic organization.

Conclusions

As evidence is insufficient to suggest PEG is beneficial in advanced dementia patients¹³, discussion is needed in the decision making process.

PEG in dementia remains strictly related to individual choices and personal evaluation of quality of life because evidence is not conclusive. Randomized clinical trials may be inappropriate and the methodological quality of available trials not sufficiently high, not preventing an intervention futile in the progression of disease. The recommendation made in a "Top Five List" is the result of reviews, guidelines and clinical discussions and could help as a general suggestion without conclusive remarks.

¹ Sampson EL, Candy B, Jones L. Cochrane Database Syst Rev 2009; Issue 2.

² Finucane TE, Christmas C, Travis K. JAMA 1999;282:1365-1370.

³ Vidoni ED, Townley RA, Honea RA et al. Neurol 2011;77:1913-1920.

⁴ Congedo M, Causarano RI, Alberti F et al for the Bioethics and Palliative Care in Neurology Study Group of the Italian Society of Neurology. Eur J Neurol 2010;7(6):774-79.

⁵ www.choosingwisely.org

⁶ www.slowmedicine.it

⁷ Palecek EJ, Teno JM, Casarett DJ et al. J Am Geriatr Soc 2010; 58(3):580-84.

⁸ Milne AC, Potter J, Vivanti A, Avenell A. Cochrane Database of Syst Rev 2009; Issue 2.

⁹ Allen VJ, Methven L, Gosney MA. Clin Nutr 2013;32:950-57.

¹⁰ Allison SP. Nutrition 2000;16(7/8):590-93.

¹¹ Finucane TE, Christmas C, Travis K. JAMA 1999;282(14):1365-70.

¹² Defanti CA, Tiezzi A, Gasparini M et al for the Bioethics and Palliative Care in Neurology Study Group of the Italian Society of Neurology. Neurol Sc 2007; 28:216-31.

¹³ Volkert D, Berner YN, Berry E et al. Clin Nutr 2006;25:330-60.