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CHOOSING WISELY

Enteral tube feeding in people with advanced dementia

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What you need to know

- Difficulty eating is a common complication of advanced dementia. Choosing Wisely lists and professional society guidelines recommend against insertion of enteral feeding tubes, and instead recommend careful assisted oral feeding
- Early discussions about prognosis, shared decision making, and advance care planning that anticipates feeding difficulties may improve care in advanced dementia
- Rates of enteral tube feeding in advanced dementia have declined in the UK, Europe, and Canada
- A palliative approach to feeding problems in advanced dementia can promote goal concordant care

Dementia is a chronic, progressive, and irreversible disease affecting cognition, behaviour, and function. Alzheimer's disease, vascular dementia, and mixed dementia (Alzheimer's and vascular pathology) constitute most cases. Worldwide, more than 57 million people are living with dementia, and this number is expected to increase to more than 152 million in 2050.[1] The regions projected to have the highest percentage increases in dementia cases are north Africa, the Middle East, and eastern sub-Saharan Africa.[1] A recent meta-analysis found that mean survival time from onset of Alzheimer's disease was 7.6 years, and this was shorter for people with non-Alzheimer's dementia (6.5 years for vascular dementia and 6.8 years for dementia with Lewy bodies).[2] While there is heterogeneity in disease progression, people dying from dementia typically experience a prolonged advanced stage.[3,4] Many people with advanced dementia experience burdensome symptoms and poor quality of life, and many of their family caregivers experience substantial caregiver strain, including physical, psychological, emotional, behavioural, and financial stress.[4-6]

Difficulty eating is a common complication of advanced dementia and can manifest as dysphagia, the inability to feed oneself, and the refusal to eat.[4,7] Many professional society guidelines advise against recommending enteral feeding tubes in patients with advanced dementia and instead suggest oral feeding (see box 1).[8-19]

Box 1: International Choosing Wisely statements on enteral feeding tubes and advanced dementia

- Choosing Wisely Canada (last updated November 2022)[8]
    - "Don't recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral feeding"
- Choosing Wisely and the American Geriatrics Society (last updated April 2015)[9]
    - "Don't recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral assisted feeding"
- Choosing Wisely Germany (last updated October 2016)[10]
    - "In patients with advanced dementia, nutrition should not be provided through a percutaneous endoscopic gastrostomy (PEG)"*
- Choosing Wisely Austria (last updated November 2018)[11]
    - "Compared to support with eating, gastric tubes have no advantage for people with dementia, but they sometimes pose serious health risks"*
- Choosing Wisely Italy (last updated February 2022)[12]
    - "Do not prescribe enteral artificial nutrition (PEG, percutaneous endoscopic gastrostomy, or nasogastric tube) to patients with advanced dementia, but instead favour manually assisted physiological feeding"*
- Choosing Wisely Switzerland (last updated June 2017)[13]
    - "Do not recommend a percutaneous gastric tube in patients with advanced dementia; offer assisted oral feeding instead"*

*Translated to English

Nasogastric tube feeding involves passing a flexible, fine-bore, radio-opaque tube into the stomach via the nose.[20] Nasogastric tubes are intended to provide temporary enteral nutrition for no more than 4-6 weeks.[21] Percutaneous endoscopic gastrostomy (PEG) tube feeding involves insertion of a feeding tube through the abdominal skin into the lumen of the stomach, and can be inserted by either an endoscopic or interventional radiology approach.[21,22] Assisted oral feeding involves offering regular reminders to swallow, prompting multiple swallows for each mouthful, encouraging soft coughs after each

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swallow, decreasing bolus size, and judicious use of thickeners (where appropriate).[23-25]

Here we discuss why enteral tube feeding is not recommended and consider some of the barriers to reducing it. Much of the existing evidence related to enteral tube feeding in advanced dementia mixes nasogastric and PEG tube feeding. As such, where evidence relates to both nasogastric and PEG tube feeding this is described as enteral tube feeding. If evidence is limited to either nasogastric or PEG tube feeding, then those terms are explicitly used.

The evidence for change

Outcomes and safety of enteral tube feeding in advanced dementia

A 2021 Cochrane Review assessed the safety and effectiveness of enteral tube feeding for advanced dementia including 14 controlled, non-randomised studies.[26] Enteral tube feeding was defined as the administration of food via a nasogastric tube, PEG tube, or jejunal post-pyloric feeding.[26] Although the certainty of evidence was low, the review found that enteral tube feeding did not substantially lengthen survival compared with standard care. There was no available evidence for any type of enteral feeding about the impact on quality of life, pain, nutrition, family or caregiver outcomes, or behavioural and psychological symptoms of dementia. The systematic review found some evidence of harm: a narrative synthesis found very low certainty evidence that enteral tube feeding was associated with an increased risk of pressure ulcers, and the balance of evidence suggested an increased risk of pneumonia.

Other reported complications of enteral tube feeding in advanced dementia include agitation, greater use of physical and chemical restraints, worsening urinary and faecal incontinence, intra-abdominal abscesses, refeeding syndrome, and increased use of acute care services (such as emergency department visits).[17]

Global trends in the use of enteral tube feeding

Choosing Wisely statements from multiple countries along with professional society guidelines recommend against insertion of enteral feeding tubes, and instead recommend offering oral assisted feeding.[8 9 14-17] Increased awareness of the harms of enteral tube feeding has developed alongside practice changes, decreasing the use of feeding tubes in patients with advanced dementia in the US, Canada, Europe, and UK.[27-30] In particular, between 2000 and 2014, the incidence of enteral feeding tube insertions among US nursing home residents with advanced dementia decreased by approximately 50% (from 11.7% to 5.7% of residents).[27] In Canada, the annual prevalence of enteral tube feeding among nursing home residents with advanced dementia decreased from 3.5% in 2006 to 1.7% in 2022.[28] Conversely, trends of enteral tube feeding use in patients with advanced dementia remain largely stable in other countries including Israel, Japan, and Taiwan.[31-34]

Even in countries where rates have decreased, there are still persistent differences in rates of enteral tube feeding. In the US, an observational study between 2000 and 2014 of more than 70 000 nursing home residents with advanced dementia found that African-American residents were consistently more than five times more likely than white residents to receive tube feeding.[27] Further, there is marked geographical and socioeconomic variation in enteral tube feeding in US nursing homes, with homes located in urban versus rural areas, and those in poorer regions having higher rates.[35 36] In Canada, there is a higher prevalence of enteral feeding tubes among non-English speaking and non-French speaking nursing home residents with advanced dementia.[28]

Barriers to change

Clinical barriers

In the advanced stages of dementia, the patient's best interest may be increasingly served by prioritising comfort, which often aligns with the patient's and caregiver's goals of care.[37 7] A randomised controlled trial of US nursing home residents living with dementia found that comfort is the primary goal of care for most (67%), with only 7% wanting life prolonging care, and the remaining 26% opting for basic medical care only (treatment including antibiotics, parenteral therapy, and hospitalisation, but not cardiopulmonary resuscitation, intubation, enteral tube feeding, or intensive care).[38-40] Despite this, many people living with advanced dementia receive measures aimed at prolonging life towards the end of life—including enteral tube feeding—which may not improve comfort, and are often distressing to both patients and caregivers.[4 7 41]

Given the often protracted and gradual decline associated with dementia, family members commonly do not realise that dementia is a terminal illness, and, further, healthcare professionals often find it challenging to identify the final phase of the disease and consider dementia as a "cause" of death.[42 43] Clinicians may also be challenged by the fact that prognosis in dementia can be unpredictable, and the trajectory of the disease can vary.[43 44] In the case of feeding difficulties, a US cohort study of nursing home residents with advanced dementia who developed an eating problem had a 38.6% mortality after six months even after adjusting for age, sex, and disease duration.[7]

Non-clinical barriers

There are notable racial inequities in the perceptions and experiences of substitute decision-makers for people with advanced dementia contributing to the disproportionately high rates of enteral tube feeding (percutaneous and nasogastric) among African-American residents of nursing homes.[27 45] Substitute decision-makers include a designated guardian, proxy, or power of attorney, and in their absence many jurisdictions have a hierarchy for default decision-makers (commonly spouse, adult child, parent, adult sibling, and then a public guardian).[46] African-American residents of US nursing homes have lower rates of completion of advance directives, and, compared with white substitute decision-makers, Black substitute decision-makers are more likely to indicate that enteral tube feeding will prevent suffering and aspiration and prolong life.[45] Furthermore, nursing home staff often assume that many substitute decision-makers of Black residents do not want to engage in end-of-life care discussions and want more aggressive care, and are less likely to be asked by nursing home staff to engage in advance care planning discussions.[35 47] Yet, a multi-site qualitative study in the US found that many Black substitute decision-makers were both willing to participate and wanting more information on the clinical course of advanced dementia.[45]

Financial and administrative incentives within many healthcare systems are not well aligned with the scientific evidence against enteral tube feeding in advanced dementia. The relative ease and availability of PEG procedures in hospital settings, particularly in high income settings, time constraints for discussion and education of substitute decision-makers, and fear of litigation may contribute to clinicians offering enteral tube feeding.[43 48 49]

There are also misaligned financial incentives for enteral tube placement; since feeding tubes require increased monitoring and care, nursing homes in several countries, including the US and

Japan, are reimbursed at higher rates for patients receiving enteral feeding, possibly providing a perverse incentive for their use.[50] In the US lower resourced nursing homes have the highest enteral tube feeding rates, likely because there are not enough staff to support residents with oral assisted feeding.[35] Finally, results from multiple countries indicate that patients with dementia have decreased access to funded palliative care compared with other end-of-life patients.[43] Specifically, funding barriers in long term care include a lack of reimbursement structures that adequately compensate for the extra time and staff required to provide palliative care for patients with dementia, and there are often limits on the funding of home care services.

How should we change our practice?

Promoting a palliative approach to feeding problems in advanced dementia

A palliative approach to dementia care, especially in the advanced stages, has the potential to address differences in quality of care, including the use of enteral tube feeding.[51]

A Cochrane review on the impact of palliative care interventions in advanced dementia found that advance care planning interventions increased the documentation of advance directives (including orders for no enteral tube feeding) and discussions of goals of care, which may increase provision of goal-concordant care. The same review suggested that changes to the organisation and delivery of care for people with advanced dementia may lead to improvements in comfort in dying (including reduced rates of enteral tube feeding, both percutaneous and nasogastric). However, overall, the evidence was limited in quantity and certainty.[44]

This uncertainty of evidence, however, does not mean that palliative interventions, including advance care planning, do not improve care for patients with advanced dementia.[52]

Recognising the need for palliative care and the limitations of existing evidence, consensus-based methodology has been used to define optimal palliative care for people with dementia.[37] This includes practising shared decision making to allow patients and caregivers to clarify the clinical situation and:

- Set goals of care and engage in advance care planning[4] that anticipates feeding problems
- Start early and actively involve patients while they are capable of expressing their values and goals[37 50 53]
- Designate a substitute or surrogate decision maker in anticipation of the person with dementia losing capacity
- Encourage regular review of goals and update the plan throughout the disease course; consider using structured communication tools such as the Serious Illness Conversation Guide and the Conversation Project from the Institute for Healthcare Improvement[54 55]
- Align treatment options (enteral tube versus careful oral assisted feeding) with preferred level or goal of care.

If patients and their caregivers do not accept the recommendation for oral feeding, treatment discussions should be guided by the goals of care, and patients, substitute decision-makers and providers, including members of the multidisciplinary healthcare team (such as dietitians and speech language pathologists), should contribute to the decision making.[4] Decision aid tools can support substitute decision-makers by increasing knowledge of feeding options and by reducing decisional conflict.[56]

- Steps include:
  - Clarifying the clinical situation and education about advanced dementia and feeding problems
  - Establishing the preferred level or goal of care (comprehensive comfort *v* life-prolonging *v* basic medical care only) based on patient preferences and any available advance care planning
  - Aligning treatment options (enteral tube *v* careful oral assisted feeding) with preferred level or goal of care.

Education for healthcare providers

Healthcare providers may benefit from more education and support.[57] A 2017 survey of internal medicine physicians across seven New York hospitals reported that 38% were unsure of what the American Board of Internal Medicine/American Geriatrics Society Choosing Wisely recommendations advised on this topic.[48] All members of healthcare teams need to understand the terminal nature and limited life expectancy of advanced dementia as well as the management of feeding problems, including relevant guidelines that recommend against enteral tube feeding.[37 50]

Administrative strategies in fee-for-service settings

Finally, in some fee-for-service settings, reimbursement and administrative structures need to be modified. For example, all nursing homes should be reimbursed similarly for patients with advanced dementia whether they are receiving enteral tube feeding or provided with oral assisted feeding, and health systems should consider incentivising, rewarding, and publicly recognising nursing homes that successfully provide oral assisted feeding to residents.[50] To further promote a palliative approach to feeding problems, clinicians working in fee-for-service settings should be properly reimbursed for the substantial time required to engage in decision making for feeding options for patients with advanced dementia.

What healthcare professionals need to know

- Eating can be an emotive issue for family caregivers, who may have concerns about starvation. They may see an enteral feeding tube as the way to ensure this does not happen
- Time must be taken at the earlier stages of dementia to have a conversation with the patient and family explaining the course of dementia and that eating difficulties may arise, particularly in the advanced stage of the condition. The risks of enteral feeding should be explained

How patients were involved in the creation of this article

JT, a coauthor on this article, is a family caregiver and patient advocate focusing on the care of frail older adults. For six years, she was a public member of the British Columbia Polypharmacy Risk Reduction Initiative and an honorary lecturer for the Department of Family Practice in the Faculty of Medicine at the University of British Columbia. She teaches as a guest lecturer for the PharmD programme at the University of British Columbia. She is a member of the Oversight Committee for the Therapeutics Initiative and is on the Executive Committee of the Canadian Medication Appropriateness and Deprescribing Network (CADeN). She was involved at every stage of writing, drafted the section on patient perspectives, and provided critical review of all manuscript sections.

Education into practice

- When might you begin discussions about feeding difficulties with patients who have a diagnosis of dementia?
- What information would you provide to patients and family caregivers and how might you arrive at a treatment decision?

Search methods

We searched Medline and the Cochrane Library for citations published from inception until 13 April 2023. Our search included subject headings and keywords for "dementia," "feeding tubes," and "palliative care." We also searched grey literature, reviewed systematic reviews and guidelines, and consulted with other clinical experts.

We further reviewed the available Choosing Wisely statements on dementia and feeding problems. Choosing Wisely is a clinician-led campaign, present in more than 25 countries, which partners with national clinician societies to develop evidence-based recommendations about unnecessary tests, treatments, and procedures.

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