



Nutrition and Cognition in Dementia Care: Feeding Difficulty, Weight Loss and Decisions Near the End of Life

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Received: 19 January 2025; Accepted: 02 July 2025; Published: 30 October 2025

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Abstract

Guidance across several countries advises against enteral tube feeding in advanced dementia, and the position is well founded. What is less often stated is the shape of the evidence behind it. Two Cochrane reviews, the first searching to 2008 and the second to April 2021, each set out to find randomised trials and each found none. The first identified seven controlled observational studies, six of which assessed mortality, and reported no evidence of increased survival, no study examining quality of life, and no evidence of benefit for nutritional status or pressure ulcers. The second found no evidence that tube feeding improves survival or quality of life, reduces pain or mortality, decreases behavioural and psychological symptoms, improves nourishment, or improves family and carer outcomes. The complication is that observational comparisons in this setting cannot separate the effect of the tube from the reason it was placed, so absence of demonstrated benefit and demonstrated absence of benefit are not the same finding. The recommendation stands on other grounds, and stating them accurately matters to the families who receive it.

Keywords: Dementia; Feeding difficulty; Enteral tube feeding; Assisted oral feeding; End-of-life care

Introduction

Weight loss accompanies dementia from before diagnosis and continues through the illness, and difficulty with eating becomes near universal in its later stages [1,2,3]. Apraxia, agnosia for food, altered appetite regulation, reduced recognition of hunger, and eventually impaired swallowing all contribute, and they arrive gradually rather than at a single point [2,3,4].

At some stage a decision is put to a family about whether to place a feeding tube. It is asked in circumstances of distress, often in hospital, often quickly, and frequently framed as a choice between feeding and not feeding, which is not what it is [5,6,7].

This review sets out what the evidence establishes about that decision, what it does not, and where the strength of current guidance actually comes from.

Objective

This review sets out to establish four things from the published literature. First, what the systematic reviews of enteral tube feeding in advanced dementia found. Second, what kind of evidence those findings rest on. Third, why that distinction matters for how the recommendation is stated. And fourth, what the alternative to tube feeding consists of.

Literature Review

Feeding difficulty is part of the illness: Reduced intake in advanced dementia is a manifestation of the disease rather than an incidental complication, and it occurs alongside the loss of other functions [2,3,8]. Weight loss is documented from before diagnosis and through every stage, which distinguishes it from the acute undernutrition of an intercurrent illness (Figure 6) [1,2,9]. Reversible contributors do occur, including untreated pain, oral and dental problems, depression, constipation and the effects of medication, and identifying them is where assessment begins [3,4,10].

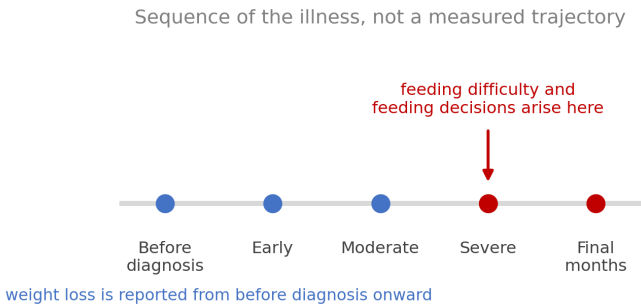


Figure 6: Where in the illness feeding decisions arise [1,2,3]

What the reviews searched for: A Cochrane review completed in 2009, searching to April 2008, set out to include randomised controlled trials, controlled clinical trials, controlled before-and-after studies and interrupted time series, and in addition controlled observational studies [11]. No randomised trials were identified. Seven controlled observational studies were included; six assessed mortality and one assessed nutritional outcomes [11].

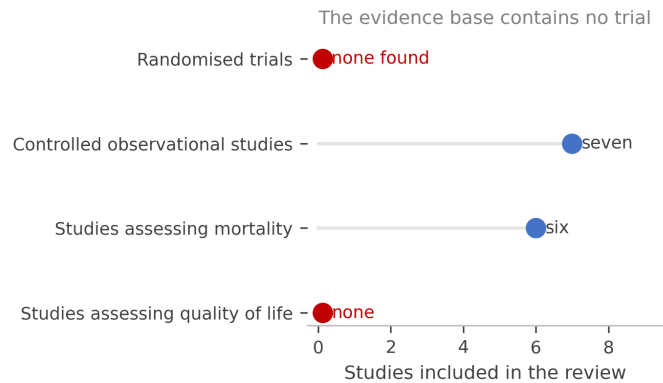


Figure 1: Studies identified by the earlier systematic review [11]

What they found: There was no evidence of increased survival among people with dementia receiving enteral tube feeding, no study examined quality of life, and there was no evidence of benefit for nutritional status or the prevalence of pressure ulcers [11]. The reviewers concluded that despite the very large number of patients receiving this intervention, there was insufficient evidence to suggest it is beneficial, and that data on adverse effects were lacking [11]. A survey cited in that review had recorded 34 per cent of 186,835 nursing home residents with advanced cognitive impairment as tube fed [11].

The position did not change with a further decade of literature: A second Cochrane review, searching to 14 April 2021, again found no randomised controlled trials [12]. It reported no evidence that tube feeding improves survival or quality of life, reduces pain, reduces mortality, decreases behavioural and psychological symptoms of dementia, leads to better nourishment, or improves family or carer outcomes [12]. Thirteen years and a second search produced the same structural finding: a very large clinical practice with no trial behind it [11,12].

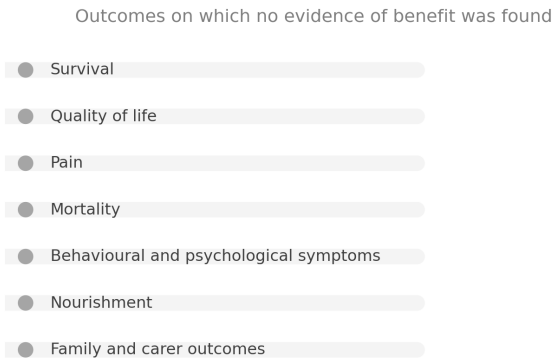


Figure 2: Outcomes on which no evidence of benefit was found [12]

Table 1: Both systematic reviews sought trials and found none [11,12]

Review	Search to	Randomised trials
Sampson and colleagues	April 2008	None found [11]
Davies and colleagues	April 2021	None found [12]

The honest complication: Every included study was observational, and in this setting the decision to place a tube is itself prompted by deterioration [11,12,13]. Patients who receive tubes are, on average, closer to death at the moment of placement than those who do not, for reasons the studies cannot fully measure and adjustment cannot fully remove (Figure 4) [13,14]. A comparison structured that way will tend to show shorter survival in the tube-fed group whether or not the tube has any effect, and could equally conceal a modest benefit [13,14,15].

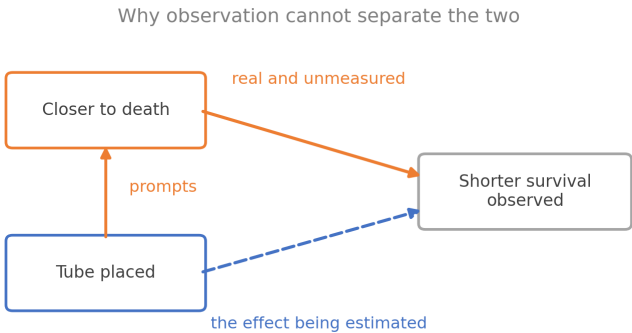


Figure 4: Confounding by indication in observational comparisons [13,14]

What follows from that: No evidence of benefit and evidence of no benefit are different statements, and the reviews assert the first (Figure 3) [11,12]. In practice the second is frequently what gets said, in guidance summaries, in teaching and in

conversations with families [7,15,16]. The recommendation against tube feeding remains sound, but it rests on the absence of demonstrated benefit combined with known burdens, on the physiology of the illness, and on the availability of an alternative, rather than on a demonstration that the intervention does nothing [12,15,17].

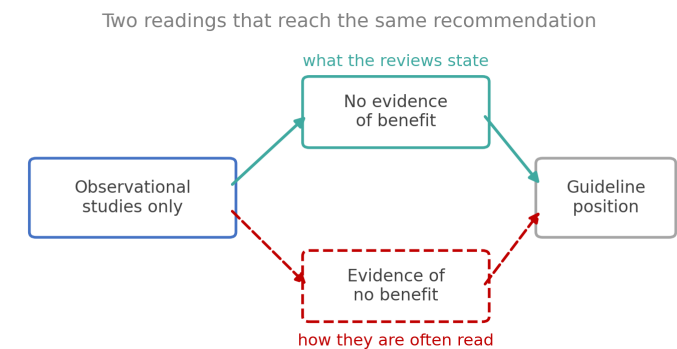


Figure 3: Two readings of the same reviews [11,12]

Why no trial exists: Randomising a person with advanced dementia to receive or not receive a feeding tube raises consent difficulties, since the population by definition lacks capacity, and equipoise is contested among the clinicians who would have to recruit [13,15,18]. Attempts to design such a study have been discussed and not carried out [15,18]. The practical consequence is that this gap is unlikely to close, so the evidence available now is probably the evidence that will be available, and framing the recommendation as provisional pending trials misdescribes the situation [15,18].

The known burdens are on firmer ground: Tube placement is a procedure with complications, and tubes in this population are associated with restraint to prevent removal, agitation, and pressure injury, alongside the aspiration risk that the tube is often intended to prevent and does not eliminate [12,17,19,20]. Aspiration of oral secretions and reflux of feed both continue after placement, which is why the protective rationale most commonly offered is the one least supported [17,19,20].

What the alternative consists of: Assisted oral feeding, with attention to texture and consistency, to the environment and timing of meals, to positioning, and to the identification of reversible contributors, is the approach guidance recommends (Figure 5) [4,10,17,21]. It is described in the literature as careful or comfort feeding, and it is not the withdrawal of nutrition but a different way of providing it [21,22]. It is also more demanding of staff time than a tube, which is among the reasons its provision varies [21,22,23].

Table 2: What can and cannot be said about the intervention

Table 3: What is known about how the decision is discussed

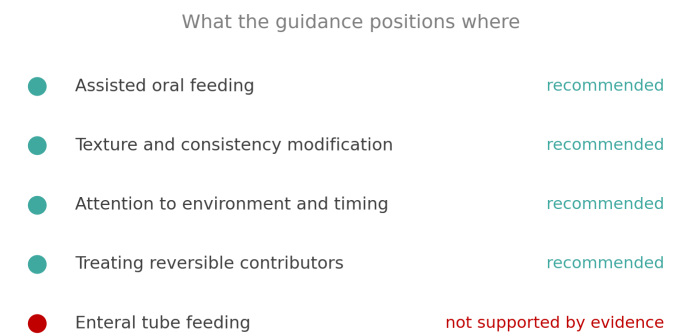


Figure 5: How the guidance positions each option [4,17,21]

Statement	Standing in the evidence
Tube feeding prolongs survival	Not demonstrated [11,12]
Tube feeding prevents aspiration	Not demonstrated [17,19]
Tube feeding has burdens	Reported consistently [12,19,20]
Assisted oral feeding is the alternative	Recommended [4,17,21]
Tube feeding is known to be useless	Not established [11,12,13]

How the decision is usually framed: Families report being asked whether they want their relative to be fed, which presents refusal of a tube as a decision to withhold food [5,6,7]. Studies of these conversations describe limited discussion of the alternative and of the natural course of the illness, and decisions made under time pressure in acute settings [6,7,24]. Where the conversation happens earlier, in advance care planning rather than in crisis, tube placement is less frequent, which suggests the framing and the timing carry substantial weight [24,25,26].

Decisional regret and carer outcomes: The second review found no evidence that tube feeding improves family or carer outcomes, and separate work on decisional regret in surrogate decision-makers reports that regret is associated with the quality of the conversation rather than with the decision reached [12,24,27]. This bears directly on how the recommendation should be delivered: a family told that a tube would be pointless is being given a stronger claim than the evidence supports, and one that may not survive contact with a relative who then dies [7,15,27].

Element of the conversation	What the literature reports
Timing	Earlier planning, fewer tubes [24,25]
Framing as feeding or not	Common and misleading [5,6]
Discussion of the alternative	Often limited [6,7]
Predictor of later regret	Conversation quality [24,27]

Cultural, religious and legal variation: Practice differs markedly between countries and between institutions within them, and the same evidence supports different positions where the surrounding obligations differ [23,28,29]. In some jurisdictions the withholding of artificial nutrition carries specific legal

requirements; in some traditions the provision of food and fluid holds a status distinct from other medical treatment [28,29,30]. A review that treated the clinical evidence as settling the question would misrepresent what is being decided [28,30].

What would improve practice without new trials: The measurable variation in this field is in how the decision is reached rather than in what the evidence shows, and interventions directed at that variation have been studied [24,25,26]. Structured decision aids for surrogates have been evaluated and report improved knowledge and reduced expectation of benefit from tube feeding [25,26]. That is a more tractable target than the trial that will not be done, and it addresses the part of the problem families actually experience [24,25,26].

The individual studies behind the reviews: The observational literature the reviews assembled is older than the reviews themselves, and its central papers were published between the late 1990s and the mid 2000s [31,32,33]. Each reported no survival advantage with tube placement, and each carried the same design limitation, since placement followed clinical deterioration in every cohort [13,31,32]. Reading them in sequence shows a consistent finding repeatedly reproduced, which is genuine evidential weight, and repeatedly reproduced by the same method, which is a limit on how much that weight can bear [13,31,32,33].

How the position reached clinical practice: Reviews written for general and family practice audiences translated the systematic review findings into practical guidance during the 2000s and 2010s, and it is largely through these that the position became familiar to clinicians outside geriatrics [33,34]. They are also where the compression from absence of demonstrated benefit to absence of benefit most often occurred, which is not a criticism of their authors so much as an illustration of what happens to a qualified finding as it travels [15,16,34]. Recovering the qualification is what allows the recommendation to be defended when a family questions it [7,16,34].

Method

This is a narrative review of published literature. Sources were assembled by searching the indexed literature for systematic reviews, controlled studies, clinical guidance and qualitative work concerning nutrition, feeding difficulty and enteral tube feeding in people with dementia, with precedence given to systematic reviews that state their search date and included study designs [11,12].

Findings are reproduced as their authors published them. Where a review reported an absence of evidence, that is stated as an absence rather than converted into a negative finding, because the distinction is the subject of this review [11,12].

No new patient data were collected and no search protocol was registered, so this is not a systematic review. Nothing here is

directed at any individual decision, which belongs to the people making it with the clinicians who know the patient.

Concluding Remarks

Two systematic reviews thirteen years apart set out to find randomised evidence on enteral tube feeding in advanced dementia and found none. What they found instead was an absence of demonstrated benefit across survival, quality of life, symptoms, nourishment and carer outcomes, in studies whose design cannot separate the tube from the circumstances that prompted it.

The recommendation against routine tube feeding is nonetheless well founded. It rests on the burdens of the intervention, on the nature of feeding difficulty as part of the illness rather than a problem alongside it, and on the existence of an alternative that provides nourishment and contact. Those grounds are stronger than an appeal to trial evidence that does not exist and probably will not.

Stating it accurately is not a technicality. A family told that a tube is known to be useless has been given a claim the literature does not support, and the difference will matter to them afterwards. What the evidence supports saying is that it has not been shown to help, that its burdens are real, and that the alternative is a form of care rather than its withdrawal.

The same question in other conditions: Advanced dementia is not the only setting in which artificial nutrition is offered without trial evidence, and comparable discussions exist in advanced cancer and in severe stroke with persistent dysphagia [15,17,29]. What distinguishes dementia is the duration over which the question stays open, since the illness runs for years rather than weeks and the decision may be revisited repeatedly as the person deteriorates [8,24]. That makes advance discussion more feasible here than in most settings where it is recommended [24,25].

Prognosis is the missing element: Recognition that advanced dementia is a terminal illness is inconsistent among both clinicians and families, and where it is not recognised the feeding question is approached as a reversible nutritional problem rather than as part of end-of-life care [8,24,27]. Work describing the clinical course of advanced dementia established the prognosis clearly, and the gap is in its application rather than in the knowledge itself [8,25]. A conversation that begins from an accurate shared prognosis reaches the feeding question differently [24,27].

Study Limitations

The evidence base is entirely observational and subject to confounding that cannot be removed by adjustment, which limits inference in both directions. Included studies differ in dementia severity, setting, tube type and duration of follow-up, and few report the burdens of the intervention systematically.

Literature on the decision-making process is largely qualitative and drawn from a small number of health systems, so its transferability is uncertain. This review does not address nutrition in earlier dementia, where the questions and the evidence differ.

Hydration is a separate question: Clinically assisted hydration near the end of life is governed by a different literature and a different set of considerations from nutrition, and the two are frequently discussed together as though one recommendation covered both [4,29,34]. Thirst and dry mouth are treatable by mouth care irrespective of hydration route, and the distress a family attributes to dehydration is often responsive to that rather than to fluids [21,34]. Conflating the two questions complicates conversations that are already difficult [7,29,34].

What good practice looks like in the meantime: The elements the literature supports are consistent across guidance: identify and treat what is reversible, provide assisted oral feeding with attention to texture, environment and time, discuss the trajectory of the illness before a crisis forces the question, and describe the alternative to a tube as a form of care rather than as its absence [4,10,17,21,24]. None of this requires resolving the evidential question, and all of it is within reach of services that currently vary widely in providing it [21,23,25].

Staffing is the constraint that is rarely stated: Assisted feeding takes time, and the settings where tube feeding rates are highest are frequently those with the least staffing available for mealtimes [6,21,23]. Where guidance recommends an alternative that costs more staff time than the intervention it replaces, the recommendation is also a resourcing claim, and treating it purely as a clinical judgement obscures why practice varies between institutions facing identical evidence [6,22,23]. This is among the more tractable explanations for the international variation described above [23,28].

A note on how this reads to families: The distinction this review draws is technical, and its practical value is not that it changes what should usually be recommended, which it does not, but that it changes what can be said honestly while recommending it [7,15,27]. Families are frequently more willing to accept a recommendation stated with its uncertainty acknowledged than one stated with a certainty they suspect is unwarranted, and the literature on decisional regret points the same way [24,27,30].

Acknowledgements

The authors thank the review groups who reported the absence of randomised evidence explicitly rather than presenting the observational findings as though they settled the question.

Funding

No dedicated funding from public, commercial or charitable sources supported the preparation of this review.

Conflict of Interest

The authors declare no competing interests.

Ethics Statement

This article reviews previously published studies only. No new patient data were collected and no participants were recruited, so ethical approval was not required.

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Citation: Sturm M, Manzoni-Ferri S, Halloran P. "Nutrition and Cognition in Dementia Care: Feeding Difficulty, Weight Loss and Decisions Near the End of Life." *J Clin Nutr Heal* (2025);6: 001-006