Gastrostomies in dementia: bad practice or bad evidence?

Tube feeding in dementia remains controversial as evidenced by recent responses to the Royal College of Physicians (RCP) report on oral feeding [1]. Criticisms of non-oral feeding are based on a failure to show a favourable outcome [2] or to lengthen survival [3, 4], a worsening of prognosis [5] and a higher mortality rate in hospitalised patients [6]. When dysphagia become severe, nasogastric tubes are often the first recommendation [1], with gastrostomies inserted once the patient is well enough to tolerate the procedure. However, there are many unanswered questions about tube feeding in general and gastrostomies in particular with respect to dementia:

(i) What causes weight loss in dementia? The cytokine-mediated cachexia syndrome is well recognised in cancer, chronic infection and cardiac disease, but is not seen in dementia. Weight loss in dementia is not an inherent part of the disease process but due to insufficient nutritional intake for the individual’s metabolic needs [7].

(ii) Is dysphagia a terminal symptom? In Alzheimer’s dementia, dysphagia can occur early in the disease process [8] and is not always a terminal symptom as is often believed [1]. Dysphagia often presents at an advanced stage having been missed because of poor screening [9], atypical presentations (e.g. in people with Down’s syndrome) and carer adjustment to its presence. There is little research exploring the extent of dysphagia in early to mid-stage dementia [10, 11], and until this is done a blanket ‘no gastrostomy’ policy cannot be justified.

(iii) Are gastrostomies inserted too late? Delay in identifying dysphagia risks malnutrition. Patients with low albumin levels do worse than those with normal levels post-gastrostomy and the risk of pneumonia due to severe dysphagia is increased [12, 13].

(iv) Is survival a relevant outcome measure? The evidence on survival is unclear varying from no effect on survival [16], a post-gastrostomy median survival of 6 months [14], and both increased [15] and reduced survival [13] with nasogastric feeding. A failure to improve survival has often been the central argument against tube feeding in dementia [1]. This observation suggests that tube feeding does not increase the risk of unnecessarily prolonging a patient’s life and is a point in favour of tube feeding.

(v) Are refeeding syndrome or gastric stasis being recognised? Refeeding syndrome results in severe electrolyte imbalances and a risk of death [17, 18]. Gastric stasis is common in patients with malnutrition and advanced disease, but is often overlooked in people with impaired cognition and increases the risk of aspiration if a standard feed rate is used. There is no mention of these problems in the gastrostomy–dementia literature.

(vi) What method of tube feeding is being assessed? It has been noted [14] that some papers do not specify whether gastrostomies or nasogastric tubes are being assessed [3, 19]. The paper by Mitchell et al. [3] describes ‘feeding tube placement’ without specifying the type, and yet the recent RCP report [1] quotes this source as applying to gastrostomy feeding.

(vii) Are the most appropriate outcomes being assessed? We lack data on outcomes more relevant to palliative care: Eating for survival or eating for pleasure: the shift from struggling to eat for survival to eating for pleasure with supplementary feeding via gastrostomy can be achieved gradually according to the patient’s swallowing ability and wishes. Gastrostomy feeding does not have to mean the end of enjoyable eating.

Patient distress: a tool to document distress in people with severe communication difficulties such as dementia [20–22] allows us to better understand the distress caused by prolonged oral meals, repeated admissions for pneumonia and fatigue caused by malnutrition.

Symptoms of malnutrition: taste changes, anorexia, fatigue, poor wound healing, susceptibility to infections and gastric stasis due to autonomic insufficiency are rarely mentioned in the gastrostomy–dementia literature.

Reducing hospital admissions: infections can be managed in the patient’s own setting because antibiotics can be administered via the gastrostomy rather than requiring intravenous routes.

Administration of medications: the gastrostomy allows patients to continue drugs such as anticonvulsants independent of oral feeding ability.

Distressing mealtimes: we strongly support enabling patients to maximise their oral intake. However, the insistence of ‘oral only’ results in prolonged mealtimes of an hour or more to ensure adequate intake, begging the question of whether anyone benefits from this process. Exhaustion and distress caused by prolonged mealtimes have not been studied, and there seems to be no consideration of the stress felt by staff concerned about worsening or precipitating aspiration-related problems.

Choice of feeding route

The current view of dysphagia and nutritional deficiency in dementia either prompts the assumption that the patient is...
terminal or results in a poorly tolerated nasogastric tube. Decisions should be based on the:

- speed and cause of deterioration
- assurance that all methods have been used to maximise oral feeding, including the transfer from plate to mouth
- consideration of the potential advantages of feeding and/or hydration
- feasibility and disadvantages of alternative routes
- presence of malnutrition, which delays healing and risks refeeding syndrome
- levels of distress from oral feeding
- patient’s present perception of benefit if they have capacity for this decision
- patient’s best interests if they do not have capacity for this decision.

‘Best interests’ is not the opinion of a clinician but a process such as that defined in the Mental Capacity Act (England and Wales). The exceptions are patients who, when they had capacity, wrote a valid and applicable Advance Decision to Refuse Treatment or appointed a Lasting Power of Attorney for Health and Welfare with the authority to make life-sustaining decisions.

**Conclusion**

We are not suggesting that every dementia patient with dysphagia should have a gastrostomy, but we are challenging the view that dysphagia is always a terminal symptom in dementia ruling out the use of gastrostomies. Any intervention that is completely ruled out for a particular population prevents clinicians from developing individually tailored support packages. Each individual deserves a holistic assessment by a skilled multidisciplinary team that includes a specialist in swallowing disorders. All appropriate interventions must be considered including the option of a gastrostomy. The absence of evidence should prompt a call for more research, not a ban on a potentially appropriate treatment.

**Conflicts of interest**

None declared.

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**References**

The implantable loop recorder in older patients with syncope: is sooner better?

Syncope is common in older people, with a three- to fourfold rise in syncope incidence with advancing age [1, 2]. Older patients with syncope disproportionately bear the burdens of morbidity, mortality and hospitalisations [1-3], while comorbidity, polypharmacy, cognitive impairment and age-related physiological change can make assigning a cause of syncope challenging. Older patients are much more likely to have a cardiac (and in particular arrhythmic) cause of syncope than younger patients, with up to 30% of older patients with syncope having such underlying diagnoses [1]. Current guidelines [1] advocate an initial evaluation strategy of detailed history, clinical examination, orthostatic blood pressure measurement and 12-lead ECG with subsequent investigations dictated by the likely aetiology based on this initial workup. The implantable loop recorder (ILR) has a role to play when the suspected aetiology is arrhythmic, either primary cardiac rhythm disturbance or as part of neurally mediated syncope, and is currently considered at the end of a series of investigations, which may include ambulatory or external loop recorder monitoring, tilt testing, carotid sinus massage, echocardiography and exercise testing. Where the cause of syncope remains unknown, the ILR has become the diagnostic test of choice when arrhythmic syncope is suspected but more invasive tests including electrophysiology studies are contraindicated, unlikely to be helpful or simply not available. ILRs are implanted in a pre-pectoral pocket in the left hemithorax (similar to a permanent pacemaker) under local anaesthetic, with a low procedure complication rate (1%, largely infection-related [4]). The models currently available in the UK have the approximate dimensions of a USB memory stick (Reveal™DX, Medtronic Inc., Minneapolis, MN and SJM Confir™, St Jude Medical, St. Paul, MN) and record a high-fidelity bipolar ECG signal stored as a loop, which can be frozen at the time of symptoms using a handheld activator by the patient, or auto-activated based on preset bradycardic or tachycardic parameters. ILRs’ key strengths lie in ECG monitoring of infrequent episodes and the ability to retrospectively assess heart rate and rhythm during a syncopal episode, both of which allow symptom–rhythm correlation, the gold standard of syncope diagnosis.

Clinical studies examining ILR use in older people are sparse. The first examined 15 patients (mean 73 years, range 61–89 years) with unexplained syncope, falls or both [5]. During 0–14 months’ follow-up, there were seven successful device activations, four identifying arrhythmia and three normal sinus rhythm [5]. While four patients experienced problems with device activation (auto-activation technology was not yet available), the high diagnostic rate established the viability of ILR use in an older cohort. The only other study to specifically assess ILR use in recurrent syncope in older people examined 103 patients split into 78 under- and 25 over-65s [6]. The older group had three-fold higher probability of an arrhythmia being recorded and were 3.8 times more likely to receive a final diagnosis [6].

Study design and data quality are thus problematic in the ILR field, with numerous observational studies [7-12] and only two randomised controlled studies in any age group [13, 14]. Both of these, however, recruited largely older patients [13, 14]. The 201 patients in the Eastbourne Syncope Assessment Study (EaSyAS) [13] had a mean age of 74 years (range 64–81 years), while the 60 patients in the Randomised Assessment of Syncope Trial (RAST) [14] were 66 ± 14 years. In both studies, patients with unexplained syncope were randomised to ILR versus a conventional investigation strategy, with improved diagnostic rates seen with ILR use. In EaSyAS, patients in the ILR group were seven times more likely to receive an ECG diagnosis (33 vs 4%, hazard ratio 8.93, 95% confidence interval 3.17–25.2, P < 0.0001) than those in the conventional group, while the RAST ILR group achieved a diagnosis in 55 versus 19% with conventional testing (P = 0.0014) [14].

Clinical experience with ILRs is not restricted to primary cardiac rhythm disturbance. The International Study on Syncope of Uncertain Etiology 2 (ISSUE 2) [4] included patients with a relatively high mean age (66 ± 14 years) though it was not restricted to older patients. Three hundred and ninety-two patients with suspected neurally mediated syncope had a