Oral feeding: practical care at the end of life

The 1999 case of Tony Bland [*Airedale NHS Trust* v *Bland* 1999], a young man in a permanent vegetative state, focused attention on the ethics and legality of providing artificial nutrition and hydration. Should tube feeding be given to patients who neither enjoy, nor have a prospect of enjoying, a meaningful life? And, of course, that raises the response articulated by Lord Browne-Wilkinson in the Bland case: 'What does life mean within the precept of sanctity of life: surely life as generally understood – not as PVS [permanent vegetative state]'. The Bland case has influenced guidance from the British Medical Association (2007), the General Medical Council (2010) and even the Department of Health (2008).

In some ways, the recent report from the Royal College of Physicians of London and the British Society of Gastroenterology (2010) is part of this legacy of guidance, but its context is different. It concerns patients who may be able to swallow, but with risk or difficulty, and/or who are dying. It provides guidance on when oral feeding should be withdrawn and tube feeding initiated and/or withdrawn.

The context

The prevalence of swallowing difficulties is estimated to be up to 60% in nursing home residents and 12–13% for patients in hospital (Cook and Kahrilas, 1999). In the 2008 annual British Artificial Nutrition Survey (Jones, 2008), 39 000 people in the UK were reported to be artificially fed outside hospital during the preceding year, 66.5% for swallowing difficulties. A third of those artificially fed live in nursing homes, of which 582 were recorded with dementia. In hospital, six out of ten older people are at risk of malnutrition, or their situation getting worse in hospital (European Nutrition for Health Alliance, 2005).

The lack of appropriate food and the absence of help with eating and drinking for those unable to manage independently is a frequent issue raised by relatives. Problems of oral feeding are therefore common, in or out of hospital. They affect a variety of specialties: physicians involved in the acute medical intake, GPs, gastroenterologists, neurologists, specialists in palliative care, geriatricians and psychiatrists. They also involve other disciplines: nurses and speech and language therapists especially. In hospital the formation of a multidisciplinary nutrition support team is therefore essential if the best standards of care are to be achieved. Other health professionals will also be involved but, critically, so must patients themselves and their families and carers.

Language

The sensitive issues in such decisions makes the use of language particularly important. Words carry particular resonances. The use of a word in one context that is customarily used in another may be chosen to emphasize a viewpoint or shock a reader. For example, to starve can mean either to cause to perish of hunger or to die of hunger. Hunger, in turn, may indicate the painful sensation caused by want of food, a scarcity of food or famine or metaphorically to suggest a vehement desire for or after something.

In our wards, a patient may die of nutritional deficiency, yet he/she has not been intentionally caused to perish of hunger or experienced the painful sensation caused by want of food. The report is careful to use the words 'hunger' and 'thirst' to refer to the sensation of the lack of food and drink, rather than merely the state of being without either. As RS Thomas (1992) says: 'we have all been victims of vocabulary too long'.

The science of feeding and its lack

Good clinical practice rests on a foundation of sound science and clear diagnosis. Feeding is more than metaphorically fuelling the engine. In health, it is both a pleasure and an opportunity for social interaction. Understanding its difficulties begins with an understanding of the pre-oral phase: the presentation of food, anticipatory behaviour and reflexes, as well as social interactions. Dentition, the ability to swallow and manipulation of the food bolus all precede swallowing, itself a complex series of events. The potential for aspiration arises from the role of the pharynx as both an airway and a 'food-way'. Those with parenchymal lung disease may be more susceptible to respiratory complications following aspiration, breathlessness may make oral feeding difficult and coughing may be less effective. Medical, surgical, neurological and psychiatric disease can all generate feeding difficulties.

The report offers illustrative examples of these pathophysiological conditions: Alzheimer's disease, Huntington's disease, motor neurone disease and so on. It is from this diagnostic understanding that feeding can be assessed both clinically and, occasionally, with special investigations such as videofluoroscopy. Effective support strategies for oral feeding can then be agreed. Some of these strategies are simple in principle, such as texture modification in foods or positioning, yet are often not applied. Behavioural and cognitive techniques may be particularly relevant in those with cognitive or affective disorders. This is practical advice that enables one of the key messages – 'nil by mouth' – to be a last resort rather than a first option.

Healthy individuals have adaptive metabolic responses to the absence of food. Disease alters this. Up to 80% of patients with terminal cancer, for example, develop the anorexia/cachexia syndrome with accelerated loss of nutritional reserves and rapid clinical decline. As death approaches, interest in food and drink lessens; good mouth care may become more important than attempting to feed a patient. At this point, the appropriateness of continuing artificial feeding should be considered.

Artificial feeding techniques

Techniques of artificial nutrition include nasogastric tubes and percutaneous endoscopic gastrostomy. Neither are risk free

and the benefits from them may be limited. For example, in dementia there is very little evidence that tube feeding either prolongs life, prevents pressure ulcers or improves functional status or comfort (Finucane et al, 1999). Percutaneous endoscopic gastrostomies may cause more suffering than they relieve. Despite these reservations, the report states that a 'wise reluctance to use artificial nutrition and hydration in dementia cannot be translated into a blanket ban'. Feeding tubes should be placed after individual assessments – and never as a condition of acceptance into a nursing home to provide a prompt discharge from hospital. International evidence suggests that some patients who could be fed adequately by mouth are being referred for tube feeding to relieve the burdens on both carers and professionals (Age Concern, 2006).

Ethics and law

Practice requires the application of a sound scientific understanding in the light of ethical principles. Ethics underpins the law. Sound ethical practice is the best protection against legal liability. Ethics also goes beyond the law, guiding action where the law is silent. The report returns to the concept of sanctity of life, given its fundamental place in English law. Such a concept has been widely criticized, yet it can be grounded in either religious or secular foundations.

In a multicultural society, issues of conscientious objection or of dissent of all sorts are more likely. How these are understood and resolved are described including the appropriate use of the courts. Without an advance refusal of treatment or lasting power of attorney, the determination of best interests poses particular difficulties for doctors, yet is crucial. 'Best interests are not limited to best medical interests', according to Baroness Elizabeth Butler-Sloss [*Re MB* 1997] and require a wider enquiry than doctors may be able to undertake. The requirements are both intimidating and mandatory. The law sets a framework within which doctors must act; it does not provide a recipe for decision making in difficult situations. Ethical debate will remain over whether offering artificial feeding is, in some circumstances, fulfilling a basic human requirement in maintaining life or prolonging death.

Conclusions

Promoting the best care for those with feeding difficulties, especially at the end of life, requires more than technical ability in placing tubes. Good communication between all involved is essential. Decisions can be agonizingly difficult. The report sets out the approach and the key considerations: physiological, pathological, ethical and legal. It has been well received by a variety of professionals and it is hoped that it may contribute to improving standards of care where there remain legitimate concerns. **BJHM**

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KEY POINTS

- Oral feeding difficulties and dilemmas are common.
- The approach to controversial issues is often coloured by the vocabulary we use.
- Eating and drinking are complex events, with social as well as physiological dimensions.
- Best practice rests upon clear diagnosis of the underlying problems with a multidisciplinary nutrition team advising on implementation.
- Ethical and legal considerations feature prominently in resolving dilemmas and should be understood.
- 'Nil by mouth' should be a last resort rather than the first option.