

CME Nutrition

Edited by Penny Neild, consultant gastroenterologist and senior lecturer, St George's Hospital, London and Mike Stroud, consultant gastroenterologist and senior lecturer in medicine and nutrition, Southampton University Hospitals Trust

Ethics and artificial nutrition towards the end of life

Barry JM Jones, consultant gastroenterologist and senior lecturer, Russells Hall Hospital, Dudley

Physicians are constantly confronted by ethical problems in their everyday practice. It is not possible to practise safely without a working knowledge of the implications of recent legislation such as the Mental Capacity Act 2005.

It is now 2,500 years since Hippocrates stated his four pillars of medical ethics. Autonomy, beneficence, malifcence and justice have formed the basis of medical ethics, but the passage of years has seen these principles ignored, altered, distorted and misinterpreted. Ethics should know no international boundaries but the law in some countries is often supportive of practices illegal elsewhere. Furthermore, the evolution of medical knowledge and technology has posed a serious challenge to our interpretation and implementation of ethics.

This challenge is especially evident in the nutritional support and hydration of patients towards the end of life.¹ For example, the natural history in advanced dementia is commonly for cognitive decline with deterioration in swallowing, leading to malnutrition and finally death from pneumonia. Until only 30 years ago, such patients were treated permissively without artificial nutrition and hydration (ANH). However, the introduction of the fine-bore nasogastric feeding tube (NGT) and percutaneous

endoscopic gastrostomy (PEG) in the early 1980s meant that many demented patients could be fed artificially – frequently without proper consent.² This inevitably led to considerable ethical debate. It is now clear that the use of PEG feeding in dementia achieves no discernible benefit in most patients but often causes mortality and morbidity.^{2–5} In other words, this treatment frequently ignores autonomy, provides no benefit (beneficence), causes harm (malifcence) and consumes resources which might benefit others (justice). A futile treatment is unethical and not in the patient's best interests.

Ethics underpin UK law which is constantly being challenged and changed. Many documents have dealt with these issues but the recently introduced Mental Capacity Act 2005 in England and Wales, together with pressures to place PEG tubes in nursing homes, has focused attention on the continuing unease about the lack of consensus, including

Table 1. Interested parties to be consulted (when patient lacks capacity to consent).

- Next of kin
- Close relatives
- Carers in community, care home or nursing home
- Nursing and medical team
- SALT
- Dietitian
- Nutrition team

When appropriate:

- Donee with Lasting Power of Attorney for Personal Welfare (MCA 2005)
- IMCA (MCA 2005)
- Court-appointed donee or deputy

IMCA = independent mental capacity advocate; MCA = Mental Capacity Act; SALT = speech and language therapist.

among doctors, about when ANH is appropriate.

This article will deal with the ethical issues relating to patients with oral feeding difficulties (OFD), particularly towards the end of life, drawing extensively on the recent Royal College of Physicians (RCP) working party report on these issues.¹

The dilemma

Why is there a dilemma in modern clinical practice? The problem with medical ethics is that their interpretation and implementation are influenced by the core beliefs of the individual concerned, whether a doctor, patient, family member or politician. Those in favour of the preservation of life at all costs vie with those who espouse euthanasia and assisted suicide.¹ A doctor may be caught between conflicting opinions expressed by colleagues, family and carers. In this situation the patient's wishes (autonomy), if they can be determined, trump all other views no matter how strongly expressed. Patients are not yet able to demand an unethical or futile treatment (*Burke v General Medical Council*¹) but are able to refuse or consent to treatment through informed consent.¹ Others are also not able to insist on, or consent to, a treatment on behalf of the patient (Table 1), but their views are invaluable in helping to understand the premorbid quality of life (QoL) and previously expressed views on end-of-life decisions.

The concept of a distressing death by starvation or dehydration as a result of a fatal condition leads understandably to the commonly held belief that nutrition must be achieved by all means possible. This is a valid belief if the patient is able to perceive ANH as beneficial. On the other hand, if cognitive capacity is seriously impaired and likely to be progressive, and if there is no potential for achieving the objectives of improving duration or QoL, no benefit can accrue from imposing ANH which would be unethical. This is particularly true for a potentially dangerous invasive procedure such as PEG.^{2–5} The possibility that ANH might prolong dying must always be considered.⁶ A decision not to provide

nutritional support while continuing intravenous (iv) hydration should also be recognised as irrational since this practice also prolongs the dying process without benefit. However, if ANH might provide support during an acute episode, such as a post-cerebrovascular accident (CVA) or head injury, it is justified even if the patient is unaware.¹

Oral feeding difficulties

It is often perceived that when a patient is no longer adequately meeting their oral nutritional requirements, they must be fed artificially by tube. This is over simplistic. Provision of oral nutrition and hydration is regarded legally as a basic duty of care whereas ANH is a treatment.¹

In early dementia and many other neurodegenerative diseases (NDs), shopping, preparation of food or even retrieval of food from the freezer may impact on nutritional status long before OFD supervenes.⁷ As the condition progresses, it may be some time before OFD is recognised as such and appropriate responses made. At this stage, 'nil by mouth' should *not* be the default option.¹ Care in the home or care home should be optimised to the individual's needs, perhaps with thickened fluids and soft foods administered by properly trained carers in an appropriate environment.

Finally, when oral feeding becomes 'unsafe', ANH may be considered. Pneumonia may already have occurred and been treated successfully. At this point, the availability of ANH leads to ethical dilemmas which may be agonisingly difficult, particularly as the patient may no longer be able to express their will. Even worse, the patient may have left no instructions to direct events at this stage of their disease. Relatives may be absent, disinterested or prejudiced in their views. Nursing homes have become more likely to insist upon a PEG before accepting the patient and National Patient Safety Agency directives on the safety of NGT feeding can lead to an ill-considered decision to place a PEG.⁸ All too often, NGT feeding will have been started without any thought to either the outcome or the patient's best interests.

Consent

Consent (autonomy) is the cornerstone of ethical practice.¹ When capacity is intact (Table 2), consent is the ethical and legal prerogative of the patient. Not all NDs are associated with cognitive decline; capacity must always be assumed to be adequate until proven otherwise. If capacity is lacking and unlikely to recover, any procedure offered must be considered to be in the best interests of the patient. The benefits and burdens of treatment must be discussed with all interested parties (Table 1), but their wishes must always be weighed against the best interests of the patient.¹ The morbidity and mortality of PEG are significant.^{2,4,5}

Multidisciplinary approach

In order to achieve the above ends, it is often helpful for a medically led nutrition team^{1,9,10} to be involved in assessing the case and advising not only on the appropriateness of ANH but also of alternatives.¹ These might include dietetic and speech and language therapist (SALT) guidance on thickened fluids given under supervision by trained nurses or carers. The principles of practical management are listed in Table 3.

Provision of oral intake also provides the opportunity for personal contact between patient and family or carers.¹ If a PEG is to be inserted, the operator must not function just as a technician but should ensure that due process has been carried out and that best interests

have been properly considered. Any operator who has 'conscientious objections' to placing the PEG should withdraw from involvement and another clinician be found. If there is conflict between the team and family or advocate (Table 1), recourse to legal opinion may be required. Fortunately, most decisions on ANH and consent are settled without dissent but consensus cannot always be achieved. In these circumstances, a 'trial of treatment' with specified and agreed objectives over a finite period of time may help to clarify the correct decision regarding ANH.⁶ It should be emphasised that withdrawal of treatment is held to be identical to withholding treatment morally, ethically and legally, despite the greater emotional burden on the relatives and care team associated with withdrawal of treatment.^{11,12}

It should be noted that some patients demonstrate disproportionate OFD at an earlier stage of dementia and might benefit from ANH, thus emphasising that all patients should be considered as individuals and not treated by rigid protocols.

Defined outcomes

When confronted by an oral feeding dilemma the first question must be 'Does this patient need nutritional support?', not 'Does this patient need a PEG?'.¹ Clearly defined outcomes must be agreed to answer this question, including:

- prevention of malnutrition
- pneumonia and bed sores

Key points

The ethics of caring for those with oral feeding difficulties towards the end of life have been challenged by the recent introduction of artificial nutritional interventions

Informed consent involving those with intact mental capacity is ethically essential before commencing nasogastric or gastrostomy feeding

Multi-disciplinary teams must be at the core of decision making for patients lacking capacity with emphasis on full consultation with family, carers and advocates

Advanced decisions should be encouraged before capacity is lost

Nil by mouth should not be the initial default option for oral feeding difficulties, but nutritional interventions are not risk free

KEY WORDS: dementia, end of life, ethics, feeding difficulties, gastrostomy

- improvement in QoL
- length of survival.

In advanced dementia, there is little or no evidence to support the achievement of any of these objectives using artificial nutritional support, rendering ANH a potentially futile and therefore unethical treatment capable of greater harm than benefit.² Instead, it is recommended that careful hand feeding be offered despite the risk of aspiration pneumonia.^{13,14}

Advanced decisions

Since consent is so crucial to medical interventions, the place of previously expressed wishes in directing decisions on ANH towards the end of life must now be considered.

Whenever possible, people with NDs known to lead to cognitive impairment should be actively encouraged to make an advanced decision (MCA 2005) in writing, with particular reference to their preferences should cognitive function and swallowing deteriorate to the point of unsafe swallow.¹⁵

Written advanced decisions are legally binding, subject to certain provisions notably that the situation conceived of when cognate applies to the present situation. Nutritional support is never an emergency⁶ and iv hydration can be provided to allow time to determine the existence of an advanced directive. Verbal wishes expressed via a concerned relative have no legal standing.¹ However, this author's experience is that many clinicians will take into account any views

expressed to them by relatives or carers when discussing the wisdom of ANH. Usually, the wishes concur with medical advice to avoid ANH. It is not necessary to seek legal opinion in most non-persistent vegetative state (PVS) cases except where major dissent exists between relatives and the medical opinion.

Nursing homes

When ANH is indicated and transfer imminent there is often controversy over the route of nutritional support. The RCP working party¹ has made the following recommendations:

- 1 There should be a careful assessment of the need for ANH. Assuming feeding is indicated ...
- 2 A trial of NGT should be carried out (with a nasal halter if necessary). If well tolerated and required for less than 6/52, a PEG is not needed.
- 3 If the NGT is poorly tolerated and frequently removed, a PEG should be inserted.
- 4 If ANH is needed for >6/52, a PEG should be inserted, preferably before discharge from hospital or shortly afterwards, a clear action plan being in place on discharge.

The RCP report states clearly that:

it would not be ethical for a care home to insist on a PEG as a criterion for admission on grounds of convenience. Where expertise in managing NGT is not and can not be made available, then a PEG may be in the patient's best interests if technically possible.

If a PEG is considered unethical, a policy of risk management must be deployed. Medical care is full of uncertainties.¹⁶ Not all patients with 'unsafe swallow' die rapidly if careful oral nutrition and hydration are practised.¹⁴ Those caring for such patients should be aware of the natural history of this terrible disease and that medical interventions have limited benefit and many risks. Nursing homes should be encouraged to accept the increased risk associated with oral feeding in preference to demanding a PEG in advanced dementia.¹

Table 2. Mental capacity assessment (Mental Capacity Act 2005).

- Capacity is not all or nothing
- Capacity relates only to the context of proposed treatment
- Capacity must be assumed unless patient is unable to:
 - understand information relevant to decision required, including consequences of decision for or against treatment and of failing to make a decision
 - retain information long enough to make a decision
 - use or weigh that information as part of decision-making process
 - communicate a decision by any means

Table 3. Principles of practical management of nutritional care towards the end of life.

- Full expert medical assessment, preferably by physician with interest in nutrition support
- Assess mental capacity for informed consent process
- Good communication with patient, relatives and advocates
- Take into account advanced directive if available
- Language should be clear and unambiguous
- Give enough time for discussion and decision making
- Coordinate all skills required through a nutrition team
- Consider trial of treatment with clear objectives over agreed duration
- Anticipate decline in cognitive function and discuss advanced decisions
- Good nursing care of mouth, attention to oral nutrition and hydration in and out of hospital
- NGT passage must be performed safely and secured with nasal halter if necessary
- SALT assessment
- Use oral fluids whenever possible, with altered consistency when needed
- Tube feeding always last resort
- What is technically possible is not always in patients' best interests
- PEG placement should be by operator involved and in agreement with consent process

NGT = nasal gastric tube; PEG = percutaneous endoscopic gastrostomy; SALT = speech and language therapist

Specific conditions

- In PVS, nutrition may have been provided for several years while all efforts to permit recovery are exhausted. Following the Bland case, it has become normal practice to seek legal opinion regarding withdrawal of ANH in PVS. In the Bland case, it was considered that continued ANH was burdensome to the patient and, for the first time, it was legally stated that death could be in the best interests of the patient. The recent discovery of cortical responses in PVS using magnetic resonance imaging may reopen this debate.¹⁷
- *Acute cerebrovascular events*, particularly when superimposed on pre-existing dementia, have a different natural history. Recovery must always be considered possible, so ANH should be offered until swallowing recovers sufficiently for ANH withdrawal.¹⁸ Early insertion of a PEG may be detrimental, so NGT feeding should be used, with a halter if necessary, until the patient has stabilised.
- In *Huntington's disease*, swallowing can remain safe even when cognitive function is declining. Attention to environment and food consistency may permit avoidance of ANH.¹
- In *motor neuron disease (MND)*, loss of swallowing is variable; when it is lost, cognitive function is usually intact.¹⁹ However, PEG insertion is associated with significant risk if forced vital capacity is below 0.5 litre. Early PEG insertion should be discussed with the patient before there is critical decline in respiratory function.
- In *multiple sclerosis*, cognitive function may remain intact and early PEG may prolong life if swallowing is unsafe.¹ However, acute infective episodes may impair swallowing temporarily and require no more than NGT feeding.
- *Cerebral palsy* in children or adults, especially when associated with epilepsy, is an appropriate indication for PEG which may transform quality

of life.¹ Loss of frequent personal contacts during oral administration of drugs, nutrition and drinks may be detrimental, but the benefit to close carers should not be ignored.

- PEG can improve survival in *oropharyngeal malignancy* and decrease morbidity, provided that disease is not advanced.¹
- *Inoperable cancerous small bowel obstruction* in patients not yet in a terminal phase and with good functional status can be treated with parenteral nutrition permitting early discharge home.²⁰ This is logistically difficult in many parts of the UK; nevertheless, it would be unethical not to discuss such a treatment option with carefully selected patients. Some will also require a drainage PEG which allows withdrawal of their drainage NGT.

References

- 1 Royal College of Physicians and British Society of Gastroenterology. *Oral feeding difficulties and dilemmas. A guide to practical care, particularly towards the end of life*. London: RCP, 2010.
- 2 *National Confidential Enquiry into Patient Outcome and Death: scoping our practice*. London: NCEPOD, 2004. www.ncepod.org.uk/2004sop.htm
- 3 Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA* 1999;282:1365–70.
- 4 Sanders DS, Carter MJ, D'Silva J *et al*. Survival analysis in percutaneous endoscopic gastrostomy feeding: a worse outcome in patients with dementia. *Am J Gastroenterol* 2000;95:1472–5.
- 5 Chernoff R. Tube feeding patients with dementia. *Nutr Clin Pract* 2006;21:142–6.
- 6 Lennard-Jones JE. Giving or withholding fluid and nutrients. Ethical and legal aspects. *J R Coll Physicians Lond* 1999;33:39–45.
- 7 Morris CH, Hope RA, Fairburn CG. Eating habits in dementia: a descriptive study. *Br J Psychiatry* 1989;154:801–6.
- 8 National Patient Safety Agency. *Reducing harm caused by the misplacement of nasogastric feeding tubes*. London: NPSA, 2005. www.nrls.npsa.nhs.uk/resources/type/alert/?entryid45=59794&p=4
- 9 Sanders DS, Anderson AJ, Bardhan KD. Percutaneous endoscopic gastrostomy: an effective strategy for gastrostomy feeding in patients with dementia. *Clin Med* 2004;4:235–41.
- 10 Burnham WR. Clinical nutrition in a district general hospital. In: Weber J (ed), *Horizons in medicine* no. 15. London: Royal College of Physicians, 2003.
- 11 General Medical Council. *Withholding and withdrawing life prolonging treatments*. London: GMC, 2002.
- 12 British Medical Association. *Withholding and withdrawing life prolonging medical treatment. Guidance for decision making*, 3rd edn. Oxford: Blackwell, 2007.
- 13 DiBartolo MC. Careful hand feeding: a reasonable alternative to PEG tube placement in individuals with dementia. *J Gerontol Nurs* 2006;32:25–33.
- 14 Treloar A, Crugel M, Adamis D. Palliative and end of life care of dementia at home is feasible and rewarding: results from the 'Hope at Home' study. *Dementia* 2009;8:335–47.
- 15 Royal College of Physicians, National Council for Palliative Care, British Society of Rehabilitation Medicine, British Geriatric Society, Alzheimer's Society, Royal College of Nursing, Royal College of Psychiatrists, Help the Aged, Royal College of General Practitioners. *Advance care planning: national guidelines*. Concise Guidance to Good Practice series, no. 12. London: RCP, 2009.
- 16 Royal College of Physicians. *Doctors in society: medical professionalism in a changing world*. Report of a Working Party of the Royal College of Physicians of London. London: RCP, 2005.
- 17 Monti MM, Vanhauzenhuyse A, Coleman MR *et al*. Willful modulation of brain activity in disorders of consciousness. *New Engl J Med* 2010;362:579–89.
- 18 Dennis MS, Lewis SC, Warlow C; FOOD Trial Collaboration. Effect of timing and method of enteral tube feeding for dysphagic stroke patients (FOOD): a multicentre randomised controlled trial. *Lancet* 2005;365:764–72.
- 19 Andersen PM, Borasio GD, Dengler R *et al*. Good practice in the management of amyotrophic lateral sclerosis: clinical guidelines. An evidence-based review with good practice points. *EALSC Working Group. Amyotroph Lat Scler* 2007;8:195–213.
- 20 Jones BJ. Nutritional support at the end of life: the relevant ethical issues. *Eur J Gastroenterol Hepatol* 2007;19:383–8.

Address for correspondence:
Dr BJM Jones,
Email: bjm.j@btinternet.com