

FEEDING THE CHRONICALLY ILL*

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INTRODUCTION

Dr NDC Finlayson, President, Royal College of Physicians of Edinburgh

The symposium was used to highlight and discuss current issues concerning the nutrition of patients with chronic illness. The 'why' and 'when' as well as the 'how' of feeding were addressed. Although few questions were definitively answered, the discussion will inform further debate and provide better information for decision-making.

SESSION 1

CHRONIC ILLNESSES, NUTRITIONAL NEEDS AND METHODS OF ASSESSMENT

Chaired by Dr A McKinlay, Consultant Physician and Gastroenterologist, Grampian University Hospitals NHS Trust

Chronic illness, nutrition and rehabilitation – an overview

Dr R Seymour, Consultant in Rehabilitation Medicine Grampian University Hospitals NHS Trust

Adequate nutrition is recognised as a vital factor in health and fitness. It does not, however, enjoy the high profile one would expect in rehabilitation practice or research. Reduction in muscle function is one important detrimental effect of undernutrition. The functional change in muscle occurs early, predating structural change, with the same being true in refeeding. Improved nutrition in hospital is hypothesised to be one explanation for the benefits achieved by in-patient rehabilitation.

Micronutrients such as vitamin D are thought to be important factors. Reduction in proximal muscle function predates bone loss in vitamin D deficiency.¹ The clinical relevance of this is seen in the high prevalence of deficiency states. In one series, 80% of females with multiple sclerosis had low vitamin D levels.²

Reduced nutritional intake can have a variety of subtle causes in chronic illness. For instance, weight loss may be desired by patients to allow easier handling by carers. Voluntary reduction in fluid intake to reduce urinary output is also well recognised. The effect of chronic underhydration has received little research attention.

When alternative forms of feeding become necessary, patients, family, friends and professional staff often have different perspectives. Enteral feeding is best used at an

early stage, as it can slow the general decline of the patient and allow marked functional improvement, despite the common view that it is an intervention of last resort.

Nutritional assessment: identifying nutritional needs

Mrs J McKinlay, Senior Dietician, Grampian University Hospitals NHS Trust

A single nutritional measure which can be adopted as a gold standard of adequacy of nutrition does not yet exist. There are, however, a number of useful tools for both screening and detailed assessment. Screening is used to identify those at risk and can be carried out by non-specialists. The Malnutrition Advisory Group (MAG) of the British Association of Parenteral and Enteral Nutrition (BAPEN) has published (and is in the process of revising) an evidence-based screening tool for this purpose. More detailed assessment of those at risk involves dietetic review of energy, nitrogen, fluid, vitamin, mineral and trace element requirement.

Meeting nutritional requirements in chronic illness is often difficult. Patients with impaired swallowing are often advised to eat puréed food and drink unpalatable thickened fluids. Liquidising food increases the total volume, particularly if the total nutritional and fluid needs are to be met; many patients find this difficult to manage. Teaspoon feeding is often suggested but can be impractical, because one litre of feed, which is often the minimum daily requirement, amounts to 200 teaspoonfuls.

The importance of early intervention in cases of voluntary abstinence from food has been well demonstrated.³ This is particularly the case if there is concomitant illness or injury. Enteral feeding is often resisted but, at an appropriate stage, it can improve function rather than being a dependency-increasing retrograde step.

Gastrostomy: placement and follow-up; technicalities of gastrostomy feeding

Dr B Jones, Consultant Gastroenterologist, Russell Halls Hospital

Introduced 20 years ago, endoscopic or radiological placement of gastrostomy rapidly supplanted surgical gastrostomy. In 1996, 6,000 patients were receiving home enteral feeding. By 2000 this had risen to 15,000, with 80% being fed via a percutaneous endoscopic gastrostomy (PEG) tube. Of these patients, 41% are in nursing homes. At present the numbers appear to be stabilising.⁴

* A Hot Topics Symposium held at the College, 24 April 2002.

The main indications for PEG insertion are hydration, drug administration and long-term enteral nutrition. Neurological conditions such as stroke are among the leading causes of inadequate or unsafe oral nutrition. Cancers obstructing the upper gastrointestinal tract are other important indications.

Contraindications to PEG insertion are few and include clotting abnormalities, portal hypertension, anomalous anatomical position of stomach, gastric carcinoma, abdominal aortic aneurysm and failure to identify an insertion point. Advanced dementia may be a contraindication in itself due to the poor prognosis and increased complication rate.⁵

Fortunately serious complications of PEG insertion are rare. Complications such as bleeding, peritonitis, gastrocolic fistula and aspiration pneumonia occur early. Percutaneous endoscopic gastroscopy site infections, abdominal wall sepsis, gastric ulceration and pyloric obstruction are later complications. Prevention of PEG site infection continues to be debated with some guidelines suggesting routine antibiotic prophylaxis. In the UK the organism responsible is often methicillin-resistant *Staphylococcus aureus* (MRSA), emanating from the patient's own nasopharynx.

Decisions to insert PEG tubes should involve the operator who inserts the tube. Overall this occurs in only 25% of cases, rising to 97% when the referral involves a nutritional assessment team. Operator involvement is felt to be particularly important in the case of patients incapable of giving consent, when the operator must be satisfied that the treatment is in the best interests of the patient.

Community follow-up of enterally-fed patients is suboptimal in many areas. This has often led to reactive rather than proactive management strategies. To improve outcomes and reduce burdens this must change.

SESSION 2

FEEDING PATIENTS WITH STROKE

Chaired by Dr CJ Scott, Consultant in Medicine for the Elderly and Rehabilitation, Woodend Hospital, Aberdeen

Nutritional intervention effects – does feeding help?

Dr J Potter, Consultant Physician and Senior Lecturer, Victoria Infirmary, Glasgow

The prevalence of malnutrition in patients admitted to hospital is high, with a tendency for their nutritional state to worsen in hospital.⁶ Nutritional support is not necessary in every patient and the question of who to treat and how has not yet been fully answered.

Dr Potter presented data taken from literature searches in each of the following areas:

1. Oral supplementation vs routine care. In these trials (33 studies, 2,494 patients) unwell older patients receiving supplementation in excess of 400 kcal/day derived the most benefit.⁷
2. Nasogastric (NG) feeding. A small evidence-base was available (15 studies, 815 patients) showing only marginal benefit.
3. Percutaneous endoscopic gastroscopy feeding. Trials tended to be of small numbers of patients and showed no significant change in the main outcome, death.

Few of the studies identified included quality-of-life data. This aspect will need to be addressed in future research.

Nutritional interventions in stroke disease

Dr M Dennis, Reader in Stroke Medicine, Western General Hospital, Edinburgh

Approximately 45% of stroke patients suffer dysphagia, which often improves with time. The sudden onset of stroke and the difficulty in assessing prognosis at an early stage make decisions regarding feeding difficult with concurrent communication difficulties of the patient, often limiting their direct involvement. The current evidence regarding feeding is sparse. Some studies have looked at PEG vs NG feeding but it is felt these may overestimate the benefits of PEG feeding.⁸ A large multi-centre trial is currently underway comparing various nutritional strategies in acute stroke.⁹ This trial looks at mortality and morbidity but not quality of life, and its final results are not expected for several years.

A view from the other side – a patient's perspective on enteral feeding

Mrs E Scott, Aberdeen

In a structured interview, Mrs Scott gave a personal insight into life on enteral feeding. She has had experience of both PEG and NG feeding, and in general she found PEG feeding preferable. A PEG tube is invisible under clothing and the patient does not look unwell. Nasogastric tubes can be unpleasant to insert and, in common with many patients, Mrs Scott found it preferable to insert the tube herself. The temperature of the feed going into a PEG tube is not noticeable, whilst cold water down a nasogastric tube can be unpleasant. An under-appreciated problem with any form of enteral feeding is the number of boxes of feed and equipment that are required, which occupy a significant amount of space in a home.

SESSION 3

CHRONIC NEUROLOGICAL DISEASE: WHO SHOULD DECIDE AND HOW?

Chaired by Dr K Beard, Consultant Physician, Victoria Infirmary, Glasgow

The courts – legal issues in nutrition

Dr V Nathanson, Head of Professional Resources and Research Group, British Medical Association

In the United Kingdom the courts have upheld the principle of an adult's autonomy to make decisions regarding their treatment. Whilst food is a fundamental human right and is not regarded as a treatment on its own, artificial methods of hydration and feeding, that involve placing tubes, are interventions and require consent. Treatment without consent can be regarded as assault. The situation can become complex when the patient lacks the capacity to give consent. Even more difficulties may arise when treatment is to be withdrawn in a patient who is incapable of giving consent, and may require to be brought before a court.

New legislation in Scotland (The Adults with Incapacity (Scotland) Act 2000)¹⁰ has provided a legal framework for decisions in patients who lack the capacity to give consent. The Act legislates for the creation of a Welfare Attorney who can be appointed by an adult while still capable and is able to consent on behalf of the adult if they lose capacity. If no Welfare Attorney exists treatment can be authorised by the doctor primarily responsible on the completion of a Certificate of Incapacity. Legislation in relation to Guardianship Orders has also been updated to allow decision-making in welfare issues. All interventions have to follow the general principles of the Act (Table 1).

TABLE 1

General principles of The Adults with Incapacity (Scotland) 2000 Act.

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| <ol style="list-style-type: none"> 1. Benefit to the adult. 2. Adherence to the adult's wishes, past and present, as far as these can be ascertained. 3. Relevant others, e.g. relatives and carers, should be consulted if practical. 4. The adult's freedom should be restricted as little as possible. 5. The adult should be encouraged to exercise residual capacity. |
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The situation regarding so-called 'living wills' or advance directive is covered by legislation at present. Dr Nathanson felt that these should be accepted as a valid testament to an adult's views held while still capable.

They are likely to be more useful when considering whether a treatment should be withheld.

Low awareness states and complex neurological disabilities

Dr K Andrews, Medical Director, Royal Hospital for Neurodisability, Putney

Chronic diseases can be usefully grouped into conditions which are essentially stable and into those which progress over time. This often determines whether the ability of the patient to make decisions is maintained or lost. If a patient remains mentally capable, then their decisions regarding their own treatment must be respected, even if they are potentially serious or go against the advice of their doctors. The courts have consistently reaffirmed the rights of a competent individual in relation to management and treatment to decide their fate even on issues that might legitimately be regarded as matters of life and death.¹¹

The main reasons for instituting enteral feeding are:

- to preserve life;
- to provide short-term support over an acute illness;
- as a trial of treatment; and
- to maintain health and function in chronic illness.

When a decision is made to withhold or withdraw any medical treatment, including feeding, the treatment may be considered to be medically futile. Enteral tube-feeding can often sustain life indefinitely, so the decision often revolves around the quality of the patient's life and whether their 'life' rather than the process of feeding is 'futile'. Such judgements can be understandably difficult. The decision usually depends on an assessment of the patient's best interests, and a number of considerations may apply.

It could be considered in a patient's interest to continue treatment if:

- their level of awareness is difficult to assess and may be higher than estimated;
- there is a possibility of late recovery;
- a real possibility of future treatment or cure exists; and
- there is difficulty in determining what the patient feels is an 'acceptable' quality of life.

The opposing view might be:

- the patient has no awareness of life and hence no quality of life;
- treatment is continuing without consent;
- no realistic chance of recovery exists;
- the family is unable to grieve; and
- there are potential resource implications.

The use of a trial of feeding for a defined length of time has many attractions and often seems less extreme than withholding treatment. A recent court ruling, however, has emphasised that a trial of treatment and withdrawal

if unsuccessful has no legal or ethical difference from withholding treatment at the outset. The rationale being that if a difference was recognised in law, the physician who attempted a trial of treatment would have less protection than one who did not offer this chance even though the outcome would often be the same.¹² Dr Andrews recognised, however, that in clinical practice, the two approaches often have very different effects on the clinical staff and families involved in the case.

The plight of people with dementia

Dr D Lyons, Clinical Director, Old Age Psychiatry, Greater Glasgow Primary Care Trust

It is recognised that patients with advanced dementia lose weight. Decreased intake, increased energy expenditure and failure of weight regulation are all implicated. Decreased intake is the main area that can be addressed clinically.

Decisions regarding enteral feeding in advanced dementia are often made late. At this stage, the views of relatives, carers and medical staff may not coincide and this conflict arises at a time when the patient's wishes are impossible to ascertain. It is currently felt that tube feeding in dementia does not provide any increase in length or quality of life but this has been difficult to prove objectively.

Discussion of issues such as feeding are probably better carried out early in the illness to allow an adult's own wishes to be made clear. Advance directives are also felt to be of value.

SESSION 4

PANEL DISCUSSION AND DEBATE – NEARING THE INEVITABLE

Chaired by Dr NDC Finlayson OBE, President, Royal College of Physicians of Edinburgh

In this session three hypothetical cases highlighting various common ethical dilemmas related to feeding were presented and discussed. The panel consisted of:

- The Right Honourable Lord Mackay of Drumnadoon, High Court Judge;
- Reverend Professor Peter Brunt, Retired Consultant Gastroenterologist and previous Physician to the Royal Household in Scotland;
- Mr Peter Cardy, Chief Executive, Macmillan Cancer Relief; and
- Dr Vivienne Nathanson, Head of Professional Resources and Research Group, British Medical Association.

During the discussion, the panel and delegates emphasised the absolute right of competent patients to make decisions about their care. The panel noted that when a competent patient disagrees with their doctor, the courts generally require that the patient's wishes be

followed. The trauma of a court case for a patient should not be underestimated and should be avoided if possible. Nevertheless, some cases can only be resolved with direct input from the courts.

Early assessment and discussion of future options is needed in cases of progressive disease whilst the capacity to make decisions is intact. Evidence suggests that in many cases agreement between proxies and patients is poor, and there is need for frank discussion with, and continued support for, the patient's family. There is also need for continuity and consistency of care in progressive disease. This requires involvement of community and primary care. General practitioners often have knowledge of a patient's views and the family dynamic, which can greatly assist the decision-making process.

Uncertainty exists about the implications of The Adults with Incapacity (Scotland) Act 2000, particularly regarding feeding decisions. There is also uncertainty about the admissibility of advance directives. Withdrawal of therapy goes against the natural inclination of clinicians of all disciplines to preserve life. Finally, prognosis in stroke is often difficult to predict at the time when feeding decisions have to be made.

CLOSING REMARKS

Dr NDC Finlayson, President, Royal College of Physicians of Edinburgh

A wide range of views was expressed throughout this symposium making a consensus difficult to obtain. Legislation may help in areas where capacity is clearly present or clearly absent. The difficult area is where capacity is debatable or variable.

The symposium has helped to stimulate continuing thinking and debate, and has provided a useful forum for outlining the current thinking in this difficult area.

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