

# Oral feeding difficulties and dilemmas

A guide to practical care,  
particularly towards the end of life

Report of a Working Party

January 2010



Royal College  
of Physicians

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BRITISH SOCIETY OF  
GASTROENTEROLOGY

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particularly towards the end of life

REPORT OF A WORKING PARTY 2010

*Endorsed by* the Association of British Neurologists,  
the British Dietetic Association, the British Geriatrics Society,  
the British Association for Parenteral and Enteral Nutrition,  
the Royal College of Nursing, and the Royal College of Speech  
and Language Therapists



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## Summary and recommendations

Patients with oral feeding difficulties deserve special care but may not receive it. Their care should be tailored to their requirements, not to the needs of others. It should, as far as possible, preserve their oral intake. If this is impossible, tube feeding may be necessary, short or long term. Very rarely, intravenous nutrition may be appropriate.

This document summarises the mechanism of oral feeding, its assessment and the modification of food and liquid to facilitate maintenance of oral nutrition. The metabolic needs of patients are described as well as the consequences of cessation of intake of nutrition. The routes for artificial nutrition and hydration are described including their risks, benefits and complications. The ethical and legal issues involved are summarised. Finally, the practical aspects are reviewed with illustrative case studies and advice on how doctors and other healthcare professionals can engage with patients to decide the best course of action. This may be particularly difficult at the end of life.

We recommend that:

- ▶ A multidisciplinary nutrition support team of healthcare professionals, ideally but not inevitably led by a doctor with special expertise in nutrition, should be available to work with patients and their families when oral feeding difficulties occur. A member of the team should be available by telephone at weekends as well to provide advice.
- ▶ Such teams should be collaborative in nature and not be made up of independent professionals who are focussed only on their area. The patient should be at the centre of their efforts.
- ▶ The first question should be ‘what are we trying to achieve?’
- ▶ Oral intake, modified as necessary, should be the main aim of treatment. Nutrient-dense foods or special provision of food (in hospital the ‘red tray’ system) is helpful.
- ▶ Even when tube feeding is necessary, this should be additional whenever possible. At the end of life, even if deemed to have an ‘unsafe swallow’ a risk management approach may offer the patient the best quality of life. If in doubt, a trial of nasogastric feeding with clearly agreed objectives may be appropriate. Tube feeding should then be

withdrawn if failing to achieve the objectives. 'Nil by mouth' should be a last resort, not the initial default option.

- ▶ When artificial nutrition and hydration are required for the medium term or longer, this should be managed by the multidisciplinary team together with other health professionals, the patients themselves and their family/carers, at home if possible. The setting may be a care home if the patient has other medical problems.
- ▶ All trusts and care homes should ensure there are sufficient staff, especially at mealtimes, to assist and feed those patients who require a long time to eat an adequate meal.
- ▶ The full facts of the situation should be understood by all involved to enable a patient-centred decision about artificial nutrition and hydration and the means of delivery. This should never be based on the convenience of the staff or carers or be required as a criterion for admission by any institution. We believe that to be unethical and bad practice.

# Introduction

This report aims to improve and facilitate care of patients by providing practical advice with a sound legal and ethical basis to healthcare professionals, patients and their families, and to advocates appointed under the Mental Capacity Act 2005. In so doing, we hope that distress, disagreements and discord will be prevented.

Respiratory problems and situational factors among others can lead to feeding difficulties, so our considerations go beyond swallowing difficulties alone.

Although it is acknowledged that feeding difficulties can arise in disabled or demented patients at an earlier stage, 'end of life' implies a group of people with substantial disability, even if not imminently dying.

These difficulties create great uncertainties, even confusion, for healthcare professionals, for patients and for relatives. One result has been poor practice. The working party was struck by anecdotal accounts of poor practice, some of which have been reported by our Patient and Carers' Network: these involve both withdrawal of feeding and its inappropriate artificial continuation. Some of these accounts, usually where the patient was unable to articulate his/her wishes, described strong differences of opinion between professionals and family members.

The language used in discussion is important. Words carry particular resonances: the use of a word in one context that is customarily used in another may be chosen to emphasise a viewpoint or shock the reader. Hunger, for example, may indicate the painful sensation caused by want of food or a craving appetite. It may also be used to indicate a scarcity of food or famine. Thirst may mean the sensation caused by want of drink; it may also mean the physical condition arising from that want. Both words may be used metaphorically to suggest a vehement desire for or after something: knowledge, revenge, righteousness.<sup>1</sup>

Starvation can mean the act of starving or of subjecting to famine. To starve can mean either to cause to perish of hunger or to die of hunger.

In medical practice patients may have a scarcity of food, yet not experience the sensation or craving of the appetite. A patient may die of hunger in the sense

of nutritional deficiency, yet they have not intentionally been caused to perish of hunger or experienced the painful sensation caused by want of food.

Nutritional deficiency is a less emotive term and we will not refer to ‘starvation’ or starving patients in this report. Similarly, we use the words ‘hunger’ and ‘thirst’ to refer to the sensation of the lack of food or drink, rather than merely the state of being without either.

Medical care is full of uncertainties.<sup>2</sup> Decisions to opt for or against artificial nutrition or hydration may be agonisingly difficult. In many cases, the will of the patient has not and cannot now be expressed. Sometimes relatives may be absent, disinterested or prejudiced. Sharp delineation of when to institute or continue artificial nutrition and hydration is not possible because differences among patients preclude strict definitions, medically and socially. At best ethical principles act as guidelines, not rules, and ambiguity often persists. Yet to avoid an obligation to advocate or decide on nutritional support, by always continuing it, is to fail to act as a moral agent.<sup>3</sup>

# 1 Background: oral feeding

## Terminology

1.1 The term ‘oral feeding’ is used here to denote eating and drinking. The term has been chosen in preference to ‘swallowing’ to facilitate a more wide-ranging discussion about the mechanisms of eating and drinking in health and disease.

1.2 The term ‘dysphagia’ can be used to refer to a symptom, a clinical sign, a radiological sign, or a putative mechanism for unexplained nutritional or respiratory problems; for this reason the term is avoided.

1.3 The term ‘oral feeding’ does not imply that the patient is passive in the organisation and timing of feeding, even if they are totally dependent on the assistance of carers.

## Oral feeding in health and disease

1.4 Successful oral feeding is characterised by enjoyable, or at least tolerable, eating and drinking, the maintenance of weight and hydration, and an acceptable frequency of coughing and other responses to things getting stuck or ‘going down the wrong way’.

1.5 Significant oral feeding problems can manifest as dehydration, weight loss, frequent coughing and spluttering, prolonged mealtimes, respiratory problems such as laryngeal obstruction and chest infections, drooling from the mouth, and withdrawal from mealtimes.

1.6 An oral feeding problem can be the first sign of some diseases. More commonly it is one of the known complications of a condition, a procedure or a situation.

## Clinical issues of relevance to oral feeding

1.7 Four main areas of clinical practice need to be addressed for a complete understanding of an oral feeding problem:

- ▶ the pre-oral phase of eating and drinking, intra-oral bolus preparation, and swallowing
- ▶ respiratory function
- ▶ the diagnosis, treatment and complications of the underlying medical, neurological, surgical or psychiatric condition
- ▶ the environment, including the availability of carers and the nature of the food and drink provided.

A description of each area follows to highlight the complexity and vulnerability of oral feeding.

### **The pre-oral phase, intra-oral bolus preparation, and swallowing**

1.8 The pre-oral phase includes appropriate and necessary implement use by patient or carer, choosing the order in which the food is to be presented, salivation and other anticipatory behavioural responses, and the traditional social interactions.

1.9 Intra-oral bolus preparation depends on dentition, salivation, chewing (muscles supplied mainly by the fifth cranial nerve (V)), and control and manipulation of the bolus by the muscles of the tongue (XII) and face (VII).

1.10 The main muscle of the upper oesophageal sphincter is the cricopharyngeus. It is attached anteriorly to the posterior part of the cricoid cartilage which sits above the highest tracheal ring and below the larynx. Bolus transit depends on the upwards and forwards movement of the hyoid and larynx (V, VII, segments 1–3 of cervical spinal cord); the cricoid follows and its movement pulls open the relaxed cricopharyngeus. The associated drop in pressure (about 30 mmHg) pulls the bolus into the upper oesophagus. Hyolaryngeal movement is easily seen and palpated at the bedside.

1.11 Airway closure depends on the sphincteric action of the larynx which entails apposition of the true and the false vocal cords, and of the arytenoids; the epiglottis completes airway protection by covering the laryngeal inlet (all X).

1.12 When the head of the bolus is in the upper oesophagus apposition of the posterior pharyngeal wall (X) and the base of the tongue (XII) initiates a propagating wave of peristalsis which first clears the pharynx of bolus residue and then continues into the oesophagus. With muscle relaxation, the involved

structures return to their starting positions, assisted if necessary by contraction of the infrahyoid musculature (C1–3).

1.13 Therefore swallowing, as defined here, comprises laryngeal elevation, laryngeal closure, opening of the upper oesophageal sphincter, bolus transit from mouth to oesophagus, and the subsequent return of the involved structures to their starting positions. The larynx is centre stage in swallowing: the upwards and forwards movement leads to opening of the cricopharyngeus, and its closure is the main mechanism of airway protection.

### **Respiratory function**

1.14 The pharynx is an airway and a ‘food-way’. This creates the potential for aspiration, usually defined as bolus reaching or breaching the true vocal cords. The main protective response is coughing which is dependent on the strength and function of the respiratory muscles, timely laryngeal closure and opening, and posture control. A bolus lodged in the larynx, or in the bronchi and more distal airways, is propelled towards the pharynx and then swallowed or expelled by further coughing, gagging, retching or vomiting.

1.15 In health, swallowing is usually preceded and followed by expiration which promotes the egress of bolus away from the laryngeal inlet before and after each swallow; the opposite would cause bolus inhalation. During a swallow respiration is necessarily arrested, the so-called deglutition apnoea.

1.16 Patients with established parenchymal lung disease may be more susceptible to the development of respiratory complications following aspiration and the diseases themselves may reduce the effectiveness of coughing. Breathlessness itself makes oral feeding difficult.

### **Medical, surgical, neurological and psychiatric conditions**

1.17 General medical problems such as loss of appetite; nausea; xerostomia (dry mouth); pain; lower oesophageal inflammation, infection and dysmotility; oral infection and ulceration; and poor dentition are some of the problems that can cause or contribute to oral feeding failure.

1.18 Structural disease of the face, mouth and upper gastrointestinal tract, including the effects of recent or past surgery and radiotherapy, can preclude effective oral preparation of the bolus and swallowing, and compromise or preclude oral feeding.

1.19 Neurological problems such as weakness; loss of voluntary control; apraxia of the face, lips tongue and palate; coma; deleterious changes in conscious level, vigilance, attention and concentration; impairments of posture, balance, visual fixation, spatial awareness; and poor coordination are examples of some of the neurological problems which may affect the pre-oral phase, bolus control in the mouth, swallowing and respiratory function.

1.20 Major psychiatric disease such as severe depression and anorexia nervosa, and some of the prescribed drugs, may compromise or preclude oral feeding.

### **Environmental and situational factors**

1.21 The availability of carers, the consistency, temperature and appearance of available food, the atmosphere in the ward or home including the number of distractions and interruptions, and a lack of appropriate seating, all have the potential to disrupt oral feeding. These are of particular relevance to the pre-oral stage, which is so important in those patients with conditions affecting social conduct and behaviour.

### **Anatomical and pathological diagnosis**

1.22 The symptoms and signs related to problems with intra-oral bolus preparation and swallowing are limited and non-specific, particularly in the early stages of a number of structural and neurological diseases. Structural disease of the head and neck and the upper gastrointestinal tract must be excluded in patients with an isolated oral feeding problem unless there is a verifiable neurological diagnosis.

1.23 The limited range of symptoms and signs can also make it difficult to differentiate between the early stages of different diseases of the central and peripheral nervous system, and between a neuropathy and a myopathy. Additional signs should be sought in the limbs, where the range of clinical signs related to bulk, speed of movement, tone, strength, reflexes, sensation and function is much greater.

1.24 For patients with an established diagnosis any weight loss should be adequately explained and commensurate with the stage of the condition and the severity of the oral feeding problem. This is particularly relevant in the elderly where additional investigations may be required to exclude the co-existence of two diseases. Conversely, many conditions commonly complicated



by oral feeding problems also cause a significant loss of muscle bulk, and the resulting weight loss does not require an alternative explanation. Motor neurone disease is a good example.

1.25 Neoplastic diseases, particularly those involving the upper gastrointestinal tract, can cause both local and systemic problems, both of which can cause weight loss and compromise oral feeding.

### **Voluntary and reflex function**

1.26 To understand the mechanisms of oral feeding problems in different neurological diseases it is useful to distinguish between voluntary and reflex swallowing, and voluntary and reflex coughing.

1.27 Reflex swallowing is best thought of as a very effective upper airway protective mechanism that promptly dispatches into the upper oesophagus anything threatening the airway. It complements other upper airway reflexes such as coughing, gagging, retching and vomiting. In some degenerative diseases affecting the central nervous system, this reflex function continues to protect the airway and provides a potential mechanism for limited oral feeding, if the appropriate support is available. Like other upper airway reflexes it is impaired in depressed consciousness.

1.28 Voluntary swallowing comprises the same immutable sequence of muscle activation but is less dependent on stimulation provided by the bolus and is preceded by intra-oral bolus preparation. Healthy adults are able to judge when a bolus is ready, and the tailored swallow that follows is initiated voluntarily. This is borne out by the experience of normal eating, and radiological observations of hyolaryngeal movement; this occurs before the first movements of a bolus held in the mouth.

1.29 The same principle applies to voluntary and reflex coughing. Degenerative diseases such as Huntington's chorea and motor neurone disease may impair voluntary coughing, notably on request during a clinical assessment, but reflex coughing in response to something threatening the airway is usually well preserved, and often is exaggerated.

1.30 This dissociation of voluntary and reflex function is best illustrated by some patients with motor neurone disease who due to central nervous system involvement are unable to speak, to summon a voluntary cough, to cooperate with simple tests of respiratory function, or to control a bolus in their mouth, but who retain effective, sometimes explosive, reflex coughing in response to a

bolus threatening the upper airway. Conditions of the peripheral nervous system do not exhibit this dissociation of voluntary and reflex function so obviously therefore the observations made during clinical examination are likely to be more representative of overall oral feeding and coughing ability.

### **Mechanisms of oral feeding problems in different conditions: illustrative examples**

1.31 The description of the component parts of oral feeding will be used to discuss the mechanisms of oral feeding problems in some neurological conditions, chosen for illustrative purposes. The emphasis is on the different mechanisms of oral feeding problems rather than the effect of the feeding problems on the natural history of the underlying condition.

#### **Alzheimer's disease**

1.32 Alzheimer's disease is a cortical dementia characterised by changes in memory, conduct and behaviour, with relative preservation – until the advanced stages of the disease – of physical functions such as oral feeding, respiratory function and mobility.

1.33 The pre-oral phase is vulnerable to changes in conduct and behaviour, agitation, restlessness, loss of appetite, changes in the response to food, and problems using cutlery and cooperating with carers.

1.34 Intra-oral bolus preparation and the voluntary initiation of swallowing can become impaired due to an apraxia of the face, lips and tongue but, in the absence of anything to cause lower motor neurone denervation of the involved structures, swallowing and coughing, certainly at a reflex level, are relatively preserved.

1.35 Other types of degenerative disease associated with dementia may cause oral feeding problems with specific mechanisms; the oromandibular dystonias of multi-system atrophy, and the swallowing problems seen in patients with Lewy body disease following exposure to drugs of the major tranquilliser group are two examples.

#### **Brain stem stroke**

1.36 Common symptoms and signs include nausea, sensory loss in the mouth and pharynx, vomiting, and vertigo, all of which disrupt the pre-oral phase and intra-oral bolus preparation.

1.37 If the tenth nerve nucleus in the lateral medulla is involved (lateral medullary syndrome) the larynx loses its nerve supply on that side. During oral feeding, aspiration is inevitable because the larynx cannot close; for the same reason, voluntary and reflex coughing are (equally) ineffective. The integration of oral feeding with the respiratory cycle may be disrupted. Oral feeding is usually impossible for weeks or months.

1.38 In medial medullary syndrome, the twelfth nerve nucleus is involved. This causes weakness and wasting of the tongue on that side but laryngeal function during oral feeding and coughing should be relatively preserved. Oral feeding is less disrupted.

1.39 The following illustrates how the mechanism of an oral feeding problem is dependent on the anatomical structures involved.

### **Left middle cerebral artery stroke**

1.40 In a typical left middle cerebral artery occlusion the patient suddenly develops dysphasia, weakness of the right side involving the face and arm more than the leg, and trunk weakness which can affect posture control during sitting and standing.

1.41 If there is extensive infarction, intracranial pressure may rise; in this situation, oral feeding is not possible mainly because of the associated drop in conscious level.

1.42 The conscious patient with an established infarct has impaired control of the arm and hand on one side which causes predictable problems with the pre-oral phase. An apraxia or paralysis of the face, lips, tongue and palate will cause problems with intra-oral bolus preparation and the voluntary initiation of oral feeding, but the reflex components of oral feeding and coughing should be relatively preserved. Oral feeding is usually possible after a period of difficulty lasting days to weeks.

### **Motor neurone disease**

1.43 This condition affects either the motor neurones from the cortex to the brain stem and spinal cord, or the lower motor neurones supplying the corresponding musculature and usually the condition (eventually) involves both, producing upper and lower motor neurone problems. It can start anywhere in the body and the rate of progression is variable; for all these

reasons it is mimicked by, and mimics, many conditions. Diagnosis may be particularly difficult in the early stages.

1.44 If there is mainly upper motor neurone involvement the patient has weakness and slowing of movement of the affected part. Hand function for the pre-oral phase is compromised by weakness and a loss of fine control but spasms and spasticity of the limbs are not usually a big problem. Tongue and facial involvement causes a dysarthria and impaired intra-oral bolus preparation. Patients may have difficulty coughing to command but reflex coughing is often dramatically well preserved.

1.45 If there is lower motor neurone involvement there is wasting and weakness of the involved structures and no reserve of function to call upon during reflex swallowing or reflex coughing. Involvement of the face and tongue produces weakness and wasting with relative preservation of fine control in the early stages. Respiratory muscle weakness manifests clinically as paradoxical (in rather than out) movement of the abdominal wall during inspiration due to the weak diaphragm being pulled into the thorax, and by reductions in the indices of lung function such as forced vital capacity, in the absence of a problem with the organisation of the required manoeuvre.

1.46 The combination of the loss of fine control and profound weakness affecting the muscles of bolus control in the mouth, oral feeding and respiration makes oral feeding impossible, although those patients with pure upper motor neurone involvement can continue to feed by mouth for many years.

### **Huntington's disease**

1.47 Huntington's disease causes a slowly progressive dementia accompanied by chorea (dancing movements) of the limbs and of the tongue. It affects only the central nervous system.

1.48 The pre-oral phase is unhinged at an early stage because of problems using cutlery and with placement of food in the mouth. Intra-oral bolus preparation can be affected by chorea of the tongue and head. The swallowing process is relatively preserved but poor oral control of the bolus can lead to aspiration. However, because coughing is preserved, certainly at a reflex level, patients can protect their airway and oral feeding is often possible until the advanced stages of the condition, particularly if there is a suitably trained carer who learns how to feed the person. In the advanced stages patients may become apathetic and withdrawn and lose their appetite.

## Clinical approach to the patient

### The common clinical situation

1.49 Clinicians may be asked to see the following types of patient specifically to consider oral feeding issues:

- ▶ patients in whom a problem with oral feeding is anticipated or suspected because the patient has suggestive symptoms, or relevant clinical or radiological signs
- ▶ patients who are recovering from a period of illness during which they were fed using a gastrostomy or nasogastric tube and the main issue relates to when they can be fed by mouth again
- ▶ patients with a problem which is commonly associated with oral feeding problems and designated 'Nil by mouth' even without any relevant symptoms and signs, or who have been observed eating and drinking. Acute stroke is the most relevant clinical example.

### The common clinical questions

1.50 The consultation between a health professional and a patient with an oral feeding problem – real or perceived – usually relates to one of three questions. Although related, the approach to each question is different. The information gathered in answering one does not directly answer the other two.

1.51 A closer examination may illuminate some common misunderstandings and help standardise the approach of all health professionals.

#### *1 What is the underlying diagnosis?*

1.52 The conventional approach of history, examination, and investigation leads to an anatomical and pathological diagnosis. Traditionally this is the remit of the doctor.

1.53 However, the information acquired during a diagnostic consultation does not always explain the exact mechanics of a feeding problem, or yield an index of feeding ability.

#### *2 What is the mechanism of the oral feeding problem?*

1.54 An understanding of the mechanism of a feeding problem comes from an understanding of the underlying condition and by watching the patient eat and drink. However, it is possible to understand the mechanism without

knowing the underlying disease or the extent to which their ability to feed by mouth is, or will be, compromised. The mechanism of a feeding problem is something that may be considered by the medical staff or by the speech and language therapist (SLT).

### *3 Can the person eat and drink, and, if so, at what risk?*

1.55 This is perhaps the most difficult question to answer for a composite function like oral feeding, which comprises many other composite functions. It concerns ability, and the risk of testing and/or using that ability. Diseases have to be diagnosed, mechanisms deduced, but abilities have to be tested. Any test of ability will inevitably involve risk. The risks causing most concern are aspiration, unacceptable coughing and choking, or of the process being an unacceptable burden; this is true for one-off assessments and long-term proposals to continue oral feeding.

1.56 An attempt to categorise abilities on a continuum is always arbitrary. Abilities are susceptible to change over time and to fatigue and situational factors. An ability sufficient to feed by mouth one day may be inadequate the next. This common conundrum may be unanswerable by single or paired assessments. In difficult cases observation over longer more representative time periods is required.

1.57 Speech and language therapists are frequently asked questions two and three. Some of their assessment techniques will be described, followed by those used to preserve or promote oral feeding.

## Assessment of oral feeding

### Methods

1.58 The **history** given by patients and carers, or their replies to semi-leading or direct questions is valuable. Information about the time before the assessment, including records of oral intake, may also help this. **Examination** includes observation of eating and drinking. Coughing, choking, or obvious distress strongly suggest a problem. Conventional observation can be supplemented by video recording of self feeding, of assisted feeding, and of carers feeding patients. Observation can be more focussed. For example, it can be inferred from specific signs such as a wet hoarse voice quality that laryngeal closure is impaired. Some clinicians record indices of function such as a timed test of swallowing for which there are normative data. Joint assessments of position, tone and abnormal responses can be very informative.

1.59 **Instrumental examination** includes videofluoroscopy, fiberoptic endoscopic evaluation of oral feeding (FEES), pulse oximetry recordings during oral feeding, and cervical auscultation.

1.60 Videofluoroscopy provides two-dimensional radiological images of the bolus and the involved structures. The amplitude and timing of movements of the bolus and the involved structures are easily appreciated. Aspiration into the airway, and the response to it, are apparent. It can be complemented by manometry to obtain pressure measurements from the pharynx and upper oesophageal sphincter and by conventional video recordings of the subject to simultaneously record their responses.

1.61 Functional endoscopic evaluation of oral feeding involves direct visualisation of the larynx and pharynx via a nasendoscopy during oral feeding. The gross anatomy can be seen at rest and during the initial phase of oral feeding but palatal elevation obscures the view of the larynx as the bolus passes into the upper oesophagus.

1.62 If intermittent hypoxia or other feeding related changes in behaviour are unexplained, recordings of arterial  $pO_2$  can be revealing. The role of cervical auscultation is unclear as the sounds of oral feeding or aspiration into the larynx cannot be reliably identified.

## Management

1.63 A well informed team in close contact with the main carers should be able to consider the net benefit of the four main options:<sup>4</sup>

- ▶ full oral feeding using a range of compensatory strategies
- ▶ a combination of oral and non-oral feeding
- ▶ palliative feeding using small amounts of food, mainly for enjoyment
- ▶ alternative nutrition using non-oral methods.

1.64 Factors to be considered when helping patients decide on immediate or long-term nutrition include:

- ▶ medical and nutritional status
- ▶ severity and prognosis of both the underlying disease and the mechanism of the oral feeding problem
- ▶ feeding and respiratory function
- ▶ risks associated with the choice.

If an element of oral feeding is involved there are strategies to help preserve and promote oral feeding.

## Strategies to support oral feeding

1.65 SLTs can advise on strategies to minimise aspiration risk,<sup>5,6</sup> facilitate eating and drinking, and improve nutritional status.<sup>7</sup> These are modifications of food and fluids including changes to texture, consistency and quantity; swallowing strategies including manoeuvres and sensory techniques; positioning and postural techniques; external strategies such as carer support, environment and administering food and drink; and behavioural and cognitive techniques.

### Dietary modifications of food and fluids

1.66 The *National descriptors for texture modification in adults* (2002)<sup>8</sup> provides SLTs and dietitians with a common terminology. Foods range in texture from a thin smooth consistency to solid food which requires chewing. Drinks range in consistency from thin to pudding. The effect of modifications on nutritional value and the need for fortification of foods and energy-dense drinks should be considered. Changes in portion and bolus size are important. Medication may have to be prescribed in alternative forms.<sup>9</sup>

### Oral feeding strategies

#### *Oral feeding manoeuvres*

1.67 The patient must comprehend the instruction, implement the manoeuvre and use the technique. Swallow manoeuvres include clearing swallows, effortful and supraglottic swallows.

#### *Sensory techniques*

1.68 Sensory loss in the mouth and pharynx can impair oral feeding but hypersensitive responses such as a bite reflex or tongue thrust can preclude oral feeding and compromise oral hygiene. In each case there are therapeutic options.

1.69 Reduced sensation may be helped by:

- ▶ thermal stimulation with ice or chilled material applied to the oropharyngeal musculature; and
- ▶ stretching and manipulation of the oral musculature to mimic the normal oral movements of teeth cleaning, eating, and clearing the mouth of food.

Oral desensitisation routines are also available.<sup>10</sup>



## Positioning and postural strategies

1.70 Postural techniques are particularly useful for changing the direction of the bolus and include chin tuck, head rotation to the affected side, head tilt, side lying or remaining upright. These must be implemented throughout the meal or drink. They require a degree of physical ability or some assistance if the patient has limited movement. All patients benefit from a period of time in an upright position after eating and drinking to reduce oesophageal reflux.

## External strategies including carer support

1.71 Many patients will require assistance to eat and drink. The level of assistance required may vary from minimal help with food preparation, to full dependence on carers to select meals and feed them.<sup>11</sup> Carers therefore play an extremely important role in carrying out the recommendations prescribed by the SLT. Carers need training and support to ensure that they are using the correct techniques and are complying with guidance. Many patients rely completely on having a carer who is familiar with their oral feeding technique, their need for appropriate cues, and their dietary preferences. Carers should be fully supported and apprised of any changes in management.<sup>12</sup>

## Behavioural and cognitive techniques

1.72 These are of particular relevance in patients with cognitive or affective disorders causing behavioural change. Snacks of appropriate consistencies for those reluctant to eat at mealtimes,<sup>13</sup> external cues to remind patients to request a drink or snack, or the planned and recorded provision of drinks throughout the day may be necessary.<sup>14,15</sup>

1.73 Carers may need to sit with patients to ensure that they finish meals. Families may be helpful in identifying known favourites particularly when a patient is reluctant to eat and drink.

1.74 Education of the patient, the family and all the caring staff – including domestic and kitchen staff – is vital for the successful implementation of an oral feeding programme. Many patients with oral feeding difficulties have reduced ability to follow or implement oral feeding strategies. This increases their dependency on carers, relatives or healthcare staff who have to ensure that oral feeding guidelines and oral feeding strategies are being implemented.<sup>16</sup> Failure to adhere to guidelines has been associated with adverse

outcomes such as increased incidence of aspiration pneumonia and high mortality rates.<sup>17</sup>

## Communication

1.75 The ability to communicate effectively is a vital skill in appropriate decision making, especially at times of crisis when stress, fear, intimidation and unfamiliarity with the setting can overwhelm even sophisticated patients and families.<sup>18</sup> Professionals are responsible not merely for attempting to communicate but for ensuring that effective communication has taken place. This can be stressful and exact a psychological toll on doctors and others.

1.76 Effective communication requires time, a commodity often in short supply. It also requires factual *knowledge* of what is to be communicated and *ethical choice* about how such information is to be selected, ordered and expressed. Esoteric vocabulary may intimidate and inappropriate tone or gesture may offend. Establishment of empathy may demand a profound cultural understanding. When working with patients who present with degenerative disease or substantial long-term conditions, advanced communication skills are an essential prerequisite in order to engage in complex negotiation on topics of an emotional nature.

### Communication of verbal and written information

1.77 Many patients with oral feeding difficulties have communication or cognitive disabilities which affect understanding, retention and processing of verbal and written information and communication of needs. The multi-disciplinary team should ensure that appropriate measures have been taken to enable participation in discussions and decision making.

1.78 The team must ensure the following practical measures are provided:

- ▶ using appropriately trained staff to speak to patients and relatives
- ▶ awareness of any communication and cognitive impairments the patient may have, eg dysphasia, learning difficulties
- ▶ familiarity with how the patient communicates
- ▶ communication aids, eg alphabet charts, hearing aids
- ▶ strategies, eg drawing, gesture
- ▶ using trained interpreters to speak to patients where English is not understood<sup>19</sup>

- ▶ accessible written and pictorial information left to be read at leisure, eg leaflets on oral feeding, alternative nutrition, videofluoroscopy or meal selection
- ▶ allocation of sufficient time for explaining information
- ▶ limitation of information given in one session; several short conversations are better than one lengthy session
- ▶ information to be repeated to aid comprehension
- ▶ opportunity to ask questions
- ▶ a quiet, private environment free from distractions
- ▶ choice of an appropriate time of day; if the patient is too tired by the afternoon, wait till the morning
- ▶ finding out whether the patient wants anyone to join them, eg a family member.

1.79 Many of the above recommendations will also apply to patients with no specific communication difficulties, especially if unwell.

### **Non-verbal communication**

1.80 Communication is not always about factual information. It may be to express solidarity with a fellow human being, compassion or respect. Staff members' frequent attendance at the bedside may prevent the perception that the patient is being abandoned, for example, if nutrition and hydration have been withdrawn. Physicians ought not to use 'busyness' and the presence of a team as excuses to abdicate their responsibilities for comprehensive compassionate care of dying patients. The concerned physician who spends extra time at the bedside becomes an invaluable exemplar.<sup>20</sup> 'They also serve who only stand and wait.'<sup>21</sup>

### **Advance care planning**

1.81 Patients with progressive conditions that are likely to lead to artificial nutrition and hydration should be encouraged to discuss their preferences about care in situations that are likely to occur. Most patients welcome such discussions.

1.82 Advance care planning has been defined as a process of discussion between an individual, their care providers, and often those close to them, about future care. Discussion may lead to a statement of wishes and preferences

(an advance statement), and advance decision to refuse treatment in a pre-defined potential future situation or the appointment of a personal welfare Lasting Power of Attorney. All of these can help care providers should the individual lose capacity. Concise evidence-based guidelines on advance care planning were published by the RCP in 2009.<sup>22</sup>

1.83 Doctors have a responsibility to consider timely discussions,<sup>23</sup> but not all may do so consistently. The best time to begin such discussions is during the course of routine, non-emergency care, remembering that not all patients are emotionally prepared, by virtue of their stage in life, their psychological make-up or the stage of their illness. Nevertheless, as a matter of routine, doctors should become acquainted with their patients' personal values and wishes and should document them. Such discussions and the resultant documentation should be part of the minimal standard of acceptable care. The doctor should take the initiative in obtaining any documentation and should enter it in the medical record. Such issues may need a higher profile in training programmes.

## The team

1.84 Multidisciplinary team working is essential in managing individuals with oral feeding difficulties.<sup>24</sup> Healthcare professionals should include doctor, speech and language therapist, dietitian and nutrition nurse working closely with the patient as well as the family and carers. Best practice occurs with collaborative working free from demarcation disputes, termed 'cross functionality'.<sup>25</sup> Advice on how to set up a nutrition support team is available in the literature<sup>26</sup> together with the qualities required for the physician involved.

## Metabolic consequences of withholding nutrition

1.85 Food and water are essential for life. Where nutrition is withheld, death will follow. The duration between withholding nutrition and death can be as long as 10 weeks but where hydration is also withdrawn may be as short as three days and usually no longer than 14. If water is given in the absence of food, survival is long enough for death from nutritional deprivation to occur. Whilst giving hydration seems a humane act, it may prolong dying. Artificial nutrition requires a liquid medium. Withholding artificial nutritional support (nasogastric tube (NGT) or percutaneous endoscopic gastrostomy (PEG))

excludes both nutrition and hydration. Water may be given without nutrition but artificial nutrition cannot be given without water. If artificial non-oral nutrition is withdrawn or withheld, death will be rapid from dehydration unless an alternative route for hydration is used. Withholding food alone with adequate hydration leads to death in approximately nine weeks (Northern Ireland hunger strikers survived 57–70 days), provided nutrition was initially normal and the subject well. If any injury is present, including infection, death from nutritional deficiency is accelerated. The presence of cancer, systemic inflammation, advanced AIDS or end stage dementia may also limit the benefits of any food given due to adverse metabolic changes often caused by cytokine-induced catabolism. If this can be reversed (not always possible) then nutritional support will be more effective.

1.86 In healthy individuals, absence of food leads to an adaptive metabolic response with a marked reduction in metabolic demands. Reserves of protein, fat, electrolytes, vitamins and trace elements can be used more economically thereby protecting essential organs and postponing death from malnutrition. Such patients demonstrate increased insulin sensitivity and may become hypoglycaemic. This adaptive response is protective but fragile. It can be reversed by low levels of carbohydrate intake, infection, injury and other forms of stress. Such stresses may include surgery, fractures and terminal cancer.

1.87 Under these conditions, the metabolic rate may rise to greater than normal, thus consuming fat and protein reserves rapidly. Insulin resistance leads to hyperglycaemia. In the absence of nutritional intake, nutritional decline is rapid and leads to death. Coma often supervenes. If injury/infection occurs in a patient already depleted by nutritional deficiency, decline is even more rapid. In malignant disease, this is called anorexia/cachexia syndrome (ACS).

1.88 ACS affects up to 80% of those in terminal stage cancer and describes a state in which the patient is anorexic (poor appetite), and cachexic (weight loss and muscle wasting). The incidence of cachexia is highest in lung and gastrointestinal (GI) cancers. The pathophysiology is not fully understood but involves cytokines and hormones released by the cancer.

1.89 In comparison to simple starvation in which there is conservation of skeletal muscle over fat stores, in cancer cachexia neither fat nor protein is spared. There is an imbalance between skeletal muscle protein synthesis and breakdown, resulting in a net loss of muscle. The metabolism of fat is also

altered with increased lipolysis, ie fat breakdown, contributing to the overall reduction in weight. A higher relative state of anaerobic metabolism in cancer cells leads to increased lactic acid production, which signals the liver to increase glucose production. Glucose then returns to the tumour cells to produce more lactic acid – known as the ‘Cori cycle’. The activity of this cycle is increased up to 50% in patients with cancer. These changes in metabolism are resistant to increasing the calorie intake of the patient, either enterally or parenterally. Any weight gain with nutritional support in such patients is due to increased body water, often seen as oedema. At most, nutritional support in such patients may do no more than limit lean body weight loss.

## End of life

1.90 One prognostic indicator that the life expectancy of a person with advanced cancer has dropped from months to a few weeks or days is the development of a lack of interest in food and drink. In the dying phase, a patient’s desire for food and drink lessens. Good mouth care rather than attempting to feed a patient becomes the more appropriate intervention. This is one of the goals of care outlined and monitored in the Liverpool Care Pathway for the Dying Patient. It is important at this stage to consider the appropriateness of continuing PEG or NGT feeding if this has previously been carried out. Indeed, the discontinuation of iv fluids must also be considered, as at this late stage it often only serves to exacerbate pulmonary oedema, peripheral oedema and increased secretions, which the semi-conscious patient is unable to manage. Clear reasons should, of course, be identified for withdrawal of nutrition and hydration, not blind adherence to a protocol.

## Nature/mode of death if nutrition is withheld

1.91 The consequences of malnutrition are lethargy, apathy, impaired muscle function leading to immobility, hypostatic oedema, respiratory muscle failure and pneumonia, myocardial muscle dysfunction, thromboembolism, impaired temperature control, falls, pressure sores. Specific deficiency syndromes such as scurvy or Wernicke–Korsakov’s syndrome may be manifest. If hydration is also withdrawn, death occurs rapidly due to renal failure or pneumonia.

1.92 Those with intact cognitive function who are unable to eat or drink must be involved in decision making as their perception of the process resulting from absence of food will be different from those with absent

cognitive function. It is commonly believed that death from absent nutrition or hydration is distressing or painful for the patient. This may be true for some, especially those with better cognitive function. However, appetite is often severely reduced in terminal disease and the sensations of hunger and thirst are suppressed. For those who are severely cognitively impaired, there is little evidence that hunger or thirst are perceived significantly. Indeed, such patients may resist the efforts by carers to offer food or fluids. Such rejections may be no more than reflex responses. The dilemma of whether to ‘force feed’ such patients by mouth or artificially then arises.

# 2 Techniques of artificial nutrition

2.1 Tube feeding means feeding via naso-gastric (NG) or naso-jejunal (NJ) tube, percutaneous endoscopic gastrostomy (PEG), radiologically inserted gastrostomy (RIG), percutaneous endoscopic jejunostomy (PEJ), and surgically placed jejunostomy. The NG and PEG routes are usual.

## Enteral nutrition

2.2 Modern artificial nutrition began in the early 1980s with the introduction of fine bore nasogastric tubes (NGT) and, almost simultaneously, endoscopic placement of a percutaneous endoscopic gastrostomy tube (PEG). Hitherto, only large bore tubes were available. These were poorly tolerated and rarely used for more than a few days feeding. Widespread use of fine bore tubes or PEGs then enabled home artificial nutrition. Perhaps unexpectedly, this development postdated home intravenous nutrition (see below). Patients with difficulties in oral feeding would spend longer in hospital without routine artificial nutritional support. Death would result from aspiration pneumonia induced by ongoing oral nutrition and hydration or from malnutrition and dehydration. The advent of artificial nutrition in hospital and at home or in nursing homes radically challenged the permissive management of the advanced stages of neurodegenerative diseases. Patients with obstructive dysphagia due to inoperable oropharyngeal, laryngeal or oesophageal cancer could also now be fed artificially for long periods at home. In addition, enteral access also enables non-nutritional treatments such as analgesia.

2.3 The British Artificial Nutrition Survey (BANS) has been following trends in home enteral nutrition since 1996. Recent data indicate that 50% of new cases and 58.5% of established patients on home enteral tube feeding (HETF) have neurological diagnoses, with cerebrovascular accident the dominant diagnosis. However, there is a wide range of diagnoses represented (Table 1). In many, nutritional interventions raise ethical dilemmas towards the end of life, especially in those with impaired cognitive function. This is

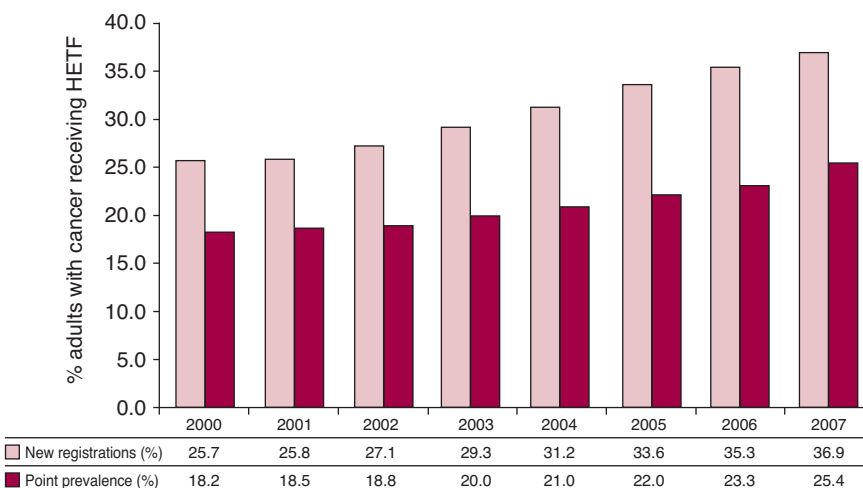


not uncommon in degenerative neurological disease. Cancer continues to increase as the primary diagnosis in enterally fed patients at home (Fig 1). By contrast with patients with neurological diseases, cognitive function is usually maintained.

**Table 1** Adults with neurological conditions receiving HETF in UK, 2007.<sup>27</sup>

	New registrations		Point prevalence	
	n	%	n	%
Cerebral palsy	85	1.6	1,093	5.0
Cerebral trauma	140	2.7	831	3.8
Cerebral tumour	23	0.4	97	0.4
Cerebrovascular disease	1,241	23.9	5,553	25.4
Congenital handicap	27	0.5	371	1.7
Dementia	109	2.1	582	2.7
Huntington's chorea	39	0.8	280	1.3
Motor neurone disease	268	5.2	792	3.6
Multiple sclerosis	214	4.1	1,386	6.3
Muscular dystrophy	19	0.4	130	0.6
Parkinson's disease	169	3.3	603	2.8
Unspecified CNS condition	254	4.9	1,065	4.9
<b>Total</b>	<b>2,588</b>	<b>49.9*</b>	<b>12,783</b>	<b>58.5*</b>

\*% of BANS registrations with neurological disease.



**Fig 1** Increasing proportion of patients receiving HETF with cancer (2000–2007).<sup>27</sup>

## Choice of enteral route

2.4 It is best to consider three main routes for enteral feeding – NGT, gastrostomy or jejunostomy. NGTs are easily displaced but can be re-passed frequently, albeit with some minor distress. Ensuring a satisfactory intra-gastric infusion may be difficult. PEG or PEJ placement is invasive with significant morbidity and mortality, particularly in the elderly and those with debilitating disease. Alternatives are radiologically placed gastrostomy, a jejunal extension passed via the PEG tube, direct percutaneous endoscopic jejunostomy and surgical jejunostomy. Some patients find such treatments burdensome. Patients and carers may assess the risk:benefit ratio differently from professionals.

2.5 To place these three methods of enteral feeding in perspective, UK data from the British Artificial Nutrition Survey indicate that in 2007 there were at least 2,859 patients receiving their nutrition via a nasogastric tube in the community at any one time. This figure is derived from an audit of 80% of all known adult home enteral feeding cases in the UK. The proportional representation of each route has not changed since 2000.

**Table 2** Enteral tube feeding in the community, 2007.<sup>27</sup>

2007	Nasogastric tube		Gastrostomy		Jejunostomy		Total numbers
	n	%	n	%	n	%	
New cases (incidence)	841	16.2	4,010	77.4	331	6.4	5,182
Point prevalence	2,859	13	18,075	82.7	924	4.2	21,858

**Table 3** Enteral tube feeding by location outside hospitals, 2007.<sup>27</sup>

2007	Own home		Residential home		Nursing home		Total numbers
	n	%	n	%	n	%	
New cases (incidence)	3,545	68.4	77	1.5	1,503	29	5,182*
Point prevalence	13,406	61.3	573	2.6	6,822	31.2	21,858*

\*Information not provided on all cases.

Table 4 Enteral tube feeding in nursing homes, 2007.<sup>27</sup>

2007	Nasogastric tube		Gastrostomy		Jejunostomy		Total numbers
	n	%	n	%	n	%	
New cases (incidence)	137	9	1,352	90	14	1	1,503
Point prevalence	391	6	6,362	93	69	1	6,822

2.6 NGT feeding accounts for 16% of total incidence and 13% of the point prevalence of enterally fed patients in the community. Most of those receiving HETF have oral feeding difficulties. Many are towards the end of their lives or will become so while receiving artificial nutritional support.

## Nasogastric versus gastrostomy feeding

### Complications on insertion

2.7 NGT placement is usually extremely safe but complications may occur if attention is not paid to detail. Intracranial passage via the cribriform plate is recorded. More commonly, epistaxis or bronchial placement can occur. Perforation of the oesophagus is unlikely unless inappropriate re-passage of the wire stylet leads to a false passage. Assessing successful placement by measuring the length of tube from the nares is unreliable as the tube may double back in the oesophagus or pharynx. Compliance with National Patient Safety Agency advice is important. Failure to obtain an aspirate of pH <5.5 poses difficulties which require an X-ray to confirm tip position. This may be difficult since patients in the community cannot be transported for X-ray every time the tube is replaced, so there needs to be an element of clinical judgement employed in managing the risk if this cannot be done easily.

2.8 PEG placement usually requires conscious sedation with midazolam, although use of a narrow bore endoscope can obviate this need. The risks are those of sedation, endoscopy and penetration of the peritoneal cavity and stomach wall. These include visceral perforation, intra-abdominal haemorrhage, peritonitis, stomal sepsis and colonic perforation or transfixion. Morbidity and mortality are common with PEG insertion which should never be undertaken lightly. Antibiotic prophylaxis is recommended (British Society

of Gastroenterology). Non-endoscopic techniques (RIG) still require nasogastric tube placement to inflate the stomach but sedation is not required. Whatever method is used, it is important to recognise that for some patients placement of a gastrostomy is not possible because the stomach is above the diaphragm. Such patients will need a nasogastric tube and it is important that arrangements exist for them to be cared for outside an acute hospital (see [para 2.20](#)).

2.9 *Replacement and removal:* removal of an NGT is simple. Replacement is usually straightforward but confirmation of tip position is required. NGTs can be re-passed frequently, albeit with some distress, but their disadvantages are ease of displacement and the difficulties of ensuring a satisfactory intragastric infusion. Delays in re-passing displaced NGTs are common and interfere with achieving nutritional objectives.

2.10 A new placement system for NGTs permits repeated insertion of NGT and simultaneous confirmation of its position in the stomach without aspiration of gastric contents.<sup>28</sup>

2.11 PEGs by comparison cannot be replaced or removed without repeat endoscopy unless of the balloon or skin level type. Gastrostomies may be placed or replaced by non-endoscopic (eg radiological) methods but such techniques are not practised widely throughout the UK. PEGs can be allowed to pass through the GI tract after cutting off at skin level if there is no increased risk of obstruction. If PEG feeding is withdrawn, the PEG can be left in situ unless associated with complications such as infection. PEGs should not be replaced or removed in the first two weeks after insertion as a track will not have formed.

### **Complications after tube placement**

2.12 NGTs may be associated with sinusitis, sore throats, difficulty swallowing, candidiasis or aspiration pneumonia. Displacement, blockage and even knotting are frequent. PEGs also block and can become displaced. Excessive traction on the inner flange leads to the buried bumper syndrome, treatment of which can be difficult and dangerous. Haemorrhage from the gastric wall, peristomal sepsis including MRSA, and pyloric obstruction add to the potential list of complications.

2.13 *Security:* NGTs are notoriously liable to displacement and then require replacement and reconfirmation of distal tip position. If the tube is

frequently displaced, a nasal loop can be placed but these are not foolproof. Unnoticed displacement into the oesophagus or hypopharynx poses serious risk of aspiration. Risk of aspiration from NGT feed cannot be eliminated. Many patients are at increased risk of aspiration of secretions even without NGT feeding.

## Consent

2.14 As discussed elsewhere, consent before placing a PEG is essential. However, NGTs are sometimes placed without similar discussion. Often, the most basic question has neither been posed nor answered – is feeding appropriate at all? Requests for PEG placement are often received after NGT feeding has commenced without due process of consent or ethical discussion. Even in the short term, NGT feeding requires proper consent and consideration of best interests with benefit weighed against potential complications.

## Parenteral nutrition (PN)

2.15 These techniques include all non-enteral approaches, such as intravenous, and subcutaneous routes. Home parenteral nutrition (HPN) was first described using modern techniques of vascular access in 1969<sup>29</sup> and introduced in the UK in the late 1970s. PN was facilitated by the introduction of the ‘big bag’ in the mid 1980s, enabling easier home administration.

2.16 The case mix of HPN patients varies (Table 5) and is largely limited to affluent countries. In the UK, its commonest indication is short bowel syndrome due to Crohn’s disease as compared to cancer in the USA and mainland Europe. PN/HPN has not been widely used in UK palliative care, as opposed to adjunctive cancer therapy, partly because the enteral route is preferred, and partly because of the risks, logistics and costs of PN. In the UK, PN/HPN is offered to selected patients, usually with high inoperable small bowel obstruction, often in conjunction with drainage of gastric secretions via a PEG. Elsewhere this may be offered to many cancer patients to offset the weight loss from cancer cachexia. Some patients find such complex and demanding treatment burdensome.

2.17 The British Artificial Nutrition Survey (BANS) showed 15 of 88 new HPN registrations in 2000 were for cancer; 16 of 137 in 2007. Point prevalence was 20 in 2000 compared to 48 in 2007.<sup>27</sup>

Table 5 Worldwide HPN differences (point of prevalence).

	Europe	USA	Japan	BANS
Year(s)	1997	1989–92	1990	1998
Number	494	5,357**	231	360
M:F	0.7	1	1.6	
<b>Aetiology</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>
Cancer	39*	41	40	4.2
Crohn's disease	19	11	20	39.8
Vascular disease	15	6	19	9.9
Irradiation	7	3	2	6
AIDS	2	5		
Other	18	34	19	40.1

\*78% in Germany, 80% in Sweden.

\*\*may be as high as 40,000.

## Subcutaneous hydration

2.18 This can be useful as a short-term measure, for example in terminally ill patients, particularly in those with thirst or other symptoms of dehydration, poor venous access and inability to take oral fluids. Pain with larger volumes and subcutaneous bruising or cellulitis may limit its utility and the benefits to the patient are not always obvious.

## Rectal hydration

2.19 This route for administration of drugs and water is rarely used although it is an effective method of hydration and giving some drugs, eg analgesia.

## PEG feeding

2.20 An audit of 719 PEG procedures<sup>30</sup> recommended that it should always follow a multidisciplinary discussion of its value. This followed the demonstration that 19% of PEG placements were futile, and that of those dying, 43% did so within one week. As stated in [para 2.8](#), some patients cannot have a gastrostomy and it is essential that a detailed and informed discussion takes place. The risks and benefits of the procedure versus nasogastric tube

placement must be made clear. A blanket refusal by an organisation to accept a patient for care without a gastrostomy is unethical. The pros and cons must be discussed by all concerned and the risks identified and accepted.

2.21 Rabeneck *et al*<sup>31</sup> developed a decision-making algorithm integrating medical and ethical dimensions that some may find helpful.

## PEG in dementia

2.22 Patients with advanced dementia frequently develop oral feeding problems, eating difficulties or an indifference to food<sup>32,33</sup> leading to a reduction in nutritional intake, weight loss and an increased risk of aspiration. This is often a late event, associated with the final phase of the illness when it is not possible to understand the patient's wishes. The Alzheimer's Society has stated that 'quality of life rather than length of life should be prioritised'. Nevertheless, data from the British Artificial Nutrition Survey indicate that at least 109 new dementia patients and 582 established cases were being fed artificially in the community in 2007 (see [Table 1](#)). See also Alternatives to ANH: social feeding – oral feeding techniques, [paras 2.46–51](#).

2.23 Some doctors and relatives of people with dementia believe PEG feeding to be beneficial. However, there are no randomised controlled trials comparing PEG feeding to hand feeding or other methods of support. Several studies have suggested that where dementia is the reason for PEG placement, it does not extend life and is associated with a greater mortality. In a review of PEG placement in dementia<sup>34</sup> PEG was seldom effective in improving nutrition, maintaining skin integrity, preventing aspiration pneumonia, in improving functional status or extending life. There is no good evidence to support PEG feeding in advanced dementia. These conclusions are echoed in Chernoff,<sup>35</sup> Sanders *et al*,<sup>36</sup> and Finucane *et al*.<sup>37</sup> These studies do not prove that PEG is never indicated in dementia, but do show that the indication is rare. It is of concern that so many new patients are being given tube feeding and raises the question as to whether informed discussion can have taken place.

2.24 In a retrospective five-year analysis of PEG placement in 361 patients,<sup>38</sup> the overall mortality was 28% at one month, compared to 54% in the dementia group (28.5% of entire cohort) and 63% vs 90% at one year ([Table 6](#)). Mitchell<sup>39</sup> found that PEG feeding has not been shown to alter mortality or improve survival.

Table 6 Mortality rate post PEG insertion.<sup>38</sup>

	Patients with advanced dementia (%)	Non dementia patients (%)
At one month	54	28
At one year	90	63

2.25 PEG placement in acutely ill patients with dementia could contribute to mortality. This led to a proposal to defer placement for 30–60 days.<sup>40</sup> The authors made no suggestion as to the interim nutritional management but NGT with a nasal loop to prevent displacement is usual.

2.26 Best practice in these patients might be:

- ▶ discussion of possible oral feeding difficulties in the future and education on ANH with personal wishes documented
- ▶ assessment by a senior physician in nutrition support and SLT before admission to a nursing home
- ▶ in an ‘unsafe swallow’ altering the consistencies, eg thickening fluids, may make feeding manageable and preserve quality of life. This is preferable to routine tube feeding
- ▶ ongoing assessment and support of oral nutrition and hydration with progressive modification of diet towards mushy food and thickened fluids.

2.27 In general then, careful hand feeding is preferred<sup>41</sup> and gastrostomy should not be offered in advanced dementia.<sup>42</sup> The actual insertion of a feeding tube carries risk; patients with advanced dementia have a higher rate of mortality than those without dementia following PEG insertion (Table 6).

2.28 The most extensive review of PEG feeding in dementia is that of Finucane.<sup>37</sup> Although the working party heard questions about its methodology, the review was considered helpful and carried weight.

2.29 Using a PEG in dementia might be expected to show an improvement in certain outcomes including:

- ▶ quality of life
- ▶ aspiration pneumonia
- ▶ prevention of malnutrition
- ▶ prevention/improvement in pressure sores
- ▶ increased survival.



**Box 1 Tube feeding in advanced dementia: the evidence**  
(based on Finucane *et al*<sup>43</sup>).**Does tube feeding prevent aspiration pneumonia?**

It cannot prevent aspiration of oral secretions. There are no data that it reduces risk from regurgitated gastric contents.

It may reduce lower oesophageal pressure and increase risk of gastro-oesophageal reflux, but there are no direct data in the elderly. Diverting the feeding stream lower in the gastrointestinal (GI) tract may reduce aspiration pneumonia.<sup>37</sup>

No published studies show a reduced risk of aspiration pneumonia.

**Does tube feeding prevent the consequences of malnutrition?**

Demented patients with eating problems frequently lose weight. Despite this, provision of apparently adequate nutrition does not prevent weight loss or depletion of lean and fat body mass in those with long-term neurological impairments. In wasting disorders associated with cancer or AIDS, numerous studies have failed to provide evidence either that wasting is a cause of death or that reversal of wasting improves outcome.

In advanced dementia, relationships between nutritional intake, markers of nutritional status, and clinically meaningful outcomes remain uncertain. For some, nutrients might provide benefits, but these may be outweighed by adverse effects of tube feeding.

**Is survival improved by tube feeding?**

Survival of very low weight carefully hand-fed demented patients may be the same as those fed by tube.

Feeding tube placement may itself cause death (up to 2% for PEG). Of 882 patients given fluoroscopic nasogastric tube placements, three died during the procedure. Median survival after PEG in 7,369 patients was 7.5 months; and among 31,105 patients death at one year was 63%, at three years 81.3%. (These studies were not limited to demented patients.)

Observational studies have shown no survival benefit in demented patients, even after adjusting for age, history or pulmonary aspiration or stroke, presence of oral feeding disorder, functional state resuscitation wishes, or cognitive status.

**Are pressure ulcers prevented or improved by tube feeding?**

Data are limited, but no benefit has been demonstrated.

Tube feeding also makes use of restraint more likely which could worsen outcomes.

**Is the risk of other infections reduced by tube feeding?**

There is no evidence of reduced urinary tract, gastrointestinal, eye or other infections.

**Can tube feeding improve functional status**

There is no evidence that strength, function or self care are improved.

*cont'd*

**Box 1 Tube feeding in advanced dementia: the evidence**  
(based on Finucane *et al*<sup>43</sup>). – *continued*

**Does tube feeding improve patient comfort?**

There is no evidence that dysphagic demented patients are more comfortable with tube feeding.

However, family and caregivers may experience a greater sense of accomplishment and a lesser sense of failure, despite lack of objective evidence of improvement in quality of life.

**Does tube feeding have adverse effects?**

Adverse effects may be local and mechanical, pleuropulmonary, abdominal or other (agitation, increased secretions etc).

Finucane *et al* conclude their extensive review by asserting that no direct data support tube feeding in demented patients for any of the commonly cited indications. They suggest that a comprehensive, motivated, conscientious programme of hand feeding is the proper treatment. If the patient continues to decline in some clinically meaningful way, tube feeding might be considered as empirical treatment, but all involved should understand that best evidence suggests that it will not help.

2.30 The working party found no evidence of reduced risk of any of these in dementia although a jejunostomy might reduce the risk of aspiration.<sup>44</sup> Pressure ulcers do not improve with PEG feeding, nor is their occurrence reduced.<sup>45</sup> Incidence of infections is unchanged.<sup>37</sup>

2.31 The quality of life in advanced disease is restricted, but eating and drinking are likely to provide some basic satisfaction that is removed by a PEG and ‘nil by mouth’. Social interaction is reduced by PEG feeding.<sup>35</sup> Discomfort may be increased as the oral cavity is not regularly moistened.<sup>46</sup> The irritation of a foreign tube may require restraint.

2.32 PEGs have not been shown to make demented patients more comfortable<sup>44</sup> and they may cause more suffering than they relieve.<sup>47</sup> Possibly severely demented patients lack the potential for physical or neurological rehabilitation, and are not nutritionally deprived.<sup>48</sup> With progress into the advanced stage, metabolic rate falls. This is attributed to muscle wasting that has diminished lean body mass and to a brain that has atrophied. Although people with advanced dementia may be thin and eat less food they may be in a state of physiological homeostasis.

2.33 In dementia, there will be a few cases where without PEG or NG feeding the patient will be poorly nourished and may die, but with treatment

may live well. This is most likely when there is a specific disability of oral feeding, such as a related brain stem stroke.

2.34 Despite all the reservations, the working party was advised by several sources that the wise reluctance to use artificial nutrition and hydration in dementia cannot be translated into a blanket ban. See Case 4, Chapter 5, para 5.32.

### **Delirium**

2.35 Delirium is an acute confusional state related to acute medical illness and its primary treatment is to deal with its cause. But it may be associated with sedation, confusion and difficulty in oral feeding and may show a slow recovery. Generally it will be enough to provide fluids intravenously or subcutaneously to tide the patient over the period of worsened disability. Other forms of artificial nutrition and hydration will not be necessary.<sup>49</sup>

### **PEG in learning disability**

2.36 Learning disability in itself does not normally produce difficulty in oral feeding. People with learning disability frequently have comorbidities (including, for example, cerebral palsy or progressive neurodegenerative conditions) that affect oral feeding. People with learning disability associated with oral feeding difficulties are at risk of becoming dehydrated and undernourished. In two recent reports from MENCAP,<sup>50,51</sup> people with learning disabilities were said to suffer from institutional discrimination and receive worse healthcare. An independent inquiry<sup>52</sup> found evidence that people with learning disabilities had a higher level of unmet needs, less effective treatment and that organisations did not make reasonable adjustments to support delivery of equal treatment. Most often, the best care will be maintained by careful oral techniques and support as described elsewhere.

## **Feeding techniques/oral support issues**

### **Risk management**

2.37 Any medical intervention carries a risk and the benefits of the intervention should outweigh that risk. Patients nearing the end of life may prefer to be fed orally and enjoy the taste of food. Coughing and spluttering are a normal means of clearing the airway. They are not necessarily an indication

for 'nil by mouth'. Similarly, the risks of NG tube insertion are much lower than those for gastrostomy. It is bad practice and unethical for patients to have a PEG or RIG inserted in order to be transferred to another facility, either if the risks of insertion are high or if the patient does not wish to have the procedure.

2.38 Every effort should be made by hospital trusts, PCTs and care homes to establish a system that allows NG tube feeding patients to be managed outside hospital. This will usually mean more expert trained nutrition nurses to support healthcare professionals inside and outside hospital. Thus, if a NG feed is causing difficulty, it can be stopped until specialised nursing support can be provided outside hospital or if necessary as part of an outpatient or day case visit. Senior, nutritionally trained, medical advice should be available to these healthcare professionals and specialist nurses in cases of difficulty or uncertainty.

2.39 The National Patient Safety Agency (NPSA) has produced a suite of guidance available on its website<sup>53</sup> including guidance on the assessment and management of feeding difficulties. The suite includes, among others, the following guidance:

- ▶ ensuring safer practice for adults with learning difficulties who have dysphagia
- ▶ risk assessment and guide to levels of risk
- ▶ dysphagia risk assessment form
- ▶ dysphagia report
- ▶ eating, drinking and swallowing care plan
- ▶ specific high-risk eating, drinking and swallowing care plan
- ▶ mealtime information forms
- ▶ mealtime information sheets.

2.40 In January 2007, the NPSA commented on seven deaths and four near misses as a result of misplaced NG tubes. All occurred in acute care settings in England. This followed advice issued in 2005, when the NPSA commented on reports of 11 deaths over a two-year period. The NPSA advised that:

- ▶ the 'whoosh' test should not be used to test for correct placement (auscultation of air insufflated through the feeding tube)
- ▶ pH strips must be properly stored and used. Blue litmus paper should not be used

- ▶ X-ray requests should be properly documented, results communicated to nursing staff, and read by trained clinicians
- ▶ absence of respiratory distress should not be used as an indicator of correct positioning
- ▶ observing the appearance of feeding tube aspirate is not a reliable indicator of positioning.

2.41 NPSA guidance is likely to be updated from the February 2005 version and their website should be consulted for this.

2.42 Many care homes may not feel confident to follow this advice as they may lack sufficiently trained personnel. GPs supervising such patients may also lack expertise or confidence in managing NG tubes. In these circumstances we suggest:

- ▶ There should be a particularly careful assessment in deciding the appropriateness of artificial feeding in the first place.
- ▶ If feeding is necessary, a trial of treatment with NGT should be carried out. If well tolerated and required for less than six weeks, then a PEG is not needed.<sup>54</sup>
- ▶ Most patients will have some cognitive capacity and can experience discomfort and distress. If tube feeding is appropriate and a NGT is poorly tolerated, a PEG should be inserted.
- ▶ If feeding is required for more than six weeks, a PEG should be inserted preferably before discharge or shortly afterwards, the patient having left hospital with a clear action plan.

2.43 The risks of placing a PEG must be balanced against the need of the patient for a particular environment. It would not be ethical for a care home to insist on PEG as a criterion for admission on grounds of convenience, but where expertise in managing a NGT is not and cannot be made available, PEG placement, if technically possible, may be in the patient's best interests.

### **Aspiration pneumonia**

2.44 Aspiration can occur with both gastrostomy and NG feeding. There is a danger that any episode of pneumonia will be ascribed to aspiration of feed when in fact the patient has developed nosocomial pneumonia because of their frailty and respiratory muscle weakness. Also, any pyrexia in someone with upper airways noise may be wrongly diagnosed as aspiration when a urinary tract infection is the real cause.

## General nursing care

2.45 Good nursing care can overcome most if not all of the difficulties with feeding patients. We have been impressed by the special skills available from well trained general nurses as well as specialist and community nurses. This includes good mouth care. Maintaining oral hygiene in health and disease are simple and effective ways of improving patient comfort and good oral feeding. Attention to oral cleaning, including teeth and dentures, in patients who are 'nil by mouth' will facilitate the reintroduction of oral feeding. Those with ill fitting dentures can be identified more quickly if a nurse is examining the mouth frequently but other healthcare professionals should also do this. Mouth care will reduce the chance of infection in patients who are having a gastrostomy placed by reducing the bacterial load in the mouth through which the tube passes. Monilia can occur in debilitated patients and its early detection and treatment is of great benefit to the patient. Discomfort from stomatitis due to medication, chemotherapy or radiotherapy can be minimised by good mouth care.

## Alternatives to ANH: social feeding – oral feeding techniques

2.46 As illness and frailty worsen, eating and drinking become harder. Poor nutrition in hospitals and elsewhere, rigidity of mealtimes and other issues have been identified as problems. Age Concern's 'Hungry to be heard' campaign highlights that six out of 10 older people are at risk of malnourishment, or their situation worsening, in hospital.<sup>55</sup> The working party heard evidence that malnutrition is common and reducible by improved feeding techniques.<sup>42,56</sup> Malnutrition in hospital may result from poor timing and delivery of nutrition. Nutrient-dense foods and special provision in hospitals such as the 'red tray' system can be helpful. This is a visible indicator that a patient is at risk of malnutrition and needs special attention. Nurses should play a central role in the assessment of feeding difficulties.

2.47 In addition to the restlessness that may increase metabolic need, patients with dementia may forget about meals, or even forget what food is or how to eat it. Additional dysphasia or other communication problems may compound these difficulties.

2.48 Feeding some patients may take longer and place additional demands on staff at mealtimes, both to assist feeding and ensure that food remains hot. Sufficient staff should be available for this support and there may be a judicious role for family and friends.

2.49 Responses to these problems include:

- ▶ allowing the person more time to feed him/herself
- ▶ quiet mealtimes with opportunity to eat supported by adequate staff time
- ▶ more flexible mealtimes so the patient can feed when they want to or (as is sometimes the case in dementia) are willing to
- ▶ adjusting the consistency and presentation of food and fluid to that which can be safely swallowed etc
- ▶ feeding the patient either some of the time or all of the time
- ▶ special training for staff in administering food and fluids
- ▶ structuring staff duties to deliver proper nutritional support
- ▶ care planning of feeding and nutritional support; prioritisation of weighing and other nutritional monitoring
- ▶ support, eg remembering to swallow multiple times with a food bolus, and a gentle cough afterwards
- ▶ increasing meal frequency
- ▶ concentrating on the midday meal in dementia, which has been shown to provide the greatest calorie intake.

2.50 Sometimes the easiest response will be a PEG tube, but this does not make it the best response. For those with a specific difficulty of oral feeding who cannot be adequately supported orally, PEG or NG feeding may be appropriate. Nevertheless for many with, for example, dementia, considerable success can be achieved by good nursing and care support with varied mealtimes and an ability to adapt diet. Also, it should be remembered that metabolic requirements are lower in bed-bound patients for whom central obesity is often a problem.

2.51 Diet supplements improve nutrition in people with dementia and other conditions though in these circumstances nutrition is not really the core issue. Some patients may well like strawberry flavoured milk-like preparations, but other non-milk based products (eg Maxijul, Calogen, Scandishake, Procal) may be more appropriate. Some may prefer savoury foods; others will prefer sweet foods. The working party heard from the medical director of BUPA homes about the importance of soft and modified consistency food. The Greenwich Advanced Dementia Service<sup>57</sup> has now supported over 50 patients to live at home with dementia until they die and none of those have required tube feeding or intravenous or subcutaneous fluids. Good care has enabled nutritional support until death. Carers have

reported that some foods are especially useful and discover for themselves options such as thick soups and guava juice. Perhaps most of all, individuals require flexibility and innovations tailored to them, and the advice of a dietitian is often very helpful in achieving this.

## The Care Quality Commission and individual social services departments' expectations of services

2.52 The Care Quality Commission (CQC) is the independent regulator of health and social care in England. Its aim is better care for everyone, including those in care homes. It regulates health and adult social care services, whether provided by the NHS, local authorities, private companies or voluntary organisations, and protects the rights of people detained under the Mental Health Act 2007. The CQC gives advice to all types of residential care providers and has expectations of the care for specific conditions. Along with social services and, in England, the primary care trust, who will commission the majority of placements, the onus will be on the care home to provide an individualised care plan in line with the National Minimum Standards Regulations.<sup>58</sup>

2.53 Standard 3 requires that 'new service users are admitted only on the basis of a full assessment undertaken by people trained to do so, and to which the prospective service user, his/her representatives and relevant professionals have been party'. A care plan must be produced for care management purposes, which include physical health, diet and dietary preferences. Section 3.5 states that in residential homes with nursing, this type of assessment must be carried out using a recognised tool according to Department of Health guidance. This ensures that the service user can be sure the care home will meet their needs before admission.

## Older people

2.54 Older people have the right to expect that they will be treated with respect and with the same care and consideration as younger people. Restricting access to assessment and therapeutic interventions on the basis of age is not acceptable and runs counter to anti-discrimination policy.

2.55 Increasing age is associated with physical and mental health co-morbidities, disability, social isolation and poverty. All of these may cause



disadvantage and increased vulnerability. An accurate diagnosis will improve discussion with the patient and the family. Unwarranted assumptions should not be made. For example, tugging at a NG feeding tube should not be taken to mean that the patient does not want to be artificially fed. Sensory and cognitive impairment means that extra time will be required when discussing feeding and other decisions. Such conversations may need to be repeated.

2.56 A number of factors, including their age and culture, may affect patients' health beliefs.

2.57 A growing number of older people will have made known their views about end of life care but few will have appointed welfare attorneys. Faced with a real clinical situation the patient may change their mind about feeding and other decisions. Involvement of families in decision making is usually good practice but the participation of family or individual family members should not be assumed. Their involvement in decision-making may require tactful discussion.

# 3 Ethics

3.1 Ethics underpins the law. The application of ethical principles provides the basis of parliamentary debate on statute law and informs the development of case law in the common law tradition. Sound ethical practice is the best protection against legal liability. Ethics also goes beyond the law, guiding action where law may be silent.

## Ethical principles

3.2 Beneficence in the medical context refers to the doctor's responsibility to preserve life, restore health and relieve suffering: in the traditional formula, to cure sometimes, to alleviate often, to comfort always.<sup>59</sup> Its corollary is non-maleficence, the responsibility to avoid harm: in the traditional formula, *primum non nocere*. Both principles apply almost exclusively to the day-to-day work of doctors. They define the appropriateness of medical care and the quality of the dying process.<sup>60</sup> They may often come into conflict with autonomy and justice.

3.3 By contrast, autonomy and justice are principles that govern the roles of patients, family and society in medical decision-making. Autonomy (literally, self rule) opposes paternalism and asserts the ultimate authority of the patient. In Kant's sense, autonomy is a matter of acting on principles that can be principles for all, not an individual's total sovereignty over his choices.<sup>61</sup> Justice may limit patient choice in the interests of the fair distribution of resources. Justice determines that patients do not have rights to useless treatments and may thus limit treatment options.

3.4 These principles must be considered against the background of patient expectation for good clinical care, which is appropriate to their needs and not burdensome.

## Sanctity of life

3.5 The idea of the sanctity of life (SOL) is often associated with religion.

For example, Christians believe that life derives from God as creator and is therefore sacred. Thus the Christian attitude to life is one of reverence. ‘Our life, grounded in our divine origin, is the basis of all other human rights, natural and legal, and the foundations of a civilised society.’<sup>62</sup> Similarly, Muslims believe life is sacred because God is its origin and its destiny.<sup>63</sup> However, the idea is explicitly valued in a secular context – for example, Taylor LJ<sup>64</sup> in *Re J (a minor) (wardship: medical treatment)* [1991]: ‘...the court’s high respect for the sanctity of human life imposes a strong presumption in favour of taking all steps capable of preserving it, save in exceptional circumstances ...’

3.6 Although this belief is common to most religious traditions, such beliefs do not equate to vitalism: none are opposed to withdrawal or withholding of treatment under all circumstances.<sup>65–67</sup>

3.7 By contrast, Singer comments that ‘the traditional view that all human life is sacrosanct is simply not able to cope with the array of issues that we face’.<sup>68</sup> From this viewpoint, life is valuable because of what we are able to do with it. It is not worthy of respect in itself.

3.8 Sacrosanct may imply absolute inviolability. Some may distinguish the sanctity of life which may (for example) be a fundamental doctrine of English law, but not an absolute one – as stated in the Bland case.

3.9 Dworkin<sup>69</sup> contrasts *detached* and *derivative* objections to the destruction of life. A derivative objection stems from the status of the thing under consideration: a fetus, if considered a human being, acquires attributes derivatively, such as rights. If, on the other hand, it is considered sacred then its inviolability (relative or absolute) is intrinsic and life preservation is irrelevant to its interests or rights. SOL concerns intrinsic value. We preserve life on the basis of SOL because of its intrinsic value, not because of an individual’s interest in continuing to live.

### Intrinsic and instrumental value

3.10 *Intrinsic* value means that things have value even if we gain nothing from them. Great art would be an example of this: we lament the loss of a great painting or sculpture even though we would never have been likely to see it. Human life is also frequently held to be intrinsically valuable. Thus a man with one leg cannot run as fast as a man with two: we do not think (or think decently) that the one-legged man has less value than the two-legged

man. We think (or should think) that the intrinsic value of both lies in their humanity, not in their ability to do things. Something with intrinsic value has value independent of its utility, or of any faculty it possesses.

3.11 *Instrumental* value implies that a thing is valuable because of what it enables. An object or a life is valuable because it makes certain things possible.

3.12 *Subjective* value, a third sense of value, holds that 'life is valuable because it is the most important thing that I have'.

3.13 Sacredness is not confined to matters of life. 'Something is sacred or inviolable when its deliberate destruction would dishonour what ought to be honoured.'<sup>70</sup> It may do this either by *association* or *designation*. For example, cats in Ancient Egypt were sacred by association with certain goddesses; or the US flag is sacred by designation with certain ideals. History sanctifies things by how we have created them: we consider the processes of human creation important. See also [para 4.33](#).

3.14 With regard to human life, sacredness comes from the *natural* and the *human*. (The Greek word 'zoe' means physical or biological life, while 'bios' means a life as lived – the events that compose a biography.) This sense of the sacred has no essential link to the religious, even though it may appeal more easily to those of religious belief. To quote Dworkin:<sup>70</sup>

*The life of a single human organism commands respect and protection, no matter in what form or shape, because of the complex creative investment it represents and because of our wonder at the divine or evolutionary processes that produce new lives from old ones, at the processes of nation and community and language through which a human being will come to absorb and continue hundreds of generations of cultures and forms of life and value...*

3.15 As Shakespeare writes, human life is 'the most replenished sweet work of nature that from the prime creation e'er she framed.'<sup>71</sup>

3.16 People may disagree about the relative importance of the natural and human investment in normal human life. If one believes human life is intrinsically or transcendentally important, there is a natural desire to preserve and cherish it whenever reasonably possible. If one believes that life is important only because of what the individual can do or contribute (instrumental value) then one might conclude that life for some near the end of life should end before further significant human investment is doomed to frustration. There is a serious risk in the latter: it might mean that the right

to life or treatment becomes contingent upon a requirement to be able or healthy. If that is the case, the disabled or sick may be seen as less human than the healthy.

3.17 That concern is perhaps one reason why a conviction about the sanctity of life is attractive to both conservatives and liberals, religious believers and non-believers. Although it can be agreed that every individual should receive the best care and equal respect, answers in practice require further exploration and discussion.

### Ordinary and extra-ordinary means

3.18 In its classic form the principle of distinguishing ordinary and extra-ordinary means is used to imply an obligation to use the former but no strict obligation to use the latter. Extra-ordinary means are those which do not offer any reasonable hope of success or cannot be obtained or used without excessive hardship (pain, cost or other inconvenience). The decision whether to employ a treatment is therefore based on a calculation of the likely net balance between benefits and burdens. The doctrine therefore introduces a concept of proportionality.

3.19 ‘Ordinary’ is not to be confused with customary or usual, for what is usual may not be appropriate for a given individual patient and what is unusual could be both effective, cheap and problem free for a given patient.

3.20 Proportionality involves balancing the two separate factors of efficacy and burdens: how much burden for how much benefit? The distinction between ordinary and extra-ordinary may be vague as it relies on judgements concerning what is reasonable, beneficial, excessive or proportionate. Hence the ordinary and extra-ordinary distinction functions less as guiding ethical standard than as a conclusion of moral reasoning. It appears to provide a practical standard but actually obscures the real ethical judgement and criteria on which decisions rest.<sup>72</sup> It is better to consider a proposal on the basis of proportionality of benefits and burdens in promoting the best interests of a given patient.

3.21 On the other hand, at least to a degree, English Law has now formalised the concept of ordinary and extra-ordinary care via the Mental Capacity Act 2005 in its definition of ‘basic care’ (see Chapter 4).

## Intended and foreseeable

3.22 Intention is a mental concept. An intended act is done to produce a particular result. We can intend to do what we do not do; and we can do what we do not intend. Many acts will have results that are foreseeable yet not intended. I dive into water and make a splash but I have not dived in with the intention of making a splash.

3.23 In a moral context, the intentional causation of evil (for example, a death) and foreseeing an evil (another's death) as a possible or even probable result of what one does is a crucial distinction. There is an obvious practical test of this distinction: if the foreseen but unintended outcome of, shall we say, death does not occur, it would not then be acceptable to kill the patient. Intention points to the importance of the good will.

3.24 Intention is fundamental to medical practice.<sup>73,74</sup> The Mental Capacity Act (s.4(5)) endorses this principle in stating that decisions made in a patient's best interests must not be 'motivated by a desire to bring about the patient's death'.

## Doctrine of double effect

3.25 Building upon the distinction between the intended and the foreseeable, the doctrine of double effect asserts that an action is justified if it is performed primarily to produce a good effect, provided that the means are good, that the effect is not produced by the bad effect and that the result is grave enough to permit the bad effect. Thus withholding feeding may foreseeably end the life of the patient. This effect is not aimed at death but is aimed at avoiding the suffering or burdens associated with (artificial) feeding therapies, relative to their possible benefits.

## Withholding and withdrawing

3.26 It is widely held that there is no intrinsic moral difference between withholding and withdrawing treatment.

3.27 A treatment that proves useless may be initiated to assess its effects before it is withdrawn. If withdrawing treatment was ethically worse than withholding it, then it may not be initiated in circumstances where it may be beneficial. As the General Medical Council (GMC) points out:<sup>75</sup>

*Although it may be emotionally more difficult for the health care team, and those close to the patient, to withdraw a treatment from a patient rather than to decide not to provide a treatment in the first place, this should not be used as a reason for failing to initiate a treatment which may be of some benefit to the patient. Where it has been decided that a treatment is not in the best interests of the patient, there is no ethical or legal obligation to provide it and therefore no need to make a distinction between not starting the treatment and withdrawing it.*

3.28 Attempts to establish a moral distinction between withholding and withdrawing life-prolonging treatment have failed.<sup>76</sup>

### Substituted judgement

3.29 This refers to the requirement of the surrogate decision maker to ascertain, as far as possible, the incompetent person's actual interests and preferences, making a decision which would be made by the individual if that person were competent. However, such a principle is impossible or unrealistic to apply if the incompetent patient never was competent or if little is known about their previous behaviour in circumstances a long way from the ward.

### Best interests

3.30 By a test of best interests, the decision maker assesses the burdens and benefits of treatment, taking into account both the patient's values and beliefs in determining the therapeutic goal. An attempt is made to assess what the incompetent patient might construe as worthwhile. The focus includes the medical treatment best interests but is more than just the *medical* best interests.

3.31 It is, of course, hard to identify what is valuable, worthless, beneficial or burdensome. For this reason, it is essential that the consultation with those who might have insights into the patient's values and beliefs is carried out sensitively and thoroughly whenever such issues arise.

3.32 Sometimes physicians must make judgements without an explicit social consensus on what might constitute 'best interests'.

3.33 There remains the difficulty of distinguishing between critical and experiential interests. The former reflect the incompetent patient's lifelong interests and values; the latter reflect the pleasures of the moment. These may come into conflict when an advance refusal of treatment of a competent

person is based on the former, yet the incompetent patient appears to be enjoying life based on the latter. Advanced refusals may require careful appraisal for their validity as a result of this difficulty.<sup>77</sup>

## Medical treatment and basic care

3.34 Dialysis or artificial ventilation are medical treatments; cleanliness, hygiene, prevention of pressure sores are basic care. The former may not be initiated or may be stopped; the latter are always mandatory in the absence of explicit refusal by the patient.

3.35 Basic care is defined (Mental Capacity Act Code of Practice) as those procedures essential to keep an individual comfortable. They include warmth, shelter, pain and distressing symptom relief, hygiene measures and the offer of oral nutrition and hydration. Appropriate basic care should always be provided unless actively resisted by the patient.

3.36 Some have argued that nasogastric or gastrostomy feeding and hydration represent basic and not medical care.<sup>78</sup> The need for nutrition and water are requisites for life. They should therefore be regarded as basic care. The implication of this view is that they should not be withdrawn. They should always be given because they represent love and care for the helpless.<sup>79</sup>

3.37 Procedures to institute, support and maintain such feeding require medical or nursing skills. Like other treatments, such procedures have a series of side effects discussed elsewhere in this report. While acknowledging the difficulties of drawing a line through a grey area, we believe such procedures and their use should be regarded as medical treatments and not as basic care. In making that judgement, we acknowledge the agreement of both the courts, professional bodies<sup>80,81</sup> and the overwhelming majority of ethical and medical opinion.

## Euthanasia

3.38 The word euthanasia literally means ‘an easy death’. But it has come to mean the deliberate ending of life on medical grounds. It has been classified as active or passive. Each of these could be voluntary (wishes known), non-voluntary (wishes cannot be ascertained) or involuntary (wishes are against). Active voluntary and non-voluntary euthanasia remains the subject of widespread and impassioned debate. That debate has extended to the assertions



of moral equivalence between active and passive euthanasia in certain circumstances.

3.39 The use of the term ‘passive euthanasia’ to refer to treatment withdrawal is polemical in drawing a parallel with active life termination. We believe the word ‘euthanasia’ is best restricted to the active and intended termination of life in the way the term is defined in Dutch practice.

### Killing and letting die

3.40 Causing death by acts is morally equivalent to causing death by omissions, other things being equal. ‘Other things’ are often not equal, and ignoring this fact leads to confusion and erroneous judgements.<sup>82</sup>

3.41 Whereas failing to stop a blind man walking over a cliff edge may be as morally reprehensible as pushing him off, it would be absurd to claim that sending poisoned food to starving people is morally equivalent as allowing them to die by not sending food.<sup>83</sup>

3.42 Killing and letting die are not therefore necessarily morally equivalent. Medicine, law and everyday morality distinguish clearly between a strong universal though *prima facie* prohibition on killing and a very much more equivocal attitude to letting die. The avoidance of this confusion is another reason for avoiding the term ‘passive euthanasia’.

### Surrogate decisions and standards

3.43 Surrogates may be nominated to make decisions for incapacitated patients under the Mental Capacity Act. Yet many patients consider placing trust in their surrogate more important than assuring their surrogate’s ability to accurately predict the patient’s preferences. They may also want their surrogates to interpret their stated preferences according to the details of the situation. Some concerns, such as those for minimising emotional or other family burdens, are not easily dealt with in the current autonomy model of advance treatment refusals. A rigidly hierarchical view of surrogate decision making oversimplifies a process that is complex, dynamic, personal and even idiosyncratic, and tends to de-emphasise other considerations, such as mutual responsibility. Flexibility in the interpretation of advanced refusals of care is important.<sup>84</sup>

## Conscientious objection

3.44 *Conscience* refers to an inner conviction of the morality of one's acts: the judgement of the practical reason as it brings moral principles to bear on questions of right or wrong.<sup>85</sup> *Conscientious objection* to an act is the claim that it would violate the individual's conscience, resulting in a loss of integrity or shame. A conscience may not, of course, be well informed, but the claim to conscience implies a certain seriousness of conviction or belief.

3.45 The right to freedom of conscience is affirmed in Article 9 of the European Convention on Human Rights as given effect by the Human Rights Act 1998.

3.46 Participation in withholding or withdrawal of feeding could lead to conscientious dissent. Where such dissent cannot be overcome by discussion within the multidisciplinary team, the practitioner should withdraw from the patient's care, having first ensured that continuity of care is maintained with the involvement of another practitioner. A similar situation could arise where a practitioner might have an objection to providing or not withdrawing treatment.

3.47 Whenever possible, patients or families should be notified of the professional's views at the time of admission or before a crisis occurs. Such disclosures are especially important in nursing homes and longer stay institutions. Allowing patients or their surrogates time to choose another doctor or facility that will honour their decision is far preferable to waiting until the patient's condition deteriorates before attempting a transfer.<sup>86</sup>

## Trust and transparency

3.48 Trust is essential to the relationship between professionals and patients or their relatives. In principle, transparency and openness should aid trust but while they destroy secrecy they may not limit deception. Increased transparency can lead to a flood of unsorted information that may even enable deception or increase uncertainty.<sup>87</sup> Excessively optimistic predictions may also erode trust, making future advice less likely to be accepted. The challenge is often to tell the truth in a way that does not destroy all hope of some benefit.

### The ethics of process

3.49 Radical moral disagreement implies the impossibility of consensus between interested parties. As noted in the introduction, the ambiguities that characterise decision making around nutrition and hydration may make decisions finely balanced for all concerned. There is no ethical calculus that can determine what is 'right' in some situations. Respect is then demonstrated by following a process that at least ensures that all involved have the opportunity to express opinions and that the final decision is made with serious thought and over a reasonable time. Instant or casual decisions, even when finely balanced, do not show the respect that is found in a serious or structured process.

# 4 Law

## Capacity

### General principles

4.1 The law governing the treatment of a patient with capacity is different from that governing the treatment of a patient without capacity. The crucial first step is therefore to decide whether or not the patient has capacity.

4.2 Capacity is not an all-or-nothing attribute. It will only be in rare cases, approaching a permanent vegetative state (PVS), where it will be possible accurately to say simply that ‘Patient X lacks capacity’. One has to ask: Capacity to do what? One needs to understand relatively little to be able validly to consent to the dressing of a bed sore. One needs to understand much more to be able to consent validly to a heart transplant.

4.3 The idea that one can talk meaningfully about capacity only in the context of a particular proposed treatment decision is central to the operation of the Mental Capacity Act 2005.

4.4 A person must be assumed to have capacity unless it is established that he lacks capacity.<sup>[1]</sup>

4.5 The 2005 Act provides that a person lacks capacity if he is unable:

- (a) to understand the information relevant to the decision
- (b) to retain that information
- (c) to use or weigh that information as part of the process of making the decision, or
- (d) to communicate his decision (whether by talking, using sign language or any other means).<sup>[2]</sup>

4.6 The ‘information relevant to the decision’ includes information about

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<sup>[1]</sup> Section 1(2).

<sup>[2]</sup> Section 3(1), which draws heavily on *In Re C (Adult Refusal of Treatment)* [1994] 1 WLR 290.

the reasonably foreseeable consequences of deciding one way or the other, and of failing to make the decision.<sup>[3]</sup>

4.7 One cannot conclude that a patient does not have the necessary capacity simply because his decision endangers him or is otherwise objectively foolish. The English law is robust in its protection of even life-endangering eccentricity. This principle is now embodied in the 2005 Act, which provides that ‘a lack of capacity cannot be established merely by reference to ... a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about his capacity.’<sup>[4]</sup> That does not mean that the nature of the patient’s decision is irrelevant to the determination of capacity: it very often will be.

## Children

4.8 A child, for these purposes, is anyone under the age of 18. Particular rules apply to 16- and 17-year-olds.

4.9 The law treats a child’s consent to treatment differently from a refusal of consent. This is because it assumes that clinicians who propose treatment do so for good reasons. It accordingly makes it more difficult validly to refuse consent than to consent to treatment.

4.10 Consent to treatment can be obtained from a *Gillick* competent child of any age (*Gillick* competency is discussed below, para 4.13), or a 16- to 17-year-old, or from a person with parental responsibility, or from the court.

4.11 So far as refusal of treatment is concerned, the consent of a person with parental responsibility trumps the refusal of a child of any age, and the consent of the court trumps the refusal of either.

4.12 In deciding whether to exercise its trumping power, the court applies the ‘best interests’ test. The views of the parents are relevant only as a factor in the application of that test. If parental cooperation with the treatment is vital to the treatment’s success, the court, faced with parental non-cooperation, might decline to order the treatment, notwithstanding its view that the treatment, given proper compliance, would be in the child’s best interest. But this will be very rare.<sup>[5]</sup> It will normally be possible (through wardship or

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<sup>[3]</sup> Section 3(4) and 4(1).

<sup>[4]</sup> Section 2(3).

<sup>[5]</sup> An example is *Re T (a minor) (wardship: medical treatment)* [1997] 1 WLR 242.

otherwise) to ensure that the child gets the treatment that the court and the clinicians think it needs.

4.13 The notion of *Gillick* competency comes from the House of Lords case of *Gillick v West Norfolk and Wisbech AHA*.<sup>[6]</sup> It is simply that a child should be regarded as having capacity when in fact he can be demonstrated to have capacity. Legal presumptions have no place in the determination of capacity. It should not be presumed, for instance, that a child has capacity for all purposes at the age of 14, 16 or any other time. A child has the capacity to consent to medical treatment ‘when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed’.<sup>[7]</sup> Whether the child has that understanding and intelligence is a question of fact in each case. Although Lord Scarman referred to understanding ‘fully’, it is plain that the test really is understanding sufficiently – according to the criteria laid down for adults in the Mental Capacity Act 2005; see above.

4.14 The law applying to refusals of consent to treatment by children aged 16 and 17 is identical to that for all other children. But consent by such children to treatment is different. It is governed by statute. Section 8 of the Family Law Reform Act 1969 provides that:

- (1) *The consent of a minor who has attained the age of 16 years to any surgical, medical or dental treatment which, in the absence of consent, would constitute a trespass to his person, shall be as effective as it would be if he were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be necessary to obtain any consent for it from his parent or guardian.*
- (2) *In this section ‘surgical, medical or dental treatment’ includes any procedure undertaken for the purposes of diagnosis, and this section applies to any procedure (including, in particular, the administration of an anaesthetic) which is ancillary to any treatment as it applies to that treatment.*
- (3) *Nothing in this section shall be construed as making ineffective any consent which would have been effective if this section had not been enacted.*

Where a child is already a ward of court and consents to treatment, it is sensible and courteous, although probably not legally obligatory, to seek the court’s approval.

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<sup>[6]</sup> [1986] 1 AC 112.

<sup>[7]</sup> Per Lord Scarman at 185.

## Patients with mental disorder

4.15 It is certainly not the law that patients detained under the Mental Health Act 1983 can have anything done to them if the treating clinicians think it is in their best interests to do it. The 1983 Act does contain various provisions relating to consent to treatment for patients who are liable to be detained under those sections.<sup>[8]</sup> But those sections only authorise treatment in the absence of consent for the condition which brings the patient under the provisions of the Act in the first place. The Mental Capacity Act 2004 expressly provides:

- (1) *Nothing in this Act authorizes anyone:*
- (a) *to give a patient medical treatment for mental disorder, or*
  - (b) *to consent to a patient's being given medical treatment for mental disorder,*
- if, at the time when it is proposed to treat the patient, his treatment is regulated by Part 4 of the Mental Health Act.<sup>[9]</sup>*

4.16 For treatment which does not fall within the provisions of the Mental Health Act, the normal law of consent applies. Some patients with mental disorder will be fully able to give or withhold consent. Remember that capacity is not an all or nothing thing: patients may have capacity for some things, and not for others. Where a patient with mental disorder does not have the capacity to consent to the proposed treatment, the usual rules apply: treatment will be lawful if it is in the patient's best interests.

## Competent patients

4.17 A competent patient – one who has capacity to consent to treatment and to the refusal of treatment – has an absolute right to decline even life-preserving treatment. He does not, however, have the right to demand any treatment. The treatment available will be determined (a) by the treating clinician's willingness to provide it; and (b) by considerations of resource allocation. The clinician's willingness will in turn depend on (a) his clinical judgement about the efficacy and desirability of the treatment; and (possibly) (b) other ethical considerations – which can generally be thought of under the heading of conscientious objection. The law will not compel an individual clinician to provide treatment which he does not consider is clinically justified or (except in the rare case where a woman needs an abortion to save her own

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<sup>[8]</sup> See sections 56–64.

<sup>[9]</sup> Section 28.

life), impose on a clinician an obligation to do something to which he has a conscientious objection. The trust, however, may have an obligation to provide so-called ‘basic care’. This is explained below.

4.18 If the reason for non-provision of treatment is that the trust has decided that there are insufficient resources to provide it, or that the funds that would be needed to pay for the treatment would be better spent elsewhere, the general law will only compel the paying trust to provide the treatment if the decision not to provide the treatment was frankly irrational. The law will look much more critically, though, at a decision by a treating clinician in an individual case (as opposed to a policy decision by a trust about allocation of resources to particular classes of case) not to give treatment to particular patient X because it would divert resources from particular patient Y. Such a decision might well be vulnerable to challenge under the European Convention on Human Rights’ prohibition on discrimination.<sup>[10]</sup>

### The duty to provide ‘basic care’

4.19 It is plain that, when a hospital accepts a patient, the hospital generally has a duty to provide basic medical care.<sup>[11]</sup> This will include the provision of food and fluid, and will include their provision by artificial means.

4.20 Leslie Burke suffers from a progressive condition with a clinical course like that of multiple sclerosis. Ultimately he may need artificial nutrition and hydration. He is likely to be competent at the time that he needs the ANH. He was worried that even if, as a competent patient, he begged to be given ANH, his clinicians might refuse to give it to him.

4.21 Was there a duty to give ANH? Yes. The Court of Appeal in *Burke* put it like this:<sup>[12]</sup>

*So far as ANH is concerned, there is no need to look far for the duty to provide this. Once a patient is accepted into a hospital, the medical staff come under a positive duty at common law to care for the patient.... A fundamental aspect of this positive duty of care is a duty to take such steps as are reasonable to keep the patient alive. Where ANH is necessary to keep the patient alive, the duty of care will normally require the doctors to supply ANH....*

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<sup>[10]</sup> Article 14.

<sup>[11]</sup> See, for example, *Cassidy v Ministry of Health* [1951] 2 KB 343; *Barnett v Chelsea & Kensington Hospital Management Committee* [1969] 1 QB 428; *Kent v Griffiths* [2001] QB 36; *Watson v British Boxing Board of Control* [2001] QB 1134.

<sup>[12]</sup> Paragraph 32 of the Court of Appeal’s judgment.



4.22 As a statement of general legal principle this would of course have to be hedged round with some fairly significant caveats. Patients in conclusively diagnosed PVS, for instance, would have to be excluded. And if continued existence is demonstratively intolerable (or otherwise if continued existence is not in the patient's best interests), continued invasive treatment would not only not be mandatory; it would be unlawful. But the core of the statement is old and trite law. Even incompetent patients must be given basic care unless there is compelling reason to suppose that it is not in their best interests.<sup>[13]</sup> The obligation is all the more obvious (although no legally stronger) in the case of a patient like Leslie Burke, who, regardless of the pain, suffering or indignity of his condition, makes it plain that he wants to be kept alive.

*No authority lends the slightest countenance to the suggestion that the duty on the doctors to take reasonable steps to keep the patient alive in such circumstances may not persist. Indeed, it seems to us that for a doctor deliberately to interrupt life-prolonging treatment in the face of a competent patient's expressed wish to be kept alive, with the intention of thereby terminating the patient's life, would leave the doctor with no answer to a charge of murder.*<sup>[14]</sup>

4.23 The argument can be put in European Convention on Human Rights terms too. But the result would be the same.<sup>[15]</sup>

4.24 The GMC was very concerned that Munby J may have suggested that doctors might be obliged to provide, or to procure another doctor to provide, treatment wanted by the patient but which the clinicians concerned do not think is clinically indicated. The Court of Appeal doubted that there had been such a suggestion, but endorsed the following propositions, which together purport to be a workmanlike practitioners' guide for sticky clinical decision-making:

- (i) *The doctor, exercising his professional clinical judgment, decides what treatment options are clinically indicated (ie will provide overall clinical benefit) for his patient).*

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<sup>[13]</sup> This formulation implies the persistence in some form, and the necessity of, the *Re J* intolerability test. For discussion of this, see [para 4.33](#) below.

<sup>[14]</sup> Paragraph 34 of the Court of Appeal's judgment.

<sup>[15]</sup> If an NHS doctor were deliberately to bring about the death of a competent patient by withdrawing life-prolonging treatment contrary to the patient's wishes, Article 2 would be violated, and any English law which purported to permit such conduct would be incompatible with Article 2. Articles 3 and 8 have nothing to contribute to this debate. They do have something to say where the patient is incompetent.

- (ii) *He then offers those treatment options to the patient in the course of which he explains to him/her the risks, benefits, side effects, etc involved in each of the treatment options.*
- (iii) *The patient then decides whether he wishes to accept any of those treatment options and, if so, which one. In the vast majority of cases he will, of course, decide which treatment option he considers to be in his best interests and, in doing so, he will or may take into account other, non clinical, factors. However, he can, if he wishes, decide to accept (or refuse) the treatment option on the basis of reasons which are irrational or for no reasons at all.*
- (v) *If he chooses one of the treatment options offered to him, the doctor will then proceed to provide it.*
- (vi) *If, however, he refuses all of the treatment options offered to him and instead informs the doctor that he wants a form of treatment which the doctor has not offered him, the doctor will, no doubt, discuss that form of treatment with him (assuming that it is a form of treatment known to him) but if the doctor concludes that this treatment is not clinically indicated he is not required (ie he is under no legal obligation) to provide it to the patient although he should offer to arrange a second opinion.<sup>[16]</sup>*

## How are 'best interests' determined?

### The relevance of the Bolam test

4.25 In *Re SL (adult patient) (medical treatment)*,<sup>[17]</sup> the Court of Appeal deployed a two-stage test for deciding whether the proposed treatment is in the patient's best interests. First: would the treatment be endorsed by a responsible body of medical opinion? If no, the matter ended there. If yes, the second question was asked: was the treatment *in fact* in this patient's best interests in these circumstances?

4.26 It was not just the court, on an application for a declaration, which had to ask these questions. Doctors considering treatment without the patient's consent had to ask them too.

### A holistic determination

4.27 It is well established that 'best interests' means more than 'best medical interests'.<sup>[18]</sup> Evaluation of best interests is a holistic exercise. Thorpe LJ said, in *Re SL*:

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<sup>[16]</sup> Paragraph 50.

<sup>[17]</sup> [2000] 1 FCR 361.

<sup>[18]</sup> See the famous dictum of Butler-Sloss LJ in *Re MB (an adult: medical treatment)* [1997] 8 Med LR 217 at 225: 'Best interests are not limited to best medical interests'.

*In deciding what is best for the disabled patient the judge must have regard to the patient's welfare as the paramount consideration. That embraces issues far wider than the medical. Indeed it would be undesirable and probably impossible to set bounds to what is relevant to a welfare determination.*

4.28 This still represents the law, and it poses difficulties for doctors. They are obliged to act in a patient's best interests, but are told effectively that they will be in breach of their duty as doctors if they take merely medical criteria into account in deciding where the best interests lie. This wider enquiry into 'best interests' is often one which doctors simply do not have the time or the raw factual material to undertake.

4.29 These principles have now been consolidated in the Mental Capacity Act 2005. Section 4 is an attempt to give practical guidance to people facing the difficult task of assessing what is in a person's best interests. It adds nothing to the common law. It provides that the assessor:

- ▶ Must consider all the relevant circumstances, and in particular take the following steps.<sup>[19]</sup>
- ▶ Must consider whether it is likely that the person will at some time have capacity in relation to the matter in question, and if it appears likely that he will, when that is likely to be.<sup>[20]</sup>
- ▶ Must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.<sup>[21]</sup>
- ▶ Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.<sup>[22]</sup>
- ▶ Must consider, so far as is reasonably ascertainable: (a) the person's past and present wishes and feelings (and in particular any relevant written statement made by him when he had capacity); (b) the beliefs and values that would be likely to influence his decision if he had capacity; and (c) the other factors that he would be likely to consider if he were able to do so.<sup>[23]</sup>

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[19] Section 4(2).

[20] Section 4(3).

[21] Section 4(4).

[22] Section 4(5).

[23] Section 4(6).

- ▶ Must take into account, if it is practicable and appropriate to consult them, the views of (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind; (b) anyone engaged in caring for the person or interested in his welfare; (c) any donee of a lasting power of attorney granted by the person; and (d) any deputy appointed by the court, as to what would be in the person's best interests and, in particular, as to the matters dealt with in the previous bullet point.<sup>[24]</sup>

4.30 This is quite an intimidating list. But it is mandatory. Big questions will arise for decisions about (for example), what 'reasonably ascertainable' means, and when it is 'practicable and appropriate to consult'. An assessor who has worked his way diligently through the list can then (but only then), take refuge in the provision that 'there is sufficient compliance with [section 4] if [having worked through the list] he reasonably believes that what he does or decides is in the best interests of the person concerned'.<sup>[25]</sup>

4.31 Someone who does an act 'in connection with the care or treatment of another', and has taken 'reasonable steps to establish whether [the other] has capacity...' and reasonably believes that the other lacks capacity and that the act is in the best interests of the other, will incur no liability in relation to the act that he would not have had if the other had capacity and had consented to the act.<sup>[26]</sup> Criminal and civil liability are excluded.<sup>[27]</sup>

4.32 The provisions of the Act<sup>[28]</sup> dealing with advance refusals of treatment are unaffected by section 5.<sup>[29]</sup>

### The idea of intolerability

4.33 The notion of the sanctity of life has long been recognised as having a central place in English law. That notion now finds additional expression in the language of Article 2 of the European Convention on Human Rights. One of the ways in which the notion has historically been entrenched is by the so-called 'intolerability test'. The idea of the test is as follows:

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<sup>[24]</sup> Section 4(7).

<sup>[25]</sup> Section 4(9).

<sup>[26]</sup> Sections 5(1) and 5(2).

<sup>[27]</sup> Section 5(3).

<sup>[28]</sup> Sections 24, 25 and 26.

<sup>[29]</sup> See section 5(4).

- (a) The principle of the sanctity of life creates a presumption in favour of the maintenance of life.
- (b) That presumption can be displaced only if it is demonstrated that continued existence will be intolerable.<sup>[30]</sup>

4.34 Doubt has recently been cast on the intolerability test in the cases of Leslie Burke<sup>[31]</sup> and Charlotte Wyatt.<sup>[32]</sup> The right test, said the Court of Appeal in these cases, was the untrammelled ‘best interests’ test. If recourse to the courts is unavoidable,

*the forensic debate should ... be unfettered by any potentially contentious glosses on the best interests test which are likely either inappropriately to shift the focus of the debate, or to restrict the broad exercise of the judicial discretion involved in balancing the multifarious factors in the case.’<sup>[33]</sup>*

But intolerability is not dismissed entirely as a criterion. While ‘it should not be seen as a gloss on or a supplementary guide to best interests, it is...a valuable guide in the search for best interests...’<sup>[34]</sup> There are clear signs that the practical utility of the intolerability test is still recognised by judges.

4.35 In *An NHS Trust v MB and Mr and Mrs B*<sup>[35]</sup> (‘*Re MB*’) an NHS Trust made an application to withdraw life-sustaining ventilation from a conscious, cognate 18-month-old child suffering from spinal muscular atrophy. The test to be applied was of course the ‘best interests’ test. Holman J, the trial judge, knew very well how dismissive of the idea of intolerability the Court of Appeal had been. And in *Re MB* he was careful not to endorse the idea expressly. He said this:

*I avoid reference to the concept of ‘intolerability’. It seems to me that it all depends on what one means by ‘intolerable’ and that use of that word really expresses a conclusion rather than provides a test. If it is correct to say, or once it has been concluded, that life is literally ‘intolerable’, then it is hard to see in what circumstances it should be artificially prolonged. If, conversely, it is ‘tolerable’ then it is hard to see in what circumstances it should be permitted, avoidably, to end. In any event the most recent word from the Court of Appeal on this concept of ‘intolerability’ is that contained within the reserved judgment of the court in*

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<sup>[30]</sup> See, for instance, *Re J (a minor) (Wardship: Medical Treatment)* [1991] Fam 33, per Taylor LJ at 55.

<sup>[31]</sup> *R (on the application of Burke) v GMC* [2005] 3 WLR 1132.

<sup>[32]</sup> *Wyatt v Portsmouth Hospitals NHS Trust* [2005] 1 WLR 3995.

<sup>[33]</sup> Wyatt, paragraph 86.

<sup>[34]</sup> Paragraph 91.

<sup>[35]</sup> [2006] EWHC 507 (Fam).

*Wyatt v Portsmouth Hospital NHS Trust [2005] EWCA Civ 1181 at paragraphs 76 and 91 where they say that the concept of ‘intolerable to the child’ should not be seen as gloss on, much less a supplementary test to, best interests. Although they continue by saying that the concept is a ‘valuable guide in the search for best interests in this kind of case’, I doubt my own intellectual capacity on the one hand to exclude it even as a ‘gloss on’, much less supplementary test to, best interests; and yet on the other hand treat it as a ‘valuable guide’. If it means no more than that the conclusion that it is in the best interests of the patient to be allowed to die should only be reached in a clear and strong case, then that is already part of the intellectual milestones ..... and the quoted passage from Lord Donaldson of Lymington [in Re J].<sup>[36]</sup>*

4.36 The judge was pointing up the clear internal inconsistency of the Court of Appeal’s comments about intolerability. We suggest that he was right, too, to comment that it is hard to envisage circumstances in which the life of an incompetent patient not in PVS which is ‘tolerable’ should be permitted, avoidably, to end. That is a necessary consequence of the presumption in favour of the continuation of life.

4.37 We consider that the intolerability test is a useful and practical guide. A hard-pressed clinician is far more likely to be able to answer the question ‘Is his life demonstrably intolerable?’, than the question ‘Is it in his best interests to continue to exist?’. The intolerability question has far less philosophy, theology and downright speculation in it. And for that reason the clinician is far less likely to import his own values and other superfluous criteria into the decision.

4.38 The intolerability test will clearly be most often useful where there is real doubt about where best interests lie. This is frequently the case with very ill or very young children, but may also be true for adults – and classically those with dementia.

## The relevance of advance decision

4.39 An advance decision or directive is a declaration by a person about how he would like to be treated in the event of finding himself in the future in a specified medical state. It might say, for example, that an individual would not want to be maintained by the administration of artificial nutrition and hydration if he were ever in a persistent vegetative state.

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<sup>[36]</sup> Paragraph 17.

4.40 The Mental Capacity Act 2005 refers expressly to advance decisions. Section 4(6)(a) provides that a person making a ‘best interests’ determination ‘... must consider, so far as is reasonably ascertainable, (a) the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity)...’

4.41 Sections 24, 25 and 26 deal with advance decisions. Those sections provide as follows:

24. *Advance decisions to refuse treatment: general*
  - (1) ‘Advance decision’ means a decision made by a person (‘P’), after he has reached 18 and when he has capacity to do so, that if –
    - (a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and
    - (b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.
  - (2) For the purposes of subsection (1)(a), a decision may be regarded as specifying a treatment or circumstances even though expressed in layman’s terms.
  - (3) P may withdraw or alter an advance decision at any time when he has capacity to do so.
  - (4) A withdrawal (including a partial withdrawal) need not be in writing.
  - (5) An alteration of an advance decision need not be in writing (unless section 25(5) applies in relation to the decision resulting from the alteration).
25. *Validity and applicability of advance decisions*
  - (1) An advance decision does not affect the liability which a person may incur for carrying out or continuing a treatment in relation to P unless the decision is at the material time –
    - (a) valid, and
    - (b) applicable to the treatment.
  - (2) An advance decision is not valid if P:
    - (a) has withdrawn the decision at a time when he had capacity to do so,
    - (b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or
    - (c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision.
  - (3) An advance decision is not applicable to the treatment in question if at the material time P has capacity to give or refuse consent to it.

- (4) *An advance decision is not applicable to the treatment in question if –*
    - (a) *that treatment is not the treatment specified in the advance decision,*
    - (b) *any circumstances specified in the advance decision are absent, or*
    - (c) *there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.*
  - (5) *An advance decision is not applicable to life-sustaining treatment unless –*
    - (a) *the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and*
    - (b) *the decision and statement comply with subsection (6).*
  - (6) *A decision or statement complies with this subsection only if –*
    - (a) *it is in writing,*
    - (b) *it is signed by P or by another person in P's presence and by P's direction,*
    - (c) *the signature is made or acknowledged by P in the presence of a witness, and*
    - (d) *the witness signs it, or acknowledges his signature, in P's presence.*
  - (7) *The existence of any lasting power of attorney other than one of a description mentioned in subsection (2)(b) does not prevent the advance decision from being regarded as valid and applicable.*
26. *Effect of advance decisions*
- (1) *If P has made an advance decision which is –*
    - (a) *valid, and*
    - (b) *applicable to a treatment, the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.*
  - (2) *A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment.*
  - (3) *A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment.*
  - (4) *The court may make a declaration as to whether an advance decision –*
    - (a) *exists;*
    - (b) *is valid;*
    - (c) *is applicable to a treatment.*
  - (5) *Nothing in an apparent advance decision stops a person –*
    - (a) *providing life-sustaining treatment, or*
    - (b) *doing any act he reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court.*



4.42 Three observations: First: references in sections 24 to 26 are references only to advance *refusals* of treatment. Second: section 4 of the Mental Capacity Act (which relates generally to ‘best interests’ determinations), refers specifically to advance decisions, but requires only that they are *considered* as part of the overall best interests determination. Advance decisions, on this view, are merely evidence of what an incompetent patient might have said had he been competent. This is the traditional common law view. Third: section 26 appears to make compliance with an applicable advance decision mandatory.

4.43 However one looks at it, section 26 does not sit easily with section 4.

4.44 *Burke*<sup>[37]</sup> contains an important comment on advance decisions. Leslie Burke had contended that if a patient had made an advance directive requiring him to be kept alive in specified circumstances, this must be complied with as a matter of law. The Court of Appeal gave this short shrift, mainly on the ground that while one could validly order doctors *not* to do things, there were very few circumstances in which one could validly order them to do positive acts. In commenting on this, however, the Court of Appeal could not avoid noting the tension between sections 4 and 26.

*The position of a patient in a PVS was addressed at length by the House of Lords in Bland and we do not consider it appropriate in this case to add to what was said by their Lordships, other than to make the following observation. While a number of their Lordships indicated that an advance directive that the patient should not be kept alive in a PVS should be respected, we do not read that decision as requiring such a patient to be kept alive simply because he has made an advance directive to that effect. Such a proposition would not be compatible with the provisions of the Mental Capacity Act 2005, which we consider accords with the position at common law. While section 26 of that Act requires compliance with a valid advance directive to refuse treatment, section 4 does no more than require this to be taken into consideration when considering what is in the best interests of a patient.*<sup>[38]</sup>

4.45 This is hardly a definitive resolution of the conflict between sections 4 and 26, but section 4 does seem to have come off best. The Court of Appeal seem to agree that despite section 26, there is no magic in an advance decision: it is merely evidence to be taken into account in deciding whether or not treatment should be given or withheld. In the case of an advance decision to refuse treatment, that decision, if found to apply, will bring the

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[37] *Supra*.

[38] Paragraph 57.

principle of autonomy swinging decisively in. In the case of an advance decision that treatment should be given, the decision is, again, evidence relevant to the issue of autonomy. But here, as is usually the case in medical law, autonomy does not always have the final word. In either case there will have to be detailed consideration of the question of whether the directive applies. Were the exact clinical circumstances that have arisen envisaged at the time the directive was made? Has the prognosis changed in the light of medical advance since the directive was made? Was the patient adequately counselled about the relevant treatment options and the prognosis at the time the advance directive was made? And so on.

### **Advance decisions and personality-transforming illnesses**

4.46 Some conditions, and notably dementia, will transform a patient's personality. They may have an apparently beneficial effect, stripping a person of the neuroses that have previously made their life miserable.

4.47 What is the position where (a) a patient has executed an advance decision saying that in the event of them developing (for instance) Alzheimer's disease, they do not want to be given any life-sustaining treatment; and (b) they develop Alzheimer's disease and seem wholly happy; but (c) need antibiotics to stave off a life-threatening chest infection? Are the treating clinicians bound to comply with the terms of the advance decision, and refuse to give the life-saving antibiotics?

4.48 Assuming that personality changes have occurred, there are three possible conclusions:

- (a) It has no legal consequences. An advance decision validly executed is binding. There is nothing more to say. A blissfully happy or even merely contented demented patient who signed an advance refusal 10 years before saying that they wanted no life-sustaining treatment in the event of becoming demented must be refused antibiotics when they get a chest infection.
- (b) The position is unclear: a legal opinion should be sought and, if necessary, an adjudication by the Court of Protection requested.
- (c) The advance decision is not binding, for the reasons given below (paras 4.49, 4.50)

4.49 This question has not yet come before the courts for decision, but it is submitted that the answer is clearly no. That is a consequence of something in

section 4 of the 2005 Act that is so obvious that it is easily missed: the tense. The opening words of section 4(1) are: ‘In determining for the purposes of this Act what *is* in a person’s best interests ...’ (emphasis added).

4.50 What Parliament commands decision-makers to inquire into is the best interests of the patient *at the time that the decision is made*. If a personality-changing disease has transmuted person A (who made an advance declaration indicating that if he became person B he wanted to die), into person B, it is the patient facing the doctors – patient B – whose best interests have to be considered. Person A is an irrelevance: he does not exist.<sup>[39]</sup>

### Lasting powers of attorney and court-appointed donees

4.51 Under the Mental Capacity Act 2005 a donor can confer on a donee authority to make decisions about (amongst other things), ‘personal welfare or specified matters concerning [the donor’s] personal welfare ... which includes authority to make such decisions in circumstances where [the donor] no longer has capacity’.<sup>[40]</sup>

4.52 There are, of course, restrictions on the extent to which a donee can force a donor to undergo an act that the donor resists, or restrict the donor’s liberty of movement.<sup>[41]</sup> These restrictions will quite often be relevant in medico-legal practice. A donee can only do or authorise these things if (a) he reasonably believes the donor to lack capacity in relation to the matter in question,<sup>[42]</sup> (b) he reasonably believes that it is necessary to do the act to prevent harm to the donor,<sup>[43]</sup> and (c) the act is a proportionate response to

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<sup>[39]</sup> The explanatory notes to the Act tend to support this construction. They say, at paragraph 28: ‘Best interests is not a test of “substituted judgment” (what the person would have wanted), but rather it requires a determination to be made by applying an objective test as to what would be in the person’s best interests’. The Code of Practice to the Act is to similar effect. It states, at 5.38: ‘In setting out the requirements for working out a person’s best interests, section 4 of the Act puts the person who lacks capacity at the centre of the decision to be made. Even if they cannot make the decision, their wishes and feelings, beliefs and values should be taken fully into account – whether expressed in the past or now. But their wishes and feelings, beliefs and values will not necessarily be the deciding factor in working out their best interests. Any such assessment must consider past and present wishes and feelings, beliefs and values alongside all other factors, but the final decision must be based entirely on what is in the person’s best interests.’

<sup>[40]</sup> Section 9(1).

<sup>[41]</sup> Section 11.

<sup>[42]</sup> Section 11(2).

<sup>[43]</sup> Section 11(3).

the likelihood of the donor suffering harm, and to the seriousness of that harm.<sup>[44]</sup>

4.53 A lasting power of attorney which permits decisions about a donor's personal welfare is subject to the provisions of the Act relating to advance refusals of treatment,<sup>[45]</sup> does not extend to decisions relating to circumstances other than those where the donor lacks capacity (or the donee reasonably believes that he does),<sup>[46]</sup> but does extend to 'giving or refusing consent to the carrying out or continuation of a treatment by a person providing healthcare for [the donor]'.<sup>[47]</sup> An instrument creating a lasting power of attorney relating to personal welfare matters cannot authorise impliedly the giving or refusing of consent to the carrying out or continuation of life-sustaining treatment. This can only be done expressly.<sup>[48]</sup>

4.54 The court has power to appoint a 'deputy' to make decisions on behalf of a person.<sup>[49]</sup> Any decision by a court about what is in a person's best interests trumps a decision by a deputy.<sup>[50]</sup> A court-appointed deputy can extend to 'giving or refusing consent to the carrying out or continuation of a treatment by a person providing health care...'<sup>[51]</sup> and to 'giving a direction that a person responsible for ...health care allow a different person to take over that responsibility'.<sup>[52]</sup> Similar restrictions apply to the exercise of a deputy's power as apply to a donee under a lasting power of attorney.<sup>[53]</sup> A deputy 'may not refuse consent to the carrying out or continuation of life-sustaining treatment ...'<sup>[54]</sup>

## When to go to court

4.55 Almost all dilemmas in the law of consent are resolved by clinicians, in consultation with the patient and the family. For details of the procedures to

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<sup>[44]</sup> Section 11(4).

<sup>[45]</sup> Section 11(7)(b). The advance refusal provisions are sections 24, 25 and 26.

<sup>[46]</sup> Section 11(7)(a).

<sup>[47]</sup> Section 11(7)(c).

<sup>[48]</sup> Section 11(8).

<sup>[49]</sup> Section 16.

<sup>[50]</sup> Section 16(4).

<sup>[51]</sup> Section 17(1)(d).

<sup>[52]</sup> Section 17(1)(e).

<sup>[53]</sup> See generally section 20.

<sup>[54]</sup> Section 20(5).

be followed, see the GMC's guidance: *Consent: patients and doctors making decisions together*.<sup>[55]</sup> But nonetheless there are sometimes difficulties. The House of Lords has said that all cases of withdrawal of nutrition and hydration from patients in a PVS should go before the court.<sup>[56]</sup> It is conventional, and wise, to take several other classes of case there too. Despite the Court of Appeal deploring applications in several types of case unless there is real doubt about capacity,<sup>[57]</sup> the mood of the Family Division has generally been to encourage recourse to the court.

4.56 The Court of Appeal has cast recent doubt on the desirability of getting court authorisation in many cases in which it would seem prudent to ask for it. In the *Burke* case (in the context of a debate about the withdrawal of ANH), Munby J, at first instance, said that the court's guidance should be sought:

- ▶ *where there is any doubt or disagreement as to the capacity (competence) of the patient; or*
- ▶ *where there is a lack of unanimity amongst the attending medical professionals as to*
  - *the patient's condition or prognosis; or*
  - *the patient's best interests; or*
  - *the likely outcome of ANH being either withheld or withdrawn; or*
  - *otherwise as to whether or not ANH should be withheld or withdrawn; or*
- ▶ *where there is evidence that the patient (even if a child or incompetent) resists or (iv) disputes the proposed withdrawal of ANH; or (v) where persons having a reasonable claim to have their views taken into account (such as parents or close relatives, partners, close friends, long-term carers) assert that withdrawal of ANH is contrary to the patient's wishes or not in the patient's best interests.*<sup>[58]</sup>

4.57 Unfortunately Munby J rather overstated things, saying that there was a legal obligation to seek approval from the court in these circumstances, rather than it being desirable.

4.58 Munby J's view gave rise to a lot of consternation. The Intensive Care Society told the Court of Appeal that each year about 50,000 patients were admitted to intensive care units. Of these, 30% die in the unit or on the wards. Most of these deaths are a result of the withdrawal or limiting of treatment – albeit in circumstances where the treating clinicians conclude that treatment would be likely merely to prolong the process of dying. There

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[55] [www.gmc-uk.org/guidance/ethical\\_guidance/consent\\_guidance/contents.asp](http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance/contents.asp).

[56] *Airedale NHS Trust v Bland* [1999] Fam 36.

[57] See, for instance, *St George's Healthcare NHS Trust v S* [1999] Fam 36.

[58] See the judgment of Munby J, paragraph 214(g).

is not always agreement on the part of all concerned about the withdrawal of treatment. The Society said that that if Munby J's criteria were applied, about 10 applications a day would have to be made to the courts.<sup>[59]</sup> This last observation seems to have carried some weight with the Court of Appeal.

4.59 The Court of Appeal in *Burke* did not deal at all with the important question of the desirability of court endorsement in difficult situations, other than to say that 'Good practice may require medical practitioners to seek [a declaration as to whether proposed treatment or the withdrawal of treatment would be lawful] where the legality ... is in doubt.'<sup>[60]</sup> It gave no guidance as to when 'good practice' might require such a declaration. It dealt only with the question of whether there was a legal obligation to seek that endorsement. It concluded that there was not.

*We asked [Counsel for Mr Burke] to explain the nature of the duty to seek the authorisation of the court and he was not able to give us a coherent explanation. So far as the criminal law is concerned, the court has no power to authorise that which would otherwise be unlawful – see, for instance, the observation of Lord Goff of Chievely in Bland<sup>[61]</sup> at p. 785 H. Nor can the court render unlawful that which would otherwise be lawful. The same is true in relation to a possible infringement of civil law. In Bland the House of Lords recommended that, as a matter of good practice, reference should be made to the Family Court before withdrawing ANH from a patient in a PVS, until a body of experience and practice had built up. Plainly there will be occasions in which it will be advisable for a doctor to seek the court's approval before withdrawing ANH in other circumstances, but what justification is there for postulating that he will be under a legal duty so to do?<sup>[62]</sup> (Original emphasis).*

4.60 Munby J had concluded that the European Convention on Human Rights, as construed by European Court of Human Rights in *Glass v UK*,<sup>[63]</sup> had transmuted the seeking of court approval in controversial cases from a rule of good practice to a rule of law.<sup>[64]</sup> This was a misreading of *Glass*, said the Court of Appeal: 'The ECtHR did no more than consider the implications of the doctors' conduct in the light of what the ECtHR understood to be English law.'<sup>[65]</sup>

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<sup>[59]</sup> See paragraph 69 of the Court of Appeal's judgment.

<sup>[60]</sup> Paragraph 81. See too the comment in paragraph 71.

<sup>[61]</sup> *Airedale NHS Trust v Bland* [1993] AC 789

<sup>[62]</sup> Paragraph 71.

<sup>[63]</sup> (2004) 1 FLR 1019.

<sup>[64]</sup> See the judgment of Munby J, paragraph 210.

<sup>[65]</sup> Paragraph 81.

4.61 The Court of Appeal has been less than helpful. Even if Munby J did indeed elevate *Glass* to a status that it does not have, at least he took the trouble to identify the situations where the oversight of the court might be desirable. There is nothing legally offensive about the court laying down rules of good practice. That, after all, was precisely what the Court of Appeal found had been done by the House of Lords in *Bland*. Call it merely a rule of practice if you like: since *Bland* all practitioners have regarded it as mandatory to seek the approval of the court to the withdrawal of ANH in all cases of PVS.

4.62 The tone of the Court of Appeal's comments on court authorisation will have the effect of discouraging applications to the court in difficult cases. This could make patients, relatives, carers and clinicians less confident that the right thing has been done.

4.63 We advise clinicians to consider whether to seek the approval of the court in any of the circumstances set out in Munby J's list of criteria in case of doubt (see [para 4.56](#)).

# 5 Practice

## Overview

5.1 Eating and drinking are among our most important activities. They are essential for nutrition and hydration, pleasurable and important socially. If they become difficult, malnutrition and dehydration are possible as well as the loss of an enjoyable experience and social interaction. Thus every effort should be made by healthcare professionals to maintain them.

5.2 Inability to eat and drink can be devastating to patients and their families, particularly at the end of life. There are two aspects to management: (1) Is artificial feeding necessary for adequate nutrition or can sufficient for basic needs be taken orally, albeit with difficulty? This may differ from the ideal requirements for a normal healthy individual as nutritional needs may be less. (2) If artificial nutrition is necessary, what is the best method (eg PEG)? It may not be desirable if the aim of care is palliative.<sup>88</sup>

### Case 1

An 83-year-old man is admitted on a Friday evening to the medical assessment unit. He has a neurological deficit and a stroke is suspected. In line with the local protocol his oral feeding is assessed by a nurse from the stroke unit. It is 9 pm so the speech and language therapist is not available. His swallow is deemed 'unsafe'. He is managed 'nil by mouth' and given iv fluids.

On the following Monday morning he is referred for a PEG. He is seen by the nutrition team who arrive to an emotional scene. The family is demanding an immediate 'pegging' as they have been informed it will provide nutritional support and improve his condition. They have seen him deteriorate over the weekend and feel that he may well die if a PEG cannot be placed. The nutrition team talks to the family who have firmly arrived at the consensus view that the PEG is vital not only to support him, but to reverse his current problems.

First the medical problems are discussed; a clear diagnosis of stroke has yet to be made. An NG tube has been attempted over the weekend but a number have been pulled out and this has fuelled family distress and anxiety. The benefits and risks of a PEG are discussed, but this seems to be interpreted by the family as 'delaying and trying to cost save' by the hospital.



A PEG is sited uneventfully a few days later, having been considered appropriate. However, the patient dies 10 days later. In discussion, some family members believe his early nutritional deprivation caused this, while his wife was saddened that he was unable to enjoy any of the edible treats that she had made for him. How can this be avoided?

5.3 Case 1 is real and contrasts with the principles elucidated in the previous chapters. The circumstances are far from ideal but illustrate how a situation may get out of hand if the right process is not followed and if staff do not explain the facts clearly. This could have been resolved by consistent policy based on the advice of an experienced physician and involving other members of the nutrition support team. For example, the patient might have been able to feed by mouth if he had been given food of the appropriate consistency by a carer with sufficient training and the time to attend to his needs. It is known that oral feeding problems are common in ischaemic stroke on admission and most resolve within days or weeks. In case of uncertainty, a temporary NG tube during this time is safer than a PEG.<sup>26</sup> It must be made clear to the family that this is an interim step to allow assessment of benefit. In this instance, such an explanation and its placement would have reassured the family that a careful and considered approach was being taken. If displacement is a problem, a nasal loop can be used to reduce the chance of this occurring. Initiation of nutrition support is not essential over the weekend and attempts by non-experts may cause distress. Sometimes, intravenous fluids alone will be given over the weekend to avoid dehydration and the untreated development of the refeeding syndrome.

5.4 Unfortunately, an appropriately experienced physician may not always be available at the time of admission so some guidelines to assist clinicians dealing with the situation may be helpful until one is available. However, every effort should be made by trusts to provide someone who can help at all times. The importance of a 'lead clinician' in complex cases and of the skills required by medical leaders of a nutrition support team are well described so trusts should know the sort of person to recruit if they do not have one.<sup>26,89</sup>

5.5 A dying patient does not need nutrition purely to maintain life but food to give pleasure; this does not signify that the patient is being 'starved to death'.

5.6 When artificial nutrition/hydration is required, the aim should be to improve the overall condition of the patient. If it does not then the treatment

is futile, so it may be advisable to set criteria for success in advance of a trial of tube feeding. The criteria should be discussed with the patient and/or relatives.

5.7 Examples of such goals may include:

- ▶ decrease in discomfort/symptoms as medication can be given
- ▶ increase in weight if the patient is underweight
- ▶ improvement of healing of pressure ulcers
- ▶ increased capacity for rehabilitation
- ▶ reversal of confusion.

5.8 Expectations from a PEG in any particular patient that need to be discussed are:

- ▶ life expectancy with or without PEG or NG feeding
- ▶ quality of life with or without PEG or NG feeding
- ▶ changes to daily living, and the impact on both the patient and carers.

5.9 Negative aspects of PEG placement are:

- ▶ Invasive, medical risks of placement and reflux. Even in the best units, 30-day mortality is 6% with 10% morbidity.<sup>90,91</sup> Some patients with certain pre-existing conditions such as motor neurone disease have a much higher mortality.
- ▶ Social: the individual is attached to a pump for up to 20 hours per day, or may require repeated bolus administrations every one to two hours. As they are not involved in mealtimes, there will be less social interaction. There is also a significant alteration in body image.
- ▶ May be legal risks: against wishes, assault.
- ▶ Deprived of pleasure of eating.

5.10 Give alternatives:

- ▶ Nothing: non-invasive, and if the patient is asymptomatic (not hungry or thirsty) then this may be reasonable. Nutrition should be appropriate to need but fluids should always be made available.
- ▶ Risk management, allowing modified consistency oral nutrition.
- ▶ Patient support: this is time consuming and requires training.

5.11 The views of those involved need to be sought and documented.

5.12 In those with a chronic condition in which artificial feeding may become necessary then information should be given that explains:

- ▶ details of what a PEG is and how it is placed
- ▶ daily use and care and that it may not manage all the patient's problems
- ▶ discussion on the potential impact on morbidity and mortality
- ▶ details of how to make wishes known in future.

## Teams and responsibility

### Case 2

Mrs KH, aged 60, was diagnosed with multiple sclerosis aged 43. She has had progressive problems with oral feeding so a PEG was inserted three years before. This had become naturally worn so that it was planned, in line with local policy, to insert a balloon gastrostomy at her nursing home. This would enable her to have repeated replacements locally without hospital admission. This was placed at her nursing home with her consent and her family's support.

Despite previous training in gastrostomy care with the nursing staff at the home, the gastrostomy tube fell out four months later and the stoma subsequently closed before a replacement could be fitted. She was then admitted as an emergency to her local hospital, and came under the care of a general physician with a respiratory interest.

At this point she was re-assessed by the nutrition nurse specialist (who had placed her balloon gastrostomy). She noted a significant physical deterioration and that she, the patient, was now unable to communicate her wishes. Her family did not wish her to have a further PEG placement as they felt her condition was too advanced to warrant feeding by this means. The nursing home staff believed that she had previously consented to enteral feeding.

The admitting medical team at the hospital thought that the family view was wrong and that safe feeding and hydration should be provided. With the lack of family consent, legal advice was sought and the case was heard at the High Court. The court found in favour of feeding and a PEG was placed.

The patient died two years later. It is not known what her quality of life was during this period.

5.13 Case 2 illustrates how decisions taken by doctors require a full understanding of the views of those close to the patient, especially if there is disagreement. The courts will place a great deal of weight on medical opinion so it is important that this is well informed and based on best evidence.

5.14 Multidisciplinary team working aims to minimise personal preferences and ideologies, whether scientific, moral or religious, and maximise multi-professional resources. The team members may take responsibility for

different aspects but work together so that the patient is provided with holistic care. Needs other than the nutritional, such as the quality of life and social support, are important to consider (see Chapter 1).

5.15 Individuals whose involvement is commonly sought:

- ▶ patient and family
- ▶ speech and language therapists
- ▶ dietitian
- ▶ nutrition nurse specialist
- ▶ team looking after the patient at the current time
- ▶ GP and any community team involved
- ▶ those placing the PEG, usually the gastroenterology or nutrition team.

### Case 3

Aged 76 with known dementia, the patient was referred for a PEG having had a right-sided stroke. He had been initially fed using NG tubes, but had repeatedly pulled them out. His underlying condition deteriorated and it had been explained to his family that he should be for 'tender loving care only'.

Two weeks later he was still alive and referred for a PEG. The family was in agreement. On assessment, he was very frail. It was noted that he had previously refused artificial feeding when discussed, although he had had some confusion.

A PEG was inserted and five days later he died.

5.16 In Case 3, it may have been better for the nutrition team to have stated clearly that they did not feel that a PEG was appropriate. It also illustrates the useful role that a physician experienced in medical, nutritional, ethical and legal issues might have in avoiding this scenario. Common dilemmas experienced by the nutrition team regarding PEG involve:

- ▶ late referrals in typically bed bound patients who are unable to communicate their wishes, with an underlying irreversible condition
- ▶ patients at the end of life, with a predominant carer, able to eat small (but adequate) amounts each day who may be greatly distressed if this is removed. An inappropriate hospital admission for PEG insertion compounds the problem.

5.17 PEGs are sometimes seen as an 'easy option', which may briefly prolong a life but with poor quality. PEG referral should not be designed to overcome a lack of carer time.

5.18 An assessment taken in isolation that designates the patient as ‘nil by mouth’ without considering the patient holistically or offering oral fluids is bad practice.

### Approach to patients

5.19 Team members may be in conflict with each other as their goals may be different. Goals should therefore be set at the start of a discussion so that discussion is then followed with an agreed end. (See also [paras 1.50–1.57](#).)

5.20 An example of an ethical decision-making process is:<sup>92</sup>

- 1 Each member of the team must state their opinion.
- 2 The underlying reason for each decision is then determined.
- 3 The concerns of each group member are discussed and common themes identified.
- 4 An action plan is agreed and the best solution adopted.<sup>93</sup>

5.21 The benefits and risks of ANH must be communicated with the individuals involved, so that an informed decision can be made. In the acute situation this requires a more rapid assessment than in a chronic disease. In any chronic disorder early discussion should take place so that decisions can be made in an unhurried manner, and documented. This should prevent rapid decisions that may not reflect a patient’s wishes. Such decisions must be easily accessible so that in an emergency they can be known and used.

5.22 In an acute situation where there is no known previous discussion and views then the practices in the flowchart (Fig 2) are recommended.

5.23 The team need to communicate benefits and burdens of ANH and PEGs. It should be stressed that a PEG will not alter the course of an underlying disease.

5.24 PEG placement has been believed to prolong life by:

- ▶ improving nutrition
- ▶ minimising dehydration
- ▶ reducing aspiration
- ▶ aiding pressure sore healing.

5.25 However, the evidence that it does so is lacking and insertion is associated with hazard. PEG placement has been associated with 23.5%

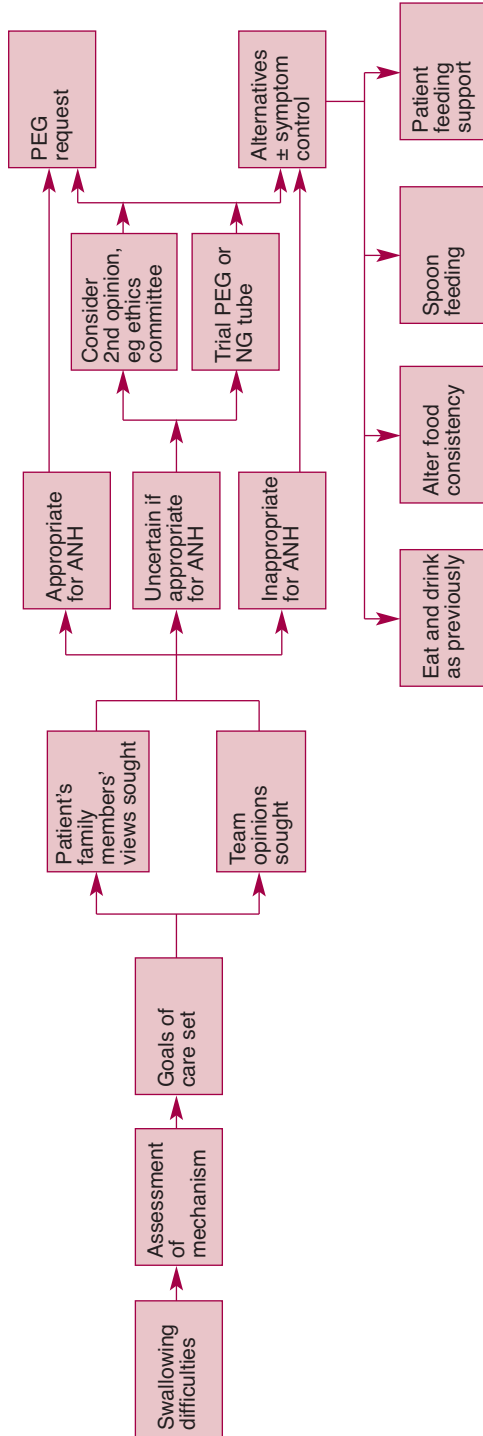


Fig 2 Decision-making in patients with feeding dilemmas.

mortality during the hospital admission of placement and a median survival of 7.5 months.<sup>31</sup>

## Specific medical conditions

5.26 **Persistent vegetative state:** PEGs will prolong life without improving its quality. A court order may be necessary if placement is inappropriate or PEG needs to be removed.

**Stroke:** A PEG enables feeding during rehabilitation because it is more secure than a NG tube and is out of sight if the patient can converse with others. However, the Food trials<sup>94</sup> showed that it was associated with increased mortality and poor outcome, although this may be because those receiving a PEG may be a more unwell group of patients.

**Oropharyngeal malignancy:** PEG can improve survival and decrease morbidity; however, in advanced disease there is no evidence of benefit.

**Amyotrophic lateral sclerosis** (progressive weakness and loss of muscular control): With respiratory and nutritional support patients can rarely survive indefinitely. Patients remain mentally alert, so they retain decision-making capabilities. PEG palliates by improving nutrition, but there is no evidence it prolongs survival. It has been advised that a PEG should be inserted early to improve nutritional status as a respiratory vital capacity of >50% is required. Every effort should be made to maintain patient autonomy.<sup>95</sup> A frank discussion about risks and benefits is required.

**Dementia, delirium and learning difficulties.** See [paras 2.22–2.36](#).

**Multiple sclerosis.** A PEG can be helpful in some patients but if used inappropriately can prolong the dying process and increase suffering.

**Cerebral palsy.** A PEG may be inserted to reduce the time required by parents to feed children with cerebral palsy but this can also increase the stress for the carer. It does deprive the child of the pleasure of eating and the positive interaction with the parent from careful hand feeding.

## Who decides if the patient cannot decide?

If a patient cannot decide, the following people/groups may need to be involved in decision-making:

- ▶ doctor/team in the patient's best interests

- ▶ relatives – their input is essential
- ▶ independent mental capacity advocate (IMCA) – to advise the decision maker if relatives are not available.

5.27 Relatives may feel that individuals may ‘starve to death’ without a PEG and so the physiological processes resulting in a reduced metabolic rate need to be conveyed with an explanation that it is the disease itself causing the problem, and that a PEG will not alter the underlying course of the disease.<sup>34</sup>

5.28 When relatives have been the principal decision-makers regarding a PEG and are asked *after* the event if they felt that the PEG had improved the quality of life, 44% felt it had, while before PEG insertion 66% were expecting this.<sup>96</sup> Similarly, 56% thought it would positively affect the course of the underlying disease beforehand, while afterwards only 25% thought it had done so. This illustrates the high hopes and faith that is often placed in a PEG, and that accurate information must be given beforehand. It has been shown that the patient’s family often benefits more from PEG placement than the patient, particularly in terms of overall management and time needed.<sup>97</sup> However, doctors have a duty to put the patient first rather than the family.

5.29 The principal complaint from relatives regarding the procedure is the lack of information given, particularly on alternative feeding methods and possible complications.<sup>98</sup> Those caring for patients with a PEG are much more reluctant to consent to a PEG for themselves, should that possibility arise, than those less informed.<sup>96</sup>

### If the patient can decide, who decides what process should be followed?

5.30 There needs to be a full discussion. A checklist of topics for this discussion may include:

- ▶ diagnosis
- ▶ prognosis
- ▶ ANH, effect on :
  - prognosis
  - morbidity
  - quality of life.

The patient needs to decide in event of:

- ▶ gradual decline
- ▶ intercurrent illness



- ▶ other options:
  - thickened feeds
  - assisted oral feeding
  - hydration via subcutaneous fluids.

5.31 The most important factors in decision making have been shown to be the visible deterioration in the physical condition and the medical opinion. Patients often have no prior knowledge of PEG feeding and therefore rely on the information given. They need to be given time to become involved in the decision making process and maintain their autonomy.<sup>4</sup> Information should be given, but be non-directive so that patients are free to make an independent decision.<sup>31</sup>

5.32 Within the hospital setting, PEG referrals from an outpatient setting may involve patients and families who, if properly informed of the facts, may understand the reasons for the feeding and the means for it. Referrals from a clinician not previously known to the patient, often while an inpatient, may cause controversy before and after PEG placement; see case 4.

#### Case 4

Mrs AR, a 77-year-old woman with very mild dementia and a normal swallow, was admitted with a stroke. A PEG was requested as she had oral feeding difficulties. The family openly resisted this as they had been involved in a discussion in the psychogeriatrics outpatients and knew that Mrs AR was not keen to have a PEG if required.

Much discussion followed regarding the dual pathology, of which the stroke was potentially reversible. Resolution occurred after a visit from the psychogeriatric consultant who concurred that, in this case, PEG feeding would be appropriate as the situation had become complicated and the stroke was the dominant acute pathology.

5.33 This case illustrates that other physicians may prove useful in difficult situations. In this instance, a perceived temporary impairment of swallowing in a mild dementia due to another condition may mean that a PEG is helpful. Time spent in explaining this was clearly valuable.

### Dealing with disagreement

5.34 The clinician is obliged to make a decision in the patient's best interests. Similarly, the family/carers of the patient must contribute to a decision based on the patient's views, beliefs and situation, not their own.

5.35 It is reasonable to have a *trial of NG tube feeding* with a fixed time for a review of the clinical condition if goals are achieved. If they are not achieved, this method of feeding should be reviewed.

5.36 In making any decision the following need to be considered:<sup>34</sup>

- ▶ *Is there an advance directive* to provide evidence of the patient's wishes or priorities? It may be overruled if there are concerns about its exact applicability to the situation but it should be taken into account. For example, if it was made some time previously, when the clinical condition of the patient was significantly different, it may be ruled out.
- ▶ *Ethical principles*. Clinicians should not support an intervention that has no benefit. If it is equivocal then consideration of other factors surrounding the condition can be helpful to enable all parties to arrive at a decision.
- ▶ *Legal or financial concerns*. Some nursing homes are unwilling to accept patients who are NG fed. However, they may well do so with a PEG so that there may be pressure on hospital staff to place a PEG (an invasive procedure with risk without benefit to the patient) to provide a prompt discharge. We believe this to be unethical and bad practice but feel also that specialist nursing advice should be commissioned by the PCT from the hospital.
- ▶ *Emotional factors*. Feeding issues are emotionally charged and it is vital for all parties to be well informed to avoid potential guilt factors.
- ▶ *Cultural background*. In some cultures the eldest male may make the family decisions and so other family members' beliefs may have to be actively sought.
- ▶ *Religious beliefs*
- ▶ *The need for a family meeting to consider all of the above* so that informed decisions are made that ideally all parties can agree. See [para 5.20](#) above.

### Referring to others: ethics committees, courts

5.37 In the event that all parties cannot come to a reasonable decision then a further opinion may be helpful.

5.38 Clinical ethics committees provide a valuable opinion.<sup>99</sup> These committees usually include lay representatives so it is important that they are given accurate medical information.

5.39 The view of a court may be sought to make a judgment on the legality of any action the doctor proposes. Again, clear and expert medical advice is essential to inform the court.

### Summary of principles of practical management

There is not always a simple easy answer to a difficult problem in this area but application of the following principles will aid a solution.

- 1 A full, expert medical assessment is the first priority, preferably by a physician experienced in nutrition support.
- 2 Good communications with patients, relatives and advocates to inform them are essential in resolving difficulty in these emotional and contentious areas. Doctors should not be afraid of speaking about difficult issues.
- 3 Language should be clear and unambiguous.
- 4 Time is required to do this effectively. Rushed and ill informed discussion will lead to unhappy patients and relatives.
- 5 A medically led nutrition support team is the best way to coordinate all the skills required.
- 6 Good nursing, particularly mouth care and attention to oral nutrition and hydration, is the key to improving outcomes both inside and outside hospital. There must be hospital staff available who can pass an NG tube safely when required.
- 7 Patients should always have oral fluids, modified in consistency if necessary, available to them. The speech and language therapist can be of great value in supporting this approach. Small quantities of fluid can improve mental alertness. Food and fluid orally have value beyond biological usefulness and should always be offered but palliative care physicians believe that to force fluid into a dying patient does not relieve suffering (see [paras 1.90–1.92](#)) Tube feeding is always a last resort.
- 8 Technical understanding and skills are essential for the gastroenterologist so that they can advise on what is possible in individual cases. This extends beyond endoscopic expertise but also involves an understanding of the techniques that can be employed by other healthcare professionals. They also require good judgement because what is possible may not necessarily be in the patient's best interests.

# Appendix 1

## Witnesses and written submissions

The working party is very grateful to the following people who made presentations or sent written submissions.

### Witnesses

Dr Clive Bowman, medical director, BUPA

Dr Ailsa Brotherton, British Dietetic Association

Professor Christine Collin, Chair, Joint Specialty Committee for  
Rehabilitation Medicine

Dr Gillian Craig FRCP

Professor Raanan Gillon, professor of medical ethics, Imperial College

Dr Peter Saunders, Dr John Wiles, Care Not Killing

Ms Sarah Wootton, Professor Ray Tallis, Dignity in Dying

### Written submissions

Alzheimer's Society

Association for Rehabilitation of Communication and Oral Skills

Catholic Bishops Conference of England and Wales

Faculty of Old Age Psychiatry

National Council for Palliative Care

Progressive Supranuclear Palsy Association

Royal College of General Practitioners

Royal Hospital for Neuro-Disability

Dr John Coakley FRCP

Reverend Phyllis Eaton MBDA (ret.)

## Appendix 2

# Guidelines and other guidance

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Feeding is basic to life but it can also be an artificial medical procedure in the power of health professionals. Sometimes it causes dilemmas and strong differences of opinion between patients, relatives and professionals. This report is the result.

It acknowledges the confusion and uncertainty that sometimes surround decision-making and practice, including the difficulties of carrying out some of the technical interventions involved.

The report provides evidence-based guidance on the mechanisms and techniques of oral and artificial nutrition in health and disease. It sets out the ethical and legal concerns that provide the framework for decision-making. Case studies then illustrate dilemmas and solutions, for example on deciding whether to withhold or provide artificial nutrition.

This guide is essential reading for all those involved in caring for people who have nutritional and oral feeding difficulties.

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