



# Supporting people who have eating and drinking difficulties

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



# **Supporting people who have eating and drinking difficulties**

**A guide to practical care and clinical assistance, particularly towards the end of life**

## The Royal College of Physicians

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## Stakeholder organisations

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These guidelines are endorsed by the following organisations:

- > British Association for Parenteral and Enteral Nutrition
- > British Dietetic Association
- > British Geriatrics Society
- > British Society of Gastroenterology
- > Dementia UK
- > Malnutrition Task Force (Age UK)
- > National Nurses Nutrition Group
- > Royal College of Psychiatrists
- > Royal College of Speech and Language Therapists
- > Royal Pharmaceutical Society

## Contents

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Acknowledgements .....	7
Foreword .....	8
Executive summary .....	9
Introduction .....	11
<b>Chapter 1: Clinical factors affecting our ability to eat and drink.....</b>	<b>13</b>
1.1 Introduction.....	13
1.2 Clinical issues of relevance to eating and drinking .....	13
1.3 Mechanisms of problems with eating and drinking.....	17
1.4 Clinical approach to patients .....	19
<b>Chapter 2: Strategies to support eating and drinking .....</b>	<b>22</b>
2.1 Introduction.....	22
2.2 Timely intervention .....	22
2.3 Oral nutrition support .....	23
2.4 Communication .....	29
2.5 Advance care planning .....	30
2.6 Consequences of withholding nutrition .....	31
<b>Chapter 3: Clinically assisted nutrition and hydration.....</b>	<b>33</b>
3.1 Introduction.....	33
3.2 Trends.....	33
3.3 Indications for clinically assisted nutrition and hydration .....	35
3.4 Enteral tube routes.....	35
3.5 Mouth care.....	36
3.6 Nasogastric tubes .....	36
3.7 Gastrostomy tubes .....	39
3.8 Parenteral nutrition .....	42
3.9 Subcutaneous and rectal hydration.....	43
<b>Chapter 4: The law.....</b>	<b>44</b>
4.1 Introduction.....	44
4.2 General principles.....	45
4.3 Advance decisions .....	49
4.4 Children .....	52
<b>Chapter 5: Ethics.....</b>	<b>54</b>
5.1 Introduction.....	54
5.2 Ethical principles.....	54
5.2 The sanctity of life .....	56
5.3 CANH and basic care .....	56

5.4 Ordinary and extraordinary means of care.....	57
5.5 Intended and foreseeable .....	57
5.6 Withholding and withdrawing .....	58
5.7 Killing and letting die .....	58
5.8 Surrogate judgement and best interests .....	58
5.9 Conscientious objection .....	59
5.10 Trust and transparency .....	60
5.11 The ethics of process .....	60
<b>Chapter 6: Illustrative examples of patients to guide practice .....</b>	<b>61</b>
6.1 Introduction.....	61
6.2 Kwame, a stroke patient.....	63
6.3 Sarah, a patient with dementia .....	66
6.4 Sean, a young person with cerebral palsy .....	68
6.5 Nina, a patient with functional GI disorder / psychological illness .....	70
6.6 Priya, a patient with abdominal malignancy.....	71
6.7 Guiding decision making: a summary .....	72
<b>Glossary .....</b>	<b>74</b>
<b>Declaration of interests.....</b>	<b>76</b>
<b>References .....</b>	<b>77</b>

## Acknowledgements

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On behalf of the RCP, I would like to thank all of the working party members who gave freely of their time to contribute to the substantial work involved in the development of this guidance.

We have not been the first to discover that writing guidance on aspects of eating and drinking is not for the faint-hearted, particularly when looking at the difficulties and dilemmas that often arise. Whether to start, continue or withdraw nutrition towards the end of life remains a contentious issue.

We were fortunate on this occasion to have the highly regarded first edition of this guidance, published in 2010, to work from and are hugely indebted to the working party that put it together. Two members of the original working party kindly agreed to contribute to this edition. New to this updated version of the guidance is the welcome and timely input of dietetic colleagues and the addition of a chapter focusing on strategies to support eating and drinking.

There has been a lot of case law pertaining to nutrition in the past decade, which the 2018 BMA/RCP guidance on clinically assisted nutrition and hydration has helped to put in a framework that clinicians and healthcare workers can use to guide decision making.

The law, and in particular, understanding of the Mental Capacity Act 2005, has continued to evolve since 2010. The courts have explored the nuances of what it means to lack capacity to make specific decisions, and have placed an increasing focus on the patient's wishes and feelings in determining what is in their best interests if they cannot be supported to make their own decisions. The Supreme Court also confirmed in 2018 that decisions about life-sustaining treatment (including clinically assisted nutrition and hydration) in relation to those patients unable to consent to or refuse such treatment do not need to be placed before the court for approval where all those concerned with the patient's welfare are in agreement.

The difficulties, uncertainties and confusion associated with decisions regarding provision of nutrition and hydration towards the end of life remain extremely challenging. We hope this document will guide an approach to finding a way through these difficulties that is legally sound, pragmatic and compassionate.

**Dr Aminda De Silva**  
**Working party chair**



## Foreword

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Over the past 2 decades we have seen a dramatic change in patient populations in our hospitals with an older demographic who have increasingly complex multiple long-term conditions. Difficulties with eating and drinking are common in this population and the challenges these present to healthcare professionals caring for those patients are frequent and no easier for this frequency. COVID-19 has highlighted how important it is to understand patient wishes and the views of patients and carers when making difficult decisions as well as the pitfalls that result if this is not done.

This updated guidance is therefore both timely and welcome. The law has changed slightly since the first version and the new report covers this. To me, though, the addition of guidance about what to do in cases where patients have capacity and yet still have risks associated with eating and drinking is the most welcome addition. Making patient-centred plans in this particular setting is never easy and unless handled well can pit professional groups against each other.

I hope this guidance allows doctors and other healthcare professionals to work with patients, their families and their carers to make the best decisions around nutrition and hydration. There is often no easy right or wrong decision but understanding the pros and cons (both clinically and legally) allows a shared decision between all parties. I hope you too find this guidance helpful – it has certainly changed how I treat my patients both on the ward and in clinic.

Finally, it has been a privilege and a pleasure to work with the members of the working group to produce this document. Without their time and hard work it would not have been possible.

**Professor Andrew Goddard**  
**RCP president**

## Executive summary

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This guidance updates the previous *Oral feeding difficulties and dilemmas* published in 2010. It aims to guide healthcare professionals supporting people with nutrition and hydration towards the end of life. It covers the factors affecting our ability to eat and drink, techniques of clinically assisted nutrition and hydration, and the legal and ethical aspects of giving and withholding treatment.

Illustrative examples of patients with different conditions and circumstances describe common difficulties with eating and drinking and how to ensure decisions are guided by the best interests of the patient.

It is divided into six chapters that cover the following areas:

### **Chapter 1 gives an outline of eating and drinking and the factors that affect it**

- > It covers the anatomy and physiology of eating and drinking and underlines the complex mechanisms involved.
- > It examines the determinants of successful eating and drinking, including the preparatory phases and the act of swallowing, pulmonary function, underlying disease and environmental factors.
- > It describes clinical issues of relevance to eating and drinking, the diagnosis of problems and examples of conditions where eating and drinking problems are common.
- > It concludes with how to assess eating and drinking and its relative risks.

### **Chapter 2 describes strategies to support eating and drinking to optimise nutritional intake**

- > It outlines when oral nutritional support should be considered and its aims.
- > It emphasises that effective eating and drinking strategies involve multidisciplinary team working together with good communication with patients, family members and carers.
- > It describes tailoring dietary advice to ensure it remains a benefit, not a burden.
- > It covers how to make decisions on eating and drinking with acknowledged risks and recommends policies should seek to mitigate unnecessary delays in providing food, fluid and medications and undesirable restrictions of oral intake.

### **Chapter 3 looks at clinically assisted nutrition and hydration (CANH)**

- > It covers the reasons and techniques for CANH.
- > It underlines that decisions to use CANH can be complex and should carefully consider individual circumstances; patients and their families should always be supported by a multidisciplinary team.
- > A nutrition support team should assess all patients referred for gastrostomy placement; consideration of the risks versus benefits is key.
- > Home parenteral nutrition is only required for a small proportion of patients, but has an increasing role in the end-of-life care of patients with advanced malignancy.

### **Chapter 4 covers the law and the changes since the last edition**

- > It looks at capacity and best interests as the two key concepts in decisions around medical treatment.
- > It covers the Mental Capacity Act as the legal framework for determining mental capacity and making decisions on behalf of people who lack the capacity to decide for themselves.
- > An adult patient with capacity has the right to decline even life-preserving treatment. They do not, however, have the right to demand any treatment which the healthcare team does not consider is clinically appropriate.

- > Where no advance decision applies, best interests decision making should be constructed around the known wishes and feelings of the person lacking capacity.
- > The differences in decision making in relation to adults and children are covered.

### **Chapter 5 sets out the ethical framework for decision making**

- > It describes ethical opinion and legal precedent in terms of the patient's best interests.
- > It covers the important principles of 'sanctity of life' and the 'preservation of dignity'.
- > The patient, or their representatives, should understand that CANH is a burdensome treatment with risks.
- > It advocates transparency, honesty and respect to guide discussions around CANH.
- > Finally, it covers the importance of the law and the Mental Capacity Act as a framework within which ethical considerations are considered.

### **Chapter 6 considers a range of eating and drinking difficulties and dilemmas with illustrative patient examples**

- > It underlines that all patients who need nutrition and hydration support should receive coordinated care from a multidisciplinary team.
- > It emphasises that the risk versus benefit of any intervention should be clearly documented and treatment goals articulated and offers seven key questions to consider when treating patients with eating and drinking difficulties.
- > It includes illustrative examples of patients with different conditions, capacities and wishes to help guide decision making.

## Introduction

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Eating and drinking are essential for maintenance of nutrition and hydration but are also important for pleasure and social interactions. The ability to eat hinges on a complex and coordinated system, resulting in significant potential for things to go wrong.

Difficulties with eating and drinking may have both physical and psychological consequences. It is therefore important for healthcare professionals to make every effort to maintain and support these activities. An inability to eat and drink can be devastating to patients and their families, particularly at the end of life, and can be a significant source of anxiety and distress.

Decisions about nutrition and hydration are some of the most challenging to make in medical practice. This guidance aims to support healthcare professionals to work together with patients, their families and carers to make decisions around nutrition and hydration that are in the best interests of the patient.

### Objective

The overall objective was to update the previous guidance *Oral feeding difficulties and dilemmas*, published in 2010, particularly in relation to developments in assessment and management; and with respect to recent changes in the law governing procedures for the withdrawal of clinically assisted nutrition and hydration (CANH) and other life-sustaining treatments.

### The patient group covered

The guidance focuses on patients who have difficulties with eating and drinking, often as one of the known complications of a condition, a procedure or a situation. This includes people with dementia, motor neurone disease and cerebral palsy as well as those who have had a stroke. There is a particular focus on patients approaching the end of life, at the point where their ability to take in food and drink orally may change and give rise to specific challenges and dilemmas.

### Target audience

The audience for this guidance is primarily medical and healthcare professionals. It is aimed at all those involved in caring for people who have eating and drinking difficulties, including gastroenterologists, ward nurses, geriatricians, dietitians, speech and language therapists, neurologists, palliative care teams, care home and community nurses.

### Scope and areas covered

The Mental Capacity Act 2005 applies in England and Wales. The equivalent legislation in Scotland is the Adults with Incapacity (Scotland) Act 2005. A Mental Capacity Act for Northern Ireland has been passed but is not yet fully in force; currently decisions about medical treatment take place under the common law. This guidance does not consider Scottish or Northern Irish legislation and readers are recommended to seek expert legal advice in those devolved parts of the UK about legal matters, but the general clinical principles will still apply.

Chapter 6 includes illustrative examples of patients to consider specific dilemmas and solutions, such as deciding whether to withhold or provide CANH.

### Guidance development

The working party and reviewers of the guidance have come from a multidisciplinary group representing nutrition nurse specialists, barristers, dietitians, speech and language therapists, and

physicians working in the specialties of gastroenterology, neurology, palliative care, intensive care and geriatric medicine.

### **A note on terminology**

The term 'oral feeding' used in the 2010 guidance has been avoided in this updated edition. Where possible, 'eating and drinking' has been used in preference in order to adopt a more patient-centred approach and avoid use of the word 'feeding'.

Where the term 'feeding' has been used (eg in 'risk feeding'), this does not imply that the patient is passive in the organisation and timing of eating and drinking, even if they are totally dependent on the assistance of carers.

# Chapter 1: Clinical factors affecting our ability to eat and drink



## Key points

- > The maintenance of weight, nutritional status and adequate hydration without clinical intervention depend upon on a person's ability to eat and drink.
- > The determinants of successful eating and drinking include swallowing, airway protection, general medical and surgical problems, and the caring environment.
- > Problems with eating and drinking can be the first sign of some diseases. More commonly they are one of the known complications of a condition, a procedure or a situation. They depend on the underlying pathology and impairments, and can change during the course of a disease.
- > Swallowing involves the propulsion of food and airway protection and can be initiated voluntarily or reflexly.
- > Environmental factors can also disrupt eating and drinking, including the availability of carers, consistency of food and appropriate setting.
- > A range of assessment techniques is available to assess the mechanism of the eating and drinking problem, and the effect of interventions.

## 1.1 Introduction

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Successful eating and drinking are characterised by the maintenance of weight, adequate hydration, and an acceptable frequency of coughing and other responses to things getting stuck or 'going down the wrong way'.

This chapter looks at the factors that affect oral nutrition, including the phases and neurology of swallowing, the determinants of successful eating and drinking, and how different conditions may impact these mechanisms.

## 1.2 Clinical issues of relevance to eating and drinking

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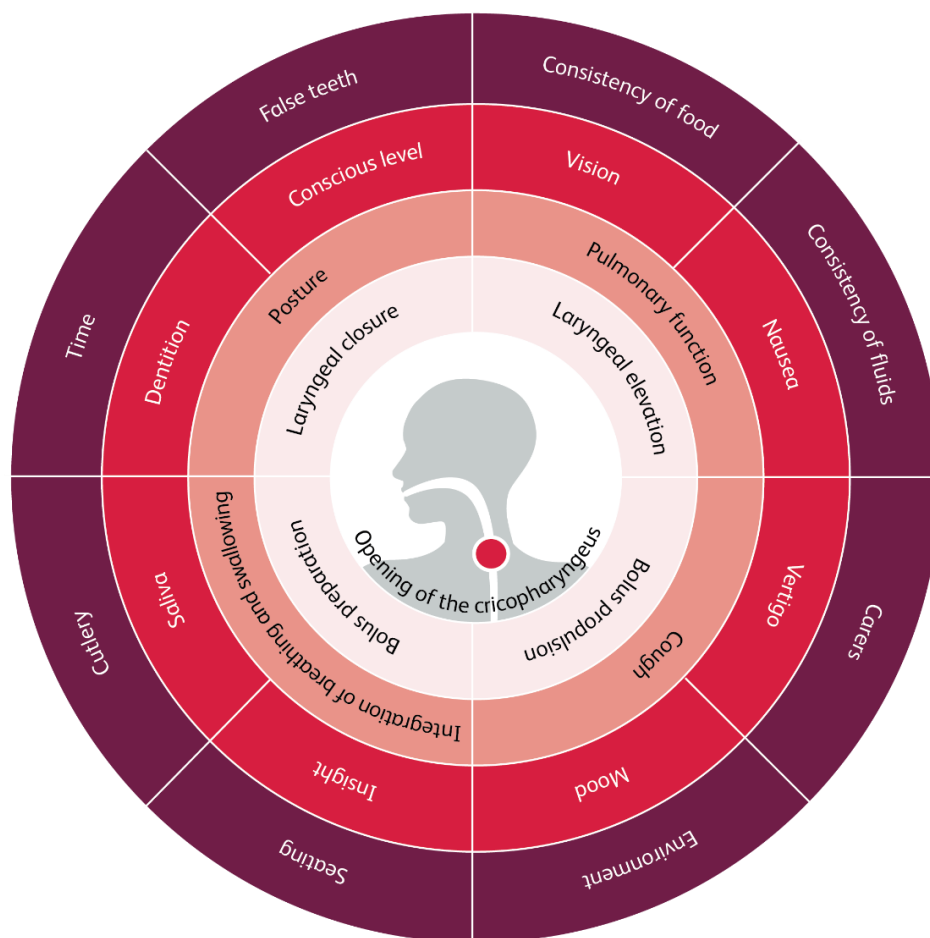
Significant eating and drinking problems can manifest as dehydration, weight loss, food refusal or a reluctance to eat, frequent coughing and spluttering, prolonged mealtimes, pulmonary problems such as laryngeal obstruction and chest infections, drooling from the mouth, and withdrawal from mealtimes.

Problems with eating and drinking can be the first sign of some diseases. More commonly they are one of the known complications of a condition, a procedure or a situation.

To gain a complete understanding of an eating and drinking problem it is important to assess four main areas of clinical practice:

- > the pre-oral phase of eating and drinking, intra-oral preparation of food, and swallowing
- > laryngeal closure, cough, and pulmonary function
- > the underlying medical, neurological, surgical or psychiatric conditions
- > the environment, including the availability of carers and the consistency of food and fluids.

Fig 1 illustrates the some of the key determinants of successful eating and drinking. Each ring comprises factors from the four areas of clinical medicine that are of relevance. These key determinants highlight the complexity and vulnerability of oral nutrition and hydration – impairment in any one of these areas will affect the ability of a person to eat and drink.



**Fig 1. Some of the key determinants of successful eating and drinking**

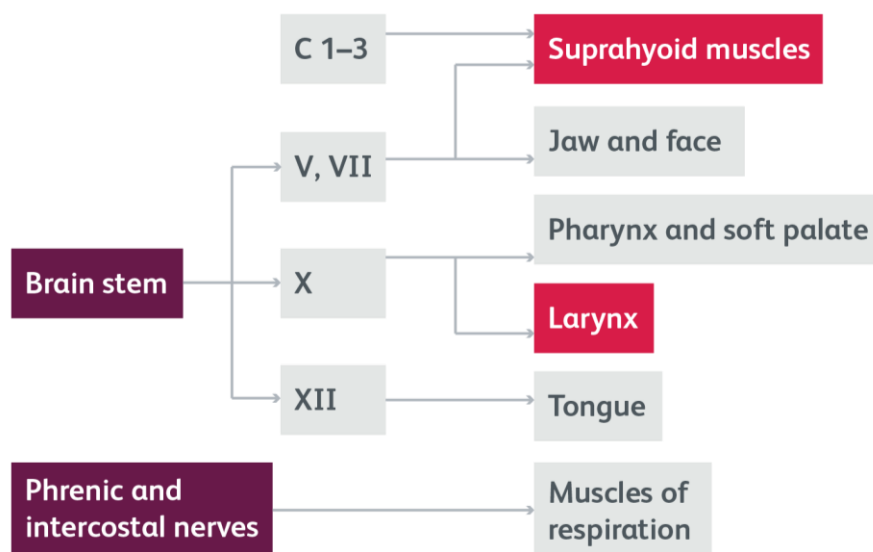
### 1.2.1 Preparatory phases and swallowing

The process of swallowing can be described as a series of phases starting before food enters the mouth and ending when it reaches the stomach. It involves a complex sequence of voluntary muscular movements triggered by nerves and reflexes to protect the airway.

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

The **oral phase** depends on dentition, salivation, chewing, and control and manipulation of food by the tongue and face. During this phase, solid food is broken up and mixed with saliva to form a bolus in preparation for swallowing.

This oral phase is reliant on muscles and glands, all of which have a nerve supply. Chewing is carried out by muscles supplied mainly by the trigeminal or fifth cranial nerve (V), the production of saliva by the salivary glands supplied mainly by the facial nerve (VII), the movement of muscles in the tongue by the hypoglossal nerve (XII), and the control of muscles in the throat and digestive tract by the vagus nerve (X) (see Fig 2).



**Fig 2. The neuroanatomy of swallowing**

The **swallowing** of food or drink is reliant on the successful opening of the main muscle of the upper oesophageal sphincter – the cricopharyngeus. This is attached anteriorly to the posterior part of the cricoid cartilage which sits above the highest tracheal ring and below the larynx and hyoid. The transit of the bolus into the oesophagus – the **pharyngeal phase** of swallowing – depends on the upward and forward movement of the hyoid, larynx and cricoid (by the suprahyoid muscles innervated mainly by V and VII) which pulls open the relaxed cricopharyngeus. The associated drop in pressure (about 30 mmHg) pulls the bolus into the upper oesophagus. Hyolaryngeal movement during swallowing is usually visible, or is easily palpated.

Airway closure depends on the reflex sphincteric action of the larynx and of the arytenoids; the epiglottis completes airway protection by covering the laryngeal inlet (all controlled by the vagus nerve X).

When the head of the bolus is in the upper oesophagus, the posterior pharyngeal wall (X) and the base of the tongue (XII) initiate 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 (innervated by the cervical nerves C1–3).

The larynx is crucial in swallowing: the upward and forward movement leads to the opening of the cricopharyngeus and the associated movement of the bolus into the upper oesophagus, and its closure is the main mechanism of airway protection.

### 1.2.2 Pulmonary function

The pharynx is both an airway and a ‘food-way’. This creates the potential for aspiration (breathing in a foreign object), usually defined as food or liquid reaching or breaching the true vocal cords and entering the airway or lungs.

The main protective response is coughing. This is dependent on the strength and function of the diaphragm and intercostal muscles, timely laryngeal closure and opening, and posture control. If food is lodged in the larynx, or in the bronchi and more distal airways, it will be propelled towards the pharynx and then swallowed or expelled by further coughing, gagging, retching or vomiting.



In healthy adults, swallowing is usually preceded and followed by expiration to encourage food away from the laryngeal inlet before and after each swallow; the opposite would cause food inhalation. During a swallow, breathing is temporarily prevented. This is known as deglutition apnoea.

Patients with established parenchymal lung disease may be more susceptible to the development of pulmonary complications following aspiration and the disease may also reduce the effectiveness of coughing. Breathlessness itself makes eating and drinking difficult.

### 1.2.3 Underlying conditions

A range of underlying medical, neurological or psychiatric conditions as well as the effects of surgery can cause or contribute to eating and drinking difficulties. Table 1 includes examples of conditions and problems that can affect effective oral preparation of the bolus and swallowing.

**Table 1: Underlying conditions that may contribute to difficulties with eating and drinking**

Area	Causes and symptoms
General medical problems	Loss of appetite, nausea, xerostomia (dry mouth), pain, lower oesophageal inflammation, infection and dysmotility, oral infection and ulceration, poor dentition
Structural disease	Disease affecting the face, mouth and upper gastrointestinal tract, and the effects of recent or past surgery and radiotherapy
Neurological problems	Weakness, adverse changes in conscious level, vigilance, attention and concentration, impairments of posture, balance, visual fixation, spatial awareness and poor coordination
Psychiatric disease	Severe depression, anorexia nervosa and some of the drugs used to treat major psychiatric disease

### 1.2.4 Environmental and situational factors

A number of environmental factors have the potential to disrupt eating and drinking. These include 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.

These factors are of particular relevance to the pre-oral stage and are particularly important for patients with conditions affecting social conduct and behaviour.

### 1.2.5 Anatomical and pathological diagnosis

Establishing a diagnosis for the condition underlying a patient's difficulties with eating and drinking can be complex and challenging.

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

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.

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 problem with eating. This is particularly relevant in older people where additional investigations may be required to exclude the coexistence of other diseases.

Conversely, many conditions commonly complicated by eating and drinking problems also cause a significant loss of muscle bulk, so the resulting weight loss does not require an alternative explanation, eg motor neurone disease.

Neoplastic diseases, particularly those involving the upper gastrointestinal tract, head and neck, can cause both local and systemic problems, both of which can cause weight loss and compromise eating and drinking.

### 1.2.6 Voluntary and reflex function

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

**Reflex** swallowing protects the upper airway very effectively by promptly dispatching food into the upper oesophagus. 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 intake, if appropriate support is available. Like other upper airway reflexes it is impaired in patients with a depressed conscious level.

**Voluntary** swallowing uses the same sequence of muscle activation but is less dependent on the stimulation provided by the bolus. It 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.

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

This dissociation of voluntary and reflex function can be illustrated by some patients with motor neurone disease who, due to central nervous system involvement, are unable to speak, cough voluntarily, cooperate with simple tests of pulmonary function, or control a bolus in their mouth, but who retain effective, sometimes explosive, reflex coughing in response to a threat to the upper airway. Conditions of the peripheral nervous system do not exhibit this dissociation of voluntary and reflex function.

## 1.3 Mechanisms of problems with eating and drinking

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Neurological conditions such as dementia are frequently associated with eating and drinking difficulties. Table 2 describes the different mechanisms that give rise to problems in a number of conditions.

**Table 2: The effect of neurological conditions on eating and drinking**

Common signs and symptoms	Potential effect on eating and drinking
<b>Alzheimer's disease</b>	
<ul style="list-style-type: none"> <li>&gt; changes in memory, conduct and behaviour</li> <li>&gt; physical functions such as eating and drinking, pulmonary function and mobility are able to be maintained until the advanced stages of the disease</li> </ul>	<p>The pre-oral phase is vulnerable to changes in a person's conduct and behaviour, agitation, restlessness, loss of appetite, changes in the response to food, and problems using cutlery and cooperating with carers.</p> <p>Intra-oral bolus preparation and voluntary initiation of swallowing can become impaired due to a dyspraxia of the face, lips and tongue but, in the absence of anything to cause lower motor neuron denervation of the involved structures, swallowing and coughing, certainly at a reflex level, continue to function.</p> <p>Other types of degenerative disease associated with dementia may cause problems with specific mechanisms, eg oromandibular dystonias in patients with multiple system atrophy, and swallowing problems in patients with Lewy body dementia following exposure to major tranquillisers.</p>
<b>Brain stem stroke</b>	
<ul style="list-style-type: none"> <li>&gt; nausea, vomiting, vertigo</li> </ul>	<p>If the tenth nerve nucleus in the lateral medulla is involved the larynx loses its nerve supply on that side. When eating and drinking, aspiration is inevitable because the larynx cannot close. For the same reason, voluntary and reflex coughing are ineffective. Oral intake is usually impossible for weeks or months.</p> <p>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 eating, drinking and coughing should be relatively preserved. Oral intake is less disrupted, mainly as a result of preserved laryngeal function during swallowing and coughing.</p>
<b>Left middle cerebral artery stroke</b>	
<ul style="list-style-type: none"> <li>&gt; sudden development of 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</li> </ul>	<p>Intracranial pressure may rise in patients with extensive infarction. In this situation, oral intake is not possible mainly because of the associated fall in conscious level.</p> <p>Conscious patients with an established infarct have impaired control of the arm and hand on one side which causes 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 eating and drinking, but the reflex components of oral intake and coughing should be relatively preserved. Depending on the size and location of the infarct, eating and drinking is usually possible after a period of difficulty lasting days to weeks.</p>
<b>Motor neurone disease</b>	
<ul style="list-style-type: none"> <li>&gt; affects either the upper motor neurons from the cortex to the brain stem and spinal cord, or the lower motor neurons supplying the corresponding musculature</li> </ul>	<p>Upper motor neuron problems lead to weakness and slowing of movement of the affected part, eg hand function for the pre-oral phase. The effects on the tongue and facial muscles cause dysarthria and impaired intra-oral control of the bolus. Patients may have difficulty coughing to command, but reflex coughing is often well preserved.</p> <p>Lower motor neuron problems lead to wasting and weakness of the bulbar muscles and involved structures (such as face and tongue) and</p>

Common signs and symptoms	Potential effect on eating and drinking
<ul style="list-style-type: none"> <li>&gt; usually the condition (eventually) involves both, producing upper and lower motor neuron problems</li> <li>&gt; can start anywhere in the body and the rate of progression is variable. For these reasons it mimics many conditions and diagnosis may be particularly difficult in the early stages</li> </ul>	<p>no reserve of function to access during reflex swallowing or reflex coughing. There may be relative preservation of oral control of a bolus in the early stages. Weakness of the respiratory muscles may manifest as paradoxical movement of the abdominal wall during inspiration as the weak diaphragm is drawn into the thorax, and/or as a reduction in indices of pulmonary function such as forced vital capacity.</p> <p>The combination of the loss of fine control and profound weakness affecting the muscles involved in bolus control in the mouth, swallowing, coughing and breathing makes oral intake impossible, although some patients with pure upper motor neuron involvement can continue to eat and drink by mouth for many years.</p>
<b>Huntington's disease</b>	
<ul style="list-style-type: none"> <li>&gt; causes a slowly progressive dementia accompanied by chorea (dancing movements) of the limbs and of the tongue. It affects the central nervous system</li> </ul>	<p>The pre-oral phase is affected at an early stage because of problems with using cutlery and placement of food in the mouth. Intra-oral bolus preparation can be affected by chorea of the tongue and head.</p> <p>The swallowing process is relatively preserved but poor oral control of the bolus can lead to aspiration. However, because reflex coughing should be relatively preserved, patients can protect their airway and oral intake is often possible until the advanced stages of the condition, particularly if there is a suitably trained carer who learns how to support the person. In the advanced stage patients may become apathetic and withdrawn and lose their appetite. Oral intake is then severely compromised.</p>

## 1.4 Clinical approach to patients

### 1.4.1 Common clinical situations

Eating and drinking difficulties arise for many different reasons. Clinicians may be asked for advice on patients who fall into the following broad areas:

- > patients with suggestive symptoms, a particular medical condition (eg suspected aspiration pneumonia), or relevant clinical or radiological signs
- > those in recovery preparing to reintroduce eating and drinking by mouth following a period of gastrostomy or nasogastric tube feeding
- > patients with a condition commonly associated with eating and drinking difficulties (eg acute stroke) who have been designated 'nil by mouth' until further clinical assessment is possible.

### 1.4.2 Common clinical questions

The consultation between a health professional and a patient with eating and drinking difficulties – real or perceived – usually relates to one of three questions. Although related, the approach to answering each question is different. The information gathered in answering one question does not directly answer the other two. The three questions are explored in Box 1 to help standardise the approach for all healthcare professionals.

## **Box 1: Clinical questions to guide a consultation**

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

The conventional approach of history, examination, and investigation leads to an anatomical and pathological diagnosis. Traditionally this is the remit of the doctor. However, the information acquired during a diagnostic consultation does not always explain the exact mechanics of the problem, nor give an index of the ability to eat and drink.

### **2 What is the mechanism of the eating and drinking problem?**

An understanding of the mechanism of a 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 of a problem without knowing the underlying disease or the extent to which their ability to eat and drink is, or will be, compromised. The mechanism of a problem is something that should be considered by the medical staff or the speech and language therapist (SLT).

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

This is perhaps the most difficult question to answer for a composite function like eating. 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 to the patient. This is true for both one-off assessments and for long-term proposals to continue eating and drinking.

An attempt to categorise someone's abilities on a continuum is always arbitrary. Abilities are susceptible to change over time, to fatigue and to situational factors. Sufficient ability to eat 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.

SLTs are frequently asked questions two and three. The next section describes some of their assessment techniques, followed by those used to preserve or promote eating and drinking.

### **1.4.3 Assessment of eating and drinking**

Assessment of eating and drinking can be achieved through a combination of history taking, observation and clinical examination.

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 and previous weight loss may also help. 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 eating and drinking, and of carers feeding patients. Professional observation can be more focused. For example, it can be inferred from specific signs such as a wet hoarse voice quality that laryngeal closure is impaired or that aspiration has occurred. 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.<sup>1</sup>

Other clinical examination techniques include pulse oximetry recordings of a person eating and drinking,<sup>2</sup> and cervical auscultation. The role of cervical auscultation is unclear as the sounds of oral intake or aspiration into the larynx cannot be reliably identified.<sup>3</sup> If intermittent hypoxia or other eating-related changes in behaviour are unexplained, recordings of arterial pO<sub>2</sub> can be revealing.

Instrumental examination includes fiberoptic endoscopic evaluation of swallowing (FEES) and videofluoroscopy.<sup>4</sup> FEES involves direct visualisation of the larynx and pharynx. Using a nasendoscope the gross anatomy can be seen at rest and during the initial phase of eating, but palatal elevation obscures the view of the larynx as the bolus passes into the upper oesophagus.

Videofluoroscopy provides two-dimensional radiological images of the bolus and the involved structures. It can be used to view the amplitude and timing of movements of the bolus and the involved structures as well as aspiration into the airway and the response to it. It can be complemented by manometry to obtain pressure measurements from the pharynx and upper oesophageal sphincter and by conventional video recordings of the patient to simultaneously record their responses. This technique can also be useful for identifying strategies and exercises to improve swallowing function.

# Chapter 2: Strategies to support eating and drinking



## Key points

- > Oral nutritional support should be considered for patients with inadequate food and fluid intake.
- > While swallowing problems present a significant challenge, other factors such as taste changes, loss of smell or appetite, changes in bowel habit and nausea can all impact on intake.
- > The aims of oral nutritional support should take into account the stage of disease and prognosis. Dietary advice should be tailored to the individual and family and adjusted to ensure it remains a benefit, not a burden.
- > Dietitians and SLTs can provide advice on texture-modified diets and educate and train others in care settings to provide safe, patient-centred nutritional care.
- > Multidisciplinary team working together with good communication with patients, family members and carers are essential to effectively manage eating and drinking strategies.
- > Policies on eating and drinking with acknowledged risks should seek to mitigate unnecessary delays in providing food, fluid and medications and unnecessary restrictions of oral intake.

## 2.1 Introduction

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Eating and drinking are not simply essential for maintaining nutrition and hydration. They are important for pleasure and social interactions – food and mealtimes are a way we connect with others and can often be an expression of our cultural identity.

The provision of oral nutritional support should therefore be the preferred method of choice for any patient with inadequate food and fluid intake to meet requirements, unless they cannot swallow safely, have inadequate gastrointestinal function or if no benefit is anticipated, for example in the last days of end-of-life care.<sup>5,6</sup>

This chapter covers strategies to support eating and drinking, including timely intervention, managing symptoms, the provision of modified diets, and policies on eating and drinking with acknowledged risks.

## 2.2 Timely intervention

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Many life-limiting conditions and treatments impact negatively on a person's ability to eat and drink. Additionally, symptoms of pain, breathlessness and fatigue can often impair intake of normal food and drink and predispose someone to malnutrition along with its associated adverse consequences.<sup>7</sup>

With reduced ability, the enjoyment and pleasure usually derived from eating and drinking can decline, and diet can become a source of stress and anxiety among both patients and their family members and carers.<sup>8</sup> The effective management of symptoms and the provision of psychological,

social and spiritual support are therefore paramount, particularly in palliative and end-of-life care.<sup>9</sup>

If feasible and acceptable to the patient and their carers, timely interventions to modify the diet to optimise nutritional intake, alleviate symptoms, and maintain nutritional status will enhance the quality of life, physical functioning, immunity and wellbeing of those approaching the end of life.<sup>7,10</sup>

At this stage a person may have multiple dietary issues adversely affecting nutritional status and the ability to eat, drink and absorb and use nutrients. Where possible, underlying causes of disrupted intake that can be reversed or are modifiable should be addressed using the skills of the multidisciplinary team.<sup>11</sup> While eating and drinking difficulties relating to swallowing present a significant challenge, other factors such as changes in taste, loss of smell, loss of appetite, change in bowel habit and nausea can all impact on intake.

## 2.3 Oral nutrition support

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Oral nutrition support should aim to optimise nutritional intake of both macronutrients such as energy and protein, and micronutrients (vitamins and minerals).

Support strategies can include fortification of food and drinks, use of snacks, finger foods, nourishing drinks and oral nutritional supplements (all of which need to be of suitable texture and consistency).<sup>5</sup> Oral interventions can be used on their own or in combination with other nutritional support strategies such as clinically assisted nutrition and hydration (CANH). Individual patient preferences should always be taken into consideration.

During the last year of life, screening for malnutrition using a validated screening tool such as the Malnutrition Universal Screening Tool (MUST)<sup>12</sup> or the Patients Association Nutrition Checklist<sup>13</sup> can be helpful in identifying nutritional problems at the earliest opportunity, so that action can be taken to reverse or slow down nutritional deterioration. However, using objective measures such as weight need to be carefully considered in patients approaching the terminal phase of illness, as they may add to patient and family anxiety when the measures cannot be influenced.

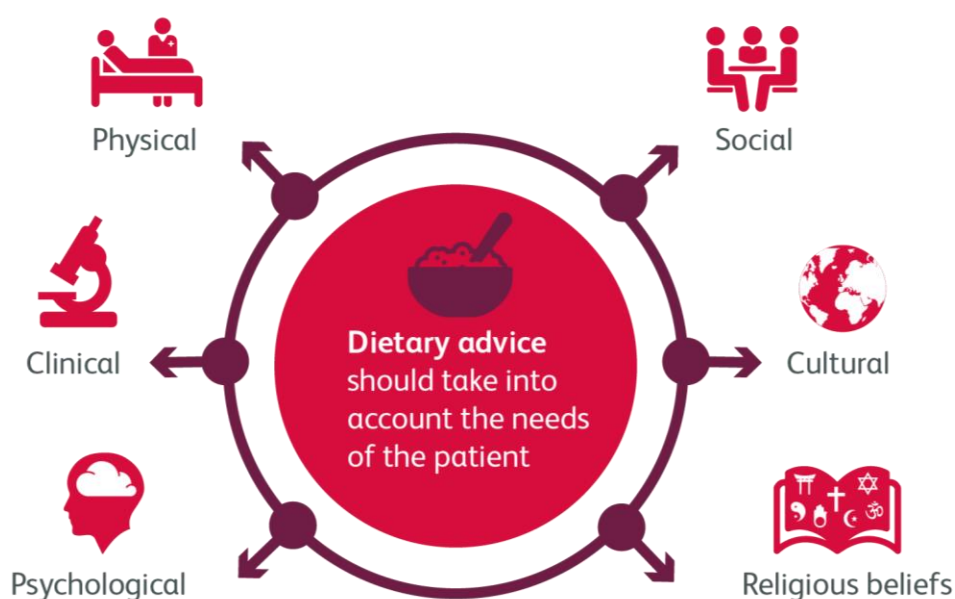
Patients receiving oral nutritional support should be monitored regularly against the goals of the intervention.<sup>5,14</sup> Goals should be adjusted according to the trajectory of the disease, clinical manifestations and disease progression. For example, the role of nutrition and emphasis on food may change as a patient moves from the last few months of life into the last few weeks or days when achieving nutritional requirements may not be a realistic or helpful aim. Family members may require psychosocial support and an understanding of why appetite diminishes and why the aims of oral nutrition support may change towards the end of life.<sup>11,15,16</sup>

### 2.3.1 Dietary advice

Patients and their carers should be offered advice on how to manage specific difficulties with eating and drinking, perhaps due to side effects or symptoms associated with a disease or its treatment. It is important to consider the patient's social, physical, psychological, clinical, and cultural needs as well as their religious beliefs (see Fig 3).

The effectiveness of dietary advice will depend on many factors, including the method of counselling used, the content and form of the advice given, the patient themselves and carers acting on the advice given. It will be more difficult in very sick people, those with poor consciousness or limited cognitive ability, those who lack carer support, and in settings where time and catering constraints exist. Dietitians have a role as educators of medical, social care and nursing staff, particularly in primary and social care, to advise on the identification of eating difficulties and how to improve oral intake in a timely manner, appropriate to the patient.





**Fig 3. The factors impacting on dietary advice**

National evidence-based pathways such as [www.malnutritionpathway.co.uk](http://www.malnutritionpathway.co.uk) can improve the use of food-based oral nutritional strategies and oral nutritional supplements (ONS). Local resources also guide management of malnutrition in acute trusts and in primary care. General guidance should support rather than replace clinical judgement and individual assessment undertaken by skilled practitioners.

There is limited evidence for recommendations regarding nutrition in end-of-life care due to the challenges in undertaking intervention studies in this population. Decisions should be made on an individual basis and take into account the meaning of food and nutrition to the person.

### **2.3.2 Eating and drinking with acknowledged concerns**

The term 'risk feeding' has been used to refer to individuals who continue to eat and drink orally despite a perceived risk of choking or aspiration. Different terms may be preferred in different settings, and the terminology may well change in future to become more patient-centred. However, given that 'risk feeding' is currently widely understood and recognised we have kept it in place for the purposes of this document. 'Risk feeding' may occur in a range of situations, such as:

- > when someone with capacity makes a decision to eat and drink despite the risk
- > where CANH is not appropriate or declined
- > where the benefits of eating and drinking orally (such as enjoyment and enhanced quality of life) are deemed to outweigh the risks (such as chest infections or choking).

## Box 2: 'Risk feeding' decisions

'Risk feeding' decisions should be made carefully, balancing the risks and safety with a person's quality of life. The decision process must comply with relevant law and professional guidance. Close communication and coordination with service users, carers and MDTs is mandatory and should be undertaken in a timely manner. If this is lacking, clinical indecision may lead to patients being kept nil by mouth for inappropriately long periods to the detriment of their comfort and quality of life.<sup>17</sup>

'Risk feeding' can begin when an informed decision has been made by an individual with capacity, or as a result of a best interests decision if the person lacks capacity to decide for themselves. 'Risk feeding' decisions should be clearly documented and any changes to current advice should be promptly communicated to all relevant parties. Carers, or those assisting people to eat or drink, must be familiar with the current recommendations.

Following a dysphagia assessment, a multidisciplinary approach should be adopted to consider possible 'risk feeding' recommendations. This will include consideration of food and fluid textures, positioning, equipment, environment, level of assistance and supervision.<sup>18</sup> The MDT should take into account risks, benefits and burdens. The least distressing consistencies and textures of food, fluid and medication should be considered, acknowledging fully the associated risks over the individual's quality of life. Further details of these considerations and the responsibilities of the MDT within this process are highlighted in a framework by the Royal College of Speech and Language Therapists.<sup>18</sup>

It is important that policies relating to eating and drinking in the presence of known or acknowledged risks avoid perpetuating common misperceptions that there is a straightforward relationship between aspiration and pneumonia and that interventions like nil by mouth or CANH will reduce the risks – such misperceptions can reduce the potential for individualised and flexible decision making. Swallowing abilities and preferences fluctuate. Suitably skilled staff should be encouraged to use common sense, flexibility and judgement in these circumstances to avoid unnecessary delays in providing food, fluid and medications.<sup>19,20</sup> Advance care planning and treatment escalation plans should be reviewed in line with the 'risk feeding' decision.

In any 'risk feeding' decision, there needs to be a calibration between being risk averse, and placing carers in an impossible position in the name of patient autonomy.

The legal framework for decision making is set out in chapter 4. As emphasised there, an adult with capacity can choose to make a decision which appears to others to be unwise. That could include a decision that they wish to be fed in a way that puts them at risk. If the person has understood and accepted that risk, then, as long as the carers who act upon their request have acted with due care, they should not be exposed to any liability if the person does, in fact, suffer adverse consequences.

However, there are circumstances in which the carers may feel that the risks are so great that they cannot properly respond to the individual's request. In such cases, all those concerned (including relevant professionals and others interested in the person's welfare) should consider whether there are ways in which the risks can be mitigated. It may be that some members of the MDT conscientiously feel that they cannot take part in feeding even at a mitigated level of risk, while others are willing to do so. If (1) the risks of the relevant route cannot be mitigated to a degree sufficient to satisfy the concerns of the team as a whole; and (2) the patient still wishes only to receive nutrition and hydration by that route, then legal advice should be sought as to whether a court application is required, for instance that a declaration that the team are not under a duty to provide nutrition and hydration in the fashion chosen by the person, even if the end result is their death.

There may be circumstances in which it is clear that a patient lacking capacity to make the relevant decisions wishes to be fed in a specific fashion, but the team conscientiously consider that this would place the person at an unacceptably high level of risk. In such a situation, responsibility for

the risk does not lie, ultimately, with the patient because they lack capacity. Rather, it lies with the team responsible for their care. This means that a best interests decision could properly be taken that another route should be adopted to secure nutrition and hydration. Exceptionally, it might be sufficiently clear that the patient would not find that alternative route acceptable so that to assist them to eat and drink in that fashion could not properly be said to be in their best interests. Again, at that point, legal advice should be sought as to whether a court application is required.

The approach set out above is **not** intended to serve as a licence for either individual decisions to be made or policies adopted based upon undue risk aversion. Rather, it reflects the fact that the law recognises that, notwithstanding the importance of respecting the rights of individual patients to make their own decisions, the law does not require those involved to be placed in situations that they conscientiously consider either undignified or dangerous.\*

### 2.3.3 Manoeuvres and sensory techniques

Swallow manoeuvres or strategies such as clearing swallow, effortful swallow or supraglottic swallow may improve swallow effectiveness and safety.<sup>21</sup>

Sensory loss in the mouth and pharynx can impair oral intake. Enhancing sensory stimulation of the oropharynx can compensate for loss of sensitivity and benefit the swallow response. Alteration in sensation may be helped by thermal tactile stimulation with ice, chilled or sour material applied to the oropharyngeal musculature.<sup>22–25</sup>

Hypersensitive responses such as a bite reflex or tongue thrust can preclude oral intake and compromise oral hygiene. Therapeutic options such as oral desensitisation techniques should be considered to address oral hypersensitivity, incorporating meaningful activities such as teeth brushing.<sup>26</sup>

### 2.3.4 Positioning and postural strategies

Postural techniques can be useful for protecting the airway and changing the direction of the bolus. These include chin tuck, head rotation to the affected side, head tilt or remaining upright. These should be implemented throughout the course of a meal and require a degree of physical ability or some assistance if the patient has limited movement. All patients will benefit from a period of time in an upright position after eating and drinking to reduce the risk of oesophageal reflux. Implementing any postural technique will be dependent on an individual's condition and abilities.

SLTs can advise on strategies to minimise aspiration risk, enhance safety when eating and drinking and optimise the mealtime experience which in turn can improve nutritional status.<sup>27</sup> Strategies include change to texture, consistency, and quantity of food; swallowing manoeuvres and sensory techniques; positioning and postural techniques. Carer support and managing the eating environment when offering food and drink, eg minimising distractions; and behavioural and cognitive techniques are all valuable.

### 2.3.5 Texture modifications and adaptation of food and fluids

The International Dysphagia Diet Standardisation Initiative<sup>28</sup> (see Fig 4) was developed to provide a framework, common terminology and descriptions for the consistency of foods and fluids on a worldwide basis. Changes in both portion and bolus size are important. Medication may also have to be prescribed in alternative forms requiring liaison between doctors, pharmacists, SLTs and dietitians.<sup>5</sup>

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\* See, by analogy, *R(A & Ors) v East Sussex County Council & Anor* [2003] EWHC 167 (Admin)

Catering staff and carers should have knowledge about the preparation and provision of modified texture foods and fluids. Recipe ideas, easy-to-adopt modifications to standard recipes to fortify, enhance or texture-modify food and fluid, the serving of small appetising portions, and assistance at mealtimes in a supportive environment can improve a patient's experience and quality of life even when they are unable to manage significant amounts of food or fluid.

Food fortification may be an attractive option for patients with poor intake secondary to swallowing problems, anorexia or cachexia, as the volume of food consumed does not increase and familiar ingredients are used. However, it is important to bear in mind that modifying food may alter its sensory properties, which may not be desirable for individual patients. Fortification using mainly high-fat foods is not evidence-based and may not be suitable for many patients, including those with conditions such as steatorrhoea or poor gastric emptying. Using nutrient-dense ingredients (eg dried milk powder, ground nuts), rather than just energy-dense (eg butter, cream) is likely to be a better option but consideration should be given to the taste and acceptability to patients. Cost, practicality and convenience should all be considered as well as any practical barriers to acting on advice and the additional burden on family members of modifying the diet of the patient.

In patients with limited ability or appetite to consume food, nourishing drinks and oral nutritional supplements of an appropriate consistency should be encouraged as a more nutrient-dense alternative to drinks such as tea or water. Such fluids count towards requirements and, as they tend to be less satiating than solid foods, they can be a useful adjunct in optimising intake in patients with very poor appetites.<sup>29</sup>



**Fig 4. The International Dysphagia Diet Standardisation Initiative**

© The International Dysphagia Diet Standardisation Initiative, 2016

<https://iddsi.org/framework>

### 2.3.6 Psychological role of eating and drinking

The role of eating and drinking extends significantly beyond the provision of nutrients. Eating with others is a core human activity and is associated with rituals, routines and roles and the expression of care and love for others. When someone reaching the end of life is unable or unwilling to eat, this can create significant anxieties for relatives and carers. It is important to support understanding that both the social significance of eating and the atmosphere created around eating may be more important at that time than the nutritional content of the food itself.<sup>30</sup>

Quality of life and enjoyment of food, even if only a little is consumed, may become paramount. Healthcare professionals should be mindful of whether any nutritional interventions being considered are genuinely intended to treat the patient or to allay fears or anxieties in their relatives/carers. The importance of dealing with concerns and food-related anxieties of family members should not be underestimated.<sup>9,10,15,30,31</sup>

### 2.3.7 External strategies including carer support

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 assist with eating.<sup>32</sup> Carers may need training and support to ensure that they are using the correct techniques and are following guidance regarding consistency and the modification of food and fluids.

If someone is eating or drinking with acknowledged risks (see Box 2) then this decision must be documented with clear guidance for carers on how to assist the person to eat.

### 2.3.8 Behavioural and cognitive techniques

Techniques to encourage eating and drinking are particularly relevant for patients with cognitive or affective disorders causing behavioural change.

Education and involvement of the patient, their family and all the caring staff – including domestic and kitchen staff – is vital for the successful implementation of a nutrition programme. Due to the nature of underlying conditions, many patients will have a reduced ability to follow or implement eating and drinking strategies. This will increase their dependency on carers, relatives or healthcare staff to ensure that eating and drinking guidelines and strategies are being implemented.<sup>33</sup> Failure to adhere to guidelines has been associated with adverse outcomes such as increased incidence of aspiration pneumonia and high mortality rates.<sup>34</sup> Support to ensure advice is practical, feasible and acceptable is crucial.

Snacks/finger foods of appropriate consistencies for people reluctant to eat at mealtimes<sup>35</sup> or whose appetite at mealtimes is small, external cues to remind patients to request a drink or snack, or the planned and recorded intake of food and drinks throughout the day may be necessary.<sup>36,37</sup>

Carers may need to sit with patients to assist at mealtimes and encourage them to finish meals. Meals may be prolonged in duration and families and carers should be forewarned of the need to allow adequate time. In care settings, family members may be helpful in identifying favourite foods and drinks, particularly when a patient is reluctant to eat and drink.

A patient's tastes may change and offering new or stronger flavours can be positive. Enhancing the flavour of modified texture foods in particular is important and lack of texture may in part be compensated for by stronger flavours and variety of colours.

### 2.3.9 People with dementia

Unplanned weight loss and its association with dementia, even pre-diagnosis, is becoming more widely recognised. The benefits of both identifying nutritional risk as early as possible and continuing to monitor nutritional status have been demonstrated by many studies.<sup>38</sup>

Maintaining independence with eating and drinking for as long as possible is important, and mealtimes should continue to provide a key opportunity for social interaction and enjoyment as well as nutritional intake. Mealtime adaptations should be made for the person living with dementia, including considering when and how meals are served; the support provided during meals; the environment (lighting, minimising distractions, music) and support to eat outside of mealtimes.<sup>39</sup>

Prevalence of malnutrition increases as the disease progresses and in the later stages more than two-thirds of all those living with dementia are likely to be at risk.<sup>40</sup> It is unlikely that malnutrition or dysphagia can be reversed in advanced dementia, but both can usually be managed with continued oral intake, and slowing nutritional deterioration with adapted oral intake remains a positive outcome.<sup>41</sup>

For hospitals, implementing a protocol to guide eating and drinking despite aspiration risks for people with dementia has been shown to result in a reduced length of stay.<sup>42</sup>

## 2.4 Communication

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Effective communication requires time. It also requires knowledge of what is to be communicated and ethical choice about how this information is to be selected, ordered and expressed. Supporting patients who present with degenerative disease or substantial long-term conditions, requires advanced communication skills to engage in complex negotiation on emotional topics, including the loss of ability to eat, drink and participate in meals.

MDT working is essential in treating people with eating and drinking difficulties.<sup>43</sup> The team should work closely with the patient as well as the family and carers, and all team members should give consistent messages.

### 2.4.1 Communication of verbal and written information

Many patients with eating and drinking difficulties have communication or cognitive disabilities which affect understanding, retention and processing of verbal and written information and communication of needs. The MDT should ensure that appropriate measures have been taken to enable participation in discussions and decision making. This is required as a matter of law to support a person to make their own decisions and to enable best interests decisions to be made where they lack capacity to do so (see chapter 4).

### Box 3: Practical measures to support communication

The following measures are recommended to support effective communication on eating and drinking orally:

- > access to an SLT for support, advice and education
- > 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
- > accessible written and pictorial information left to be watched or read at leisure, eg online videos or leaflets on eating and drinking, 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 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 until the next morning
- > finding out whether the patient wants anyone to join them, eg a family member

## 2.5 Advance care planning

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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), an advance decision to refuse treatment in a predefined potential future situation or the appointment of a personal welfare lasting power of attorney. All of these can assist care providers should the individual lose capacity. Concise evidence-based guidance on advance care planning has been published by NICE<sup>44</sup> (see also chapter 4).

A person with a progressive condition that may lead to a need for CANH should be encouraged to discuss their preferences about care in situations that are likely to occur.

Professionals must ensure that people who are making decisions about their future care are presented with all options based on the most up-to-date national guidance and recommendations. This should be communicated clearly and where possible the advantages and disadvantages of these options should also be highlighted.

The best time to begin discussions regarding advance care planning and the potential need for CANH is during the course of routine, non-emergency care, remembering that not all patients are emotionally prepared for these conversations. Advance care planning must always be done in conjunction with the person, be guided by their wishes, be informed by their prognosis and relevant guidelines and should never be done by reference to blanket policies about categories of people.

## 2.6 Consequences of withholding nutrition

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### 2.6.1 Metabolic response

Food and water are essential for life. Where nutrition and hydration are withheld, death will inevitably 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 3 days and usually no longer than 14 days. If water is given in the absence of food, survival is long enough for death from nutritional deprivation to occur. While giving hydration seems a humane act, it may prolong dying and exacerbate symptoms.

Clinically assisted nutrition requires a liquid medium so cannot be given without water. If clinically assisted nutrition is withdrawn or withheld, death will be rapid from dehydration unless an alternative route for hydration is used.

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.

In healthy individuals, absence of food leads to a marked reduction in metabolic demands. Reserves of protein, fat, electrolytes, vitamins and trace elements are used more economically to protect essential organs and postpone death from malnutrition. People 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 physiological stress. The metabolic rate may then rise to greater than normal, consuming fat and protein reserves rapidly, with insulin resistance leading to hyperglycaemia. In the absence of nutritional intake, decline is rapid and often results in coma and then death. If injury/infection occurs in a patient already depleted by nutritional deficiency, decline is even more rapid.

### 2.6.2 Anorexia-cachexia syndrome

Anorexia-cachexia syndrome (ACS) affects up to 80% of people with terminal stage cancer and describes a state in which the patient is anorexic (poor appetite), and cachexic (experiencing weight loss and muscle wasting). In comparison with simple starvation (in which there is conservation of skeletal muscle over fat stores), neither fat nor protein is spared in cancer cachexia; 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.

In patients with the early to mid-phase of cachexia, loss of lean tissue and weight loss may be slowed through the provision of nutritional support combined with resistance training. In patients with late-stage cachexia, nutritional support may not halt nor reverse loss of lean tissue and body weight but instead provide a baseline of nutrients to support for example activities of daily living and preservation of skin integrity.<sup>45</sup> This should be communicated to patients and carers to set realistic expectations.

### 2.6.3 Adjustment towards the final stages of life

Towards the end of life a person's desire for food and drink lessens. Good mouth care rather than attempting to assist a patient to eat and drink becomes a more appropriate intervention. At this stage the appropriateness of continuing enteral and/or parenteral nutrition support should be considered. The discontinuation of intravenous fluids must also be considered, as at this stage it may only serve to exacerbate pulmonary oedema, peripheral oedema and increase secretions, which a semi-conscious



patient is unable to manage. Clear reasons should be identified and recorded for withdrawal of nutrition and hydration.

The provision of compassionate care is paramount. Frequent attendance of healthcare staff at the bedside is important to support the patient and the family and ensure they do not feel abandoned, especially if nutrition and hydration have been withdrawn.<sup>46</sup>

Some patients with capacity may choose for themselves to stop eating and drinking, as they are free to do. Some staff may find this particularly challenging and need support to respect the patient's decision. The Association for Palliative Medicine has a position statement and guidance to support clinicians in such cases. These can be found on its website at [apmonline.org](http://apmonline.org). Search for 'voluntarily stopping eating and drinking' (VSED).

#### **2.6.4 Death in the absence or withdrawal of CANH**

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

People with preserved cognitive function who are unable to eat or drink must be involved in decision making (with all the necessary support). Their perception of the process resulting from absence of food will be different from those with impaired cognitive function. It is commonly believed that death from lack of 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, patients may resist efforts by carers to offer food or fluids. These rejections may be no more than reflex responses. The dilemma of whether to 'force feed' such patients by mouth or with clinical assistance then arises. Advice and support for the family members and carers is paramount to help them deal with the sense of loss of not being able to provide food, fluid and sustenance to the person for whom they care.<sup>47</sup>

# Chapter 3: Clinically assisted nutrition and hydration



## Key points

- > Clinically assisted nutrition and hydration (CANH) refers to all forms of artificial nutrition support, including tube feeding and parenteral nutrition.
- > A decision to use CANH can be complex and should carefully consider individual circumstances. Patients and their families should be supported by a multidisciplinary team.
- > Nasogastric tube placement is generally a safe procedure when undertaken by trained clinicians but complications can occur if attention is not paid to detail. Compliance with NHS guidelines on tube placement and position checking is mandated.
- > A nutrition support team should carefully assess all patients referred for gastrostomy placement. Consideration of the risks versus benefits is key.
- > Home parenteral nutrition is needed for a small proportion of patients, typically those with short bowel syndrome. It has an increasing role in end-of-life care of patients with advanced malignancy.

## 3.1 Introduction

This chapter covers the reasons for and techniques of clinically assisted nutrition and hydration (CANH). CANH refers to all forms of artificial nutrition support including tube feeding and parenteral nutrition. It does not cover oral nutrition by cup, spoon, or any other method for delivering food or nutritional supplements into a patient's mouth.<sup>48</sup>

Tube feeding means nutritional intake via nasogastric (NG) or nasojejunal (NJ) tube, percutaneous endoscopic gastrostomy (PEG), radiologically inserted gastrostomy (RIG), per-oral inserted gastrostomy (PIG), percutaneous endoscopic jejunostomy (PEJ), and surgically placed jejunostomy. The NG and PEG routes are most common. Note that throughout this guidance the term 'gastrostomy' is used for feeding directly into the stomach.

Any medical intervention carries a risk and the benefits of the intervention should outweigh that risk. These should be discussed with the patient and their family/carers. Patients nearing the end of life may prefer to take in food orally and enjoy the taste even though intake may be suboptimal. 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 gastrostomy inserted purely in order to be transferred to another facility, if the risks of insertion are high or if the patient does not wish to have the procedure.

## 3.2 Trends

The British Artificial Nutrition Survey (BANS) has been following trends in home enteral nutrition since 1996. Data from 2016 indicate that 35% of new patients and 48% of established patients on home

enteral tube feeding (HETF) have neurological diagnoses, with cerebrovascular disease the dominant diagnosis.<sup>49</sup> However, a wide range of neurological conditions is represented (see Table 3). In many, nutritional interventions raise ethical dilemmas towards the end of life, especially in people with impaired cognitive function. This is not uncommon in degenerative neurological disease.

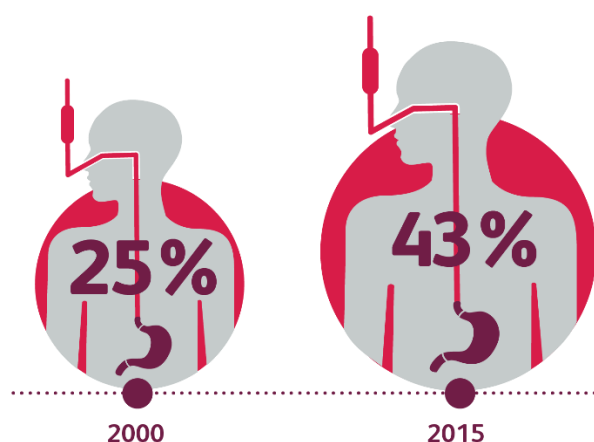
**Table 3: Adults with neurological conditions receiving HETF in the UK, 2016\***

Condition	New registrations		Point prevalence	
	n	%	n	%
Cerebral palsy	48	1.5	332	6.37
Cerebral trauma/brain injury	100	3.2	279	5.3
Cerebral tumour	11	0.35	19	0.4
Cerebrovascular disease	461	14.5	766	14.6
Congenital handicap	12	0.38	67	1.3
Dementia	17	0.54	42	0.8
Huntington's chorea	26	0.8	102	1.95
Motor neurone disease	207	6.53	243	4.64
Multiple sclerosis	73	2.3	234	4.5
Muscular dystrophy	5	0.2	42	0.8
Parkinson's disease	62	2.0	97	1.85
Unspecified CNS condition	93	2.9	277	5.3
<b>Total</b>	<b>1,115</b>	<b>35.2**</b>	<b>2,500</b>	<b>47.8*</b>

\* Table constructed from data provided to the author from the BANS dataset held by BAPEN

\*\* % of BANS registrations with neurological diagnoses

Cancer continues to increase year on year as the primary diagnosis in enterally fed patients at home (Fig 5); 43% of new patients receiving HETF in 2015 had an underlying diagnosis of cancer (predominantly head and neck or upper GI cancer).<sup>49</sup> By contrast with people with neurological diseases, cognitive function is usually maintained in those with a primary diagnosis of cancer.



**Fig 5. Growth in the proportion of newly registered patients receiving HETF with a primary diagnosis of cancer**

### 3.3 Indications for clinically assisted nutrition and hydration

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The key indications for nutrition support are summarised in NICE guidance.<sup>5</sup> It should be considered in people who are malnourished, as defined by any of the following:

- > a BMI of less than 18.5 kg/m<sup>2</sup>
- > unintentional weight loss greater than 10% within the last 3–6 months
- > a BMI of less than 20 kg/m<sup>2</sup> and unintentional weight loss greater than 5% within the last 3–6 months.

Nutrition support should be considered in people at risk of malnutrition who, as defined by any of the following:

- > have eaten little or nothing for more than 5 days and/or are likely to eat little or nothing for the next 5 days or longer
- > have a poor absorptive capacity, and/or have high nutrient losses and/or have increased nutritional needs from causes such as catabolism.<sup>3</sup>

Eating and drinking orally should always be considered as the preferred method of providing nutrition support to patients. Strategies to support oral nutrition and hydration are considered in detail in chapter 2.

CANH should be considered for people who are malnourished or at risk of malnutrition and have inadequate or unsafe oral intake. A decision to use CANH (tube feeding or parenteral nutrition) can be complex and should follow careful consideration of the person's individual circumstances. Patients and their families should be supported by a multidisciplinary nutrition support team of healthcare professionals. The patient should always be at the centre of clinical decision making and the focus should be on reaching the best decision for that person.

Enteral tube feeding should be considered in patients with inadequate or unsafe oral intake with a functional and accessible gastrointestinal tract. Tube feeding should be stopped when the patient is re-established on adequate oral intake. Parenteral nutrition should only be considered in those with a non-functional, inaccessible, obstructed or perforated gastrointestinal tract.<sup>5</sup>

BMA/RCP guidance from 2018 covers decisions to start, continue or stop CANH in adult patients in England and Wales who lack the capacity to make the decision for themselves. It focuses on patients who could go on living for some time if CANH is provided, where CANH is the primary life-sustaining treatment.<sup>48</sup> RCP guidelines cover decision making (including CANH) in relation to patients with prolonged disorders of consciousness.<sup>50</sup>

### 3.4 Enteral tube routes

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It is best to consider three main routes for enteral feeding – nasogastric tube (NGT), gastrostomy or jejunostomy. The indication for enteral feeding, the predicted length of time required and any relevant disease-related or anatomical factors, eg obstructing tumour, requirement for 'venting' etc, will be key in deciding which route to take.

NGTs are easily displaced but can be re-passed frequently, although this may be distressing for some patients. Ensuring a satisfactory intragastric infusion may be difficult. Gastrostomy placement is invasive with significant morbidity and mortality, particularly in older people and those with debilitating disease. Gastrostomies can be inserted endoscopically (PEG) or radiologically (RIG). Alternative enteral access techniques include a jejunal extension passed via the gastrostomy tube, direct percutaneous endoscopic jejunostomy and surgical jejunostomy. Endoscopically placed

gastrostomy tubes require infrequent change, typically every 2–4 years, whereas radiologically placed tubes and balloon gastrostomies require elective change at 3- to 6-month intervals. This can be a significant burden to some patients. Patients and carers may assess the risks and benefits differently to health professionals, so careful consideration and planning is required to establish the most appropriate form of enteral feeding. If in doubt, a trial of enteral tube feeding and management may be undertaken prior to a longer-term solution being attempted.

In terms of prevalence, UK data from the 2016 British Artificial Nutrition Survey (BANS) indicate that 84% of patients received their nutrition via a gastrostomy tube, 5% via a jejunostomy and 10% via a nasoenteric tube (with 8% via an NGT and 2% via an NJT). While voluntary reporting to BANS has reduced over the years (the BANS dataset is thought to represent approximately one-third of HETF activity in the UK), the proportional representation of each route has not changed since 2000.

Most patients receiving HETF in the community have difficulties with eating and drinking. Many patients are approaching the end of their lives or will do so while receiving clinically assisted nutritional support.

## 3.5 Mouth care

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Assessing and maintaining good oral hygiene is a simple way to improve oral nutrition and can help patients to overcome some of the difficulties associated with supported nutrition. Attention to cleaning teeth and dentures in patients who are 'nil by mouth' will help facilitate the reintroduction of oral nutrition and can reduce risks associated with aspiration.

Oral hygiene 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. Oral candida can occur in debilitated patients and it is important to detect and treat it at an early stage. Discomfort from stomatitis due to medication, chemotherapy or radiotherapy can be minimised by good mouth care.

## 3.6 Nasogastric tubes

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A nasogastric tube (NGT) is inserted through the nose into the stomach via the oesophagus. NGT placement is a safe procedure when undertaken by trained healthcare professionals, but complications may occur if attention is not paid to detail. Although rare, inadvertent intracranial insertion via the cribriform plate has been well-documented. 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. The NEX (nose to ear to xiphisternum) measurement should be used to guide practitioners as to how much tube is needed to reach the stomach; it should never be used to confirm tube position.

New technologies, including placement devices for NGTs, have been developed to aid confirmation of tube position. However, in 2013 the National Patient Safety Agency (NPSA) issued a safety alert, stating that these devices should not be used to replace initial NGT position checks using pH testing or X-ray.<sup>51</sup>

Compliance with guidance published by NHS Improvement<sup>52</sup> is very important as feeding through a misplaced NGT is associated with a significant risk of death or serious harm and is considered a 'never event' in the NHS. Failure to obtain an aspirate of pH <5.5 poses difficulties which require an X-ray to confirm tip position prior to initiating feeding. 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.

### 3.6.1 NGT placement and management

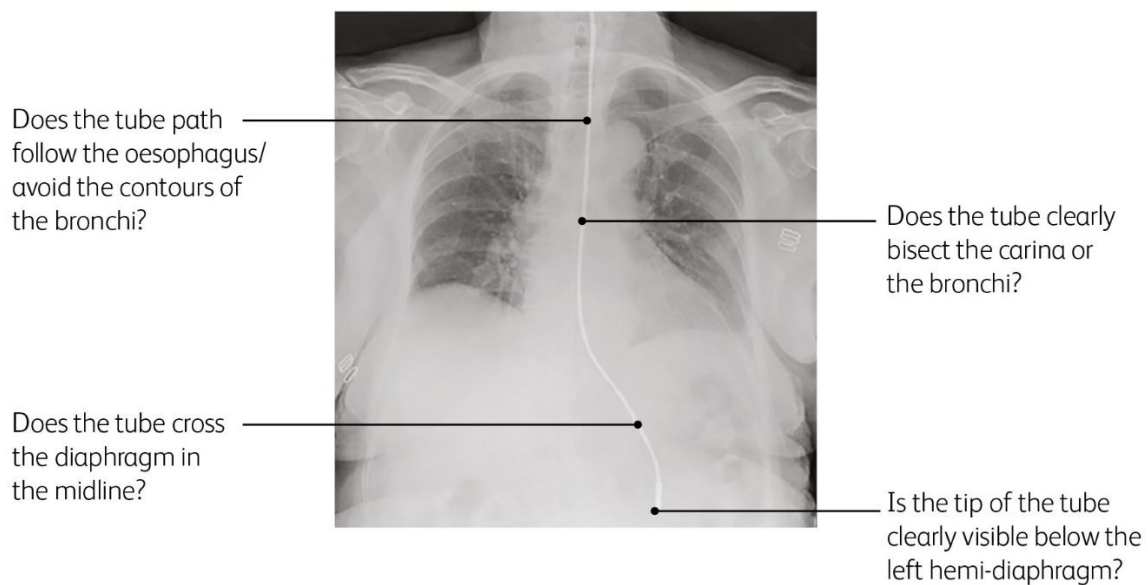
Side effects of NGT placement may include sinusitis, sore throat, difficulty swallowing, candidiasis or aspiration pneumonia. Displacement, blockage and even knotting are frequent complications. If the tube is frequently displaced by the patient, a nasal loop can be placed and/or mittens may be considered. It should be noted that both of these actions are considered a form of restraint and local policies should be adhered to. The National Nutrition Nurses Group (NNNG) has produced a good practice guideline relating to the safe insertion and ongoing care of patients with a nasal retaining device for NG or NJ feeding tubes in adults.<sup>53</sup> Unnoticed displacement into the oesophagus or hypopharynx poses serious risk of aspiration, although risk of aspiration from correctly placed NGT feed cannot be completely eliminated. Many patients are at increased risk of aspiration of secretions even without NGT feeding.

The NPSA reported on patient deaths and near misses as a result of misplaced NG tubes, publishing safety alerts in 2005, 2007 and 2011.<sup>54</sup> In 2016, NHS Improvement took over from the NPSA and published a further safety alert highlighting the continuing risk of death and severe harm caused by misplaced NG tubes and inadequate training and care.<sup>55</sup> Box 4 outlines the NPSA and NHS Improvement recommendations for tube placement.

#### Box 4: NPSA and NHI nasogastric tube placement recommendations

- > The 'whoosh' test must never be used to test for correct tube placement (auscultation of air insufflated through the feeding tube).
- > Blue litmus paper must never be used.
- > Do not interpret absence of respiratory distress or the appearance of the aspirate as an indicator of correct positioning.
- > Ensure all pH test strips are CE marked and intended by the manufacturer to test human gastric aspirate.
- > pH in the 'safe range' of 1 to 5.5 can be used as the first-line test to exclude placement in the respiratory tract.
- > Nasogastric tubes should not be flushed, nor guidewires pre-lubricated, nor anything introduced through the tube until initial placement has been confirmed.
- > Radiology (X-ray) can be used as a second-line test to confirm tube placement; it should not be used routinely as a first-line test.
- > X-ray request forms should clearly state that the purpose of the X-ray is to establish the position of the nasogastric tube for the purpose of feeding or the administration of medication.
- > Checking tube placement via X-ray should include confirming and recording in the patient record that any X-ray viewed is the most current one for the correct patient.
- > Fig 6 shows the four criteria for confirming gastric placement of an NGT on X-ray.

There should be clear instruction/communication documented in the patient's notes as to whether the NGT is safe to use or other required actions. Any tubes identified in the lung should be removed immediately, either in the radiology department or clinical area.



**Fig 6. The four criteria for confirming gastric placement of an NGT on X-ray\***

Care homes may not feel confident to follow NPSA/NHS Improvement advice as they may lack suitably trained staff. GPs overseeing patients may also lack expertise or confidence in managing NG tubes. In these circumstances we recommend the following:

- > There should be a particularly careful assessment in deciding the appropriateness of clinically assisted nutrition in the first place.
- > If tube feeding is necessary, a trial of treatment with NGT should be carried out in hospital. If well tolerated and required for less than 6 weeks, then a gastrostomy is usually not needed.<sup>5</sup>
- > If tube feeding is required for more than 6 weeks, gastrostomy insertion should be considered, preferably before discharge, and the patient should leave hospital with a clear action plan.
- > Every effort should be made by hospital trusts, clinical commissioning groups (CCGs) and care homes to establish a system that allows NG tube fed patients to be managed outside hospital (where this is indicated in preference to gastrostomy placement). This will usually require more expert trained nutrition nurses to support healthcare professionals inside and outside hospital. Thus, if an 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. Expert, nutritionally trained, medical advice should be available to these healthcare professionals and specialist nurses in cases of difficulty or uncertainty.

### 3.6.2 Removal and replacement

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 to the patient, 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 nutritional objectives.

\* Image reproduced with permission from: NHS Improvement. *Resource set: Initial placement checks for nasogastric and orogastric tubes*. NHSI, 2016

## 3.7 Gastrostomy tubes

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Endoscopic gastrostomy placement usually requires conscious sedation, although use of a narrow bore endoscope can occasionally obviate this need. The risks are those of sedation, endoscopy itself and penetration of the peritoneal cavity and stomach wall. These include visceral perforation, intra-abdominal haemorrhage, peritonitis, stomal sepsis and colonic perforation or transfixion and ileus. Morbidity and mortality are common following gastrostomy insertion, which should never be undertaken lightly. Antibiotic prophylaxis is recommended.<sup>56</sup> Non-endoscopic techniques (radiologically inserted gastrostomy (RIG) or per-oral inserted gastrostomy (PIG)) still require nasogastric tube placement to inflate the stomach but sedation may not be required – this requires individual patient assessment. 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. These patients should be considered for NGT placement, although the logistics for delivering NGT care outside an acute hospital can be very complex.

### 3.7.1 Replacement and removal

The most common types of gastrostomy tubes cannot be replaced or removed without repeat endoscopy. It is therefore important to ensure that the correct tube is chosen at the time of insertion based on clinical indication and patient preference. Previous advice that gastrostomies can be removed using the 'cut and push' technique (allowing the gastrostomy bumper to pass through the gastrointestinal tract after cutting off at skin level), has been the subject of a 'One Liners' alert from the Medicines and Healthcare products Regulatory Agency.<sup>57</sup> The MHRA advises that the manufacturer's guidelines are followed when removing gastrostomy tubes, which in most cases means endoscopic removal. Where endoscopic removal is not feasible, clinicians should ensure that an appropriate risk assessment is undertaken. Patients at particular risk of the remnant tube lodging in the small bowel are those with a history of Crohn's disease, adhesions or dysmotility and those taking non-steroidal anti-inflammatory drugs or opiates. If gastrostomy feeding is withdrawn, the gastrostomy tube can be left in situ unless associated with complications such as infection. Gastrostomy tubes should not be replaced or removed in the first 2 weeks after insertion as a secure tract will not have formed between the stomach and anterior abdominal wall.

### 3.7.2 Gastrostomy placement

Informed consent before placing a gastrostomy is essential. There must be careful consideration of the patient's best interests, with benefits weighed against potential complications.

An audit by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) of 719 gastrostomy procedures recommended that gastrostomy placement should always follow a multidisciplinary discussion of its value.<sup>58</sup> The audit reported that 19% of gastrostomy placements were futile and 43% of patients who died following gastrostomy placement did so within 1 week of insertion. 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 NGT placement or 'risk feeding' must be clearly articulated and documented. The risks of inserting a gastrostomy must be balanced against the needs of the patient for a particular environment. It would not be ethical for a care home to insist on gastrostomy placement as a criterion for admission on grounds of convenience. However, where expertise in managing an NGT cannot be made available, gastrostomy placement, if technically possible, may be in the patient's best interests.



### 3.7.3 Complications

Complications associated with gastrostomies beyond the immediate post-insertion period include tube blockage and displacement. Excessive traction on the inner flange can lead to ‘buried bumper’ syndrome, the treatment of which can be complex and associated with significant morbidity. Haemorrhage from the gastric wall, peristomal infection and pyloric obstruction are all potential complications. Meticulous care of any type of gastrostomy is required to minimise the risk of complication and all healthcare professionals, patients and/or their carers should be trained in the management of gastrostomy tubes.

Aspiration pneumonia can occur with both gastrostomy and NGT feeding,<sup>59</sup> although there is a danger that pneumonia may be ascribed to aspiration of feed when in fact the patient has developed nosocomial pneumonia because of their frailty and respiratory muscle weakness. Furthermore, pyrexia in a patient with upper airways noise may be wrongly diagnosed as aspiration pneumonia when (for example) a urinary tract infection is the real cause.

### 3.7.4 Gastrostomy feeding in patients who have dementia

Observational studies on the effects of tube feeding in patients who have dementia are generally of poor quality. In most studies the control group is not adequate, the population is not well defined, and the stage of dementia remains unclear. Studies on the effects of parenteral nutrition are completely lacking. Therefore, existing scientific evidence is inconclusive, and recommendations have to include expert consensus.<sup>60</sup>

Patients with advanced dementia frequently develop eating and drinking difficulties or an indifference to food leading to a reduction in nutritional intake, weight loss and an increased risk of aspiration.<sup>61,62</sup> This is often associated with the final phase of the disease when it is not possible to understand the patient’s wishes. The Alzheimer’s Society’s view is that ‘quality of life, rather than length of life’ should be the focus.<sup>63</sup> Data from the British Artificial Nutrition Survey indicate that less than 1% of patients fed with clinical assistance in the community have a diagnosis of dementia. This represents a significant reduction in the number of patients with dementia receiving gastrostomy feeding over the past 10 years (see Table 3). Alternatives to CANH and strategies to support eating and drinking (discussed in chapter 2) should be carefully evaluated for every patient.

There are different opinions around the benefits of gastrostomy feeding in people with dementia. Several studies have suggested that where dementia is the reason for gastrostomy placement, it does not extend life and is associated with a greater mortality. In a review of gastrostomy placement in dementia, gastrostomy feeding was seldom effective in improving nutrition, maintaining skin integrity, preventing aspiration pneumonia, improving functional status or extending life.<sup>64</sup> There is no good evidence to support gastrostomy feeding in people with advanced dementia. These conclusions are echoed by Chernoff,<sup>65</sup> Sanders<sup>66</sup> and Finucane<sup>67</sup> and more recently by the European Society of Enteral and Parenteral Nutrition (ESPEN) guidelines on nutrition in dementia.<sup>60</sup> These studies indicate that gastrostomy feeding in advanced dementia should only occur in exceptional circumstances.

In a retrospective 5-year analysis of gastrostomy placement in 361 patients the overall mortality was 28% at 1 month, compared with 54% in the dementia group (28.5% of the entire cohort) and 63% vs 90% at 1 year (Table 4).<sup>66</sup> A study of 1,386 nursing home residents in the USA found that gastrostomy feeding did not alter mortality or improve survival.<sup>68</sup>

**Table 4: Mortality rate post gastrostomy tube insertion<sup>66</sup>**

Time	Patients with advanced dementia (%)	Non dementia patients (%)
At 1 month	54	28
At 1 year	90	63

In general, careful support with oral nutrition is preferred, and a gastrostomy should not be offered to patients with advanced dementia. The actual insertion of a feeding tube carries risk; patients with advanced dementia have a significantly higher rate of mortality than those without dementia following gastrostomy insertion (Table 4). Best practice in this area is covered in chapter 2.

A number of clinical questions are frequently asked in relation to gastrostomy in patients with advanced dementia. An evidence-based response to these questions is shown in Box 5.

### **Box 5: Tube feeding in people with advanced dementia**

(based on Finucane *et al*<sup>67</sup>)

#### **Does tube feeding prevent aspiration pneumonia?**

It cannot prevent aspiration of oral secretions. There are no data that tube feeding 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 on older people.

Diverting the feeding stream lower in the gastrointestinal (GI) tract may reduce aspiration pneumonia from regurgitation of gastric contents. However, there are no published studies to show that tube feeding reduces the risk of aspiration pneumonia.

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

More than two-thirds of people with the later stages of dementia are likely to be at risk of malnutrition.<sup>69</sup> It is unlikely that either malnutrition or dysphagia can be reversed in advanced dementia. Furthermore, the 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 advanced dementia, relationships between nutritional intake, markers of nutritional status, and clinically meaningful outcomes remain uncertain. For some, nutrition 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 patients with dementia who are supported with eating and drinking may be the same as those fed by tube. Feeding tube placement may itself cause death.

Observational studies have shown no survival benefit in patients with advanced dementia who are tube fed, even after adjusting for age, history of pulmonary aspiration or stroke, difficulty with eating and drinking, 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 may also require the use of restraint in some patients which is likely to increase the risk of pressure ulcers.

#### **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 care is improved.

#### **Does tube feeding improve patient comfort?**

There is no evidence that dementia patients with dysphagia are more comfortable with tube feeding. It is unlikely that either malnutrition or dysphagia can be reversed in advanced dementia, but both can usually be managed with continued oral intake, and simply slowing nutritional deterioration through adapted oral intake remains a positive outcome.

In people with mild to moderate dementia, there will be some cases where, without enteral tube feeding, they will be poorly nourished and may die, but may achieve a better clinical outcome with appropriate nutrition support. This is most likely when the patient also has an acute condition, such as stroke or sepsis. In these circumstances it may be appropriate to offer NGT feeding for a limited period of time while the patient is treated for the acute reversible condition. If tube feeding is given in such a situation, the indication should be reassessed every week.<sup>60</sup>

Current European guidance recommends that any decision for or against CANH for patients with dementia is made on an individual basis with respect to general prognosis and the patient's preferences.<sup>60</sup>

### 3.7.5 People with delirium

Delirium is an acute confusional state related to acute medical illness and the primary treatment is to deal with its cause. It may be associated with sedation, confusion and difficulty with eating and drinking and patients may show a slow recovery. Generally, providing fluids intravenously or subcutaneously will be enough to support the patient during the period of delirium. Other forms of clinically assisted nutrition and hydration will not usually be necessary.<sup>70</sup>

### 3.7.6 People with learning disabilities

Two Mencap reports show that people with learning disabilities suffer from institutional discrimination and receive worse healthcare.<sup>71,72</sup> An independent inquiry 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.<sup>73</sup> Most often, the best nutritional care for people with learning disabilities will be maintained by careful oral techniques and support as described in chapter 2.

Learning disability in itself does not usually mean people have difficulties with eating and drinking. However, people with learning disabilities frequently have multiple conditions (including, for example, cerebral palsy or progressive neurodegenerative conditions) that affect oral intake and are therefore at risk of becoming dehydrated and under-nourished.

### 3.7.7 People with functional gut disorders

Many hospitals have seen an increase in patients referred with severe functional gut disorders who require short or longer-term nutrition support. These patients often have complex multiple conditions and require a multidisciplinary approach to their care.

There has also been an increasing awareness of people with hypermobile Ehlers-Danlos syndrome and gastric and/or GI tract dysfunction. The Royal College of GPs has published [a toolkit for clinicians](#) as experience of managing this condition is relatively limited.<sup>74</sup>

## 3.8 Parenteral nutrition

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Parenteral nutrition refers to the delivery of nutrients into a vein. It is reserved for patients with acute or chronic intestinal failure where food and fluids cannot be absorbed normally or if oral/enteral feeding is not possible or sufficient.

Parenteral 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 and introduced in the UK in the late 1970s.<sup>75</sup> Parenteral nutrition (PN) was facilitated by the introduction of the 'big bag' in the mid-1980s, enabling easier home administration.

In the UK, the commonest indication for HPN is short bowel syndrome, which historically has been predominantly due to Crohn's disease or mesenteric ischaemia. In contrast, cancer has been the major diagnostic indication for HPN in the USA and mainland Europe. In the UK, cancer has been a growing diagnostic indication for HPN in recent years, with one in four patients starting HPN now having a primary diagnosis of cancer.<sup>76</sup> The British Artificial Nutrition Survey dataset does not currently identify the proportion of patients receiving palliative HPN. 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, HPN is offered to a growing number of selected palliative patients, usually with proximal inoperable small bowel obstruction, often in conjunction with drainage of gastric secretions via a venting gastrostomy. Elsewhere this may be offered to many cancer patients to offset the weight loss from cancer cachexia. This complex and demanding treatment may present a significant burden for some patients.

The British Intestinal Failure Alliance (BIFA) has produced a [detailed position statement](#) on the use of HPN in advanced malignancy.<sup>77</sup> This document is a useful guide for nutrition teams when considering patient selection, prescribing, discharge planning, monitoring and points to consider when planning the withdrawal of HPN.

### 3.9 Subcutaneous and rectal hydration

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

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

NICE has published a good summary on managing fluids in the last days of life, along with a helpful decision tool.<sup>47</sup>

# Chapter 4: The law



## Key points

- > In relation to adults, capacity and best interests are the two key concepts in decisions around medical treatment. This also applies to CANH.
- > The Mental Capacity Act sets out the legal framework for determining mental capacity and making decisions on behalf of people who lack the capacity to decide for themselves.
- > All practicable steps should be taken to support decision-making capacity.
- > An adult patient with capacity has the right to decline even life-preserving treatment. They do not, however, have the right to demand any treatment which the healthcare team does not consider is clinically appropriate.
- > Clinicians must not go against an advance decision to refuse medical treatment.
- > Where no advance decision applies, best interests decision making should be constructed around the known wishes and feelings of the person lacking capacity.
- > The nature of decision making in relation to young people under 18 will depend upon whether they are aged 16/17 or aged 15 or below.

## 4.1 Introduction

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For adults, the two key concepts in decisions around medical treatment are **capacity** and **best interests**. This chapter examines those concepts in detail and covers the relevant legislation and guidance to be followed. It focuses on the legal rights of patients, focusing first on adults (ie people aged over 18), followed by children.

The chapter is framed by reference to the law in England and Wales. While the clinical principles are the same, the law in Scotland and Northern Ireland is not the same, and readers are recommended to seek expert legal advice in those devolved parts of the UK about legal matters. Key provisions in Scotland and Northern Ireland are set out in AAGBI consent guidance.<sup>78</sup>

There are some circumstances where the rights of healthcare professionals and employed carers will have to be considered, for instance in relation to circumstances where supporting a patient to eat and drink orally gives rise to a very high risk of aspiration. Professionals and employed carers may consider that the fact that the patient has capacity to decide to accept that risk is not enough to protect them from the risk of legal or professional sanction should they support the patient to eat and drink when it leads to a serious clinical complication or the patient's death. See also box 2 (chapter 2) on eating and drinking with known risks.



## Box 6: Relevant legislation and key terms

**Mental Health Act 1983** – the main piece of legislation covering the assessment, treatment and rights of people with a mental health disorder. People detained under the Act need urgent treatment for a mental health disorder and are at risk of harm to themselves or others.

**Mental Capacity Act 2005** – sets out a legal framework for determining mental capacity and making decisions on behalf of people who lack capacity. The Act came into force in 2007 and is supported by a Code of Practice.

**Mental Capacity (Amendment) Act 2019** – under this amendment, Deprivation of Liberty Safeguards will be replaced by **Liberty Protection Safeguards** (LPS). It is expected that LPS will come into force in April 2022. These new safeguards will apply to anyone over 16.

**Advance decision** – allows someone with capacity to refuse specified medical treatment for a time in the future when they may lack capacity. Healthcare professionals must follow the decision.

**Lasting power of attorney** – a legal document allowing someone to appoint one or more people (attorneys) to help make decisions or to make decisions on their behalf.

**Independent mental capacity advocate** (IMCA) – an advocate trained to support people who do not have capacity to make their own decisions if there are no appropriate relatives or friends available.

**Court of Protection** – deals with decisions or actions taken under the Mental Capacity Act on financial and welfare matters for people who lack capacity.

## 4.2 General principles

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### 4.2.1 Capacity

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 the patient has capacity to make the decision in question.

Someone's capacity may be affected by a learning disability, dementia or a mental health problem. The Mental Capacity Act 2005 (MCA) is a statute in force in England and Wales. It sets out a legal framework for determining mental capacity and making decisions on behalf of people aged 16 and over who lack the capacity to decide for themselves.

The MCA states that a person should be assumed to have capacity until it is established that they lack capacity. It dictates that a person is not to be treated as lacking capacity, until 'all practicable steps' have been taken to assist them in the assessment process. A lack of mental capacity must be established before a decision can be made on someone's behalf.

Capacity is not an all-or-nothing attribute. It is important to ask whether the patient has the capacity to **make the decision in question**. Meaningful discussion about capacity in the context of a particular proposed treatment decision is central to the operation of the MCA.

The 'information relevant to the decision' includes information about the reasonably foreseeable consequences of deciding one way or the other, and of failing to make the decision.<sup>a</sup>

Healthcare professionals should not conclude that a patient does not have the necessary capacity to make decisions about their medical treatment simply because their decision endangers them or is seen as eccentric or unwise. This principle is now embodied in the 2005 Act.<sup>b</sup> However, this does not

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<sup>a</sup> Section 3(4) and 4(1)

<sup>b</sup> Section 2(3)

mean that the nature of the patient's decision is irrelevant to the determination of capacity: it very often will be. For instance, a person who had always sought out and acted upon medical advice is now suddenly, and without any apparent reason, refusing to accept advice about how best they can maintain their need for nutrition and hydration. In such a situation, the team concerned with their care should be alert to the need to consider whether the person has capacity to make the decisions in question.

A person only lacks capacity for purposes of the 2005 Act if the reason that they cannot make a decision is an impairment of, or disturbance in the functioning of the mind or brain. If the cause of their apparent inability to make the decision is fear of another person, then the 2005 Act is irrelevant. In this situation, healthcare professionals will have to consider whether to make an application to the High Court for an order against the person coercing the patient.<sup>c</sup> This has been described as 'the great safety net' and is used by High Court judges to protect adults who **do** have mental capacity but are vulnerable.

### Box 7: Determining capacity

The Mental Capacity Act says that a person has capacity if they are able to:

- > understand the information relevant to the decision
- > retain that information
- > use or weigh that information as part of the process of making the decision
- > communicate their decision (by talking, using sign language or any other means).<sup>d</sup>

### Patients with a mental health disorder

Patients detained under the Mental Health Act 1983 cannot have treatment imposed on them simply because the treating clinicians think it is medically justified. The 1983 Act does contain various provisions which allow treatment to be given even where the patient is either incapable or refusing to consent,<sup>e</sup> but those sections only authorise medical treatment for a mental health disorder. Depending on the circumstances, CANH may be considered a medical treatment for a mental health disorder. However, this only applies if it is properly characterised as a treatment of a symptom or manifestation of the patient's mental health disorder.

For treatment which does not fall within the provisions of the Mental Health Act, the normal law of consent applies. Some patients detained under the Mental Health Act 1983 will have the capacity to give or withhold consent. Remember that capacity is not an all or nothing thing: patients may have capacity to make some decisions, but not others. Where someone detained under the Mental Health Act does not have the capacity to consent to the proposed treatment, the usual rules under the 2005 Act apply: treatment will be lawful if it is in the patient's best interests.<sup>f</sup>

### Patients with capacity

An adult patient with capacity has an absolute right to decline even life-preserving treatment. They do not, however, have the right to **demand** any treatment which the healthcare team does not consider is clinically appropriate. Treatment will be determined by the healthcare team's willingness to provide it as well as resource considerations. The healthcare team's willingness will in turn depend on their clinical judgement about the safety, efficacy and desirability of the treatment; and (possibly) other ethical considerations. These can generally be thought of under the heading of conscientious objection (see chapter 5). The law will not compel healthcare professionals to provide treatment

<sup>c</sup> See *Re DL* [2012] EWCA Civ 253

<sup>d</sup> Section 3(1)

<sup>e</sup> See sections 56–64 of the Mental Health Act 1983

<sup>f</sup> A child could also be detained under the 1983 Act, in which case the same rules as identified in this and the above paragraph apply

which they do not consider is clinically justified or (except in the rare case where a woman needs an abortion to save her own life), impose on a healthcare professional an obligation to do something to which they have a conscientious objection. The NHS trust, however, may have an obligation to provide so-called 'basic care'. This is explained below.

If the reason for non-provision of treatment is that the trust has decided that there are insufficient resources or funds to provide it, the law will only compel the paying trust to provide the treatment if the decision not to provide it was irrational. The law will look much more critically, though, at a decision by a 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 patient X because it would divert resources from patient Y. Such a decision might well be vulnerable to challenge under the European Convention on Human Rights' prohibition on discrimination.<sup>g</sup>

In relation to the provision of food and fluid, the position is starker. When a hospital accepts a patient, it has a duty to take reasonable steps to keep the patient alive. This duty arises both in common law<sup>h</sup> and in Article 2 of the European Convention on Human Rights. These reasonable steps include the provision of food and fluid with clinical assistance where required. Where a patient with capacity has expressed a wish to be kept alive, deliberately withholding this treatment would be unlawful. There may be circumstances in which the clinicians consider that the provision of food and fluid is not clinically appropriate because the individual is dying and the priority is to allow the patient to die with dignity and free from pain. In the event that discussions with the patient or (where the patient lacks capacity) those interested in their welfare do not produce an agreement as to the way forward, then the clinicians should seek legal advice as to how to proceed.

### **Adult patients lacking capacity**

Where someone has been assessed as lacking capacity to make a specific decision regarding their care and treatment, section 5 of the MCA provides legal protection for a clinician to carry out an act in their best interests. This includes both the giving and withholding of treatment.<sup>i</sup>

The Supreme Court has confirmed that it is lawful to give treatment only if it is in the patient's best interests. Accordingly, if the treatment is not in the patient's best interests, then it would be unlawful to give it, and therefore lawful to withhold or withdraw it.<sup>j</sup>

### **A holistic determination**

It is well established that 'best interests' means more than 'best medical interests.' To paraphrase Lady Hale, healthcare professionals making decisions must look at a patient's welfare in the widest sense – not just medical but social and psychological. They must consider the nature of the medical treatment, what it involves and its prospects of success. They must ask what the patient's attitude to the treatment is or would be likely to be; and they must consult others for their view of what his or her attitude would be.<sup>k</sup>

Section 4 of the MCA sets out a series of steps that must be taken by anyone seeking to determine whether a decision or action is in a person's best interests. These are described in Box 8.

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<sup>g</sup> Article 14, read together (depending on the seriousness of the situation) with Article 2 (the right to life), Article 3 (the right not to be subject to inhuman or degrading treatment) or Article 8 (the right to private life encompassing the right to 'physical and psychological integrity')

<sup>h</sup> *R (Burke) v General Medical Council & Ors* [2006] QB 273

<sup>i</sup> *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 at paragraphs 20 and 22

<sup>j</sup> *NHS Trust v Y* [2018] UKSC 67 at paragraph 92

<sup>k</sup> *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 at paragraph 39



### Box 8: Determining best interests

The MCA sets out a checklist of key things to consider when assessing what is in someone's best interests. In summary, healthcare professionals should:

- > not discriminate or make assumptions on the basis of the person's age, appearance, condition or behaviour
- > consider whether the person will at some time regain capacity, and if this is likely, whether the decision could be postponed
- > encourage participation by doing whatever is possible to permit or encourage the person to take part
- > not be motivated by a desire to bring about the person's death where the decision relates to life-sustaining treatment
- > consider all the relevant circumstances by trying to identify the things the person lacking capacity would take into account if they were making the decision themselves
- > find out the person's views, including their past and present wishes and feelings, and any beliefs or values that might influence their decision if they had capacity. This should include consulting family, carers and anyone granted a lasting power of attorney.

A healthcare professional who has worked their way diligently through the list can then (and only then) take refuge in the provision that there is sufficient compliance with section 4 if they reasonably believe that their decision is in the best interests of the person concerned.<sup>l</sup> All other things being equal, the healthcare professional can then rely upon the defence in [section 5 of the Act](#). See below for when it may be necessary to seek a decision of the Court of Protection.

The MCA 2005 includes the Deprivation of Liberty Safeguards (DoLS), which protect people who do not have the mental capacity to consent to circumstances where they need to be deprived of their liberty to receive treatment. DoLS are a set of checks that aim to make sure that any care that restricts someone's liberty is both appropriate and in their best interests. DoLS only apply in hospitals and care homes to those aged 18 and above. Where DoLS do not apply and the person needs to be deprived of their liberty to receive care and treatment, an application to the Court of Protection is required. The Mental Capacity (Amendment) Act 2019 replaces the DoLS with the Liberty Protection Safeguards (LPS) in England and Wales. The LPS scheme will apply to people over 16 and in all settings, including hospitals, care homes and people's own homes. It is expected to take effect in April 2022.

The statutory provisions of the 2005 Act are fleshed out in the Code of Practice which is being revised, with an update expected in the course of 2021.<sup>79</sup> Specific practical guidance about the process of determining best interests in the context of patients unable to make decisions about CANH can be found in joint guidance by the British Medical Association and Royal College of Physicians.<sup>48</sup> Further guidance concerning decision making for those in a prolonged disorder of consciousness (PDOC), about CANH, but also about other decisions, has been produced by the Royal College of Physicians.<sup>50</sup>

### 4.2.2 Best interests and life-sustaining treatment

In making a best interests decision about giving or continuing life-sustaining treatment, there is always a strong presumption that it will be in the patient's best interests to prolong his or her life,<sup>m</sup>

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<sup>l</sup> See Section 4(9)

<sup>m</sup> *Briggs v Briggs* [2016] EWCOP 53, overview 6(9)

and as we have seen, the decision-maker must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion.

However, the strong presumption in favour of prolonging life can be displaced where:

- 1 it can be ascertained with sufficient certainty that the person would not want the treatment in question in the circumstances that have arisen. In this case the patient's views should generally be followed or afforded great respect and prevail over the very strong presumption in favour of preserving life<sup>n</sup>
- 2 the treatment itself would be overly burdensome for the patient, in particular with reference to what is known about whether it is more important to the patient to be kept alive at all costs or to be kept comfortable
- 3 there is no prospect that the treatment will return the patient to a state of a quality of life that the patient would regard as worthwhile. The important viewpoint is that of the patient, not of the doctors or healthcare professionals. Where the patient's condition may improve, a best interests decision may be based on the 'best case scenario' as advised by the relevant clinicians and experts.<sup>o</sup>

Oral nutrition support or CANH may help in symptom control (see chapters 2 and 3). If it does, that will be relevant to the question of whether it is the patient's best interests to start, continue or withdraw it.

## 4.3 Advance decisions

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### 4.3.1 The legal framework

An advance decision is a decision by a person to refuse particular medical treatments at a time in the future when they may be unable to make such a decision. It is sometimes referred to as a living will or advance directive. It might say, for example, that an individual would not want to be given CANH if they were ever in a permanent vegetative state.

Advance decisions were recognised in common law and are legally binding. The 2005 Act puts them on a statutory footing – applying solely to people aged over 18 – and most importantly provides that an advance decision to refuse life-sustaining treatment only applies where it is in writing, witnessed, and verified by a statement by the person to the effect that it is to apply to that treatment even if life is at risk.<sup>p</sup>

If a valid advance decision is applicable to the treatment in question, then it is unlawful to provide the treatment. A healthcare professional would be civilly and criminally liable if they deliberately carried out treatment in face of an advance decision or, potentially, where they did not take adequate steps to investigate precisely the terms of an advance decision where alerted to them.<sup>q</sup>

Note that if the advance decision does not comply with all the statutory requirements, it will still serve as a (written) statement of wishes and feelings, which must be considered when determining whether treatment is in the patient's best interests.<sup>r</sup>

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<sup>n</sup> *Salford Royal NHS Foundation Trust v Mrs. P* [2017] EWCOP 23, at paragraph 29

<sup>o</sup> *Briggs v Briggs*, *ibid*, at paragraph 25

<sup>p</sup> Section 26(5). Note that the statement can be completed at the direction of a person unable to write or sign the document if it is completed in their presence and at their direction

<sup>q</sup> See by analogy, *NHS Cumbria CCG v Rushton* [2018] EWCOP 41

<sup>r</sup> Section 4(6)(a)

An advance decision cannot **require** a healthcare professional to provide a specific medical treatment, just as a person with capacity at the time of treatment cannot make such a demand, nor can they seek to do so by doing so in advance.

An advance decision must identify with clarity the treatment to which, and the circumstances in which it is to apply. The court has observed that these factors ‘go a long way [towards] identifying what the person who has made it has considered and taken into account.’<sup>s</sup>

### 4.3.2 Changes of circumstances

An advance decision will only be used if, at some time in the future, someone is unable to make their own decisions about treatment. However, a person’s life may well change between the point at which they make an advance decision and the point at which they no longer have capacity and a decision about treatment has to be made. A ‘safety net’ is provided by the MCA, which provides that an advance decision is not applicable:

- > if the person has done anything else (other than withdrawing the decision or subsequently granting the power to someone to make the decision under a lasting power of attorney) clearly inconsistent with the advance decision remaining their fixed decision
- > to the treatment in question if at the time the person has the capacity to give or refuse consent to it
- > if there are reasonable grounds for believing that circumstances exist which the person did not anticipate at the time of the advance decision and which would have affected their decision.

Any healthcare professional who considers that they are not bound to follow an advance decision to refuse treatment on any of the bases set out above is strongly advised to obtain the agreement of the Court of Protection in advance of providing the treatment.

### 4.3.3 Lasting powers of attorney and court-appointed deputies

There are two types of lasting power of attorney (LPA): one covering property and financial affairs, the other health and welfare.

Under a health and welfare LPA an individual (the ‘donor’) can give authority to someone (the ‘attorney’) to make decisions on their behalf in circumstances where they no longer have capacity. It can be used to give an attorney the power to make decisions about things like medical care, moving into a care home and life-sustaining treatment.

There are, of course, restrictions. Section 11 of the MCA prohibits an attorney from doing anything which restrains the donor, unless certain conditions are satisfied, ie the donor lacks, or there is a reasonable belief that the donor lacks capacity regarding the decision, the restraint is necessary to prevent harm to the donor and the type of restraint is in proportion to the seriousness of the harm.<sup>79</sup>

A health and welfare LPA is subject to the provisions of the 2005 Act relating to advance refusals of treatment.<sup>†</sup> It only applies where the donor lacks capacity (or the attorney reasonably believes that they do), and extends to giving or refusing consent to starting or continuing treatment.<sup>‡</sup> An attorney can only authorise the giving or refusing of consent to starting or continuing life-sustaining treatment if the power to do so has been expressly included in the LPA.<sup>‡</sup>

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<sup>s</sup> *Briggs v Briggs*, *ibid*, paragraph 21

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

<sup>‡</sup> Section 11(7)(c)

<sup>‡</sup> Section 11(8)

The Court of Protection has power to appoint a ‘deputy’ to make decisions on behalf of a person.<sup>w</sup> Any decision by a court about what is in a person’s best interests trumps a decision by a deputy.<sup>x</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>y</sup> and to ‘giving a direction that a person responsible for ...health care allow a different person to take over that responsibility’.<sup>z</sup>

Similar restrictions apply to the exercise of a deputy’s power as apply to an attorney under a lasting power of attorney.<sup>aa</sup> However, unlike an attorney, a deputy ‘may not refuse consent to the carrying out or continuation of life-sustaining treatment ....’<sup>bb</sup> but **can** give consent.

#### 4.3.4 When to go to court

Almost all dilemmas in the law of consent are resolved by healthcare professionals in consultation with the patient and their family. For details of the procedures to be followed, see the GMC guidance on consent,<sup>80</sup> for CANH, the guidance produced by the BMA and RCP,<sup>48</sup> and for decision making for those in a PDOC, the RCP guidelines.<sup>50</sup>

Healthcare professionals must ensure that they follow the provisions of the MCA as well as the relevant guidance in the Code of Practice.

The Supreme Court has made clear that, ‘if the provisions of the MCA 2005 are followed and the relevant guidance observed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that agreement without application to the court’.<sup>cc</sup>

This means that medical treatment may be provided, withdrawn or withheld in accordance with the agreement, without application to the court, in reliance upon the defence in section 5. This is the case even for the withdrawal or withholding of life-sustaining treatment, including CANH.

However, if at the conclusion of a medical decision-making process in relation to life-sustaining treatment, there remain concerns that the way forward in any case is **finely balanced**, there is a **difference of medical opinion**, or a **lack of agreement** as to a proposed course of action from those with an interest in the person’s welfare then an application to the Court of Protection **must** be made. This is an inalienable right of the individual, guaranteed by the European Convention on Human Rights.

The Supreme Court has emphasised that there should be ‘no reticence about involving the court’ where the circumstances of any patient’s case warrant.<sup>dd</sup> The courts have also emphasised that where an application is merited, it is crucial that it is brought at the earliest possible opportunity so as to ensure that there is the opportunity for proper investigation and representation of the patient. Guidance was issued in January 2020 by the Court of Protection about serious medical treatment cases, including as to when consideration should be given to bringing a case to court, and what is required where one is brought.<sup>ee</sup>

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<sup>w</sup> Section 16

<sup>x</sup> Section 16(4)

<sup>y</sup> Section 17(1)(d)

<sup>z</sup> Section 17(1)(e)

<sup>aa</sup> See generally section 20

<sup>bb</sup> Section 20(5)

<sup>cc</sup> *NHS Trust v Y* [2018] UKSC 46 at paragraph 126

<sup>dd</sup> *NHS Trust v Y* [2018] UKSC 46 at paragraph 126

<sup>ee</sup> Serious Medical Treatment Guidance [2020] EWCOP 2

## 4.4 Children

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Generally in law, the term ‘child’ is used to refer to people under the age of 18. Under the MCA and its Code of Practice, a child is anyone under the age of 16. Particular rules apply to 16- and 17-year-olds.

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

Consent to treatment can be obtained from a Gillick competent child aged under 16 (Gillick competence is discussed below), from a person with parental responsibility in the case of a child under 16 lacking Gillick competence, or from the court.

So far as refusal of treatment is concerned, the consent of a person with parental responsibility trumps the refusal of a child under 16 (whether or not the child has Gillick competence), and the consent of the court trumps the refusal of either. In deciding whether to exercise its trumping power, the court applies the ‘best interests’ test (see below). 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 interests; but this will be very rare.<sup>ff</sup> It will normally be possible to ensure that the child gets the treatment that the court and the clinicians think the child needs.

### 4.4.1 Gillick competence

The notion of Gillick competence comes from the House of Lords case of *Gillick v West Norfolk and Wisbech AHA*.<sup>gg</sup> It is simply that children under 16 should be regarded as able to make the decision if they are believed to have enough understanding and intelligence to fully appreciate what’s involved in their treatment. Whether the child has that understanding and intelligence is a question of fact in each case. Although the judge in the case 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).

In relation to 16- and 17-year olds, consent to surgical, medical or dental treatment can be obtained from the child themselves, the presumption under the 2005 Act being that they have capacity to give such consent. Where such consent has been obtained, the Family Law Reform Act 1969 provides that no further consent from a person with parental responsibility is then required. Where the 16- or 17-year old lacks capacity to make the relevant decision, medical treatment can be provided – as with adults – on the basis of the defence provided by section 5 of the 2005 Act (see 4.2.1) where the treatment is reasonably believed to be in the best interests of the child. There is therefore, in law, no need to obtain consent from a person with parental responsibility before the treatment is carried out, but they must be consulted.

### 4.4.2 Capacity and best interests

A court can override the refusal of medical treatment by a 16- or 17-year-old who has capacity. However, it is doubtful whether a parent can consent to medical treatment in the face of a refusal of a child aged 16 or 17 with the capacity to do so. Government guidance since 2009 has provided that it is ‘prudent’ to obtain a court declaration or decision to determine whether treatment is lawful in such circumstances.<sup>81</sup> If a 16- or 17-year old lacks the capacity to make the decision about the treatment,

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

<sup>gg</sup> [1986] 1 AC 112

then in law there is no 'refusal' to override. Healthcare professionals could either proceed by reference to the best interests framework of the 2005 Act or seek consent from a person with parental responsibility. Our suggestion is that the decision making should take place by reference to the 2005 Act because it provides a more carefully calibrated mechanism to determine the interests of the child.

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.

In determining what best interests mean in relation to children, the courts apply the same principles as set out on p50,<sup>hh</sup> and have emphasised that the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view.<sup>ii</sup> Specific professional guidance on children has been published by the Royal College of Paediatrics and Child Health.<sup>82</sup>

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<sup>hh</sup> See *Re A (A Child)* [2016] EWCA Civ 759; for a detailed summary, see *Kings College Hospital NHS Foundation Trust v Takesha Thomas* [2018] EWHC 127 (Fam)

<sup>ii</sup> See *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410 at para 112

# Chapter 5: Ethics



## Key points

- > A consensus of ethical opinion and legal precedent accepts that clinically assisted nutrition and hydration (CANH) constitutes a medical treatment, rather than basic care. As such, ethically and legally, it can be withheld or withdrawn if it is thought not to be in the patient's best interests.
- > When considering a patient's best interests, the healthcare team should make the patient the centre of discussions.
- > Important principles to guide these discussions are the 'sanctity of life' and the 'preservation of dignity'.
- > The patient, or their representatives, should understand that CANH is a burdensome treatment with risks.
- > Withholding CANH may permit the patient's underlying condition to progress and threaten life. This is not the same as killing.
- > Among the healthcare team, patient and relatives may well be people with different ethical and cultural views, including that food and water are basic necessities and should never be withheld.
- > Transparency, honesty and respect should be the characteristics of the discussions around CANH.
- > The legal position on CANH is clear and it is important that our actions remain within the law. The Mental Capacity Act can help provide a framework within which ethical considerations are considered.

## 5.1 Introduction

Good medical practice is informed by ethical principles. These principles shape legislation and the thinking of the courts about particular cases. As was said by a judge in the Bland case: '... behind the questions of law lie moral, ethical, medical and practical issues of fundamental importance to society'.<sup>a</sup>

Ethical principles both underpin the law and go beyond it, guiding action where the law is silent, in defining the best professional way of meeting legal duties. This chapter explores those principles and outlines some of the ethical considerations when making decisions in this complex area. Any course of action should be the result of careful consideration and what is believed to be in the best interests of the individual patient.

## 5.2 Ethical principles

In decisions regarding nutrition and hydration, the healthcare team should always make the patient the centre of discussions. Both legally and ethically, the starting point is to determine whether the patient has the capacity to make the relevant decisions (see chapter 4).<sup>b</sup> When patients have capacity, the guiding principle should be that of **autonomy**, which involves the right of the patient to refuse

<sup>a</sup> Browne-Wilkinson LJ. *Airedale NHS Trust v Bland* [1993] 1 All ER 821, at 878

<sup>b</sup> Note that the position in relation to children is slightly different, and set out at section 4.4

treatment, even at the cost of hastening death. The exercise of autonomy is limited by the principle of justice. The right of a patient to refuse treatment does not imply the right of the patient to demand treatment if the healthcare team do not consider provision of that treatment to be in the patient's best interests.

If the patient does not have capacity and cannot make their own decisions about what to do, then their voice will have to be relayed by others. The various legal mechanisms by which this is done are set out in chapter 4. However, the central message is that the collection of information and opinions should be respectful, unhurried and comprehensive, as well as carefully documented.

Important principles to help guide these decisions and discussions are the **sanctity of life** and the preservation of **dignity**. The sanctity of life means that the life of a patient is valuable in itself and does not depend on their social or economic achievements. The preservation of dignity means that, at all times, the patient should be treated with respect. These principles complement the medical duties of **beneficence**, the doctor's responsibility to do good, and **non-maleficence**, the doctor's duty to avoid harm. These ethical principles are explained further in Box 9.

### Box 9: Ethical principles guiding medical practice



**Autonomy** (literally, self-rule) opposes paternalism and asserts the ultimate authority of the patient, including the right of the patient to refuse care and so hasten death.

**Beneficence** refers to the doctor's responsibility to preserve life, restore health and relieve suffering: in the traditional formula, to cure sometimes, to alleviate often, and to comfort always.

**Justice** involves the principle that all should be given what is rightfully theirs. In healthcare, principles of justice define the claims that individuals can make on the resources that are available to provide treatment, if the financial and/or human cost of providing that treatment would deprive others of their rightful claims.

**Non-maleficence** is the responsibility to avoid harm in any clinical encounter.<sup>83</sup>

**Dignity** is not easy to define and has a number of nuanced meanings, including (from the OED) 'the state or quality of being worthy of honour or respect'. Although hard to define, it is generally easy to recognise when an individual is not being treated with dignity; avoiding this should be a primary aim for the healthcare team assessing a patient for CANH.

**Sanctity of life** means that life has intrinsic value and therefore should be protected and not violated. The idea is central to the Abrahamic faiths, but it is also explicitly valued in secular contexts – for example: '... 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...'<sup>c</sup>

<sup>c</sup> Taylor LJ64 in *Re J (a minor) (wardship: medical treatment)* [1991]



The principles must be considered against the background of rightful patient expectations that they receive good clinical care, that they are included in decisions about their care and that they are treated with dignity. Healthcare professionals should be aware that 'good' for a patient may be a complex notion that cannot be reduced to a single ethical dimension and may not coincide with their own point of view.

The supervising doctor (usually the named consultant or patient's GP) should also be aware that, among the healthcare team, patient or relatives, there may well be people with different ethical positions, including those who think that food and water (as long as there is a method whereby they can be given), are basic necessities of life and should never be withheld.

Transparency, honesty and respect should be the characteristics of the discussions around CANH. Every case is different and there is not one correct answer which fits all situations. It may be helpful to seek additional professional opinions (eg from other experienced healthcare professionals, local ethics forum or legal representatives).

## 5.2 The sanctity of life

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Under the principle of the sanctity of life, we preserve life because of its intrinsic value. Intrinsic value means that persons are to be valued as such and not because of their social or economic achievements. For example, a person with one leg cannot run as fast as a person with two; however, we do not think (or think decently) that the one-legged person has less value than the two-legged one. We 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.

The principle of the sanctity of life does not mean that life should be preserved at all costs. For instance, it need not oppose withdrawal or withholding of treatment in particular cases.<sup>84–86</sup> Neither does the principle of the sanctity of life mean that a patient's autonomous wish to refuse treatment may be overridden. This ethical view is consistent with English law, which recognises the sanctity of life but does not treat it as an absolute principle – as stated in the Bland case.<sup>d</sup>

## 5.3 CANH and basic care

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Basic care is defined as those procedures essential to keep an individual comfortable.<sup>79</sup> These include warmth, shelter, pain and distressing symptom relief, cleanliness and hygiene measures and the offer of oral nutrition and hydration. Dialysis or artificial ventilation are medical treatments. Medical treatments may not be initiated or may be stopped; basic care is always mandatory in the absence of explicit refusal by the patient.

The provision of CANH could be considered as an element of symptom control. Keeping the patient comfortable can still involve medical treatment though and as such in this situation could be considered burdensome.

Food and water are fundamental to life. The critical question is whether all measures to provide them to a patient are basic care, or whether some may better be regarded as medical care. Some have argued that nasogastric or gastrostomy feeding and hydration represent basic care<sup>87</sup> and should not be withdrawn because they represent love and care for people who are helpless.<sup>88</sup>

However, the majority opinion of the courts and professional bodies is that some feeding treatments constitute medical care.<sup>89,90</sup> For instance, gastrostomy feeding has all the characteristics of medical

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<sup>d</sup> *Airedale NHS Trust v Bland* [1993] AC 789 House of Lords

care; it requires prescription, medical and nursing skills and has potential adverse effects. It is clearly more hazardous and involved than the simple offer of food and water (which is defined as basic care). As such, ethically and legally, it can be withheld or withdrawn if it is thought not to be in the patient's best interests. The physician's duties to do no harm and to benefit the patient permit the withholding of clinically assisted nutrition and hydration.

## 5.4 Ordinary and extraordinary means of care

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Patients, or their representatives, need to understand that CANH may be a burdensome treatment with risks. In some cases, it ceases to be a form of 'ordinary' care and becomes an 'extraordinary' means of treating the patient.

Extraordinary 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 intrusiveness). The decision whether to employ any treatment is therefore based on a calculation of the likely net balance between benefits and burdens and the acceptance of the proposed treatment by the patient. To distinguish between ordinary and extraordinary means is to imply an obligation to use the former but no strict obligation to use the latter. The doctrine therefore introduces a concept of proportionality.

'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. Nor does 'ordinary' equate with patient (or carers/relatives) expectations, which may unknowingly be for treatments that are extraordinary.

Proportionality involves balancing the two separate factors of efficacy and burdens: how much burden for how much benefit? The distinction between ordinary and extraordinary will often be vague as it relies on judgements concerning what is reasonable, beneficial, excessive, proportionate or understood. Hence the ordinary and extraordinary distinction functions less as a 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>91</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, which can be extremely complicated to elucidate and should not be assumed.

## 5.5 Intended and foreseeable

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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. A treatment given with one intention in mind (to reduce blood pressure, for instance) may have foreseeable but unintended effects (to increase the risk of falls).

Intention is fundamental to medical practice.<sup>92,93</sup> The Mental Capacity Act (Section 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'.

Morally, intention is critical. On the one hand, acting in order to cause harm is wrong. On the other hand, the same harmful consequence may not be wrong, even if it can be foreseen as a possible or even probable outcome, when the overall intention of the action is to do good. Intention points to the importance of the goodwill.

Building upon this distinction, the doctrine of ‘double effect’<sup>e</sup> asserts that an action is justified if the intention is to produce a good effect, despite the foreseeable possibility of unintended harm, provided that: the means are good, that the good effect is not produced by the harmful effect and that intended outcome is of appropriate significance to permit the harmful effect. Thus allowing oral intake in a person with impaired swallowing may foreseeably lead to a life-threatening pneumonia, but may not be bad if the intention is to avoid the suffering associated with (clinically assisted) nutrition and hydration therapies and to promote the pleasure of taste.

## 5.6 Withholding and withdrawing

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It is widely held that there is no intrinsic moral difference between withholding and withdrawing treatment.<sup>90,94</sup>

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, which is clearly not in the patient’s best interests. As the General Medical Council (GMC) points out:<sup>95</sup>

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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.

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It may be helpful in managing the expectations and emotions of staff, patient and relatives around withdrawal, if the treatment is characterised as ‘on trial’ for a fixed period of time with pre-defined criteria of success and failure.

## 5.7 Killing and letting die

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In ethical terms, there is a distinction between killing and letting die. Medicine, law and everyday morality distinguish clearly between a strong universal prohibition on killing and a more equivocal attitude to letting die. The focus of this chapter is patients whose underlying condition threatens to end their life. In that context, CANH is treatment which supports the patient, but does not fundamentally alter the underlying condition. Withholding such treatment, if it is considered excessively burdensome, allows the effects of the terminal condition to conclude; in the same way, burdensome treatments may be reasonably withheld in terminal respiratory or renal disease. If the patient’s underlying condition deteriorates and they begin to die, withdrawing CANH is not the same as killing.

## 5.8 Surrogate judgement and best interests

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If the patient lacks the capacity to make a decision about their care, a surrogate decision maker should seek to come to the decision that is, as far as possible aligned to the decision that person would make if they had the capacity to make it. This is complex and easier to achieve when the patient’s wishes and preferences are already known, through past actions, written instructions or in conversation with family and friends.

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<sup>e</sup> credited to Thomas Aquinas in *Summa Theologica* (II-II Qu 64 Art 7)

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 patient lacking the relevant decision-making capacity might construe as worthwhile and bearable. The focus includes the medical treatment best interests but is more than just the medical best interests.

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. And where disagreement arises, this should be handled in a sensitive manner. An additional opinion may help. It is important that these consultations do not leave those close to the patient feeling they, solely, have determined the choice of treatment. This may inadvertently burden them with feeling responsible for unexpected harmful consequences. Rather, patient's families and friends should be regarded as experts in the patient's wishes, and doctors as experts in translating those wishes into treatment decisions, for which they take responsibility.

Difficulties arise when the previously expressed and long-held wishes and values appear to be in conflict with the current state of the patient. For example, there may have been an advance refusal of treatment by a patient with capacity, yet the patient now lacking capacity appears to be enjoying life. Advance refusals may require careful appraisal for their validity as a result of this difficulty.<sup>96</sup>

Under the Mental Capacity Act, surrogates may be nominated to make decisions for patients lacking capacity. Yet many patients consider placing trust in their surrogate more important than assuring their surrogate's ability to accurately predict their preferences. They may also want their surrogates to interpret their stated preferences according to the details of the situation. Notwithstanding that it is a legal requirement under the Mental Capacity Act, it is right to acknowledge that a rigidly hierarchical view of surrogate decision making can oversimplify a process that is complex, dynamic, personal and even idiosyncratic, and tends to de-emphasise other considerations, such as mutual responsibility.<sup>97</sup>

## 5.9 Conscientious objection

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Conscience refers to an inner conviction of the morality of one's acts.<sup>98</sup> Conscientious objection to an act is the claim that it would violate the individual's conscience, resulting in a loss of integrity. A conscience may not, of course, be well informed, but the claim to conscience implies a certain seriousness of conviction or belief.

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.

A member of the healthcare team may have conscientious objections to the way a particular patient is being treated. Where such dissent cannot be overcome by discussion within the 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.

Where the healthcare team cannot arrive at a consensus, or a key healthcare worker has conscientious objections to the team's advice, patients or families should be notified. Involving local clinical ethics support and review, if available, may be useful at this juncture. 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>88</sup>

## 5.10 Trust and transparency

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Trust is essential to the relationships between professionals, patients and their relatives. In principle, transparency should aid trust but excessive unsorted information may increase uncertainty.<sup>99</sup> Excessively optimistic predictions may also erode trust, making future advice less likely to be accepted. Under the model suggested above, professionals should respect the expertise of the patient's family and friends.

## 5.11 The ethics of process

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Decisions about CANH may be finely balanced. It is possible for varying legitimate opinions to be held by different members of the multidisciplinary team. There is no ethical calculus that can determine what is 'right' in all situations. Respect and hence maintenance of dignity 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. This obviously should include the patient if they are able to participate in the discussion. It can be useful to seek external help such as healthcare workers from other teams or institutions or ethicists. Instant or casual decisions, even when finely balanced, do not show the respect that is found in a serious or structured process.

This chapter has aimed to outline some of the ethical considerations which come into play when making decisions in this complex area. It is not intended to be didactical but to give a framework whereby a patient, their carers and clinicians can come to an agreement as to the correct path for that individual. It is also important to remember that the decision will not automatically result in not providing rather than providing CANH, but that the course of action or inaction has been as a result of careful, measured consideration and is what is believed to be in the best interests of the individual patient.

# Chapter 6: Illustrative examples of patients to guide practice



## Key points

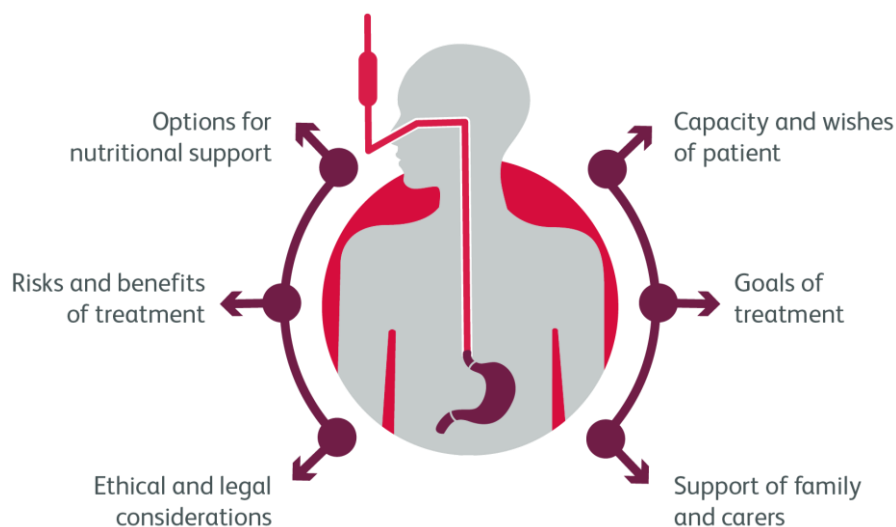
- > All patients who need nutrition support should receive coordinated care from a multidisciplinary team.
- > It is important to explore key questions in relation to eating and drinking and the benefits of treatment.
- > The balance of risk versus benefit of any intervention should be clearly documented and treatment goals articulated.
- > In many cases there are no easy answers but rather approaches to follow to reach the best decision for each individual patient.

## 6.1 Introduction

Eating and drinking are essential for maintenance of nutrition and hydration but are also important for pleasure and social interactions. Difficulties with eating and drinking may have both physical and psychological consequences. Thus, every effort should be made by healthcare professionals to maintain and support these activities. An inability to eat and drink can be devastating to patients and their families, particularly at the end of life, and can be a significant source of anxiety and distress.

Healthcare professionals should ensure that all patients who need nutrition support receive coordinated care from a multidisciplinary team.

This chapter is intended as a tool to inform and guide decisions around supported eating and drinking. Fig 7 summarises the key factors impacting on those decisions. In most cases there are no easy answers but rather approaches to follow to reach the best decision for each individual patient.



**Fig 7. The key factors impacting on nutrition support decisions**

The chapter includes illustrative examples of patients who have difficulties with eating and drinking as a result of a disease or condition. The different circumstances have been chosen to illustrate common dilemmas and to help guide practice. Each one is followed by key questions to consider relating to supporting people with eating and drinking and best interests.

Box 10 explores a number of important questions to ask in relation to **all** patients regarding eating and drinking and the benefits of treatment.

### **Box 10: Key questions regarding the benefits of treatment**

- 1 Is clinically assisted nutrition and hydration (CANH) necessary for adequate nutrition/hydration or can sufficient intake to cover basic needs be taken orally, albeit with difficulty? This may differ from the ideal requirements for a healthy individual as the requirements or the targets for nutritional support may be lower.
- 2 Does the patient have capacity to decide upon the method of receiving nutrition/hydration? If not, what decision is in their best interests and in accordance with their wishes (if known)?
- 3 If CANH is necessary, what is the best method/route for giving it (eg by nasogastric, gastrostomy or jejunostomy tubes, or parenteral)?
- 4 Do the benefits of treatment outweigh the burdens/risks of treatment? If they do not, then the treatment is clinically inappropriate and is not an option to be considered in the patient's best interests. This question often arises when the aim of care is palliative and life expectancy is unlikely to be prolonged.
- 5 What are the goals of the nutrition/hydration support, the expected duration, and the criteria for stopping? These should be decided at the start of treatment following a discussion with the patient, relatives, carers, healthcare workers and advocates. The goals of CANH may include:
  - > decrease in discomfort/symptoms (partly because medication can be given)
  - > improvement in quality of life
  - > increase in weight (if the patient is underweight)
  - > improvement of wound healing (including pressure ulcers)
  - > reduced infections
  - > increasing mobility so there may be a better prospect for rehabilitation
  - > improvement of confusion which may occasionally result in the return of mental capacity.
- 6 With whom should discussions about the future management be held? If patient/relatives cannot decide about having nutritional support, the following people/groups may need to be involved in the decision making:
  - > Medical/nutrition team/carers acting in the patient's best interests
  - > Relatives and friends interested in their welfare
  - > An independent mental capacity advocate (IMCA) – to advise the decision maker if there are no appropriate relatives or friends available to be consulted.
- 7 What are the key issues to discuss with the patient, relatives, carers, healthcare workers and advocates?
  - > Underlying diagnosis
  - > Prognosis with and without CANH
  - > Other options to CANH (eg modified texture food and/or fluids, assisted eating and drinking)
  - > Prognosis, morbidity and quality of life with CANH
  - > The goals of CANH
  - > The anticipated time when the feeding tube will need replacement
  - > What needs to be done when/if there is a gradual decline or intercurrent illness.

## 6.2 Kwame, a stroke patient



Kwame, an 83-year-old man who lives alone, has had a sudden right hemiplegia and is aphasic. A formal speech and language therapy (SLT) assessment has identified Kwame as having a high risk of aspiration with any oral intake. Nasogastric tube (NGT) feeding was tried. However, Kwame repeatedly pulled out the NGT so the multidisciplinary team decided to insert a nasal loop which allowed the NGT to stay in longer. At 2 weeks Kwame was referred for a gastrostomy. His relatives report that when his sister had a stroke he had said 'You must shoot me if I am ever like that'. Currently, he lacks capacity to consent to any procedure. Should Kwame have a gastrostomy?

### Key questions to consider

#### 1. What is the significance of being assessed as having a high risk of aspiration?

Following a stroke, 45% of patients will have difficulty swallowing – this will return within 14 days for 86% of them.<sup>100</sup> The effect of stroke can include impaired oral control as a result of slow and weak tongue movements, impaired posture control and, if hemisphere swelling occurs, an impairment of vigilance or consciousness. A right middle cerebral artery stroke involves only the central nervous system, so when the patient is conscious there should be relative preservation of reflex coughing which will protect the airway and allow eating and drinking to be done safely.

A swallow assessment can be difficult to perform and will often err on the side of considering swallowing to be unsafe. An SLT assessment is essential and it is helpful for a discussion to take place between the patient, relatives and healthcare professionals before the outcome and implications of being assessed as unsafe to swallow are documented and enacted. Once a decision for a patient to be 'nil by mouth' is made it may be difficult for clinicians or family to override it. Sometimes the family will say that the patient's eating/swallowing is no different from normal or that if they eat in a certain way they will manage as they have been doing for a long time. Despite an identified risk of aspiration, some patients determine that they derive such pleasure from eating that they will not discontinue eating or comply with texture modification, in spite of advice to the contrary.

A formal MDT meeting should be convened at which the risks of aspiration are discussed. The importance of serial assessment to ascertain progress/improvement and the need for any medication to be administered (sometimes this is necessary to allow swallowing, eg in Parkinson's disease) should be considered.

#### 2. What are the implications of repeated removal of an NGT?

This often occurs and results in a lack of consistent provision of feed, fluids and/or medications. It is traumatic and causes distress for the patient (and family). There is also an increased potential for misplacement as the tubes are often replaced. The patient's capacity to make a decision in relation to maintenance of the NGT must be determined. If possible, it needs to be identified if the patient has deliberately removed the NGT as a way of saying they do not want the treatment. This can be difficult to ascertain in patients with delirium, confusion, or altered mental state. If lacking capacity to make the decision, as in Kwame's case, and if deemed to be in the patient's best interests, then the tube should be re-inserted.

#### 3. Are there issues with inserting a nasal loop to hold the NGT in place?

The options for minimising NGT removal in people who lack capacity include ensuring the tube is attached securely to the side of the face, putting mittens onto the patient's hands so they cannot grasp the tube, or temporarily holding the tube in place with a nasal loop (sometimes called a nasal bridle).<sup>101,102</sup> Before any of these measures are commenced the patient's best interests must be assessed and consideration given to whether the patient will be able to tolerate a nasal



loop. If they are highly confused/agitated, then a nasal loop is inappropriate due to the potential for the patient to cause trauma to their nasal septum through continued pulling on the tube. The relatives, carers and nursing staff need to be aware that even with the placement of a nasal loop the tube can still become displaced/removed by the patient. If the patient lacks capacity (as in Kwame's case), to make the decision as to how to take nutrition/fluid, it is lawful to restrain them to enable them to be fed if this is necessary and proportionate to the risk of harm they would suffer otherwise (Section 6 of the Mental Capacity Act). If the restraint will be sustained, then a Deprivation of Liberty Safeguards (DoLS) authorisation in the hospital setting should be considered (or if in the community, consideration of an application to the Court of Protection).

When the Mental Capacity (Amendment) Act 2019 comes into force, arrangements to enable the care and treatment of a patient lacking capacity which will give rise to a deprivation of the patient's liberty will need to be authorised under the Liberty Protection Safeguards (LPS) scheme, regardless of the setting. Local policies must be followed and when appropriate the early identification of the need for a DOL/LPS application.

#### **4. Is 2 weeks the correct time to refer a patient for a gastrostomy?**

The natural history of eating and drinking problems after a stroke will inform this decision. Serial assessments and the elapse of time following an acute neurological event allow the potential for recovery to be estimated. Usually a patient is fed by a nasogastric tube for 10–14 days as an interim measure before a gastrostomy is considered. Insertion of a gastrostomy tube after 14 days reduces mortality and improves nutritional outcomes at 6 weeks compared with continued nasogastric feeding.<sup>56</sup> A proportion of patients will regain swallowing function within the first 2 weeks; at 4 weeks 20% of patients will no longer require tube feeding.<sup>56,103</sup>

Gastrostomy tube placement should not be an emergency procedure and should always be undertaken as a planned elective procedure, following clinical optimisation, in accordance with the patient's best interests, and with the agreement of the multi-professional team. Pressure to place a gastrostomy early just to help facilitate faster discharge from hospital should be resisted.

#### **5. Kwame has expressed a wish not to be treated in the past. Should this be honoured?**

Ad-hoc or 'off the cuff' comments that do not specifically pertain to personal circumstances can result in an extremely emotive reaction from relatives. The facts surrounding such comments need to be explored and the clinical similarities or differences and/or origin of the concerns ascertained. While these views should be factored into best interests discussions and clinical assessments, they do not have any legal bearing on decision making if everyone is clear that they were off the cuff and not related to the person's own circumstances. Circumstances and opinions may also change and therefore too much weight should not be placed upon ad-hoc comments made historically. Patients may refuse treatment through an advance decision which is legally binding. An advance decision to refuse life-sustaining treatment has to be written, witnessed and clear that it applies even when life is at risk. Even if there is no advance decision to refuse treatment, then if the patient's views can be ascertained with sufficient certainty, they should generally be followed or afforded great respect and will generally prevail over the very strong presumption in favour of preserving life. If a gastrostomy is not in the patient's best interests, or is against the patient's refusal (if they have capacity), inserting the gastrostomy tube could give rise to a charge of assault.

#### **6. How can Kwame's capacity be assessed?**

Generally, capacity is assumed until proven otherwise. However, after a stroke such as Kwame's, there will be reason to consider whether he has capacity to make relevant decisions, so his capacity should be formally assessed and documented. Following a stroke, a patient's ability to understand their situation and the decision to be made, retain the information, use and weigh it, and/or communicate the resulting decision can be difficult to determine. Visual aids /

communication tools and an independent mental capacity advocate (IMCA) may be needed. Disorders of language, which are common after a left middle cerebral artery stroke, make judgements of capacity particularly difficult.

### 7. Is insertion of a gastrostomy tube a risk-free procedure?

No. Even in the best units, 30-day mortality is 6% with 10% morbidity<sup>56</sup> due both to the procedure and the underlying condition. Higher figures of 28% during hospital admission and a median survival of 305 days have been published.<sup>103</sup> The risk factors for 30-day mortality include higher age, lower body mass index, C-reactive protein >21.5 g/L, diabetes mellitus, albumin <30 g/L, radiotherapy, cirrhosis, cancer, chronic obstructive pulmonary disease, and residing in a nursing home.<sup>104</sup> There is no difference in survival and post procedural complications for a gastrostomy whether it is inserted endoscopically or radiologically.<sup>105</sup> In addition, gastrostomy tube placement does not reduce the risk of aspiration of saliva, or gastric content if there is reflux.

### 8. What are the practical implications of having a gastrostomy?

The individual may be attached to an enteral feeding pump for up to 20 hours per day or may require repeated bolus administrations every few hours. Every effort should be made by the multidisciplinary team to ensure that the patient's feeding regimen is not too restrictive and burdensome.

The wider psychosocial issues associated with enteral feeding should be considered. As the patient is less likely to be involved in mealtimes, there will be less social interaction and they may feel deprived of the pleasure of eating. There can be psychological issues due to an alteration in body image following gastrostomy tube insertion and this should be considered in choosing the type of gastrostomy tube.

Consideration must be given to when and how a new gastrostomy tube will be inserted in the future.

### 9. What are the alternatives to NGT/gastrostomy feeding?

In the first instance, if there is doubt over clinical decision making and the patient's best interests, feeding via an NGT is recommended. If this is not possible or unsuccessful, options include:

- > **No active intervention.** This is non-invasive, and, if the patient is asymptomatic (ie not hungry or thirsty) then this may be reasonable. Nutrition should be provided as appropriate to the patients' needs and appropriate oral fluids should always be available.
- > **Intravenous or subcutaneous fluids.** This is usually a short-term intervention (eg less than 2 weeks) until a definitive decision is made by the multidisciplinary team and the family, taking into consideration the best approach to deliver nutrition or to decide that nutrition support is futile if the patient is dying.
- > **Initiating a 'feed at risk' policy.** Supporting oral intake with appropriately modified nutrition and hydration.

## 6.3 Sarah, a patient with dementia



Sarah is a 68-year-old woman with strong religious beliefs. She was diagnosed with dementia 2 years ago, has a poor oral intake and has lost 30% of her body weight (weight 47 kg, height 1.66 m and BMI 17 kg/m<sup>2</sup>) in the past 6 months.

Sarah remains able to mobilise freely and seems relatively happy in the family home with little distress reported by her husband and family. Her swallow is assessed as slow but safe. She had never expressed a view about being kept alive before her cognition deteriorated. Her husband wants her to stay alive and to continue living with him at home. Their children think that unless the clinical team intervene she will starve to death and are requesting a feeding gastrostomy.

### Key questions to consider

#### 1. Does religion affect clinical decisions?

Every culture or religion has beliefs regarding the sanctity of life. It is important to explore any cultural or personally held beliefs pertaining to nutrition as part of the assessment for considering CANH. While there are recognised worldwide cultural food practices and restrictions,<sup>106</sup> not all patients will adhere to all aspects of these and therefore personal beliefs and practices should be explored. A sensitive approach to discussions regarding initiation or withdrawal of CANH should be adopted in all cases with consideration of religious and cultural beliefs. However, all decisions should be made in the patient's best interests. It is imperative that the balance of risk versus benefit of any intervention is clearly documented and treatment goals articulated.

#### 2. What is Sarah's prognosis with dementia?

Life expectancy is very variable after a dementia diagnosis and depends upon disease aetiology, although most weight loss occurs in the terminal phase. Patients with degenerative diseases of the nervous system may lose their appetite as a complication of the disease. An accurate diagnosis of the cause of the dementia will inform thinking; contrasting examples to be considered include Creutzfeldt–Jakob disease in which survival beyond a year is rare and Alzheimer's in which survival for 10 years is not unusual. The provision of nutritional support may not increase survival, affect the course of an underlying disease, or improve the quality of life. The nutritional support equipment and procedures may have a major impact upon the life of a patient and/or carers.

It is also important to recognise that the risk of complication and mortality following gastrostomy tube insertion is also affected by underlying disease process and the indication for gastrostomy.<sup>56</sup> A UK study highlighted a 2-fold increased risk of 30-day mortality following gastrostomy insertion in patients with dementia of 54% versus 28% for all causes, and a 6-month mortality of 81%.<sup>107</sup>

#### 3. Does not eating or not drinking cause distress?

Often not for the patient but it can be very distressing for relatives. However, it is important that efforts are taken to improve oral nutrition and hydration and there are simple interventions that have been demonstrated to be effective in patients with dementia. (See chapter 2 for more information).

#### 4. How can a consensus agreement on long-term provision of nutritional support be reached?

In Sarah's current condition there needs to be careful consideration of her capacity. If her capacity is variable, then consideration should be given to supporting her at a point (if one occurs) when she does have capacity to set down in writing what treatments she would want and not want (complying with the provision of the Mental Capacity Act in relation to any advance decision

to refuse life-sustaining treatment). If Sarah does not have capacity to make the decision about gastrostomy feeding, then the question is what is in her best interests, and the aim is to make the decision that is right for her as an individual human being. The views of all those involved (her family, carers, and the multidisciplinary team) need to be sought and carefully documented.

The wishes of Sarah's husband/family are not relevant legally in so far as they are expressing the feelings of the husband/family themselves, but they are relevant in so far as they are relaying information about her. For instance, if they show that Sarah would have wished to be kept alive on the basis that that this would be of importance to her family, then that is going to be relevant to any best interests decision. If there is genuine consensus between those concerned with Sarah's welfare, then the decision-making process can lead to the result that CANH is not provided and consequently her death.

In the event that all parties cannot come to a genuine consensus then a further opinion may be helpful. Clinical ethics committees provide a valuable opinion. These committees usually include lay representatives so it is important that they are given accurate medical information and a full appraisal of the risks and benefits of all courses of action (including doing nothing). If there is still a lack of consensus at the end of the decision-making process, a court application will be required, and should be made by the NHS body responsible for Sarah's care.<sup>a</sup> Clear and expert medical advice is essential to inform the court. Patient support is time-consuming and requires training.

## **5. How to approach discussions with relatives or carers who are concerned that Sarah will 'starve to death'?**

In this case Sarah is dying of a degenerative disease and that is why she is not eating. Her disease, rather than a failure to eat enough, is the main cause of her deterioration. In the case of dementia, it is useful to highlight that the prognosis is the same with or without CANH. However, the risk of complications and discomfort is greater when CANH is attempted. A dying patient does not need nutrition purely to maintain life but to give pleasure; this does not signify that the patient is being 'starved to death'. Highlighting the difference between a patient dying because they are not eating or not eating because they are dying may help clarify understanding for all involved in the care of the patient.

Clinicians should not support an intervention that has no benefit to the patient simply to assuage the concerns of the family. There is good patient-level information regarding long-term nutrition support available for a number of degenerative conditions from various patient support groups which may aid discussions.

## **6. What information about gastrostomy tube placement and care should be given to Sarah's relatives/carers?**

Information about the benefits and risks should be given. Visual information in the form of leaflets or approved websites is preferable. Information should include details and discussion of:

- > a gastrostomy tube – what it is and how it is placed
- > daily use and care
- > the potential impact on morbidity and mortality; and that a gastrostomy tube may not manage all of the patient's problems and may need to be replaced in the future.

The team needs to clearly communicate both the potential benefits and burdens of CANH and gastrostomy tube placement/feeding.

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<sup>a</sup> See: *An NHS Trust v Y* [2018] UKSC 42

## 6.4 Sean, a young person with cerebral palsy



Sean is 16 and has had cerebral palsy since birth. He lives at home and has 1–2 full-time carers in addition to the care provided by his parents. He has a suprapubic catheter, and a gastrostomy tube is used for medicines (including antiepileptics, sedatives, a proton pump inhibitor and laxatives) and feed.

Sean's parents, who are vegan, report that he experiences episodic severe abdominal pain when the gastrostomy feed runs at more than 20 mL/hr and they often have to stop the feed. He has also required several courses of antibiotics to treat aspiration pneumonia over the past 8 months. His parents feel he may be getting thinner (he has not been weighed recently as the community hoist scales have broken). A CT enterography study is normal, suggesting that there are no physical or mechanical reasons for Sean's feeding intolerance.

Sean has extremely limited mobility and is confined to a supine position in bed. He is non-verbal and his responses are limited to occasional groans, pursing his lips and flexing at the hips. His parents want him to have a jejunostomy tube inserted as they have been told this will reduce the likelihood of aspiration pneumonia and the feed will be better tolerated.

### Key questions to consider

#### 1. How can Sean's best interests be determined?

When members of a family have invested their lives into looking after a relative with a long-term illness, even if that person appears to have a poor quality of life, it can be very challenging to stop treatment or even prevent escalation of treatment (eventually in Sean's case this could include for example the use of parenteral nutrition).

It is therefore of paramount importance to undertake decisions on a case-by-case basis in the patient's best interests and consider all the aims and benefits of treatment weighed against the risk of complication and harm.

It is important to assess the potential emotional and financial implications of hospital-based care as opposed to community-based care in the family home. The cost to the NHS and the wider health and social care economy may be considerable and is a factor to be evaluated in line with ethical principles.

#### 2. How should quality of life be assessed?

Sean's parents/carers have dedicated their lives for many years to care for him. In this situation he has become the centre of their world and they will do anything to ensure the care continues. They may consider that their child has a good quality of life and can express pleasure.

When CANH is required, the aim should be to improve the overall condition of the patient. If it does not, then the treatment would be considered futile and should not therefore be offered. In advance of any trial of tube feeding, a discussion should be had with the patient (where possible) and their relatives/carers to decide upon the criteria for success.

Assessing Sean's quality of life is very difficult and healthcare workers and his relatives/carers may have different opinions. To an observer it may appear that Sean's quality of life is poor. However, his parents may say that it is often good.

It is much easier to agree upon a reasonable or good quality of life when there is an easy-to-see interaction or response and especially if the patient smiles. Generally, though, the opinion of the relatives/carers should be respected.

### 3. What type of post-pyloric feeding should be tried?

In general, a nasojejunal tube should be tried first to see whether the feed can be tolerated at a rate that will increase or maintain weight. If successful, a jejunostomy may be placed endoscopically, radiologically or surgically (or through a combination of these modalities). A direct jejunostomy is usually preferred to a jejunal extension tube that comes through a gastrostomy tube (commonly a percutaneous gastrojejunostomy (PEGJ) tube) as these jejunal tubes often become displaced back into the stomach and so necessitate another procedure to replace them. However, if a large diameter gastrostomy is already in situ a jejunal extension may be tried.

Sean is 16 but has been looked after by the paediatric team and it is unlikely that he will transition/transfer to the adult team for several more years, so the procedures may be organised and performed by the paediatric team (his primary team). Body habitus is also an important factor in the decision regarding not only the modality of tube placement but who would be best placed to site a jejunostomy tube surgically. The patient may still have a 'paediatric habitus' and so an experienced paediatric surgical team may be most appropriate to carry out any procedures.

### 4. Is Sean in a permanent vegetative state?

A permanent vegetative state is when a person is awake but is showing no signs of awareness for more than 6 months if caused by a non-traumatic brain injury (12 months if a traumatic brain injury) ([www.nhs.uk](http://www.nhs.uk)). Making groaning noises to a stimulus excludes this. The RCP guidance on prolonged disorders of consciousness should be followed to support a detailed assessment of Sean's level of consciousness.<sup>49</sup>

### 5. Should treatment be stopped?

Sean is 16 and lacks mental capacity to make medical treatment decisions. This means that the doctors should either approach matters through the Mental Capacity Act (MCA) and consult with his parents and others interested in his welfare, or use the common law and rely upon parental consent. As stated in chapter 4, our view is that doctors should operate on the basis of the MCA. The question is therefore whether continued treatment is in Sean's best interests applying the test within the MCA. It is helpful, when CANH is begun, to agree on some criteria which in the future could lead to treatment being stopped. If CANH is physiologically achieving its goal, then it is difficult to see that it would not continue to be clinically appropriate. At this point, the question is whether it is in Sean's best interests to continue providing it.

Following *NHS Trust v Y*<sup>b</sup> there is no need to go to court if the decision is that it is not in Sean's best interests either to start providing CANH, or to continue it after a trial, if there is agreement between all concerned and the relevant professional guidance has been followed.<sup>48</sup> If there is not agreement, or the decision is finely balanced, an application must be made by the NHS body responsible for Sean to the Court of Protection for a decision as to whether or not continuing CANH is in his best interests.

### 6. Does his parents being vegan affect the feeds Sean can have?

It will be difficult to find appropriate enteral feeds as most are milk-based. If parenteral nutrition is needed, then it can be hard to avoid egg-based products in the lipid preparation.

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<sup>b</sup> *An NHS Trust v Y* [2018] UKSC 42

## 6.5 Nina, a patient with functional GI disorder / psychological illness

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Nina, a 23-year-old woman, is admitted with a chest infection. She weighs 38 kg (height 1.72 m, BMI 13 kg/m<sup>2</sup>). She says her weight is always low and she thinks she should weigh no more than 42 kg. She complains of episodic vomiting, abdominal distention/pain and constipation, and has not menstruated for 5 years. General medical and gastrointestinal investigations have not found a cause though she has been noted to be mildly hypermobile (Beighton score 5). It has become apparent that she eats very little. Nina takes analgesics (including opiates) and antiemetics (including cyclizine) at home. She says she sometimes gets confused and has complained of feeling 'down'. She wants to go home to finish her course of antibiotics. How should she be treated?

### Key questions to consider

#### 1. What are the risks of having a BMI of less than 13 kg/m<sup>2</sup>? Could this be the cause of Nina's infection and of her cognitive decline?

This represents severe undernutrition and so she is at risk of all her organ systems failing resulting in an increased risk of infections, cardiovascular collapse, poor wound healing/pressure sores, mental impairment, anaemia and death. In the long-term she risks osteoporosis.<sup>108,5</sup> Due to her unpredictable oral intake and life-threatening situation CANH should be the first line of treatment. Her infection may be related to the undernutrition and will certainly be exacerbated by it. Malnutrition impairs cerebral function and is associated with depression. Treating her malnutrition may improve her mood.

#### 2. Should Nina be 'sectioned' to receive treatment?

It is likely from her history that Nina has an eating disorder in addition to a gastrointestinal disorder. If she is adamant she will not have CANH then she should be seen urgently by a psychiatrist specialising in eating disorders. It is possible for her to be detained under the Mental Health Act 1983 ('sectioned') and CANH provided as a medical treatment for her mental health symptoms, if her refusal to accept CANH is a manifestation of her mental health problem.<sup>109</sup> However, case-law now suggests that the better approach is to go to the Court of Protection for determination as to whether she has capacity to make decisions on eating and drinking and, if not, it may be in her best interests to provide force-feeding.<sup>c</sup>

#### 3. Is Nina's hypermobility relevant?

There are increasing numbers of patients being recognised as having Ehlers-Danlos syndrome (EDS) hypermobility and this is often associated with abdominal symptoms including increased intestinal sensitivity giving rise to pain after eating. The symptoms are worse at times of psychosocial stress and can be aggravated by medication (especially opiates and cyclizine).<sup>110</sup> Despite an awareness of the association of hypermobility and abdominal pain, the management of malnutrition should follow that of any patient with intestinal dysmotility.

#### 4. Should Nina be given opiates for her abdominal pain and cyclizine for her nausea/vomiting?

Opiates can cause many of the features of intestinal dysmotility (especially distention and constipation) and with escalating or continuous opioid therapy may result in hyperanalgesia that presents as worsening abdominal pain (narcotic bowel syndrome).<sup>111</sup> Opioids may completely inhibit intestinal motility and so invalidate the tests of small bowel motility. Cyclizine, which has

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<sup>c</sup> See: *Cheshire and Wirral Partnership NHS Foundation Trust v Z* [2016] EWCOP 56

antihistamine and anti-cholinergic effects, is often used as a centrally acting anti-emetic. However, when given intravenously it has a euphoric effect and can cause addictive behaviour. In addition, cyclizine for injection has a low pH and so may damage veins.<sup>112</sup>

In the long term therefore, management opiates should be avoided and neuropathic type pain drugs used if needed. Cyclizine (especially intravenous) should be avoided.

#### **5. Is there a role for a gastrostomy tube in this instance? What needs to be considered when obtaining consent for the procedure (and who should be involved)?**

Nutritional support may be needed for a short time (months) to allow Nina to increase her BMI to an agreed safe level (eg 16 kg/m<sup>2</sup>). If oral intake including supplements is inadequate a nasogastric tube may be tried and failing that a nasojejunal tube. Occasionally if the nasal tube becomes frequently displaced a gastrostomy or jejunostomy may be needed to enable the patient's nutritional needs to be met.

#### **6. Is there a role for parenteral nutrition?**

Generally parenteral nutrition is avoided if there is sufficient functioning gut, though in rare circumstances it is given most commonly as a short-term measure to increase the BMI while avoiding the abdominal pain associated with oral/enteral feeding.

## **6.6 Priya, a patient with abdominal malignancy**

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Priya, a 56-year-old woman who had a rectal cancer removed 2 years previously, has malignant ascites and a nodular liver secondary to metastases. She vomits green fluid after any food and, while having a BMI of 21 kg/m<sup>2</sup>, she is clearly very wasted with her mid-arm muscle circumference (MAMC) below the 5th percentile.

Her vomiting is no better after 6 L ascitic fluid is drained. Priya's performance status has precluded even palliative chemotherapy and she is being supported by the specialist palliative care team. The oncologists predict that she will survive for 6 weeks at best. Is palliative home parenteral nutrition (HPN) an appropriate intervention?

### **Key questions to consider**

#### **1. What is the prognosis of abdominal malignancy with/without malnutrition?**

A person who is not malnourished may live without food for 2 months. However, without any fluid intake this may be 14 days. Someone who is already malnourished or dehydrated will survive for a much shorter time. If a patient has bowel obstruction and is given parenteral nutrition (including fluid) they will survive longer. They will not die of malnutrition or dehydration, but their death is likely to be secondary to tumour spread/bulk and the consequences of advanced malignancy. Malnutrition relating to inadequate intake due to bowel obstruction is reversible. However, malnutrition secondary to cancer cachexia is not reversible.

The modified Glasgow prognostic score combines an assessment of functional status with concurrent biochemical markers (albumin and C-reactive protein). It is often helpful in predicting the expected prognosis of patients with solid organ tumours.

Priya has very limited prognosis due to liver metastases and malignant ascites and therefore parenteral nutrition (PN) is less likely to be appropriate even for palliation.<sup>113</sup>

#### **2. When should HPN be offered?**

HPN should be considered in patients with malignant bowel obstruction that is not reversible with surgical intervention, and if vomiting still occurs on a liquid diet. It may be appropriate in patients



who are being considered for further oncological treatment and in those who are receiving palliative care, assuming: good performance status, expected survival of >3 months, and where the patient is keen to consider palliative PN as an option for treatment. Patients with a much shorter prognosis are unlikely to gain significant benefit from PN over and above the best supportive care. Initiation on PN risks delays to safe or timely discharge to the patient's preferred place of death and exposes the patient to undue risk of complication without benefit.

When assessing a patient for palliative PN, a full discussion with the patient and family is important to outline the key potential risks/benefits of treatment with palliative PN. All decisions should be made as part of a multiprofessional discussion in conjunction with the patient's wishes.

### 3. Is there a role for a venting gastrostomy tube?

If there is persistent vomiting due to bowel obstruction, a large diameter gastrostomy tube can be inserted to drain the stomach contents and avoid the need for a large bore NG tube. However, a venting gastrostomy tube (usually a venting gastrostomy tube) can block easily (especially if any solid food is consumed) and pain, leakage and infection at the exit site are common.

In patients with widespread omental and or peritoneal deposits additional risks include bleeding and tumour growth along the tract and these risks may outweigh the benefits of a venting gastrostomy insertion. An intravenous proton pump inhibitor can reduce the volume of gastric fluid (usually 2 L/day when taking food) and so the amount of vomiting and/or the output from a venting gastrostomy.

## 6.7 Guiding decision making: a summary

There is often no simple or easy answer to ethical dilemmas surrounding how and whether to support eating and drinking with clinical assistance. Table 5 includes a summary of the key elements to help guide these decisions.

**Table 5: Areas to guide decision making**

Area	Key points
Assessment	<ul style="list-style-type: none"> <li>&gt; A complete medical assessment is needed, preferably by a physician experienced in nutrition support. A medically led nutrition support team often includes all the required skills and is most experienced in coordinating the discussions. An understanding of the prognosis of the underlying condition (with and without CANH) and the mechanism of the impaired oral intake will inform these discussions.</li> </ul>
Communication	<ul style="list-style-type: none"> <li>&gt; Good communication with patients, relatives, carers, healthcare workers and advocates is essential, both to keep them informed and to discuss difficulties in emotional and contentious areas.</li> <li>&gt; Verbal and written language should be clear and unambiguous.</li> </ul>
Time	<ul style="list-style-type: none"> <li>&gt; Adequate time is required for discussion and for decisions to be made effectively. Rushed and poorly informed discussion will lead to unhappy patients and relatives.</li> </ul>
Capacity and best interests	<ul style="list-style-type: none"> <li>&gt; The patient's capacity must be determined and, if they lack capacity to make the relevant decision, all actions must be taken in their best interests.</li> </ul>
Care	<ul style="list-style-type: none"> <li>&gt; Good nursing care that includes attention to mouth care and oral nutrition/hydration will improve outcomes.</li> <li>&gt; There should be trained staff available to pass a nasogastric feeding tube safely when required (certainly in hospitals).</li> </ul>

<b>Oral intake</b>	<ul style="list-style-type: none"><li>&gt; Food and fluid orally have value beyond biological usefulness and should always be offered.</li><li>&gt; Patients should always have oral foods and fluids available to them, modified in consistency if necessary.</li><li>&gt; Small quantities of fluid can improve mental alertness.</li><li>&gt; Dietitians and speech and language therapists can help in supporting this approach.</li></ul>
<b>End of life</b>	<ul style="list-style-type: none"><li>&gt; Most palliative medicine physicians believe that to force fluid into a dying patient does not relieve thirst or hunger as these are not usually felt towards the end of life.</li><li>&gt; Tube feeding is therefore rarely required at this stage.</li></ul>
<b>Technical skills</b>	<ul style="list-style-type: none"><li>&gt; Technical understanding and skills are essential for the nutrition support team so that they can advise on which methods of CANH are appropriate in individual cases.</li><li>&gt; The exact prescriptions of feed should be made by experienced dietitians.</li></ul>

# Glossary

**advance decision** – a decision someone can make while they have capacity to refuse a specific type of treatment at some time in the future. Also known as an advance decision to refuse treatment (ADRT) or a living will

**advance statement** – a written statement that sets down preferences, wishes, beliefs and values regarding future care

**clinically assisted nutrition and hydration (CANH)** – used for people who cannot eat or drink. It involves different types of tube feeding, including nasogastric, gastrostomy and parenteral nutrition

**Deprivation of Liberty Safeguards (DoLS)** – a set of checks that aims to make sure that any care that restricts a person’s liberty is both appropriate and in their best interests. They apply in care homes and hospitals and will be replaced by the Liberty Protection Safeguards from April 2022

**end of life** – used to describe people with advanced, progressive, incurable conditions, those with general frailty and co-existing conditions who are likely to die within the next 12 months (General Medical Council, 2010)

**fiberoptic endoscopic evaluation of swallowing (FEES)** – a test which allows swallowing to be assessed using an endoscope

**gastrostomy** – a flexible feeding tube placed through the abdominal wall and into the stomach to allow nutrition, hydration and medication to bypass the mouth and oesophagus

**Gillick competence** – children under 16 should be regarded as able to make the decision if they are believed to have enough understanding and intelligence to fully appreciate what’s involved in their treatment

**independent mental capacity advocate (IMCA)** – a legal safeguard introduced by the Mental Capacity Act 2005 for people who lack the capacity to make specific important decisions

**Liberty Protection Safeguards** – will replace the Deprivation of Liberty Safeguards (DoLS) from April 2022 in England and Wales

**malnutrition** – a state of undernutrition in which a deficiency or excess (or imbalance) of energy, protein and other nutrients causes measurable adverse effects on tissue / body form (body shape, size and composition) and function and clinical outcome

**‘MUST’** – malnutrition universal screening tool

**palliative care** – an approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO)

**prolonged disorder of consciousness (PDOC)** – someone who remains unconscious for more than 4 weeks in either a vegetative state or minimally conscious state

**oral nutrition support** – the modification of food and fluid by fortifying food to increase its content of energy, protein, vitamins and minerals; the provision of snacks and/or oral nutritional supplements in addition to fortified meals; changing meal patterns or the provision of dietary advice to patients on how to increase overall nutrition intake by the above

**oral nutritional supplements (ONS)** – liquids, semi-solids or powders, which provide macronutrients (protein, energy, fats, carbohydrates) and micronutrients (vitamins, minerals and trace elements). They are widely used within the acute and community health settings for individuals who are unable to meet their nutritional requirements through oral diet alone but guidance about how and when to use them can differ between acute and community settings. Those endorsed by the Advisory Committee on Borderline Substances (ACBS) they can be prescribed in the community at NHS expense for the specific indications approved by ACBS

**specialist palliative care teams** – professionals working in partnership in both inpatient and outpatient settings within hospices, secondary care settings such as acute hospitals and in the community, eg homes, care homes and nursing homes

**SLT** – speech and language therapist

**videofluoroscopy** – uses video to record an X-ray examination of swallowing in real time to assess swallowing ability and allow a detailed study of any problems

## Declaration of interests

Any conflicts of interest were fully declared and are available from the RCP. A 'declaration of interests' form was completed by all working party members who were also reminded of the need to disclose any potential new conflicts of interest as these arose.

In summary, none of the working party members has any personal financial interest in the recommendations put forward in this guidance.

- > Nicola Burch is a member of the British Association for Parenteral and Enteral Nutrition (BAPEN) Medical Committee and the RCP representative on the Royal College of Speech and Language Therapists 'Feeding at Risk' Advisory Group.
- > Aminda De Silva is a member of the British Society of Gastroenterologists and BAPEN. He has accepted honoraria from several different pharmaceutical companies for attendance at medical conferences as well as for speaking / chairing symposia engagements.
- > Chris Danbury is chair of the Legal and Ethical Policy Unit of the Faculty of Intensive Care Medicine and sits on the Royal College of Anaesthetists Ethics Committee.
- > Dr Simon Gabe is a member of the NHS England clinical cell related to parenteral nutrition, BAPEN and the British Society of Gastroenterology.
- > Anne Holdoway has received honoraria for speaking engagements from Nutricia Ltd, Danone, Abbott Nutrition, and Fresenius-Kabi, and an unrestricted educational grant from Nutricia to support the work of the 'Managing disease-related adult malnutrition in the community' national expert panel and fund a website for a number of commercial organisations. All work is related to nutrition, diet and nutrition support in chronic disease.
- > Jeremy Nightingale is chair of the British Intestinal Failure Alliance (BIFA) and co-chair of the Nightingale Trust for Nutritional Support. He is chair of the adjudication committee for a phase III efficacy and safety trial of apraglutide (VectivBio AG).
- > Andrew Rochford is regional clinical director for NHS England and Improvement (Emergency Care Improvement Support Team) and a member of the Executive Board and Council of BAPEN.
- > Trevor Smith is president and chair of the Board of Trustees of BAPEN.
- > All other contributors have no interests to declare.

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This guidance updates the previous *Oral feeding difficulties and dilemmas* published in 2010. It aims to guide healthcare professionals supporting people with nutrition and hydration, particularly towards the end of life.

An inability to eat and drink can be devastating to patients and their families and can be a significant source of anxiety and distress. Decisions about nutrition and hydration are some of the most challenging to make in medical practice.

The guidance covers the factors affecting our ability to eat and drink, techniques of artificial feeding, and the legal and ethical aspects of giving and withholding treatment. It aims to support healthcare professionals to work together with patients, their families and carers to make decisions around nutrition that are in the best interests of the patient.

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