Artificial Nutrition and Hydration Difficulties and Dilemmas LEGAL & ETHICAL GUIDELINES FOR ADULT PATIENTS

Reference No: CG-T/2024/138

Introduction

Nutrition is essential to life. If it becomes difficult for someone to eat and drink, malnutrition and dehydration are possible consequences. Every effort should be made, where appropriate, by healthcare professionals to maintain nutrition and hydration, sometimes using artificial means.

In many situations, the decision to provide nutritional support is clear, particularly for those patients with potentially reversible medical conditions. However, for certain patients the decision to provide nutritional support may be less clear, or differences of opinion may emerge between patients, relatives, or health care professionals.

This is a guide, to assist with decision making regarding artificial nutrition and hydration where there are difficulties, dilemmas, or disagreements. This guide accords with the advice of the General Medical Council, Royal College Physicians and the law in England and Wales as of October 2022. Each case should be considered individually.

Current Legal Definitions and Points of Good Practice

Artificial nutrition and hydration

This is legally viewed as medical treatment and not basic care. Thus, there is no obligation to provide artificial nutrition and hydration when it would be futile.

Withdrawing and withholding artificial nutrition and hydration

There is no legal difference between withdrawing or withholding artificial nutrition and hydration. There is no obligation to continue feeding a patient, when their wishes or health change and artificial nutrition and hydration is no longer providing a benefit to the patient, simply because the treatment has been started. Similarly, artificial nutrition and hydration should not be withheld where it may benefit the patient, purely to avoid the possibility of having to stop treatment later.

Assessment of capacity

The assessment of capacity needs to be time and decision specific. If you doubt the patients capacity to consent to ANH the 2 stage assessment of capacity needs to be completed.

Stage 1: Functional test of capacity. The patient needs to demonstrate that they are able to:
1: Understand all relevant information about the decision to be made
2: be able to retain this information long enough to be able to make this decision
3: use or weigh that information as part of the decision-making process
4: communicate their decision (in any way that are able to)
Stage 2: Diagnostic test: Does the person have an impairment of, or a disturbance in the functioning of the mind or brain.

- This may be a temporary issue and not a longstanding impairment. Eg. When under the influence of drugs/alcohol.

Is this impairment causing the inability to make this decision (causative nexus).

The capacity assessment regarding the decision of ANH should be completed by the medical team that are proposing this line of treatment. This should be documented on the correct paperwork/Consent form. This can be found on Net-i or there are copies on each of the wards.

Adults who have capacity
If the patient is an adult who has capacity, they retain the right to consent to or refuse artificial nutrition and/or hydration.

Patients who lack capacity
If a patient is deemed to lack capacity the next two principles of the capacity act come into play.

- An act done, or decision made, under this act or on behalf of a persons who lacks capacity must be done or made in their best interests.
- The option that is opted for has to be the less restrictive option out of the available options.

Prior to starting the best interest process the managing team will need to ascertain if there has been any legal decision maker assigned to the patient such as:

- ADRT - Advanced decision to refuse treatment - these will need to be specific for the decision related to the use of artificial nutrition.
- LPA - Lasting power of attorney for health and welfare.
- Court appointed deputy.

These are all legal documents/agreements that would need to be seen by the medical team and filed in patients' medical notes.

If there aren't any legal decision makers for this patient the best interest process will need completing. The decision maker will be the managing medical consultant.
The managing medical team will need to do this collaboratively with family/friends and other health professionals involved in the patients care. For example: Speech and language therapy, dieticians.

This will involve ensuring the patients past and present wishes are taken in to account and their beliefs and values. Where possible the patient should still be involved in the best interest process.

If a patient is classed as unbefriended and has no family or friends to act on their behalf, they should be referred for an Independent Mental Capacity Advocate to support them with this decision. This service can also be utilised if the patient is estranged from all family or there are any safeguarding concerns regarding the family.

In a situation where there is a disagreement in what would be in the patient's best interests. The consultant should seek a second opinion from a colleague, ideally from a different speciality and liaise with the trusts legal team. Importantly, for an adult patient without capacity who is NOT expected to die imminently, a decision NOT to provide Artificial Nutrition Hydration (which would otherwise be required) MUST be supported by a second opinion, including an examination of the patient, ideally by a consultant from a different speciality. The hospital Clinical Nutrition Team and Clinical Ethics Committee are available to discuss difficult issues. In some cases, this may need to go to the court of protection and a Deprivation of liberty may need to be considered.

Documentation

All conversations (including telephone calls) should be documented in the medical notes, including the overall decision along with a summary of the factors informing that decision. Where patients undergo naso-gastric tube feeding or are referred for PEG insertion, the aim and proposed benefit of feeding should be clearly stated in the medical notes. If there is uncertainty regarding the benefit, feeding should be commenced for a timed trial period only, with subsequent review. This should be clearly identified in the medical notes**.**

Informing relatives of decisions

If feeding is to be commenced for a timed trial period and may be stopped if no benefit is demonstrated at the end of the trial, the family and carers should be informed of these facts before feeding is started. This will prepare the family/carer for later discussions.

Subsequent review of the decision

Artificial nutrition and hydration should be reviewed periodically and if the identified aims / benefits are not being met the decision regarding continued feeding should be discussed. The decision should be reviewed in the light of changing clinical circumstances or the emergence of further information about the patient's own wishes. This should apply to all artificially fed patients including those who undertake their Enteral feeding at home but have an admission into hospital**.**

Limitations of artificial nutrition and hydration (ANH)

ANH is invaluable in preventing malnutrition however there are limitations:

- It does not affect the prognosis from terminal malignancy or dementia, and in these circumstances will not prolong life, and in certain circumstances may shorten life.
- It does not prevent aspiration pneumonia.
- On its own it does not prevent the development of pressure sores.

It is a medical treatment and carries risks as well as discomfort to the patient. Its provision in palliative care patients is often futile and should be carefully considered.

Key points for specific clinical conditions

Stroke

When assessment indicates that swallowing is unsafe, the need for a timed trial of artificial nutrition must be assessed. If the patient's condition indicates that they might not survive the first 48 hours post-stroke it is wise to adopt a "wait and see approach". This approach requires the medical team to reassess the patient daily before considering commencement of nasogastric tube feeding. It also requires frequent clear communication/documentation of rationale to family and multidisciplinary team especially the nurses caring for the patient.

In all other cases of stroke with unsafe swallow, nasogastric tube feeding should be commenced immediately. After a minimum of 2 weeks nasogastric tube feeding, the MDT should discuss whether tube feeding is likely to be required for the medium to long term (greater than 4 weeks) if this is the case, referral to the Nutrition Nurse Specialists for assessment for a Gastrostomy feeding tube should made.

Dementia

Patients with advanced dementia frequently develop oral feeding problems, weight loss and an increased risk of aspiration. Artificial feeding should not generally be used in this group of patients for whom dysphagia and/or disinclination to eat is a manifestation of disease severity. This is often a late event, associated with the final phase of the illness.

Best practice in these patients might be:

- Discussion of possible oral feeding difficulties in the future and education on ANH with personal wishes documented.
- Assessment by a consultant physician and speech and language therapy (SLT) before admission to a nursing home.
- For patients with an 'unsafe swallow' altering the consistencies, e.g., thickening fluids, may make feeding manageable and preserve quality of life. A decision may be made to allow unlimited oral intake as tolerated or feeding at risk.
- Ongoing assessment and support of oral nutrition and hydration with progressive modification of diet and fluids.
- Completion of feeding at risk documentation where appropriate.

Persistent vegetative state

Enteral tube feeding may be lawfully withdrawn in certain circumstances. In practice a court declaration should be obtained.

Neurological disease

This includes conditions such as Multiple Sclerosis, Parkinson's disease, Motor Neurone Disease, Head Injury, Cerebral Palsy and Huntington's disease.

These patients and/or their families may have discussed the issues relating to artificial nutrition at an early stage of their illness with a doctor and/or specialist for the disease. There is a clear difference between an early isolated swallowing problem that may require a gastrostomy and problems at the end stage of disease, which may not benefit from nutritional intervention. Previously held views of the patient/relatives should be considered. If swallowing issues are likely to occur as the disease progresses, these should be addressed and plans made for intervention in a timely manner, before the end stage of the disease is reached. This should be coordinated by the parent specialist team with nutrition nurse and/or team involvement at an early stage of the disease.

Palliative care

Food and fluid orally have value beyond biological usefulness and should always be offered but palliative care physicians believe that to force fluid into a dying patient does not relieve suffering. Any nutritional support, enteral or parental would have to be carefully considered on an individual basis, with clear benefits versus the burden/risks of supported nutrition.

Mental health disorders (e.g., Anorexia Nervosa)

Management of these diseases requires close liaison with mental health services and/or eating disorders team and appropriate use of the mental health act.

References & further reading

Department of Health (2005). Mental Capacity Act. London, HMSO.

General Medical Council (GMC), Treatment and care towards the end of life: good practice in decision-making, General Medical Council, London, 2022.

Lennard-Jones JE. Ethical and Legal Aspects of Clinical Hydration and Nutritional Support. Maidenhead: BAPEN 2012.

NICE guidelines no.42 Dementia: Supporting people with Dementia and their carers in health and social care. www.nice.org.uk/GC042NICEguidelines

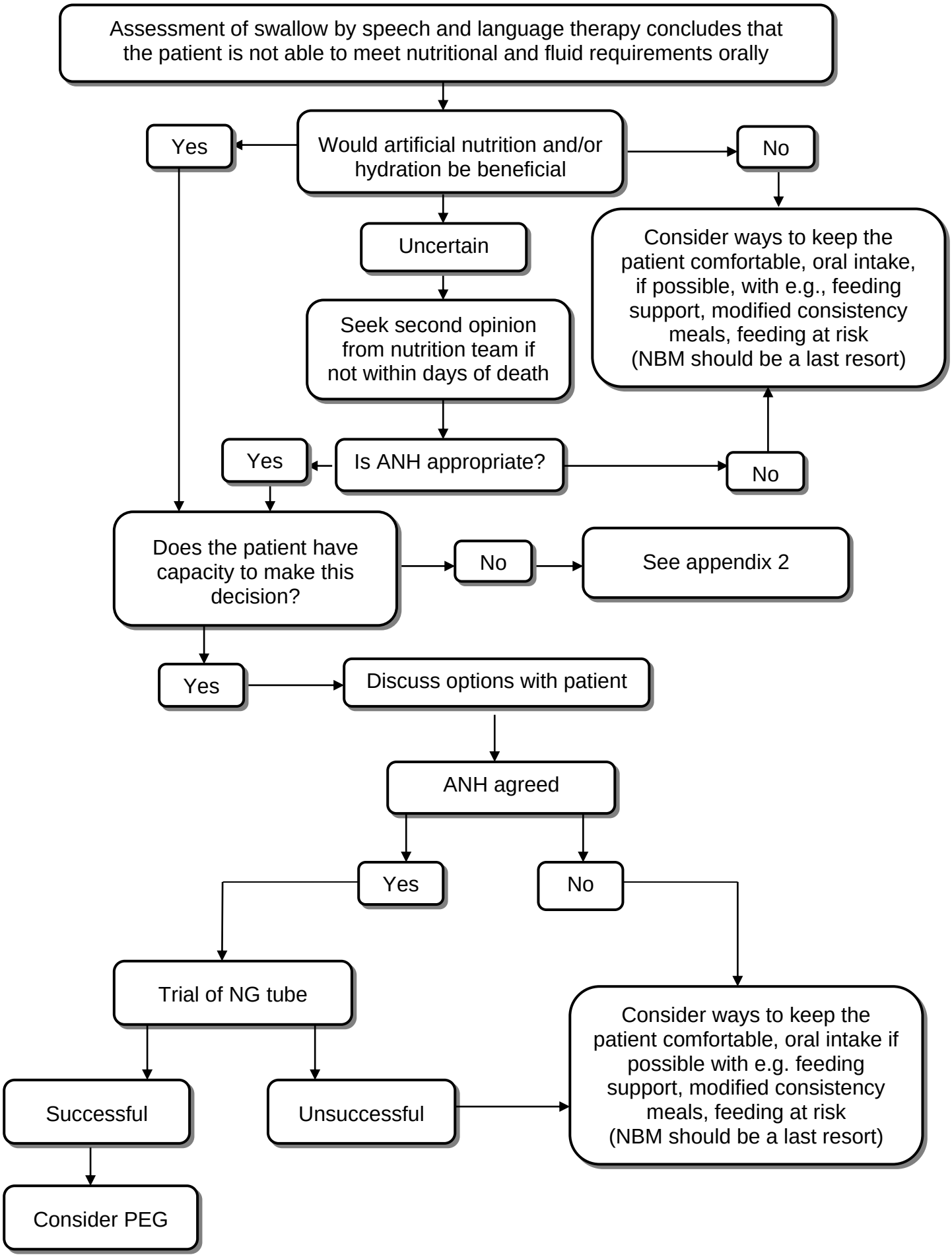
NICE guidelines no.32 Nutrition Support for Adults Oral Nutritional Support, Enteral Tube Feeding and Parenteral Nutrition, www.nice.org.uk/CG032NICEguidelines.

Royal College Physicians. Oral feeding difficulties and dilemmas. A guide to practical care, particularly towards the end of life. 2021

http://www.dca.gov.uk/menincap/legis.htm

Development of Guideline	Nutrition Team
Consultation with:	Nutrition Steering Group Vulnerable people and safeguarding (MCA)
Approved By:	Nutrition team
Approval Date:	Nutrition Steering Group - March 2024 Medicine Division – June 2024
Review Date:	June 2027
Key Contact;	Lead Nutrition Nurse Specialist

Assessment and decision making



Appendix 2

Patients who lack capacity to make an informed decision