Ethics and clinically assisted nutrition or hydration approaching the end of life – Decision Tree

1. **Patient is unable to meet nutritional and fluid requirements orally**

2. **Patient, family, carers or medical team raise the question of clinically assisted nutrition or hydration**

   - **Yes**
     - **Does patient have the capacity to comprehend and retain the information material to the decision of receiving clinically assisted nutrition or hydration? Does the patient understand the consequences of having/not having the treatment?** (The Mental Capacity Act, 2005 and GMC guidance Consent: patients and doctors making decisions together, 2008 provide information on assessment of capacity).
     - **Yes**
       - **A discussion is required between relevant, capable parties, such as the MDT, the patient, family and/or carers, considering:**
         - What is the emotional and medical condition of the patient?
         - What are the benefits, burdens and risks of providing nutrition and hydration through artificial means?
         - What are the goals of care?
         - Will the patient give consent to have artificial nutrition and hydration?
         - All cases must be considered on an individual basis. See references 1 and 3 for further information.

   - **No**
     - **Consider ways to keep patient comfortable. Can the patient take anything orally (perhaps with altered texture) for example? Keeping the patient nil by mouth should be a last resort. See p74 of ref 1 for further information.**

   - **No**
     - **Has the patient written a relevant advance directive?**
       - **Yes**
         - **Apply advanced directive**
       - **No**
         - **Investigate the following:**
           - Has the patient ever expressed his/her wishes verbally to family/friends?
           - Has the patient appointed someone with lasting power of attorney for health matters?
           - Is there an Independent Mental capacity Advocate (IMCA)?
         - **A doctor is required to provide treatment and care in the patient’s best interests but should not provide futile treatments.**

---

The BAPEN Principles of Good Nutritional Practice (Decision Trees) have been prepared to assist health care professionals in the decision making processes surrounding nutritional care. Users of these materials may only do so on the condition that they exercise their own professional knowledge and skills. BAPEN does not owe a duty of care and cannot accept liability to anyone using these Decision Trees.
Ethics and clinically assisted nutrition or hydration approaching the end of life –

Key Points

- Nutrition and hydration provided by tube or drip are regarded in law as medical treatment, and should be treated in the same way as other medical interventions.\textsuperscript{3}
- There is no ethical or legal distinction between withholding and withdrawing treatment. However, compared with the withholding of nutrition support, the withdrawal of treatment may cause more emotional distress for HCPs, patients and carers.\textsuperscript{4}
- Patients can not insist on an inappropriate treatment, but can refuse treatments.\textsuperscript{1}
- Relatives can assent but not consent on behalf of a patient lacking mental capacity. It is the doctors duty to make a decision based on full discussion with all interested parties.\textsuperscript{1}
- Healthcare professionals that may be involved in the care of patients approaching the end of life include doctors, speech and language therapists, dietitians, specialist nurses (such as Nutrition Nurses; MacMillian Nurses) and the palliative care team.

Patients with Capacity:\textsuperscript{3}

Offer the patient treatments you consider to be clinically appropriate because, for example they would provide symptom relief. Explain to the patient the benefits, burdens and risks associated with the treatments, so that the patient can make a decision about whether to accept them.

If you assess that clinically assisted nutrition or hydration would not be clinically appropriate, you must monitor the patient’s condition and reassess the benefits, burdens and risks of providing clinically assisted nutrition or hydration as the patient’s condition changes. If a patient asks you to provide nutrition or hydration by tube or drip, you should discuss the issues with the patient and explore the reasons for their request. You must reassess the benefits, burdens and risks of providing the treatment requested.

When the benefits, burdens and risks are finely balanced, the patient’s request will usually be the deciding factor. However, if after discussion you still consider that the treatment would not be clinically appropriate, you do not have to provide it. But you should explain your reasons to the patient and explain any other options that are available, including the option to seek a second opinion.

Adult patients who lack capacity & are not expected to die within hours/days:\textsuperscript{3}

If a patient is in the end stage of disease, but death is not expected within hours/days, you must provide clinically assisted nutrition or hydration if it would be of overall benefit, taking into account the patient’s beliefs and values, any previous request for nutrition or hydration by tube or drip. The patient’s request must be given weight and, when the benefits, burdens and risks are finely balanced, will usually be the deciding factor.

If you judge that providing clinically assisted nutrition or hydration would not be of overall benefit to the patient, you may conclude that the treatment should not be started at that time or should be withdrawn. You should explain your view to the patient, if appropriate, and those close to them. In these circumstances you must make sure that the patient’s interests have been thoroughly considered. This means you must take all reasonable steps to get a second opinion from a senior clinician who has experience of the patient’s condition but who is not directly involved in the patient’s care. If this is not possible for practical reasons, you must still get advice from a colleague. You should also consider seeking legal advice.

If you reach a consensus that clinically assisted nutrition or hydration would not be of overall benefit to the patient and the treatment is withdrawn or not started, you must make sure that the patient is kept comfortable. You must monitor the patient’s condition and be prepared to reassess the benefits, burdens and risks of providing clinically assisted nutrition or hydration in light of changes in their condition.

If clinically assisted nutrition or hydration is started or reinstated after a later assessment, and you subsequently conclude that it would not be of overall benefit to continue with the treatment, you must seek a second opinion (or, if this is not possible, seek advice) as above.
Adult patients who lack capacity and are expected to die within hours or days:

If a patient is expected to die within hours or days, and you consider that the burdens or risks of providing clinically assisted nutrition or hydration outweigh the benefits they are likely to bring, it will not usually be appropriate to start or continue treatment. You must consider the patient’s needs for nutrition and hydration separately.

If a patient has previously requested that nutrition or hydration be provided until their death, or those close to the patient are sure that this is what the patient wanted, the patient’s wishes must be given weight and, when the benefits, burdens and risks are finely balanced, will usually be the deciding factor.

You must keep the patient’s condition under review, especially if they live longer than you expected. If this is the case, you must reassess the benefits, burdens and risks of providing clinically assisted nutrition or hydration, as the patient’s condition changes.

Please note that if you are considering withdrawing nutrition or hydration from a patient in PVS or a condition closely resembling PVS, the courts in England, Wales and Northern Ireland currently require that you approach them for a ruling.

The courts in Scotland have not specified such a requirement, but you should seek legal advice on whether a court ruling may be necessary in an individual case.
1. Royal College of Physicians and British Society of Gastroenterology: Oral feeding difficulties and dilemmas towards the end of life: London, Royal College of Physicians, 2010

Further Reading

● MCPCIL: Liverpool Care Pathway for the Dying Patient [homepage on the internet]. Available at: http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/