Nutrition and hydration in palliative care

ABSTRACT

Anorexia, weight loss and muscle wasting commonly affect people approaching the end of life. It is critical that clinicians caring for people with advanced illness and progressive frailty can assess the nutritional and hydration needs of these people, engage them in shared decision making and support them to plan ahead regarding their nutritional care preferences as their health deteriorates.

Table 1. Recognition of malnutrition

Malnutrition can be defined by any of the following:	■ Body mass index of less than 18.5 kg/m^2 ■ Unintentional weight loss greater than 10% within the last 3–6 months ■ Body mass index of less than 20 kg/m^2 and unintentional weight loss greater than 5% within the last 3–6 months
Those at risk have:	■ Eaten little or nothing for more than 5 days and/or are likely to eat little or nothing for 5 days or longer ■ A poor absorptive capacity and/or high nutrient losses and/or increased nutritional needs from causes such as catabolism

Food and drink are essential for survival and play a significant part in multiple aspects of everyday life. Consequentially, anorexia, weight loss and sarcopenia are highly visible and distressing reminders of the impact of life-limiting illness on health and wellbeing. Given this multifaceted and fundamental role it is not surprising that decisions concerning nutrition and hydration therapy can be challenging and distressing for all involved (del Río et al, 2012). Compounding this are the concerns that dying patients have historically been denied access to food and drink (Neuberger et al, 2013), and the paucity of rigorous studies available to guide decision making (Good et al, 2014a,b).

Patients requiring palliative care have a diverse range of conditions, prognoses and goals. Decisions regarding nutrition and hydration will vary accordingly, from patients living with neurological conditions considering a gastrostomy to decision making about subcutaneous fluid therapy as someone dies. While the evidence base and expertise underpinning decision making are condition- and situation-specific a set of principles founded upon shared, informed and individualized care planning are globally relevant. Essential components of planning care are (Leadership Alliance for Care of Dying People, 2014; Druml et al, 2016):

- Thorough assessment of the cause(s) of reduced oral nutrition and hydration, the potential for correcting the underlying disorder, and the likely prognosis of the underlying condition(s)
- Exploration of the patient's and carers' priorities, preferences, concerns and expectations
- Expert multidisciplinary support including dieticians, speech and language therapists, and specialist feeding teams as required
- Candid communication about the benefits, burdens and uncertainty associated with interventions
- Agreement of realistic goals
- Regular clinical review
- Effective sharing of plans across care settings.

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Disease-related malnutrition

Malnutrition arising from a 'lack of intake or uptake of nutrition that leads to altered body composition (decreased fat free mass) and body cell mass leading to diminished physical and mental function and impaired clinical outcome' commonly affects people approaching the end of life as a result of multiple co-existent mechanisms (Cederholm et al, 2017).

Patients with or at risk of malnutrition can be identified via clinical parameters (*Table 1*) (National Institute for Health and Care Excellence, 2017). While serum albumin levels are commonly used in clinical practice there is robust evidence that albumin is neither a specific nor sensitive indicator of nutritional status (Banh, 2006).

Management of malnutrition

Minimizing the impact of disease-related malnutrition requires a multi-modal approach addressing the catabolic inflammatory processes triggered by severe chronic illness alongside other physical (*Table 2*), socioeconomic and psychological barriers to nutrition including reduced income, social isolation, self-neglect and depression (Cederholm et al, 2017).

Disease-related malnutrition with inflammation, or cachexia, is a common feature of progressive illness (*Table 3*) (Farkas et al, 2013). It is characterized by complex inflammatory processes that lead to anorexia, weight loss and muscle catabolism (Cederholm et al, 2017). Cachexia progresses through the three stages below and cannot be fully reversed by conventional nutritional therapy. This is not always well understood by patients, relatives and

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clinicians who may believe that 'increasing food and liquid intake is essential to stave off physical deterioration' (del Río et al 2012; Blum et al, 2014).

- Pre-cachexia (group I): weight loss >1 kg but <5%
- Cachexia (group II): weight loss >5% in the last 6 months, or weight loss >2% in the last 6 months and body mass index <20 kg/m^2
- Refractory cachexia (group III): weight loss >15% in the last 6 months and body mass index <23 kg/m^2 or weight loss >20% in the last 6 months and body mass index <27 kg/m^2.

Given its complex nature, therapies targeting a single aspect of the syndrome, such as appetite stimulants (glucocorticoids, megesterol acetate) for anorexia, do not consistently achieve improved muscle mass and function and expose people to unwanted side effects (Wong et al, 2018). It is thought that early multi-component interventions are most likely to delay the onset and progression of cachexia (Solheim et al, 2017). A number of interventions combining anamorelin, nutritional support, exercise, anti-inflammatories, omega (n-3) polyunsaturated fatty acids, appetite stimulants and thalidomide show promise but require further research (Dev et al, 2017; Solheim et al, 2017; Advani et al, 2018; Khatib et al, 2018).

Nutrition care and therapy

Nutrition care and therapy encompasses a range of interventions:

- Promoting a positive meal environment: protected mealtimes, appropriate food options, a positive social atmosphere
- Eating support: ensuring food and drink are accessible, e.g. position of table, use of adapted implements, physical assistance with feeding
- Therapeutic diets: modified and/or fortified food
- Medical nutrition therapy: oral supplements, clinically assisted nutrition and hydration.

Clinically assisted nutrition and hydration comprises parenteral nutrition or hydration via a intravenous or subcutaneous route (hypodermoclysis) and enteral nutrition or hydration by nasal or oral feeding tubes or by tubes inserted through a stoma in the abdominal wall.

Clinically assisted nutrition

The National Institute for Health and Care Excellence recommends that patients who are malnourished or at risk of malnourishment and have inadequate or unsafe oral intake should be considered for:

- Enteral tube feeding if the patient has a functional, accessible gastrointestinal tract
- Parenteral nutrition if there is a non-functional, inaccessible or perforated gastrointestinal tract (National Institute for Health and Care Excellence, 2017).

In the context of advanced illness it is vital to establish the patient's nutritional goals – what is insufficient to prolong life may still provide comfort. The evidence base supporting

Table 2. Non-inflammatory factors contributing to disease-related malnutrition and management

Cause	Management
Reduced nutritional intake as a result of nausea and vomiting	■ Correct underlying cause if possible, e.g. constipation, hypercalcaemia ■ Anti-emetics
Odynophagia (painful swallowing) as a result of: ■ oropharyngeal or oesophageal candidiasis and other infections ■ chemotherapy- or radiotherapy-induced mucositis	■ Antifungal treatment topical or systematic ■ Analgesia, e.g. paracetamol and aspirin gargles, non-steroidal anti-inflammatory drugs, oral or parenteral opioids, oral local anaesthetic (mucaine equivalent) ■ Coating agents, e.g. sucralfate or Gelclair ■ Treatment of secondary infection
Dysgeusia (altered taste sensation)	■ Zinc supplementation ■ Lactoferrin
Xerostomia (dry mouth)	■ Oral lubricants, e.g. oral balance gel ■ Mouth care ■ Humidification of oxygen ■ Avoid alcohol-based mouth washes or medication ■ Reduce xerogenic medication burden, e.g. anticholinergic, diuretics ■ Cholinergic-mimetic medication, e.g. pilocarpine
Gastrointestinal dysmotility	■ Prokinetics, e.g. metoclopramide
Constipation	■ Laxatives ■ Peripherally-acting opioid receptor antagonists for opioid-induced constipation ■ Review of constipating medication, e.g. anticholinergic drugs, opioids, ondansetron
Ascites	■ Drainage
Gastrointestinal obstruction	■ Surgery if appropriate ■ Stenting if appropriate
Oropharyngeal dysfunction as a result of neurological dysfunction: dysphagia dystussia, atussia	■ Postural manoeuvres ■ Exercise programmes
Other uncontrolled symptoms, e.g. pain, breathlessness	■ Targeted symptom management

Table 3. Prevalence of cachexia in selected illnesses

Disease	Prevalence (%)
Cancer	28–57
Chronic heart failure	16–42
Chronic kidney disease	30–60
Chronic obstructive pulmonary disease	27–35
Rheumatoid arthritis	18–67
HIV/AIDS	10–35

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decision making is limited and there is currently no 'gold standard' approach for assessing and identifying patients at risk of poor outcomes with clinically assisted nutrition (Goldberg and Altman, 2014; Llop-Talaveron et al, 2018).

However, studies suggest that biochemical evidence of systemic inflammation, principally elevated levels of C-reactive protein and low levels of albumin, are associated with increased morbidity and mortality across disease groups (Suzuki et al, 2010; Drinkwater et al, 2017; Keane et al, 2018; Llop-Talaveron et al, 2018; Wong et al, 2018). Consideration of inflammatory markers alongside other condition-specific factors may facilitate patient selection and inform decision making.

Cancer

In patients with cancer receiving parenteral nutrition, impaired physical function (Karnofsky Performance Scale of less than 50%) and an elevated Glasgow prognostic score, based on reduced albumin and raised C-reactive protein levels, are associated with reduced survival. Guidelines advise a predicted survival of 8–12 weeks for consideration of parenteral nutrition and studies describe median survival within this range (Naghibi et al, 2015; Keane et al, 2018). The limited evidence regarding quality of life suggests there may be early improvements but by the last 6 months of life quality of life deteriorates back to or below baseline (Naghibi et al, 2015).

Dementia

The evidence concerning gastrostomy feeding is limited to cohort studies and case series. It shows no overall survival advantage, with mortality at 30 days between 13 and 54% and mortality at 1 year between 45 and 61% (Goldberg and Altman, 2014). A 2009 review of enteral tube feeding found no studies that examined quality of life and there was no evidence of benefit in terms of nutritional status or the prevalence of pressure ulcers (Sampson et al, 2009). A systematic review of tube feeding among elderly care home residents found no benefits regarding body mass index, albumin, or dietary protein, calorie and fat intake (Lan et al, 2017).

Motor neurone disease or amyotrophic lateral sclerosis

A 2011 Cochrane review of enteral tube feeding found no randomized controlled trials. Improved survival with feeding was reported in four of the 11 non-randomized studies comparing life expectancy. Both studies assessing body mass index showed benefit with feeding, while neither study assessing quality of life did (Katzberg and Benetar, 2011). A study of 345 patients found no significant difference in quality of life after gastrostomy. While a quarter of patients gained more than 1 kg in weight 49% lost that by 3 months post gastrostomy (ProGas Study Group, 2015).

In this group higher $PaCO_2$ and complete aphagia before gastrostomy and a shorter hiatus between onset of symptoms (<20 months) and insertion are associated with worse survival (Nagashima et al, 2017). Guidelines recommend that tube feeding should be considered at an early stage and at regular intervals with insertion occurring before onset of severe weight loss and respiratory impairment (Burgos et al, 2018).

Other neurological disease

Oropharyngeal dysphagia is a common feature of progressive neurological disorders including up to 80% of those with Parkinson's disease and over a third of those with multiple sclerosis. Despite this a review found no research evidence to guide decision making about enteral tube feeding in either condition (Stavroulakis and McDermott, 2016).

Dehydration

Dehydration is a 'complex condition resulting from a reduction in total body water' caused by insufficient fluid intake (water loss dehydration) in which the water deficit exceeds solute deficit and/or solute loss in equal or greater proportion to fluid associated with diarrhoea, vomiting, diuresis and blood loss (salt loss dehydration) (Hooper et al, 2014).

The elderly are particularly at risk of water loss dehydration as a result of physiological changes including:

- Diminished muscle mass (the key bodily fluid reserve)
- Reduced ability to concentrate urine
- Diminished thirst.

This may be compounded by functional, behavioural and social factors including:

- Intentionally reduced drinking to reduce micturition, the risk of incontinence or the need for toileting assistance
- Ability to physically access drinks
- Isolation with reduced social stimulus for drinking (Hooper et al, 2014).

Assessing hydration status

There is no consensus regarding the optimum approach for assessing hydration. Serum osmolality is a common reference standard for water loss dehydration as is an elevated blood urea:creatinine ratio in the absence of hypertonicity for salt loss dehydration. The evidence base supporting this is limited. Urea:creatinine ratio may also be raised in renal failure, heart failure and sarcopenia (Hooper et al, 2015).

Clinical signs and bedside tests including urine specific gravity and colour, orthostatic hypotension, skin turgor, capillary refill, dry mouth, sunken eyes, thirst and headache are not consistently reliable markers of hydration, particularly in elderly patients (Hooper et al, 2015).

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Table 4. Clinical markers of dehydration or risk of dehydration
Water loss dehydration: missing drinks between meals, subjective fatigue, reduced drinks intake, raised urine osmolality, reduced axillary moisture, bioelectrical impedance analysis resistance at 50 kHz at 450 Ohms
Water or salt loss dehydration: salivary osmolality
Salt loss dehydration: low systolic blood pressure (<100 mmHg)

Reviews have identified a limited evidence base to guide non-invasive assessment of patients with or at risk of dehydration. Potentially useful markers have been identified (*Table 4*) (Fortes et al, 2015; Hooper et al, 2015).

Accepting the difficulty in assessing hydration, especially in a palliative context where blood tests may be deemed excessively invasive, it is likely that a significant number of patients are at risk of dehydration. Studies suggest that 20–30% of elderly care home residents are dehydrated, with this figure being higher in those with cognitive impairment (Hooper et al, 2015).

Managing dehydration

Where there is no functional or mechanical obstruction to drinking, oral fluid intake should be supported. However, the optimal way of doing so is unclear. A review of environmental and behavioural interventions in care homes found little useful evidence. Multi-component strategies involving enhanced choice and availability of beverages, increased staff awareness, and greater assistance with drinking and toileting, may be effective (Abdelhamid et al, 2016).

When behavioural and environmental approaches prove insufficient, clinically assisted hydration should be considered and the approach to hydration agreed with patients and their families.

Clinically assisted hydration in the last days of life

Proposed benefits of clinically assisted hydration for dying patients include life prolongation and reduced xerostomia, thirst, delirium, fatigue and myoclonus. The impact of modifying hydration in addition to treatment addressing other causative factors is difficult to predict (Good et al, 2014a). In a study of patients with advanced cancer, thirst was associated with unmanaged symptoms such as vomiting and stomatitis, as much as it was associated with biochemically defined dehydration (low atrial natriuretic peptide levels or high serum osmolality) (Morita et al, 2001). In healthy subjects gargling cold water for 2 minutes reduced thirst for up to 30 minutes without altering hydration (Arai et al, 2013).

The decision-making challenge is compounded by uncertainty regarding patient selection, fluid volume, and the route and rate of administration. A Cochrane review identified 'insufficient good-quality studies' to inform practice (Good et al, 2014a). The highest quality randomized controlled trial (Bruera et al, 2013) compared 129 patients with advanced cancer randomized to 1000 ml or 100 ml of subcutaneous fluid per day. Although median survival was longer in the hydration group (21 *vs* 15 days) this was not significant. There were no significant differences across a broad range of symptom scores. This study was underpowered, and excluded severely dehydrated patients. It did not dose fluid therapy by the patient's weight, which a recent feasibility study by Davies et al (2018) suggests may be a more effective way of prescribing fluid. However, the latter study was not designed to compare clinical outcomes and cannot be used as the basis for treatment recommendations (Davies et al, 2018).

One observational study of patients with gastrointestinal cancers found that pleural effusions, peripheral oedema and ascites, but not respiratory secretions, were significantly higher with clinically assisted hydration, suggesting that parenteral fluid may exacerbate symptoms of extravascular fluid accumulation in at-risk patients (Morita et al, 2005; Good et al, 2014a). If a dying patient has conditions that strongly predispose to fluid overload, such as heart or renal failure, or symptoms related to fluid accumulation, the balance of benefits and harms is likely to weigh in favour of withholding clinically assisted hydration.

Subcutaneous fluid therapy

Subcutaneous hydration is a suitable alternative for patients who do not require fluid resuscitation, correction of severe electrolyte abnormalities or high potassium concentrations; greater then 40 mmol/litre may cause tissue necrosis. (Caccialanza et al, 2018). Hypodermoclysis is less likely to be associated with insertion failure and dislodgement, agitation and local infection than intravenous fluid. However, erythema, oedema and swelling are more common (Ker et al, 2015).

Both 0.9% saline and 5% dextrose can be administered subcutaneously at 250 ml/hour, up to 2 litres/day, to areas of adequate subcutaneous tissue. The back, chest, thighs and abdomen are optimum infusion sites provided they are not affected by oedema, under-perfusion, skin compromise or infection. Although not established practice, subcutaneous administration may be a safe and effective route for nutritional support (Caccialanza et al, 2018).

Ethicolegal considerations

Clinically assisted nutrition and hydration are distinguished from other forms of nutritional care as they entail an invasive procedure, bypass physiological regulation of hunger and thirst, and require clinical supervision (Department of Constitutional Affairs, 2007). This distinction underpins legal and ethical approaches that regard clinically assisted nutrition and hydration as medical treatment and assistance with eating and drinking as basic care. It is indefensible to withhold basic care from a patient who wants to eat and drink, and can do so

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safely and comfortably with help. This applies as much to patients in the last days of life as it does to those who are not dying.

Some patients with an unsafe swallow may choose to eat and drink at risk, for others lacking capacity doing so may be in their best interests. In both instances the patient, those close to them and people providing direct care should be provided with a plan and guidance (*Table 5*). Thorough documentation and effective sharing of the plan is critical to ensure that it is implemented by care professionals across care settings (Sommerville et al, 2017).

Accepting the distinction between medical treatment and basic care, the decision-making principles common to all medical interventions apply to clinically assisted nutrition and hydration (*Table 6*) (General Medical Council, 2010). Until very recently the withdrawal of clinically assisted nutrition and hydration from patients with prolonged disorders of consciousness (permanent vegetative and minimally conscious states) had an additional safeguard, requiring approval from the Court of Protection in all cases. In July 2018 the Supreme Court ruled that routine application to the court is not necessary provided all parties involved agree that withdrawal is in a person's best interests (An NHS Trust and other, 2018).

Not all patients, families, clinicians or ethicists recognize the distinction between clinically assisted nutrition and hydration and assisted oral intake. Withdrawal of or withholding tube feeding may be perceived as morally equivalent to denying someone who can eat and drink access to food and fluid (General Medical Council, 2010; del Río et al, 2012).

Table 5. Components of a feeding at risk plan

A clear explanation of the risks (choking, aspiration pneumonia or pneumonitis)	
Guidance on how to minimize the risks	
A treatment escalation and symptom management plan including:	■ How to manage choking ■ Whether to initiate or withhold antibiotics in the event of pneumonia ■ Whether to initiate or avoid hospital admission ■ Who and when to contact for support

Moreover, clinically assisted nutrition and hydration covers a range of interventions, the benefits and burdens of which vary in both nature and degree. The decision not to insert a new gastrostomy is distinct from the decision to stop administering food or fluid via an existing gastrostomy that has been the patient's main source of nutrition and hydration for years. Decisions about the provision of clinically assisted nutrition and clinically assisted hydration must be considered separately, and the interventions that constitute clinically assisted nutrition and hydration are appraised on an intervention by intervention basis (General Medical Council, 2010).

As with other medical interventions, patients, families and legal proxies do not have a right to access clinically assisted nutrition and hydration if it is of no benefit. Given the challenges in assessing nutrition and hydration and the paucity of evidence to guide practice, there is often significant uncertainty regarding the balance of benefits and burdens.

Table 6. Clinically assisted nutrition and hydration decision-making principles

Clinically assisted nutrition and hydration should be withdrawn or withheld if:	■ A patient with mental capacity declines it (even if it may be of clinical benefit) ■ It offers no clinical benefit (it is an ineffective treatment) ■ The clinical benefits are outweighed by the treatment burdens, hence clinically assisted nutrition and hydration is not in a patient's best interests
Patients, their families and legal proxies do not have a legal right to access clinically assisted nutrition and hydration that is of no clinical benefit or not in a patient's best interests	
In the event of a dispute a second opinion should be offered	
If a patient lacks capacity and has no legal proxy or advanced decision to refuse treatment it is the multidisciplinary team's responsibility to make a best interests decision about clinically assisted nutrition and hydration	
In making a best interests decision the multidisciplinary team must:	■ Consult with those close to a patient who can inform this decision or an independent advocate if there is no-one to consult with ■ Consider the benefits and burdens of clinically assisted nutrition and hydration from a holistic perspective, not only those viewed from the clinical perspective of symptom palliation and life prolongation
Advanced decisions to refuse treatment can specify a legally binding refusal of clinically assisted nutrition and hydration but not a refusal of assistance with eating and drinking, consistent with the general principle that they cannot be used to refuse basic care	
Patients with mental capacity who have an unsafe swallow can choose to eat and/or drink despite the risk. Clinical teams should provide information regarding the associated risks of aspiration and how to minimize them, and the benefits and burdens of alternative methods of nutrition and hydration	
Eating and drinking at risk may be in the best interests of someone who lacks the mental capacity provided he/she derives pleasure or benefit from eating and drinking. This outweighs any discomfort or harm, and comfort and quality of life are prioritized over prolongation of life	

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KEY POINTS

- Impaired oral nutrition and hydration are foreseeable complications of advanced illness.
- Advance care planning should include clinically assisted nutrition and hydration to allow patients the opportunity to consider, discuss, document and share their preferences to support future decision making.
- The role of clinically assisted hydration and clinically assisted nutrition and the benefits and burdens of different interventions should be considered separately.
- Sensitive communication with patients and families is critical to ensure they appreciate the pros and cons of clinically assisted nutrition and hydration and any uncertainty, enabling them to participate in shared decision making and understand the rationale for any clinical decisions.
- Patents should be supported to eat and drink for as long as they are able to do so comfortably, up to and including the last hours to days of life.

Where there is genuine clinical equipoise, and the patient has requested that nutrition or hydration be provided until death, or those close to the patient maintain that this is what he/she would have wanted, guidelines advise starting a therapeutic trial of clinically assisted nutrition and hydration. Further assessment may provide clearer evidence regarding benefit and harm. If you have agreed to a therapeutic trial of clinically assisted nutrition and hydration it is important to establish with both the patient and those close to the patient how the treatment will be monitored and reviewed, and under what circumstances it would be withdrawn (General Medical Council, 2010).

Such equipoise is more likely to arise when considering the role of peripheral intravenous or subcutaneous hydration and continued use of an established enteral feeding tube, as the risk of harm is less than for initiation of clinically assisted nutrition and hydration through a new enteral tube or long-term intravenous device. This is especially the case in dying patients, as these patients are more vulnerable to harm, and assessment of the potential benefit is more difficult as their consciousness declines.

Planning ahead

For patients with conditions such as dementia, progressive neurological disorders or inoperable bowel obstruction, the failure to maintain adequate oral nutrition and hydration is foreseeable and may occur before the patient enters the last hours to days of life. For all patients with life-limiting illness it is probable that the ability to eat and drink will be impaired as the patient starts to die.

As the failure of oral nutrition and hydration is anticipated, patients should be offered early opportunities to discuss what approach they would like to take if and when that happens. This may prepare the patient and family for decision making in the moment, allow them to share their views and document their preferences in advance care plans, statements and advance decisions to refuse treatment. This planning is particularly important for people whose condition may impair their mental capacity by the time they lose their ability to eat and drink.

Conclusions

People approaching the end of their lives are at risk of malnutrition and dehydration. It is important that multidisciplinary teams, supported by specialist services, routinely assess patients' nutritional and hydration needs, optimize nutritional support, and address potentially treatable conditions affecting nutritional intake. Nonetheless anorexia, weight loss and sarcopenia are common, and ultimately irreversible, features of end stage treatment-refractory disease. It is important to discuss this with patients and those close to them, acknowledging the uncertainty regarding the benefit of clinically assisted nutrition and hydration. Doing so before the onset of significant nutritional compromise and while patients have mental capacity maximizes the opportunity to initiate clinically assisted nutrition and hydration while patients are fit enough to benefit, and to consider, document and share their preferences to support decision making in the future. This may go some way to minimizing the complexity of and distress arising from decision making about clinically assisted nutrition and hydration at the end of life. **BJHM**

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