

## **Nutrition and Hydration in End of Life Care**

Nutrition and hydration in relation to end of life care can be divided into two related components: 'Meeting patients' nutrition and hydration' and 'clinically assisted nutrition and hydration'. In both of these components it is paramount to ensure that the patient and the family (or those who matter to the person) are at the centre of care planning and delivery.

- **Meeting nutrition and hydration needs: The patient and the family**
- Eating and drinking is a normal part of daily living which often takes place as a social activity in addition to the provision of nourishment, hydration and comfort. It is recognised that oral intake of both food and fluids can diminish significantly at end of life, combined with weight loss and muscular weakness. This often takes place in the context of anorexia-cachexia syndrome (Del Rio et al, 2012).
- The complex syndrome known as Cachexia can occur in many chronic diseases and can present challenges. Internationally there is a consensus that Cachexia 'is characterised by progressive lean muscle loss (with or without fat loss) that cannot be reversed by conventional nutritional therapy. The muscle loss is caused by multifactorial, metabolic abnormalities, particularly in protein and energy balances because of the underlying illness' (Fearon et al, 2011).
- Research has focused mainly on cancer cachexia and more exploration is needed of the effect of this symptom on other chronic diseases.
- Cachexia can occur in different stages dependant on how the person is clinically and their circumstances: pre-cachexia, cachexia and refractory cachexia (Radbruch et al, 2010). At all stages an impeccable assessment needs to be carried out to determine functional or anatomical barriers within the gastro-intestinal tract, or symptoms such as breathlessness or incident pain affecting the

person's ability to eat (Radbruch et al 2010). All patients, regardless of setting, should have equal access to appropriate assessment and management of cachexia.

- Refractory cachexia is where reversal of weight loss seems no longer possible due to advanced progressive disease and here the burden and risks of artificial nutrition are likely to be greater than the benefits (Radbruch et al, 2010). It is here that care needs to have emphasis on alleviation of the suffering linked with cachexia, such as good symptom management with appetite stimulation, where appropriate, and treatment of nausea and vomiting (Radbruch et al, 2010). Good palliative and end-of-life care are key and all patients should be able to benefit from the palliative care approach which has an emphasis on the 'whole person' and their physical, social, emotional and spiritual needs. Care given to patients and families should recognise the holistic impact of cachexia (Reid, 2014).
- It is important that time and support are given to relieve any eating-related distress of patients and their families. Research has shown that with cachexia the accompanying symptom of anorexia can cause distress, tension and arguments among patients and their family carers, the latter who have a desire to promote food for the person's survival without understanding the futility (Reid et al, 2009).
- It is important to support family members through the transition of being able to let go of their felt responsibility to provide food to their loved one who is dying. Through the provision of appropriate information and education family members can be gently brought to an understanding that loss of appetite and desire for food is part of the disease and deterioration process.

### **Case Scenario 1**

A seventy-five year old man with end stage Carcinoma of the Lung is being cared for at home by his daughter. He is deteriorating and is thought to be the last weeks of his life. His daughter Ann is distressed as her father is reluctant to eat and does not appear to have any interest in food that she prepares for him. She feels that her father is getting thinner and weaker and that she would love to see him eating properly again. The Community Palliative Care Nurse Specialist is involved and

spends some time with Ann discussing this issue. She explains to Ann that what is happening is a loss of appetite which is part of the natural disease process. The nurse also provides Ann with some information leaflets to further explain this process and the role that family members can play at this stage. On the next visit the Community Palliative Care Nurse Specialist finds that Ann is more relaxed about her father not eating and appears to better understand what is happening.

- European experts strongly support the use of counselling to help patients and families to understand the changes taking place due to the disease, the difference between cachexia and 'starving to death', the limitations of nutrition and what can be improved (Radbruch et al ,2010). A recent study of bereaved relatives found that they had limited communication from healthcare professionals around their family member's oral intake at end of life (Raijmakers et al, 2013). There is also evidence that patients can welcome the opportunity to take part in decision making around artificial hydration (Malio and Bennett, 2011). Misperceptions can also exist between patients, their family members and healthcare professionals which need to be considered in decisions about nutrition and hydration (Del Rio et al, 2012).
- Active listening, empathising and using open ended questions encourage expression of anxieties and preferences from patients and families and thus professionals can provide information and support in an appropriate way to meet their needs. Where a patient or family member has special needs, such as a learning disability or sensory disability, or English is not their first language then professionals will need to adapt their communication and facilitate communication to and from the person throughout the care process in an accessible way. Working closely with those familiar to and with the person can be helpful. 'The Hospital Communication Book' see ([www.pah.nhs.uk/files/Hospital%20communication%20Book%2023%2006%2011](http://www.pah.nhs.uk/files/Hospital%20communication%20Book%2023%2006%2011)) or other accessible resources can be found at [www.breakingbadnews.org](http://www.breakingbadnews.org)
- Knowing how a patient will feel when they can no longer swallow to eat and drink can cause a lot of anxiety to friends, relatives and

staff. The importance of not having a blanket policy, but to assess each individual situation is imperative.

- Care planning and ensuring effective co-ordination of care across services and settings is essential. Discussion and consensus on realistic goals with the patient and family, in addition to the interdisciplinary team, is of great importance.

***Other points below still to be elaborated on:***

‘The aims of nutritional support will change as the disease progresses’ (Watson et al, 2009,p.765).

-Role of dietician

-Relaxing dietary restriction may be appropriate for example where someone is a diabetic

-Challenges of maintaining nutrition and hydration status at end of life V best interests. Site re: signs of dehydration NHS Choices [www.nhs.uk/conditions/dehydration](http://www.nhs.uk/conditions/dehydration)

-Regular assessment of swallowing ability

-Position of person to eat and drink

- **Other Helpful Tips Relevant to Nutrition and Hydration Needs**

1) Use of pureed food moulds to shape food to look like normal meal

2) Presentation techniques (small portions, garnish, balanced colourful presentation, correct temperature of food, help with eating/ drinking, providing time in allowing the person to eat slowly and relax after eating, flexibility of meal times as person discerns)

3) Create a pleasant environment for meals, where possible

4) Allow the person to eat little and often-small meals or snacks or take aways, if desired

5) A small glass of alcohol, if permitted, may be a useful stimulant

6) Involve family or those familiar to the person to help establish the person’s likes and dislikes and eat with them, where appropriate

7) Ensure respect for cultural and religious beliefs during food

selection, preparation and service

- 8) Use of teaspoon of fresh water, use of syringe filled with fresh water and ice cup wrapped in gauze where someone is profoundly weak in last days of life
- 7) Good regular mouth care before and following nutrition intake
- 8) Some foods may aggravate certain symptoms such as a sore mouth, nausea or vomiting or diarrhoea and should be avoided. (See Watson et al (2009) pages 766-767)

- **Clinically assisted nutrition and hydration: The patient and the family**

*Still to be done*

*To include vignettes*

*To make reference to recent Cochrane Reviews by Good et al and other literature including that from the review by Bazian*

- **Ethics and Decision Making**

Decisions about assisted nutrition and hydration measures should be made with the support of the multi-disciplinary team in partnership with the person and those who matter to them, where possible. The following are questions which can be considered in this decision making process:

- 1) Are the patient's wishes known
- 2) How will artificial hydration or/and nutrition benefit the patient?
- 3) Is eating and drinking normally causing the patient discomfort?
- 4) Is the patient keen or able to continue eating and drinking?
- 5) Have the risks and discomforts linked with artificial nutrition and hydration been considered? (Watson et al, 2009)

## References

Del Rio MI, Shand B, Bonati P, et al. Hydration and nutrition at the end of life: a systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff. *Psycho Oncology*. 2012;21(9):913-21.

Fearon, K., Stasser, F., Anker, SD., Bosaeus, I., Bruera, E., Fainsinger, RL., Baracos, VE (2011) Definition and classification of cancer cachexia: an international consensus. *Lancet Oncology* 12, 489-495. doi:10.1016/S1470-2045(10)70218-7

Malia C, Bennett MI. What influences patients' decisions on artificial hydration at the end of life? A Q-methodology study. *J Pain Symptom Manage*. 2011;42(2):192-201.

Radbruch, L., Elsner, F., Trottenberg, P., Strasser, F., Fearon, K (2010) *Clinical practice guidelines on cancer cachexia in advanced cancer patients*. Aachen Department of Palliative Medicine: European Palliative Care Research Collaborative

Raijmakers NJ, Clark JB, van Zuylen L, et al. Bereaved relatives' perspectives of the patient's oral intake towards the end of life: a qualitative study. *Palliat Med*. 2013;27(7):665-72.

Reid, J., McKenna, H., Fitzsimmons, D., McCance, T (2009) Fighting over food: patient and family understanding of cancer cachexia. *Oncology Nursing Forum* 36 (4), 439-445.

Reid, J (2014) Psychosocial, educational and communicative interventions for patients with cachexia and their family carers. *Current Opinion in Supportive and Palliative Care* Vol 8 (4), 334-338

Watson et al (2009)