

Role of nutrition in the final stages of palliative care

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This article examines and summarises the role of nutrition and the dietitian in the final stages of palliative care. The recent publication of *One chance to get it right* (NHS England, 2014), highlighted the need for a change in the approach to food and drink, especially when caring for those patients who are at the end of life. There is a clear need for documentation and formulation of clear, patient-centred and effective care plans, as it is vital that food and drink are offered, as long as it remains safe and is not harmful to the patient.

KEYWORDS:

■ Palliative care ■ Nutrition ■ Community nurses' experience

The National Institute for Health and Care Excellence (NICE, 2004) defined palliative care as:

... the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

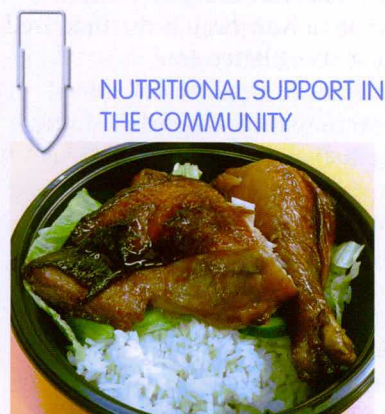
Traditionally, the discussion about the role of nutrition in palliative care has been based on ethics, focusing on the withdrawal of food and fluids especially in regard to enteral nutrition. In recent years, in the author's clinical experience,

healthcare professionals have become more aware and responsive to patients presenting with, and who are distressed by, the presence of symptoms that affect their ability to eat 'normally', i.e:

- ▶ Dysphagia (changes in swallowing mechanism due to cognitive changes or disease progression, e.g. upper gastrointestinal [GI] tumours)
- ▶ Taste changes (side-effects of medication or residual symptoms from previous treatment, e.g. chemotherapy)
- ▶ Xerostomia (dry mouth)
- ▶ Dementia (changes in cognition may result in patient not identifying food and drink, reduced interest in food and drink, pocketing food and refusal of food and drink).

Deterioration and alteration in nutritional intake often promotes weight loss, is accompanied by fatigue and results in a distressing alteration in body image for both the patient and their families (Tan and Fearon, 2008; McIntyre, 2009).

However, the evidence base for nutrition within palliative care is lacking and it would be naïve not to appreciate the difficulties, which



Within the NHS, the approach and management of palliative care is changing in response to a national review of the Liverpool Care Pathway and the publication of 'One chance to get it right' in June of this year by the Leadership Alliance for the Care of Dying People (NHS England, 2014). The push to move care closer to home and ensure the right care is delivered at the right time has resulted in more complex patients and a greater need for palliative care to take place in the community, which inevitably involves addressing the patient's nutritional needs.

include ethical approval to conduct studies examining the outcome of nutritional support within palliative care. Therefore, the challenge for healthcare professionals is to strike a balance between the evidence base and the practical nutritional needs of the individual patient.

The role of dietitians within the palliative care setting is to help identify and address nutritional factors that are affecting the patient's quality of life. Another aspect of their role is to support other healthcare professionals, and family members and carers, who are working with the patient on a frequent basis, as well as to help

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them with expectations of nutritional intervention and care plans, e.g. oral nutrition support supplements or enteral nutrition. However, in the first instance, nutritional concerns of a palliative care patient are often addressed by the community nurse dealing with the patient and their family on a day-to-day basis.

Although this article examines the role of nutrition in the final stages of palliative care, it is important to note the role of nutrition within the earlier stages of palliative care. Here, the focus of nutritional intervention is often to promote weight gain or maintain weight with an increase in total calorie and protein intake, whereas as the patient progresses into the later stages, the focus shifts to improved quality of life and symptom improvement. It is important that nutrition is addressed in the early stages of diagnosis with a life-limiting disease, so that patients do not enter the terminal stages of their illness nutritionally depleted (Eldridge and Gandy, 2014).

CHANGES TO NUTRITIONAL STATUS FROM DISEASE PROGRESSION

Within palliative care, nutrition has an important psychological, spiritual, social and cultural role (Eldridge and Gandy, 2014). Hughes and Neal (2008) identified that loss of appetite is a complex phenomenon involving the whole person — physical, social, emotional and spiritual. It centres not just on the patient, but the family surrounding that patient. Eating is a large part of people's lives, offering patients and their families a sense of normality. It can therefore result in feelings of fear and despair when a patient begins to struggle with their dietary intake. From practice, we are aware that progressive illness can result in changes to nutritional status due to a multitude of factors (Eldridge and Gandy, 2014), e.g.

- ▶ Medication can result in unpleasant side-effects, e.g. morphine-based pain relief can slow gastric transit resulting in constipation. Similarly, opioid and narcotic pain relief

Table 1: Dietary advice for symptoms of a palliative condition (Manual of Dietetic Practice, 2014)

Symptom	Dietary advice
Poor appetite	<ul style="list-style-type: none"> ▶ Encourage small and often, choosing high calorie foods in small portions, at least four to five times daily ▶ Focus on favourite foods, or those found most enjoyable ▶ Be flexible with meal pattern, e.g. rice pudding for breakfast if found enjoyable ▶ Eat with family or friends ▶ Consider appetite stimulants, e.g. low-dose steroids, small amount of alcohol
Sore mouth	<ul style="list-style-type: none"> ▶ Avoid use of spices, salt or acidic flavours ▶ Eat soft moist foods ▶ Cold food is often more soothing
Dry mouth (xerostomia)	<ul style="list-style-type: none"> ▶ Frequent sips of water or nourishing drinks, e.g. milk, malt drink, hot chocolate, milky coffee ▶ Suck ice cubes or ice lollies ▶ Citrus flavoured sweets/boiled sweets ▶ Consider artificial saliva
Taste changes	<ul style="list-style-type: none"> ▶ Encourage patient to identify problematic food and substitute with a nutritionally similar food, e.g. soft drink/milkshake in place of tea or coffee, chicken or turkey in place of red meat ▶ Add extra spices or herbs to food when cooking ▶ If metallic taste — consider rinsing mouth with lemon/lime juice (provided mouth is not sore or ulcerated)
Belching or excess wind	<ul style="list-style-type: none"> ▶ Avoid fizzy drinks and brassica vegetables (broccoli, cauliflower, beans, peas, onion and Brussels sprouts) ▶ Eat slowly to reduce amount of air ingested and keep mouth shut when chewing
Constipation	<ul style="list-style-type: none"> ▶ Medical intervention for laxatives ▶ Increase fluid intake — choose nourishing fluids, e.g. milk-based drink ▶ Speak with dietitian if considering high-fibre approach, as may compromise reduced appetite further
Diarrhoea	<ul style="list-style-type: none"> ▶ Establish cause — infective/non-infective ▶ Consider anti-diarrhoeal treatment ▶ Encourage patient to avoid restricting diet unnecessarily

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- medications can result in drowsiness and increased periods of sleep
- ▶ Worsening symptoms and disease progression can result in fatigue, dysphagia or gastrointestinal symptoms, which can make the physical task of eating difficult and uncomfortable
- ▶ The psychological effect of receiving a diagnosis of an incurable progressive illness

is profound. This can lead to feelings of anxiety, depression and feelings of anger (Barraclough, 1997). Within the dietetic profession, it has been noted that this can result in changes to appetite and dietary intake

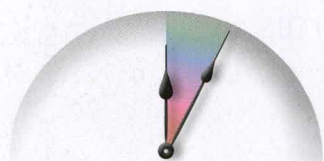
- ▶ The disease may result in increased nutritional requirements, i.e. pyrexia, infection, chest infections due to aspiration or nutritional losses, e.g. high output stoma, fistula and/or malabsorption
- ▶ During the final phase of the illness, the body may respond with declined gastric emptying, digestion and peristalsis which will be distressing for both the patient and their family and naturally reduce desire and tolerance to food and drink.

DIETARY ADVICE

It is vital that healthcare professionals support patients to be realistic with their expectations of nutrition and weight during all stages of palliative care. The goal of nutritional intervention, especially in the late stage of palliative care, should never centre on weight gain or reversal of weight loss. It should focus on quality of life, including comfort, symptom relief and enjoyment of food (Carey, 2000).

Hopkinson et al (2011) suggested that nutritional counselling should involve the use of nutrition-dense foods, finding food which the patient enjoys, and considering symptoms, emotional adaptation to illness and social circumstances. Nutrition supplement drinks can be of benefit in patients who are struggling to eat. In the author's experience within the specialism of oral nutrition support supplement prescribing, families often see the supplement as holding greater benefit to the patient than food.

Hill and Hart reported in 2001 that often patients dislike the drinks and may feel guilty if unable to



Five-minute test

Answer the following questions about this article, either to test the new knowledge you have gained or to form part of your ongoing practice development portfolio.

- 1 – Can you list some first-line measures that improve dietary intake?
- 2 – What is the main aim of nutritional care for patients at the end of life?
- 3 – What factors in progressive illness cause changes to nutritional stages?
- 4 – What factors should be to discussed with patients and carers around refusal of meals and fluids?

tolerate them. Thus, in the author's opinion, it is important to instil a flexible approach to meal and snack times, with food being offered and encouraged but not forced. Strasser et al (2007) reported that forcing food on those who have no desire to eat and drink can cause distress. Similarly, Lennard-Jones (1998) stated that food should not be forced upon a patient where this can cause unavoidable choking or aspiration. Community nurses should therefore encourage simple measures which can often make a significant difference to dietary intake. *Table 1* outlines first-line dietary advice for nurses to consider with their patients.

For those patients who have previously altered their diet for health purposes, e.g. patients with diabetes, high cholesterol, or heart disease, consideration should be given to the appropriateness of continuing to follow this lifestyle approach. For example, the Diabetes UK Nutrition Working Group (2011) acknowledged that restrictions, especially in the advanced stages of palliative care, should be relaxed or even stopped. However, this needs to be done with reassurance and encouragement from healthcare professionals supporting the patient's care. During the latter stages of a palliative condition, priorities shift to symptom management and therefore alteration of drug regimens, e.g. insulin or oral hypoglycaemic agents may be required (Rowles et al, 2010).

Within a community setting, nurses may be familiar with the Malnutrition Universal Screening Tool (MUST, British Association for Parenteral and Enteral Nutrition [BAPEN], 2004). MUST is not validated for use with palliative care patients and currently there is no specific nutritional screening tool for this patient group. The use of screening tools and weighing of patients will vary from patient to patient and dependent on local policy. This will also depend on the stage of the condition — within early stages of palliative care it may be appropriate to measure weight, but, as the condition progresses, this may not be appropriate. It is

KEY POINTS

- In the first instance, nutritional concerns of a palliative care patient are often addressed by the community nurse dealing with the patient and their family on a day-to-day basis.
- Within palliative care, nutrition has an important psychological, spiritual, social and cultural role.
- Progressive illness can result in changes to nutritional status.
- The goal of nutritional intervention, especially in the late stage of palliative care, should never centre on weight gain or reversal of weight loss. It should focus on quality of life, including comfort, symptom relief and enjoyment of food.

therefore important that healthcare professionals are sensitive to changes in body composition and dietary intake as reported by the patient and/or their family and carers.

Poole and Froggatt (2002) reported that issues relating to nutrition, especially weight loss, can be more distressing to the family than the patient. It is important that community nurses are familiar with the community dietetic department within their locality and are able to approach the dietitian for support managing this patient group and discussing whether a referral to the dietitian is appropriate.

When discussing nutrition and palliative care, it is hard to navigate away from the ethical and legal elements which surround this topic. These elements are complex and multifactorial, including the initiation of enteral nutrition in the early stages to support nutrition management and then decision on withdrawal of this treatment in the later/end-of-life care of a patient. For example, in patients with head and neck cancer, enteral nutrition is often essential to support oncology treatments and maintain nutritional status as the ability to swallow is compromised. However, if their condition deteriorates or the disease

progresses, healthcare professionals can find it hard to withdraw, while family members find it difficult to accept that providing full nutritional requirements is not always to the benefit of the patient. The use of oral syringes to feed a patient actively refusing diet is another complex area, which often happens where capacity is compromised, e.g. dementia, Parkinson's disease. Thus, healthcare professionals need to consider the harm to the patient in regard to force feeding, compromised swallowing, risk of aspiration and pneumonia.

Oral nutrition and hydration are considered basic care, both ethically and legally, and should always be provided unless actively refused/declined by the patient. It is important that healthcare professionals explore with the patient the refusal of meals and fluids and document the discussion (General Medical Council [GMC], 2010).

This is important for community nurses working with advanced dementia patients within their own home and other settings, e.g. nursing or residential homes. Concerns regarding refusal of meals and fluids should be documented and discussed with family members and members of the multidisciplinary team. The discussion needs to acknowledge that meal and fluid refusal in the terminal/advanced stages of a palliative condition are often a part of the disease process, although patients should still be encouraged and supported to take meals and fluids where safe to do so.

Within the home, the giving and receiving of nourishment is a means of showing love and affection and therefore food refusal can cause tension and anxieties within the family unit (Hopkinson and Corner, 2006). It is paramount that patients, carers and loved ones are involved in discussion on nutrition and establishing realistic expectations, and that this discussion is clearly documented. However, it is also important that, where possible, specialist palliative care professionals discuss with the patient and family the progression of the disease and the symptoms and changes to expect.

CONCLUSION

Community nurses play an integral part in the management and support of patients with palliative conditions and their nutritional status. They should consider first-line dietary advice, focusing on symptom improvement and maximising quality of life. Referral to a dietitian should also be sought if additional support and education is needed for the patient and family. This is particularly so if dietary intake does not improve following food-first information, and also if a nutritional screening tool has identified the patient as being at high risk. It is important to remember that nutritional screening tools are not sensitive as a sole assessment

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for nutritional risk within this patient group. Additional aspects, such as visual appearance, social support network, current dietary intake and clinical condition and prognosis should also be considered when referring to the dietitian. **JCN**

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