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## **BAPEN Symposium 2: Nutrition in palliative care**

# **Food for life, love and hope: an exemplar of the philosophy of palliative care in action**

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The World Health Organization's (1990) definition of palliative care describes an holistic approach to care for patients with advanced progressive illness. Issues relating to nutrition, lack of appetite and the subsequent weight loss the individuals may experience present a challenge to all concerned with providing both formal and informal care to this patient group. The philosophy of palliative care requires a multidisciplinary approach to the constellation of issues and problems related to food that are faced by both patients and carers in receipt of palliative care. The literature in this area is mainly related to those patients with a cancer diagnosis. The developing role of palliative care in patients with non-malignant disease provides further challenges for health care professionals. The present paper aims to reflect an entire philosophical approach to care through an examination of one area of practice.

### **Palliative care: Philosophy of palliative care: Nutritional support**

Palliative care has been traditionally concerned with the delivery of care at the end of life. However, in recent years its value earlier in the care process has been recognised (NHS Executive, 1995), although the care of the dying remains central to the function of palliative care.

The World Health Organization's (1990) definition: 'the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families', makes it absolutely clear that this approach to care is one that pays equal attention to physical and non-physical issues in the pursuit of improved quality of life where the quantity of life is certain to be limited. It reflects what Dame Cicely Saunders (1998), the founder of St Christopher's Hospice, refers to as the 'indivisible entity' of the individual.

Palliative care developed as a consequence of the modern hospice movement, in which the development of best practice in the care of the dying is its *raison d'être*. The palliative care approach addresses life and death in equal measure in search of attaining the best quality of life

and the best quality of death that is possible. It is a philosophy of care that can be transferred to any care setting and is not confined by bricks and mortar. Over the past 40 years this approach has been reflected in the development of both community and acute hospital palliative care services as well as specialist palliative care in-patient and day-care units throughout the country. Symptom control is a priority, not because it inherently carries more weight, but because an individual in pain or experiencing intractable vomiting or severe breathlessness is rendered unable to address the social, psychological and spiritual business of their life. Good symptom control is paramount in order to allow the patient and carers to get the most out of the time left to them, to maximise their potential for living. It is also essential to support those surrounding the sick individual, the family and friends, in order to care for their future health both physical and psychological. These principles of practice underpin not only the practice of specialist palliative care professionals, who have undergone recognised specialist palliative care training and for whom the care of patients with advanced progressive illness is their core activity, but also represent

an integral part of the clinical practice of every health care professional (NHS Executive, 1996).

Food plays a central role in the life of everyone, a role that does not diminish with advanced progressive illness; although often in this situation food is perhaps more noted for its absence than for its presence. Anorexia and subsequent weight loss are widely reported in patients with advanced cancer (Addington-Hall & McCarthy, 1995), and may occur for a variety of reasons. They may occur as a result of the disease process itself, the subsequent treatment of the disease, as a result of metabolic disturbance or as a symptom of depression, itself a common and probably under-diagnosed symptom in this patient group. However, crucial to the management of anorexia and weight loss is an understanding of the context of these symptoms and their meaning both to patients and families.

Decision making around nutritional interventions must take into account the estimated prognosis. Different interventions will be appropriate for an individual with very advanced disease whose prognosis may be measured in short weeks compared with the patient whose remaining life may be measured in months and years.

Unexplained weight loss is often a key presenting symptom. Both patients and their carers come to associate weight loss with disease activity and recognise it as a poor prognostic indicator. It is only necessary to observe the anxieties that surround the monitoring of weight in the oncology outpatient clinic to understand the meaning attached to the numbers that appear on the scales. Anorexia and cachexia can lead to aesthenia, and this cluster of symptoms can be profoundly distressing to all concerned.

In a speciality that actively pursues improved quality of life all interventions with potential benefit should be considered. Palliative care has a reputation for perhaps being on the 'low tech-high touch' side of the care continuum, with a reputation for discontinuing intravenous infusions and other technical paraphernalia, and perhaps is viewed as being inherently opposed to such interventions. However, enteral tube feeding may be highly appropriate for selected patients whose quality of life may be markedly improved through the provision of nutritional requirements through this route. Patients with a diagnosis of head and neck cancers or oesophageal tumours and those with neuromuscular dysfunction are commonly considered for percutaneous endoscopic gastrostomy placement. However, such decisions must be made within the context of the patient's lifestyle, in full consultation and within an ethical framework that supports the patient's autonomy and in which expected benefits outweigh the risks. It is essential that the whole extended team, with the patient and the carer at the centre, is involved in the decision-making process. Palliative care professionals cannot make such decisions in isolation from their professional colleagues, because their knowledge of the context will be limited by their involvement later in the patient's illness. It is far easier to introduce a new therapeutic intervention than to withdraw it, and the best decisions are made through collaborative and cooperative working between specialities. The decision on when to stop feeding through a percutaneous endoscopic gastrostomy tube in the terminal phase of an illness can be a difficult one, since family members may perceive such

a withdrawal as hastening the process of dying. It is a situation that requires sensitive counselling and explanation. Once comatose, percutaneous endoscopic gastrostomy feeding can be ethically withdrawn from a patient on the basis of an extraordinary measure as, without the tube, feeding would not be possible (Keeley, 2002).

Twycross (1999) writes: '... palliative care is not intrinsically against medical technology. High tech investigations and treatments are used only when benefits clearly outweigh any potential burdens'. For these reasons parenteral nutrition is rarely used in the palliative care setting because of its associated risks and the lack of evidence to show it is of any benefit in end-stage disease. It also may limit future choices over place of care, since many hospices or specialist palliative care units are unable to technically support its administration.

Nutritional issues stir deep emotions for patients, carers and health care professionals. A malnourished patient may not be able to tolerate anti-tumour treatment and this situation in turn may lead to feelings of guilt. The concept of food and health are inextricably linked, particularly within the present diet-obsessed society. 'Being well' is equated with a healthy lifestyle that includes a healthy diet, including fruit, vegetables and low fat. How confusing it is to then be told by well-meaning professionals 'Have what you want when you want it' and to have a high-fat diet in order to access energy. The social impact of feeling unable to participate in mealtimes may have a profound impact on patients and carers alike. Mealtimes provide the rhythm for the day, and for many individuals they are the focus of social interaction. Many religious acts and festivals of many different faiths involve food celebration and serve as a reminder of the centrality of food in the lives of all individuals. An inability to participate can leave individuals feeling disconnected from those they love and isolated from the world. The impact of weight loss may profoundly affect a sense of identity and an ability to see oneself as a sexual being.

The principles of symptom control, core to the practice of palliative care, advise the establishment of the underlying cause of the problem and its treatment wherever possible. Undertaking an in-depth assessment is essential if the true root of the problem is to be established. Table 1 illustrates some of the myriad of symptoms that may affect an individual's ability to eat. Once again some of these symptoms may be treatment induced and others may be a result of disease progression. What is essential is that wherever possible attempts to manage the symptoms are

**Table 1.** Symptoms affecting the nutritional status of the patient in palliative care

Malabsorption	Drowsiness
Nausea and vomiting	Depression
Mechanical obstruction	Dry mouth
Mucositis	Weakness
Dysphagia	Oral infection
Dyspepsia	Altered taste
Hiccup	Difficulty with food preparation
Constipation	Diarrhoea

active, for active management of the malnourished patient can be effective in improving the patient's quality of life.

Nutritional issues therefore present the palliative care specialists with some complex issues that require the skills of a large extended team. Palliative care has always promoted teamwork as being essential to success in supporting patients and their carers and in maintaining the longevity of staff working within the speciality. In recent years the number of specialist palliative care occupational therapists, physiotherapists and dietitians in palliative care has grown substantially. It is a speciality that works through collaborative and cooperative working with colleagues in primary, secondary and tertiary care settings, and it is often patients with important nutritional issues who require the widest possible team input and joint care planning. In complex situations it may be appropriate for the specialist palliative care team to assume the role of coordinators of care, or they may act in a consultancy role providing indirect care to the patient through the patient's usual professional carers.

By agreeing common goals between professionals, patients and carers it is possible to work within a rehabilitative approach; an approach that supports adaptation, both functional and psychological, to changed circumstances wherever possible. Minimising patient distress and maximising patient comfort must be the ultimate goal. In order to achieve these goals it is essential that informal carers' needs are recognised and that their role as primary care givers is supported. The scenario of the distressed carer who has laboured over a meal only to find it refused is a familiar one. The carer often interprets such a refusal as a rejection of caring and love. Family members often comment on the physical changes of their loved one, and this aspect appears to cause considerable distress. Much of the input required from both palliative care professionals and members of the wider team is directed at the diffusion of the conflict that can arise from such situations, which requires the important use of counselling and education. In addition, through inter-professional working it is necessary to collaborate on the development of assessment tools that can be used to assess and reassess the patient's nutritional needs and recognise the inevitable deterioration. Increasing attention is being focused on the meaning of weight loss and anorexia to carers, in recognition of the impact carers may have in the perception of these complex problems. Indeed, anxiety levels related to these two symptoms may be higher amongst carers than in patients themselves. Poole & Froggat (2002) challenge the professionals to consider how both patients and carers experience this anxiety, suggesting this area to be worthy of further empirical study so that appropriate and effective interventions may be established.

Inevitably, much of the focus on nutritional needs in palliative care has been concerned with advanced cancer. However, it has been asserted that 'it is the right of every person with a life-threatening illness to receive appropriate palliative care wherever they are' (National Council for

Hospice and Specialist Palliative Care Services, 1997). Access to such services should be made on need not diagnosis. As specialist palliative care becomes more involved with non-malignant conditions, the importance of the collaborative working process between specialties is becoming apparent. Patients with chronic obstructive pulmonary disease and heart failure may not have the same experiences as those related to cancer cachexia, but it is necessary to establish what their experience is during the end stages of their illness in order to provide appropriate care. Palliative care professionals need guidance on nutritional issues such as food refusal in patients with dementia (Wasson *et al.* 2001). Involvement with decision making in relation to enteral and parenteral feeding in patients with progressive neurological diseases is essential if professionals are to be able to provide support to these patients and their carers through their final illness and facilitate choice in their place of death.

The philosophy of palliative care requires acceptance of the complex meaning of food in the lives of all individuals and recognition that its loss has profound importance. Any issues related to nutrition touch the deepest fears of patients and their carers and requires the professionals to use all available resources to support them. The greatest resource is the skill and knowledge of each professional and by working together the most creative care can be provided, which in turn provides hope for the patients.

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