Anne Wright
Registered Dietitian,
AM Dietetics

Anne has extensive experience in many areas of Dietetics including clinical roles in Australia and with the NHS, in Higher Education and now is a freelance practitioner with AM Dietetics.

THE DIETITIAN IN PALLIATIVE CARE: NO SOFT OPTION

Dietitians who have worked in palliative care may have encountered some degree of misunderstanding from others when mentioning their role; even with suggestions that the specialty is a 'soft option' or akin to 'waitressing'. Nutritional management in palliative care is, in truth, a complex and clinically challenging area.

In the past, palliative care was associated with terminal care. The role of palliative care, however, not only encompasses end of life care, but also focuses on individuals with lifelong and life-limiting conditions.

WHO defines palliative care as 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'

The term 'palliative' is derived from the Latin 'palliare'(to cloak); thus palliative care 'cloaks' disease by effective symptom management, enabling patients to live with their illness as actively as possible, promoting quality of life and sustaining patients' families wherever they are located: home, care home, hospital or hospice.[1]

Palliative care focuses on preventing, treating, reducing or removing discomfort. It seeks to bring a patient personal satisfaction and improve quality of life. The goal of palliative care is to provide a balance between quality and length of life. There is an emphasis on highly integrated team care and planning with goals set also in collaboration with the patient and family members. Within palliative care, nutritional goals should reflect and be woven with those of the general goals of treatment.

NUTRITIONAL GOALS IN PALLIATIVE CARE

The aims of nutritional support in palliative care change with disease progression. Patients must receive food and nutrition, but the emphasis is on quality of life and symptom relief rather than active nutritional therapy.

The principle objectives of providing nutritional care in palliative care are to maximise food enjoyment and minimise food-related discomfort, to prevent or treat avoidable and unnecessary malnutrition and to help maintain a sense of normality within a patient's life.

When planning nutritional goals in palliative care, it is important to consider the stages through which the patient will move throughout the episode of care. During the early stages of palliative care, nutrition support is of great importance as it can provide patients with their individual energy requirements and also reduce their risk of infection, thereby improving quality of life. In the latter stages, as health deteriorates, the focus is on symptom management, physical care and psychosocial support. When moving towards the end of life, unsuitable amounts of food or fluid can negatively impact on palliative care. When the body is no longer repairing or restoring, the amount of food needed is sharply decreased.

EARLY PALLIATIVE CARE

In early palliative care, nutrition should be seen as a priority. Early nutrition screening can identify problems that

affect the success of therapeutic management. Patients who are underweight or malnourished may not respond well to treatments. Finding and treating nutrition problems early may help the patient gain or maintain weight, improve the patient's response to therapy, and reduce complications of treatment.

There are many ways to improve a patient's well- being and quality of life in the early stages of palliative care. The role of the dietitian in this stage of palliative care includes the following:

Assessment of nutritional requirements:

- Conduct screening to identify patients at risk and issues relating to medical diagnoses.
- Assessment of individuals using dietetic care process.
- Identify preferred likes and dislikes and lifelong food habits.
- Clarify interventions that are consistent with prognosis.

Symptom identification:

- Identify swallowing and chewing problems, pain, constipation, early satiety, changes in taste and smell, nausea, vomiting, dry or sore mouth or throat.
- Provide practical advice regarding symptoms and chewing and swallowing difficulties, in conjunction with the speech and language pathologist and other team members.

Nutritional counselling and interventions:

- Meal planning to meet energy and nutrient requirements in accordance with the patient's cultural customs, preferences and abilities.
- Adapt meal times to suit when a patient's appetite is best; avoiding times when they may experience pain, nausea and fatigue as that could reduce intake.
- Enable patients to eat autonomously by using adapted cutlery and / or cutting up their meals, as required.
- Offer favourite foods frequently and asking family members to bring favourite foods in to encourage enjoyment of eating.
- Ask patients where they would prefer to eat and encouraging eating in dining rooms with family and friends where possible, to enhance positive social interaction.
- Provide high calorie meals, drinks and snacks where appetite is poor.
- Consideration and recommendations of appetite stimulants.
- Dietary strategies that assist in the management of disease and the side-effects caused by treatment or medications, including:
  a. food presentation
  b. food temperature
  c. quick easy meals
  d. ready prepared meal ideas
  e. symptom management
  f. modified texture diets
  g. frequency of meals
  h. suggestions for nourishing meals and snacks
- Answer frequently asked questions by patients and family.
- Provide advice regarding supplements.
- Provide education and support for patients and their families.
- Development of enteral feeding regimes when the patient is unable to meet daily fluid and nutritional requirements and this intervention is deemed appropriate by the treating medical team.
- Practical advice and education for staff, caregivers and family in managing enteral feeding in the community setting.
- Modified management of chronic conditions with special diet requirements.
- Cessation of therapeutic special diets may be warranted.

LATER PALLIATIVE CARE

In later stages of palliative care management, aggressive feeding may not be appropriate, especially as eating and drinking can cause discomfort and increase anxiety and stress. The aim of nutritional support should not be for weight gain or reversal of malnutrition, but should be about quality of life, comfort, symptom relief and the enjoyment of food.

Strategies for supporting patients in later palliative care stages include:

- reassurance and support to patient and family that reduced appetite is a normal response;

- considering treating reversible symptoms;
- nourishing diet focusing on enjoyment of food and drink - this should be done without pressure on the patient to eat;
- ‘little and often’ - food and drink that the patient likes and enjoys;
- utilisation of the ‘Food first’ fortification approach by adding butter, cream, cheese, milk powder to enrich the nutritional value of food;
- oral nutritional supplements (ONS) which may be beneficial in some patients on psychological grounds; patients should not be made to feel that they have to take these or be given false hope that these will improve nutritional status or quality of life.

END OF LIFE CARE

In the last days of life, palliative care patients often experience progressive functional decline and worsening symptom burden. As the final phase of illness develops, physiological functions, such as gastric emptying, digestion, absorption and peristalsis, may decline. This can result in a reduced appetite and ability to tolerate food. Furthermore, the inability to eat or drink and body image changes can result in emotional distress for patients and caregivers.

At end of life, it is common for people to stop eating. Often, patients are pushed to eat at this time to provide comfort to their families, when this pressure is likely to cause more distress for the patient than not eating at all. Treatment decisions about end of life nutrition are difficult and rarely based on evidence alone. Many considerations factor into the decisions that families and providers make about end of life feeding, including provisions in advance directives or living wills, cultural, religious and ethical beliefs; legal and financial concerns and emotions.[3] The dietitian’s role is to engage in end of life discussions with the patient and family, to ensure that there are no unrealistic expectations associated with nutritional care.

ARTIFICIAL FEEDING IN PALLIATIVE CARE

Artificial nutrition is only indicated when it is in the patient’s best interests and when achievable goals can be established. The decision to commence nutritional support should take into account the associated benefits and burdens for individual patients. For patients nearing death who show interest in eating, most experts suggest hand feeding over tube feeding.[3] Although hand feeding is unlikely to satisfy a patient’s nutrition and fluid needs, it addresses important basic needs that help preserve quality of life. For example, many enjoy the routine of sharing a meal with others and the flavours and textures of food.

EXTENDED SCOPE IN PALLIATIVE CARE

Far from being in a specialisation which is a ‘soft option’, dietitians in palliative care find themselves in a role which reaches beyond the physical to other dimensions of care, such as social, psychological and existential. The role requires highly specialised skills in making ethical decisions about commencement and cessation of nutritional support.

Dietitians in palliative care also find themselves in the role of providing psychological support to patients and families, particularly given the social significance of eating and meals and providing nutritional counselling, which is influenced by religious and cultural themes around end of life care.

Dietetic consultations are often an opportunity for patients to discuss problems or issues that they are unable to raise with other healthcare professionals.[2] Dietetic counselling can address patients’ fears and discomfort around food and eating, especially given the emotive and social meaning of food and its links to nurturing and even perceived survival. Dietitians in palliative care have recognised that for many of their patients, the ability to continue to eat is related to staying alive. Working with palliative patients is a great challenge and offers a range of possibilities.

References

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