Food refusal and dysphagia in older people with dementia: ethical and practical issues

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Abstract

Food refusal poses difficulties for nurses and care staff and can place older patients with dementia at risk of undernutrition. The dangers of and reasons for food refusal in these patients are explored and the fundamental ethical and legal issues raised in caring for these patients are examined. Practical guidance and solutions are offered through dietetics and speech and language therapy with the aim of helping nurses and care staff, as well as professional carers in palliative care, explore ways of critically examining and coping with these dilemmas.

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There are approximately 700 000 persons with dementia in Britain today, and this number is expected to rise to 900 000 by 2021 (Alzheimer's Society, personal communication). A report by the Alzheimer's Society (2000) shows that around 80% of persons with Alzheimer's have eating difficulties that place them at risk from malnutrition. Typically, problems include clamping the mouth shut, dribbling food out of the mouth, pooling food in the mouth, delayed swallowing and the slumping of head on shoulders so mouth is inaccessible.

Despite being fairly common, food-related problems in older people with dementia are still poorly understood and there is a lack of guidance for carers, whether relatives, nurses or care staff. This undoubtedly contributes to the frustration felt by many as they struggle to care for such patients whose ability to eat, and interest in food, is waning. This article specifically focuses on difficulties faced by professional carers of people with dementia. Although these issues initially arose in the context of nurses and care staff in a nursing home struggling with how best to care for older patients with dementia who were refusing food, both the ethical and practical issues raised are applicable more widely to other health and palliative care professionals dealing with this group of patients.

Why older people with dementia are at risk from undernutrition

There are a multitude of possible reasons for weight loss in older people with dementia. Endogenous causes include increased energy demands (Wolf-Klein et al, 1995), loss of independence in feeding (Du et al, 1993) and destruction of the mesio-temporal cortex. Limbic structures in the mesio-temporal cortex are involved in memory, appetite, feeding behaviours and control of emotion. Deterioration of any of these can result in weight loss (Grundman et al, 1996). Reduced appetite and loss of ability to recognize food in severe dementia may also contribute. However, weight loss is sometimes observed in the absence of reduction in food intake (Singh et al, 1988).

A range of exogenous factors – not least of which are the inadequate responses of nurses and care staff to a person's reduced feeding ability – can also be important contributory factors. The Alzheimer's Society (2000) report *Food for Thought*, based on a survey of relatives' perceptions of care, highlighted several areas of concern. Only 50% of respondents thought staff understood the eating needs of people with dementia. A significant proportion thought care homes (both nursing and residential) did not provide enough time and assistance for eating, and choice of food and consideration of personal tastes were also viewed as inadequate.

Current approaches to eating difficulties and undernutrition

There is a lack of consensus around the best ways of addressing food refusal in dementia. Artificial feeding is one, although there is evidence of growing concern about the risks and lack of benefits involved in this practice (Friedel and Ozick, 2000).

In Britain, food refusal is generally treated conservatively, with an emphasis in

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care plans on caring and nursing processes. Attitudes towards the person with dementia, surroundings, feeding technique and preparation of appropriate meals are often highlighted. Undernutrition in older people with dementia is not usually treated by artificial means, e.g. nasogastric or percutaneous endoscopic gastrostomy (PEG) tube, however, it has recently been argued that this conservative approach may not always reflect patients’ best interests (Barratt, 2000), as it may leave them vulnerable to feelings of hunger and thirst, and reduce life expectancy.

Likewise, where tube feeding takes place, it may not always be in the patients’ interests. A North American study of ‘substitute decision makers’ (i.e. people entrusted with the power to participate in decision making on behalf of an incapacitated patient) showed most did not feel confident that the patient would want a feeding tube, only half felt they had received adequate support from professionals in making a decision, and only 40% felt that quality of life had been improved by artificial feeding (Mitchell et al, 2000).

There is debate among professionals in the USA, where PEG feeding is often used, about its appropriateness in dementia care (Friedel and Ozick, 2000). A review of data published between 1966 and 1999 found no evidence of enhanced survival and function or reduced aspiration and pressure ulcers in tube-fed patients with dementia (Finucane et al, 1999). Rather, there is evidence of substantially raised mortality risks after PEG placement in older people with dementia when compared to other clinical groups (Sanders et al, 2000).

The questionable efficacy of artificial feeding means that health professionals must look elsewhere for strategies to manage this problem. It also raises ethical and practical questions regarding determining what is in the patient’s best interests if he/she has difficulties eating or refuses food.

Addressing problematic eating: legal and ethical issues

Older people with dementia who refuse food highlight a potential conflict of fundamental responsibilities for nurses and care staff. Staff have both legal and ethical duties in caring for these patients. In clarifying these duties, the law outlines the minimum standards in society and professional conduct.

Legal duties

In response to situations of abuse and neglect of older patients, the British government introduced the Care Standards Act 2000 and guidelines (Department of Health (DoH), 1999) to raise standards of care and prevent harm and abuse in the future. In addition, with the introduction of the Human Rights Act 1998 into UK law, nurses and care staff must balance a new set of legal responsibilities, e.g. individuals have both a right to life (Article 2) and to be ‘free from torture or degrading treatment’ (Article 3). Although older patients with dementia need food to live, if they are refusing food staff cannot force them to eat as this would constitute assault. Staff need to be clear, and have evidence, that the patient understands the implications of not eating, that he/she is consciously refusing to eat, and that this decision is consistent over time. They should try to help the patient rather than force him/her to eat. Either consenting or refusing to eat is one way older patients with dementia can express their autonomy.

Although it may be difficult to get an idea of the wishes of older people with dementia, one way is through advance directives. These are written documents outlining a person’s wishes about medical and nursing care at the end of life. However, it is unclear whether or not they are legally binding. In UK law, there is a difference between a competent refusal of, and request for, treatment (British Medical Association (BMA), 1999), e.g. a patient’s wish not to be ventilated or PEG-fed versus a request for resuscitation. However, patients may not envisage all the possible circumstances they might encounter in the future; they may be unaware of certain advances in medical technology and nursing care, or they may change their minds.

Ethical duties

Legal duties provide minimum standards for health professionals, but by themselves are not always sufficient guidance to make difficult decisions. Ethical considerations are also needed and include the duty of care, protecting the patient’s best interests, issues of consent and refusal, and respecting patient autonomy and dignity.

Nurses and care staff have a duty of care to all their patients (United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC), 1992). A minimum level of care includes providing food, hydration, warmth and appropriate pain relief (Airedale NHS Trust *v* Bland).

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Failing to provide this care falls below a minimum professional standard and is ethically and legally unacceptable. The maximum level of care generally involves trying to cure a patient, but in the palliative setting it focuses on providing the best quality of life. For older patients with dementia, maximizing quality of life includes both the nature and amount of time and resources given to them by staff.

The duty to care involves a key responsibility of non-maleficence, or doing no harm (Beauchamp and Childress, 1994; Wasson, 2000). Nurses and care staff also have a duty of beneficence, or doing good (Beauchamp and Childress, 1994). In balancing these duties, there is a difference between sustaining and improving a patient's condition. If it is harmful to lose weight, then the staff's primary responsibility is to help older patients with dementia maintain their weight, thereby limiting harm, even if it is not possible to help them gain weight, thereby doing good.

If tube feeding is an option, nurses and care staff should weigh up the potential benefits and burdens involved. It is important to consider whether gastrostomy feeding would do good in keeping a patient alive or prolong the harm done by dementia, and try to assess if there any indication of what the patient wants. The decision to tube feed requires assessment of the patient's best interests.

Opinions about what is in a patient's best interests differ according to the individual and can conflict. Key questions must be asked about whose best interests are being considered, e.g. the patient's, family's, health professional's, and who decides what the patient's best interests are. One important way of determining best interests is to ask the patient what he/she thinks. Older patients with dementia, however, cannot always express their views and wishes, so another approach may be needed.

Assessing a patient's best interests involves building a picture of what the patient would have wanted, whether from what the patient has indicated in the past or through family and friends, and using clinical judgment to weigh up the benefits and burdens of any treatment or intervention and the resultant quality of life (BMA, 1999). A patient's best interests can change over time. The best interests of an older patient refusing food in the early stages of dementia may be viewed differently than those of a patient in the final stages. In the early stages a patient may have a better quality of life (including cognitive and physical skills and abilities) than in later stages of dementia. The extent of his/her other illnesses may be limited and possibly curable. In the later stages, the quality of life may have deteriorated and if he/she is in the terminal stages of disease it may be inappropriate and not in the his/her best interests to be kept alive by all means and at all costs (BMA, 1999). Best interests must be reassessed over time and with any change in the patient's condition or situation (Wasson, 2000).

When patients with dementia cannot provide a clear view of what they want, it is considered good practice to discuss the options with relatives (BMA, 1999). The focus should be on what the patient would have wanted, not what the relatives would choose for him/her. Ultimately, the physician has the responsibility to decide what care and treatments are in the patient's best interests, but this should be discussed with the health-care team and relatives and the physician should be able to defend his/her decisions on ethical grounds.

The normal standard for gaining a patient's consent to treatment involves ensuring that consent is fully informed and valid, and the patient has the mental capacity to give such consent (BMA, 1992; UKCC, 1992). Determining whether older patients with dementia are competent to judge what is in their best interests and give or refuse consent to treatment poses ethical dilemmas for staff. Assessing consent and capacity in this population is difficult. If the patient is deemed not to have capacity, i.e. sufficient mental capacity for competent decision making, the health-care team has a duty to care for and protect his/her best interests. These patients might lose interest in eating and have decreased appetites, which is different from a conscious refusal to eat, i.e. clamping the jaw shut or repeatedly spitting out food.

All patients express their autonomy through their choices, decisions and actions. Given their mental and physical deterioration and loss of control, one of the limited ways older patients with dementia may be able to exercise some autonomy is through food refusal. In Western society, autonomy is limited when an individual's choices potentially harm him/herself or others. By refusing food, older patients with dementia can harm themselves. It is difficult to know how hard staff can try to persuade these patients to eat without infringing on their autonomy or causing

Box 1. Recommendations for food provision in end-stage dementia

- Consider whether the cessation of eating is concordant with an overall deterioration
- Exclude the possibility of infections that could be reducing cognitive ability and the desire to eat and may require treatment
- If it seems that the patient is dying, although not immediately, it is still appropriate to offer small amounts of food and fluids and neither give up too easily nor try with undue force

harm and distress. Nurses and care staff cannot force patients to eat, but they can try to encourage patients to self-feed, thereby respecting their autonomy.

A central tenet of nursing care is to preserve a patient's dignity. Dignity comes from an individual's autonomy, and from his/her decisions and values being respected. This relies on staff recognizing the intrinsic value and worth of each individual (Wasson, 1998). Dignity is also a product of the way an individual views him/herself. Preserving dignity can be a challenge with older patients with dementia, but nurses and care staff should be aware that they can respect and reinforce patients' dignity through their daily interactions with them, i.e. helping them self-feed whenever possible.

Addressing problematic eating: practical issues

Having outlined some of the ethical and legal responsibilities faced by staff presented with an older person with dementia who does not or cannot eat, we will examine some practical issues of food provision for this population.

Dietetic perspective

The primary aim in helping this group of patients with eating difficulties should be to maintain dignity and minimize reliance on nurses and care staff around mealtimes. Self-feeding should be promoted whenever possible and staff should be aware that both the quality and attractiveness of meals is important. Individual needs and preferences should be taken into account and restrictions on certain nutrients usually seen as 'unhealthy', e.g. fat, sugar, salt, are usually not indicated as they would unnecessarily restrict calorie intake.

Monitoring nutritional status and intake

It is good practice to weigh all patients monthly to allow early identification of problems. If there are concerns for a particular patient, food intake records should be kept over a week, to identify foods most likely to be eaten (preferences for sweet and starchy foods are common), best times of the day (often mornings), and to help draw up a strategy for maximizing nutritional intake. The records can also be analysed by a dietitian who will be able to calculate the patient's average daily energy intake and ways of improving it.

Food provision

Where weight loss occurs due to reduced ability to eat, ordinary healthy eating guidelines (e.g. low fat and sugar intake, five portions of fruit and vegetables a day) no longer apply as this restricts foods which enable weight regain. High fat, high sugar foods become the 'healthy' choice unless, for example, the patient has diabetes. Calorie intake can be boosted by serving meat, fish, full-fat dairy products and adding butter to savouries and cream to puddings. Food consistency is an important factor in promoting optimal intake (Suski and Nielsen, 1989) and should be made suitable for the individual's needs. Personal tastes should be considered whenever possible.

If weight loss persists, proprietary nutritional drinks or 'sip feeds' may be appropriate, but should never replace food, and referral to a state registered dietitian should be considered. Simply giving supplements without addressing the underlying causes of undernutrition is wasteful, may not result in weight regain and does not help the client maintain eating ability.

Food provision in end-stage dementia

Towards the end of life a person with dementia will express very little interest in food (Baines, 2000). He/she may be bedbound and largely unable to communicate. This stage may endure for days or weeks. Sometimes a person may improve and spontaneously resume eating and drinking. This can lead to considerable anxiety among nurses, care staff and relatives who are unsure how hard to try to feed an unwell patient (Baines, 2000). Given the limited research specifically on food refusal in end-stage dementia and the particular factors that affect each patient, it can be difficult to formulate general recommendations, but those outlined in *Box 1* may help.

The outcome of each attempt to feed the patient should be written in the care plan. If death seems imminent, any decision to stop offering food should be discussed with the patient's family and the health-care team, and recorded in the notes (BMA, 1999). This is considered good professional practice, from both an ethical and legal perspective, as the notes document an account of the issues and with whom they were discussed, the decisions made, as well as the rationale for those decisions.

Speech and language therapy perspective

A speech and language therapy (SLT) assessment establishes whether the eating difficulty is a behavioural or a physical problem. It examines the needs of the patient, his/her retained functional skills, the swallow function and psychosocial environment. It considers cognitive impairment, the impact of normal ageing on swallow function, effects of medication, fatigue and any other medical condition. An SLT assessment also looks at the communicative competence of the patient, patient-carer interaction and feeding strategies employed by the carer which may facilitate or restrict oral intake.

Feeding difficulty in older people with dementia is well documented. Robertson (1996) summarized the issue of dysphagia in dementia as ‘an eating problem, often accompanied by a swallowing problem’, i.e. knowing what, when and how to eat in addition to having a delayed or absent swallow reflex. In the early stages of dementia the problems with eating are primarily behavioural, e.g. a change in preferences, forgetting to shop. In the middle stages, difficulty managing utensils often becomes evident as a result of, for example, agnosia or dyspraxia. Food hoarding in the mouth and failure to chew sufficiently may also occur with a resultant risk of choking. Not finishing meals, food gorging or the patient simply forgetting that he/she is hungry or when to eat may be observed. Distractibility, reduced attention and concentration may also affect eating and drinking (Robertson, 1996).

In the end stages of dementia eating may become slower and food may remain in the mouth as chewing and swallowing are not initiated. Fluids may dribble from the patient’s mouth if they are not swallowed and the patient may develop an agnosia for food and drink, i.e. not recognizing them as edible and therefore not responding when they are placed in front of him/her or in the mouth (Robertson, 1996). The person may refuse to open his/her mouth or to eat and drink. Fernberg et al (1992) found that most impairment was at the oral stage of the swallow, which is under voluntary control. Patients may also present with delayed or impaired pharyngeal stage swallow function. Other factors that may contribute to food refusal include dislike of the food, loss of thirst or hunger, and depression (Volicer et al, 1989). Andresen (1995) identified several causes for negative reactions to eating including fear or anxiety, unclear or complicated instructions, feelings of being rushed by the caregiver, caregiver tension or impatience. What appears as refusal to eat may therefore be as a result of any or a combination of the above. Whatever the cause(s) the result is usually that intake for nutrition and hydration is compromised.

Management of eating and drinking difficulties may therefore involve any or all of the following compensatory strategies to increase oral intake, depending on the individual and the stage of dementia: changes to the mealtime environment, modifying the feeding technique or strategies employed by carers and dietary modification.

Environment

When trying to increase food intake it might be useful to reduce distractions and noise to compensate for increased distractibility and reduced attention; make mealtimes relaxed and simple by reducing distractions at the table, e.g. fewer utensils, one course at a time (Ragneskog et al, 1996). Soothing music may reduce irritability and depression in patients, and therefore increase oral intake (Ragneskog et al, 1996). We also found that soothing music improved the mood of staff. It is best to:

- Encourage consistency in which staff members interact with each patient (Watson, 1990)
- Capitalize on the best times for individual patients to eat (Stahelin et al, 1983)
- Have regular mealtimes each day.

Feeding techniques of staff

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Clinical experience suggests that the level of skill of staff feeding patients can serve to limit or increase oral intake of patients. Staff should aim to allow the patient to retain independence and control over eating and drinking for as long as is possible. Independence can be facilitated through a variety of methods:

- Placing the patient’s hand on the spoon
- Showing the patient how to eat or undertaking ‘hand-in-hand’ feeding
- Encouraging chewing by touching the person’s tongue with a spoon or moving their chin

- Encouraging swallowing by gently stroking the person's throat (Andresen, 1995)
- Giving verbal prompts using simple clear instructions. Baton et al (1986) reported that touch and verbal encouragement may increase oral intake by facilitating trust between carer and patient
- Increasing the time allowed for feeding to avoid choking (Sandman et al, 1987) and allow adequate time between mouthfuls to avoid overspill and aspiration (Hu et al, 1986)
- Ensuring staff position themselves comfortably and correctly, i.e. seated and at right angles to, and in front of, the patient to facilitate eye contact and olfactory and visual cues from the food
- Ensuring patients are seated in an upright position with their head in the midline for feeding and remain seated for 20 minutes after eating
- Encouraging staff members who have been successful in feeding someone difficult to feed him/her whenever possible — staff should concentrate on the patient being fed and not socialize with colleagues
- Allow the patient the opportunity to see and smell the food before placing the spoon in their mouth
- Mealtimes provide an opportunity for interaction and socializing in addition to nutrition. Use touch and a calm, low tone of voice to convey empathy and interest in the person being fed.

Dietary modifications

In the middle stages of dementia when utensil use is problematic, staff should offer items of food that patients can eat on their own without feeding assistance or utensils; stimulate the appetite by offering chilled juice or sherry before meals (Andresen, 1995) or by serving patients' favourite foods. It is also beneficial to offer several small meals rather than three large ones, as well as giving plenty of fluids (Andresen, 1995). Staff should also try to stimulate physical activity in order to stimulate appetite.

Soft or puréed foods and thickened fluids will help to reduce aspiration, minimize the effort required for chewing, reduce the risk of choking, and make eating and drinking easier and more enjoyable (Robertson, 1996). Changing the texture of the diet can result in an increased oral intake for people with dementia (Boylston et al, 1996).

However, despite our efforts and changes to diet, feeding technique and environment there is usually a stage where oral intake is severely compromised. At this time we might do well to remember that:

> **'at this stage dementia... can only be managed not cured. We... should recognize that our contribution may even briefly improve the quality of that person's life or reduce the stress and anxiety of a carer'**
> **(*Kaatzke, 1992*).**

Conclusion

Food refusal in older people with dementia poses practical, ethical and legal dilemmas for nurses and care staff in nursing homes, as well as other professional carers in health and palliative care. Professionals should weigh up the potential benefits and burdens of their interactions with patients. They should encourage self-feeding where possible, help patients to eat when necessary, but they cannot force patients to eat as this would constitute assault. A combination of practical, ethical and legal considerations help to protect patients' best interests, maximize autonomy, and maintain dignity, which are key aims for all nurses, and professional carers in health and palliative care.

As Western populations age and the number of people with dementia rises, front-line nurses and professional carers in health and palliative care will be placed under greater pressure to deal with the problem of food refusal. Factors contributing to the this are beginning to be better understood, but are not sufficient to deal with the problem. Health professionals need to determine better strategies for addressing the difficulties raised and further research, discussion and guidance are needed to better equip professionals to cope with these dilemmas.

KEY WORDS

- Older people
- Dementia
- Food refusal
- Consent
- Autonomy

Airdale NHS Trust *v* Bland (HL) [1993] AC 789

Alzheimer's Society (2000) *Food for Thought.* Alzheimer's Society, London

Andresen G (1995) *Caring for People with Alzheimer's Disease: a Training Manual for Direct Care Providers*. Health Professions Press, Baltimore

Baines MJ (2000) Symptom management and palliative care. In: Evans JG, Williams TF, eds. *Oxford Textbook of Geriatric Medicine.* Oxford University Press, Oxford: 1113–26

Barratt J (2000) A patient with Alzheimer's disease, fed via percutaneous endoscopic gastrostomy with personal reflections on some of the ethical issues arising from this case. *J Hum Nutr Diet* **13**(1): 51–4

Baton M, Mitchell Bonnair I, Friedman E (1986) The effect of touch on nutritional intake of chronic organic brain syndrome patients. *J Gerontol* **1**(195): 111–6

Beauchamp TL, Childress JF (1994) *Principles in Biomedical Ethics*, 4th edn. Oxford University Press, Oxford

Boylston E, Ryan C, Brown C, Westfall B (1996) Preventing precipitous weight loss in demented patients by altering food texture. *J Nutr Elder* **15**(3): 43–7

BMA (1992) *Rights and Responsibilities of Doctors.* 2nd edn. BMJ Publishing, London

BMA (1993) *Medical Ethics Today: Its Practice and Philosophy.* BMJ Publishing, London

BMA (1999) *Withholding and Withdrawing Life-prolonging Medical Treatment.* BMJ Publishing, London

DoH (1999) *Making Decisions: the Government's Proposals for Making Decisions on Behalf of Mentally Incapacitated Adults.* DoH, London

Du W, Di Luca C, Growden JH (1993) Weight loss in Alzheimer's Disease. *J Geriatr Psychiatry Neurol* **6**(1): 34–8

Fernberg MJ, Ekberg O, Segall L, Tully J (1992) Deglutition in elderly patients with dementia: findings of videoflourographic evaluation and impact on staging and management. *Radiology* **183:** 811–4

Finucane TE, Christmas C, Travis K (1999) Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA* **282:** 1365–70

Friedel DM, Ozick LA (2000) Rethinking the role of tube feeding in patients with advanced dementia. *N Engl J Med* **342**(23): 1756

Grundman M, Corey-Bloom J, Jernigan T, Archibald S, Thal LT (1996) Low body weight in Alzheimer's disease is associated with mesial temporal cortex atrophy. *Neurology* **46**(6): 1585–91

Hu T, Huang LF, Cartwright WS (1986) Evaluation of the cost of caring for the senile demented elderly: a pilot study. *Gerontologist* **26:** 158–63

Kaatzke M (1992) *Swallowing Difficulties in People with Dementia.* Abridged version of a presentation to the dysphagia/geriatrics interest groups at Repatriation General Hospital, Concord, New South Wales. April, 9–12

Mitchell SAL, Berkowitz RE, Lawson FM, Lipsitz LA (2000) A cross-national survey of tube feeding decisions in cognitively impaired older persons. *J Am Geriatr Soc* **48**(4): 391–7

Ragneskog H, Brane G, Karlsson I, Kihlgren M (1996) Influence of dinner music on food intake and symptoms common in dementia. *Scand. J Caring Sci* **10**(1): 11–7

Robertson C (1996) Dysphagia in dementia. *Australian Communication Quarterly* **Spring:** 31–3

Sanders DS, Carter MJ, D'Silva J, James G, Bolton RP, Bardhan KD (2000) Survival analysis in percutaneous endoscopic gastrostomy feeding: a worse outcome in patients with dementia. *Am J Gastroenterol* **95**(6): 1472–5

Sandman PO, Adolfson R, Nygren C, Hallmans C, Winbald B (1987) Nutritional status and dietary intake in institutionalised patients with Alzheimer's disease and multi infarct dementia. *J Am Geriatr Soc* **35**(1): 31–8

Singh S, Mulley GP, Losowsky MS (1988) Why are Alzheimer's patients thin? *Age Ageing* **17**(1): 21–8

Stahelin HB, Hanfer M, Vogel Held C, Seiler WO (1983) Energy and protein consumption in patients with senile dementia. *Gerontology* **29**(3): 145–8

Suski N, Nielsen C (1989) Factors affecting food intake of women with Alzheimer's type dementia in long term care. *J Am Diet Assoc* **89**(12): 1770–3

Tate H, Wasson K, Hayes C, Curry V (In press) *Addressing Food Refusal in the Elderly Demented: A Resource Pack Including Discussion and Practical Suggestions,* 2nd edn. Palliative Care Centre, London

Thomas B (1994) *Manual of Dietetic Practice*, 2nd edn. Blackwell, London

UKCC (1992) *UKCC Code of Professional Conduct.* UKCC, London

Volicer L, Selzer B, Rheaume-Kramer J, Glennon M, Riley M, Crino P (1989) Eating difficulties in patients with probable dementia of the Alzheimer type. *J Geriatr Psychiatry* **2**(4): 188–95

Wasson K (1998) *The Ethics of Care or the Ethics of Justice?: A Middle Way*. Unpublished PhD dissertation, The Whitefield Institute, Oxford and Open University

Wasson K (2000) Ethical arguments for providing palliative care to non-cancer patients. *Int J Palliat Nurs* **6**(2): 66–70

Watson R (1990) Feeding patients who are demented. *Nurs Stand* **2**(44): 28–30

Wolf-Klein GP, Silverstone FA, Lausey SC, Tess D, Ciampaglia C (1995) Weight loss in Alzheimer's disease patients. *Nutrition* **11**(3): 264–87