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▶ **Page 59**  
Malnutrition in  
dementia multiple  
choice questionnaire

▶ **Page 60**  
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reflective account on  
end of life care

▶ **Page 61**  
Guidelines on  
how to write a  
reflective account

# Managing malnutrition in patients with dementia

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## Abstract

As dementia progresses, an individual may experience increasing difficulties in eating and drinking safely. Evidence suggests that admission to hospital may exacerbate these problems. This article aims to familiarise readers with some of the issues associated with providing good nutritional care for a patient with dementia in hospital. Strategies to address the maintenance of oral intake are suggested. The article also explores the use of artificial nutrition in dementia, with examples to clarify when its use may be helpful.

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## Keywords

Alzheimer's disease, best interest, dementia, nursing care, nutrition assessment, nutritional status

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## Aims and intended learning outcomes

This article provides a comprehensive overview of the effect dementia may have on an individual's ability to eat and drink safely and explores when the use of artificial nutrition is appropriate. After reading this article and completing the time out activities you should be able to:

- ▶ Describe the different forms of dementia.
- ▶ Explain the effect dementia may have on an individual's ability to eat and drink normally.
- ▶ Identify the actions that can be implemented to support the oral nutritional intake of the person with dementia.
- ▶ Discuss the decision-making process for using artificial nutrition in the individual with dementia.
- ▶ Understand the legal implications of the Mental Capacity Act 2005 in relation to the nutrition of the individual with dementia.

## Introduction

The word dementia is used to describe a group of symptoms including memory loss, confusion, mood changes and difficulty with day-to-day tasks (Alzheimer's Research UK 2014). The World Health Organization (WHO) (2007) defines dementia as a 'disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement'. Dementia is essentially a progressive illness that is irreversible. On diagnosis people with dementia can generally expect to live a further three to nine years (Smith 2011).

More than 800,000 people living in the UK have some form of dementia (Luengo-Fernandez *et al* 2010). Dementia affects one in 14 people over the age of 65 and one in six over the age of 80. It is not, however, restricted to the over-65s. In the UK more than 40,000 people under the age of 65 years have been diagnosed with a form of dementia (Alzheimer's Society 2014a). The Department of Health (2009) has estimated that the cost of dementia to the health economy is more than £17 billion per year and expects that figure to increase to more than £50 billion per year within 30 years.

## Types of dementia

There are several types of dementia:

- ▶ Alzheimer's disease is considered to be the most common presentation of dementia. As the disease progresses protein 'plaques' and 'tangles' develop in the brain, leading to the death of brain cells. It is an irreversible progressive disease (Alzheimer's Society 2014a).
- ▶ Vascular dementia is the second most common form of dementia. It is caused by restrictions to the blood supply to the brain and may develop following a stroke (Alzheimer's Association 2014a). Hypertension and diabetes are thought to be contributory factors (Viswanatha *et al* 2009). Symptoms may follow a stepped pattern, remaining constant for a time before deteriorating suddenly.
- ▶ Dementia with Lewy bodies derives its name from tiny spherical structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue (Alzheimer's Society 2014b). The presenting syndromes are dementia, motor parkinsonism or both (Beach *et al* 2009).
- ▶ Frontotemporal dementia is one of the less common forms of dementia. The term covers a range of conditions. Damage is usually focused in the front part of the brain and mainly affects younger people (Warren *et al* 2013). Personality and behaviour are initially more affected than memory. It is sometimes called Pick's disease or frontal lobe dementia (Alzheimer's Society 2014b).
- ▶ Creutzfeldt-Jakob disease (CJD) is the most common human form of a group of rare but fatal brain disorders known as prion diseases. Prions are misfolded versions of a protein found throughout the body, whose normal function is not yet known. Disease

occurs when prions act as a template to convert existing properly folded proteins to the abnormal three-dimensional prion form. This change in shape destroys brain cells (Alzheimer's Association 2014b).

- ▶ Mixed dementia is a condition in which abnormalities characteristic of more than one type of dementia occur simultaneously. It may also be called multifactorial dementia (Alzheimer's Association 2014c).
- ▶ Rarer causes of dementia. There are many other rarer causes of dementia, including progressive supranuclear palsy, Niemann-Pick disease, HIV-related cognitive impairment and Huntington's disease, which account for approximately 5% of all dementia cases in the UK. People with multiple sclerosis or motor neurone disease can also be at an increased risk of developing dementia (Alzheimer's Society 2014b).

## Malnutrition in dementia

Undernutrition is common among people with dementia. It tends to be progressive, with weight loss often preceding the onset of dementia and then increasing in pace as the disease progresses (Alzheimer's Disease International 2014). A study by Roqué *et al* (2013) showed that malnutrition was present in 5.2% of patients diagnosed with dementia and was more common in patients diagnosed with Lewy body dementia. Roqué *et al* (2013) also identified that women were at increased risk of malnutrition compared with men (44.3% versus 38.9%). Moreover, more women went on to become malnourished (5.9% versus 3.7%) (Roqué *et al* 2013). To identify an individual's level of risk, a validated nutrition screening tool should be completed on first contact with the patient. Some nutrition screening tools such as the Malnutrition Universal Screening Tool (MUST) (BAPEN 2011) can be used in both secondary and primary care environments, enabling repeated screenings to plot an individual's continuing level of risk.

**Complete time out activity 1**

## Caring for the patient with dementia in acute hospital wards

In many cases patients with dementia are admitted to hospital with an acute illness. The differences in environment and level of noise and enforced changes to mealtimes, food choices and



- 1 Think about patients you have cared for with a diagnosis of dementia. Did they have a nutrition screening and were they identified as being at risk of malnutrition? What nursing actions were taken? If any of the above actions were not completed, what are the implications for that person's health?

habits may contribute to a temporary worsening of dementia symptoms, particularly if the individual is unable to verbalise their concerns or explain how they are feeling. Some people may express this increase in anxiety and frustration as agitation or aggression.

Caring for a patient with dementia on an acute hospital ward can be a challenge, particularly for staff with little education or training in dementia care (Best and Evans 2013). Helping a person with dementia to eat can be time-consuming, frustrating and increasingly difficult as the disease progresses. The person with dementia may turn their head away from food, clamp their mouth closed when food is offered or wander away during mealtimes, resulting in them eating very little. This in turn can lead to weight loss and ultimately terminal decline (Cole 2012). Eating disorders such as anorexia, and other behavioural problems such as wandering, may lead not only to a reduction in eating and drinking but also to an increase in nutritional needs (Pouyet *et al* 2014). Reasons why patients with dementia may experience difficulties in eating and drinking in the hospital setting are listed in Box 1.

## BOX 1

### Reasons why patients with dementia may have trouble eating and drinking

- ▶ Altered eating behaviour, memory and emotions because of atrophy of the mesial temporal cortex which controls this.
- ▶ Difficulty in swallowing (dysphagia) in the late stages of dementia.
- ▶ Loss of ability to recognise hunger or thirst.
- ▶ Altered ability to recognise objects, leading to attempts to eat inappropriate foods or objects such as soap or flowers.
- ▶ Loss of ability to know when and how to swallow or chew.

(Hallpike 2008, Smith 2011)

## BOX 2

### Edinburgh Feeding Evaluation in Dementia scale

Score answers to questions 1-10: never (0), sometimes (1), often (2).

1. Does the patient require close supervision while feeding?
2. Does the patient require physical help with feeding?
3. Is there spillage while feeding?
4. Does the patient tend to leave food on the plate at the end of the meal?
5. Does the patient ever refuse to eat?
6. Does the patient turn his or her head away while being fed?
7. Does the patient refuse to open his or her mouth?
8. Does the patient spit out his or her food?
9. Does the patient leave his or her mouth open allowing food to drop out?
10. Does the patient refuse to swallow?

Total score = \_\_\_\_ (Total score ranges from 0-20 with a score of 20 being given to the patient with complex needs.)

Rate the level of support the patient requires during a meal as needs cueing or set up, requires physical assistance, or requires hand-feeding.

(Watson 1994)

The report *Counting the Cost: Caring for People with Dementia on Hospital Wards* (Alzheimer's Society 2009) surveyed the carers of patients with dementia who were admitted to hospital on the assistance their relative was given to help them eat and drink. Only 23% were satisfied with the standard of assistance given.

However, it is worth noting there is a potential danger in offering the patient too much help since this may have a negative effect on maintaining his or her functional status. While family and carers might want their loved ones to receive physical assistance to eat, this may not be in the patient's best interest and could potentially reduce his or her ability to eat and enjoy food (Lin *et al* 2008). Chang and Roberts (2008) suggest that many patients with dementia may not view a carer feeding them as helpful and therefore may resist the assistance. This, coupled with the fact that many trusts operate a rigid protected mealtime policy that might not allow relatives into the care setting to help their loved ones eat at mealtimes, can lead to patients with dementia in the acute setting becoming undernourished.

Recommendations from the *Counting the Cost* report (Alzheimer's Society 2009) to improve practice included:

- ▶ Assessing nutritional risk not only on admission but on a continuing basis.
- ▶ Gaining an understanding of the individual's preferences at mealtimes.
- ▶ Encouraging support and participation at mealtimes from carers, family and friends where possible.

The Edinburgh Feeding Evaluation in Dementia scale (Watson 1994) is an 11-item scale that helps practitioners determine the level of assistance needed by patients with dementia. It is based on observing patients' eating behaviours and asks ten simple questions, attributing a score to each answer (Box 2). The 11th item in the scale asks the rater to indicate the level of support the patient requires during the meal. The scores from each question are then added to provide a total score which indicates the patient's level of risk.

The Edinburgh Feeding Evaluation in Dementia scale is a useful tool to identify nutritional issues in the patient with dementia. It should be part of any assessment that a healthcare professional makes when looking after patients with dementia. While it does not address how to manage all the difficulties a patient might have, it does recommend referral to a speech and language therapist to assess

swallow, should the individual score either 1 or 2 on questions 8, 9 and 10.

## Swallowing problems

As dementia progresses, chewing and swallowing food and fluid can become problematic. The individual's ability to manage food and fluid in the mouth may deteriorate or their swallow may become ineffective which increases the risk of food entering the bronchial tract, resulting in aspiration (Williams and Weatherhead 2013). Aspiration can lead to coughing and choking and a reduction in oral intake, which in turn increases the risk of dehydration, pneumonia, malnutrition and death (Parker and Power 2013). Factors that may indicate that the patient with dementia is unable to manage his or her oral intake safely include:

- ▶ Coughing and/or choking persistently.
- ▶ Wet and/or gurgly voice.
- ▶ Taking a long time to eat a meal.
- ▶ Falling asleep over the plate.
- ▶ Complaining of difficulty eating and/or drinking.
- ▶ Expressing reluctance to eat food of particular consistencies or drink.
- ▶ Getting food stuck in his or her mouth.
- ▶ Holding food in the cheeks.
- ▶ Food and/or drink falling out of the patient's mouth.

Complete time out activity 2

## Improving the nutritional intake of patients with dementia

Finger foods are helpful for some patients with dementia because they allow them to eat independently, particularly when cutlery has become too difficult to use (Box 3). The type of finger food to be provided may differ from patient to patient and will depend on their personal taste, ability to swallow safely and manual dexterity. Finger foods may allow patients to regain some enjoyment in eating (Crawley and Hocking 2011). At present, the provision of finger foods in hospitals is variable, but the admission of increasing numbers of patients with dementia might make it more commonplace.

People with dementia may experience problems with their sight, causing them to misinterpret the world around them. What the person sees may be simply a 'best guess' with often inaccurate or distorted information being delivered from the eyes to the brain. For example, a shadow on

the carpet could be mistaken for a hole in the floor (Alzheimer's Society 2014c). People with Alzheimer's disease have an unspecific colour vision deficiency (Pache *et al* 2003). This vision deficiency may lead to misinterpretations at mealtimes with patients being unable to recognise food or drink placed in front of them.

Dunne *et al* (2004) explored the effect of providing food on contrasting coloured plates for patients with dementia. The theory was that people with dementia may experience difficulties distinguishing food on a non-coloured plate or fluid in a similar coloured drinking vessel (for example milk in a white cup), leading to a reduction in nutrition and fluid intake. At different stages in the study, red, white and blue crockery and tableware were used. The authors identified at least a 10% increase in food and liquid intake when coloured tableware was used (Dunne *et al* 2004).

Complete time out activity 3

## Artificial nutrition

The risk of malnutrition is likely to increase as dementia progresses, despite implementing nutritional strategies. Patients with advanced dementia are often most at risk (Smith 2011). As oral intake diminishes, the need for nutritional support in the form of enteral tube feeding may be discussed. This often arises when the patient becomes acutely unwell and nutrition screening shows that they are severely undernourished.

The question of whether to provide additional nutritional support can cause

### BOX 3

#### Examples of suitable finger foods

- ▶ Small bread rolls with butter.
- ▶ Sandwich cut into pieces.
- ▶ Buttered crumpet fingers.
- ▶ Buttered muffins.
- ▶ Scones with butter and jam.
- ▶ Fruit loaf or teacakes.
- ▶ Slices of ginger bread.
- ▶ Fruit cake.
- ▶ Cocktail sausages.
- ▶ Fish fingers or crabsticks.
- ▶ Mini pork pies.
- ▶ Slices of quiche or mini-pizzas.
- ▶ Hard-boiled eggs, quartered.
- ▶ Cheese cubes.
- ▶ 'Fondant fancy' cakes.



2 Talk to a speech and language therapist and observe a swallowing assessment being performed on a patient. Discuss with the therapist how the assessment affects the patient with dementia.

3 Consider a patient with dementia for whom you have provided nutritional care. How did they respond to food being placed in front of them? What was the colour of the crockery and/or drinking vessels? What assistance did you provide to help them eat? Reflecting on your responses, what changes could be made to enhance the dementia care you provide?

conflict. Relatives and carers may perceive that their loved ones might 'starve to death' if they do not receive alternative help and adequate nourishment, while healthcare professionals may consider that such

intervention would worsen the patient's quality of life and cause distress to the individual.

The evidence to support artificial nutrition in the person with advanced dementia is controversial (Cullen 2011). The National Institute for Health and Care Excellence (NICE) (2006) states that, while nutrition support can be considered in patients with early dementia in whom dysphagia is transient, it should not be offered to patients with advanced disease for whom an unwillingness to eat or drink or lack of awareness of eating or swallowing problems is part of the disease process. While some healthcare professionals and relatives of patients with dementia believe artificial nutrition to be beneficial, there is no robust research evidence comparing artificial nutrition support with careful assistance of feeding by hand (Royal College of Physicians 2010). In a review of percutaneous endoscopic gastrostomy (PEG) tube placement for patients with dementia, PEG feeding showed little effect in improving skin integrity, preventing aspiration pneumonia, maintaining weight or extending life (Cervo *et al* 2006, Kurien *et al* 2010).

Decisions about the introduction of artificial nutrition for patients with dementia should be made on an individual basis. A full multidisciplinary team discussion should take place. This should include confirmation of the diagnosis of advanced dementia and identification of whether a worsening of swallow is a result of the progression of dementia or an acute issue, for example acute delirium secondary to infection. If the deterioration is caused by an acute problem that could be treated leading to improvement in the swallow, it would be reasonable to consider a short period of artificial nutrition through a nasogastric feeding tube. If the deterioration is caused by the disease progression, introducing artificial nutrition may not be in the patient's best interest.

Such decisions should be discussed with the family and/or carers and patient. If artificial feeding is introduced, it should be made clear that the feeding is to enable the patient to recover from this acute episode and is not a long-term solution (Parker and Power 2013).

The case studies in Boxes 4 and 5 illustrate these issues. Case study 1 (Box 4) demonstrates how looking at a patient's needs

## BOX 4

### Case study 1, Marie (pseudonym)

Marie is an 82-year-old woman admitted for an emergency laparotomy because of a small bowel obstruction. She has recently been diagnosed with vascular dementia. However, she has a good quality of life. She lives with her husband and is able to maintain all activities of daily living independently.

After surgery she is confused and refuses to eat and drink. She also has a large abdominal wound that is not healing. Food charts show that she met less than one quarter of her daily nutritional requirements in the previous week, and the ward team is concerned.

A multidisciplinary team meeting is held before discussing with the patient and her husband the use of a nasogastric feeding tube to supplement her oral intake. Use of a nasogastric tube is queried by a member of the team who feels that because the patient has dementia it would be unwise to place a feeding tube, because it would cause her distress.

However, the team decides that, because this is an acute episode following surgical intervention, artificial feeding would be beneficial. A mental capacity assessment is carried out with Marie and concludes that, although she has some short-term memory loss, she is able to understand the conversation and discuss the issue with her husband. Marie agrees that a period of artificial feeding would be beneficial.

A nasogastric feeding tube is inserted through the nostril, down the oesophagus, into the stomach and she commences supplemental feeding, with encouragement to eat orally as well. Marie tolerates the tube well, although occasionally she needs to be reminded of its purpose.

After two weeks her appetite begins to improve and the level of artificial nutrition provided is reduced. After one month she is meeting her nutritional requirements orally and her wound shows signs of healing well. The nasogastric tube is removed and Marie is discharged home shortly afterwards.

## BOX 5

### Case study 2, Mike (pseudonym)

Mike is an 83-year-old man admitted to hospital from a nursing home with aspiration pneumonia. He has advanced dementia and is bedbound, incontinent and unable to communicate his needs. He has a swallowing assessment performed by the speech and language therapist who recommends a thick purée diet with custard-consistency fluids.

Mike finds it difficult to eat large quantities and enjoys yoghurts and custards only. His family is concerned and asks to speak to the medical staff about the possibility of a percutaneous endoscopic gastrostomy (PEG) tube because they are worried their father will starve when he returns to the nursing home. The medical staff are concerned that the nursing home will not admit him if he is not eating and drinking adequately and also request that Mike has a PEG tube placed. Mike is not able to express his wishes in terms of nutrition and hydration, and it is difficult to ascertain whether he understands the question when asked. A mental capacity assessment is performed and finds that Mike does not have the capacity to make decisions about his nutrition and hydration needs.

It is decided that a best-interest meeting should be held for Mike. It is decided that the PEG tube is inappropriate and that the patient should be allowed to eat for comfort. The nursing home and family will be given strategies to help Mike enjoy the food he wants to eat.

individually ensured that her nutritional care was appropriate and she made a good recovery. Case study 2 (Box 5) demonstrates how it was decided that PEG feeding was inappropriate.

### Using mental capacity legislation to help make the correct decision

Mental capacity legislation differs according to where in the UK the patient lives. The Mental Capacity Act 2005 legislates for England and Wales, while Scotland has the Adults with Incapacity (Scotland) Act 2000 and in Northern Ireland a mental capacity bill is still in consultation. All legislation aims to provide a framework to empower and protect vulnerable adults who may not have the capacity to make decisions for themselves. Generally, the principles of mental capacity are (Clegg and Hogston 2009):

- ▶ Every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless proved otherwise.
- ▶ Adults must be given all practicable help before being treated as if they are unable to make their own decisions.
- ▶ Just because a person makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.
- ▶ Anything done or any decision made on behalf of the person must be done in their best interests.
- ▶ Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.
- ▶ Mental capacity assessments should be performed by a person directly concerned with the patient at that time (Mughal 2014). This person could be a nurse, a doctor or an allied healthcare professional.

There are a number of factors to be considered during a mental capacity assessment. In particular, the patient must be capable of all of the following (Mughal 2014):

- ▶ Understanding the information relevant to the decision. For example, in case study 2 (Box 5), Mike is not meeting his nutritional requirements and a feeding tube would help him with this.
- ▶ Retaining that information. The information needs to be retained only long enough to make that decision; he or she could forget it a short while later.

- ▶ Using and/or weighing up that information.
- ▶ Communicating the decision, in any way such as gestures and behaviour.

### Acting in a person's best interest

When acting in a person's best interest, a number of issues should be considered, including:

- ▶ Whether or not the individual is likely to regain capacity.
- ▶ His or her past and present wishes and feelings, if known.
- ▶ His or her beliefs and values.
- ▶ What is best for the person.

To assist in this process all relevant other people such as relatives and carers should be consulted, although their views and opinions have no legal standing. No decision should be made based on the patient's age or appearance or on others' wishes.

#### Complete time out activity 4

When a person with dementia is near the end of life, the concern should be the quality of remaining life and quality of death, not length of life (Alzheimer's Society 2012). Making these decisions can be painful for family and carers and they will need support and empathy.

The provision of an enteral feeding tube is not always seen as a positive treatment. Families' responses to a survey on their opinions of the effect of PEG insertion on their loved one's quality of life were that, before the procedure, 66% were expecting an improvement in quality of life, but only 44% felt the same following the procedure (Royal College of Physicians 2010).

When the decision is taken not to commence artificial nutrition support on a patient with advanced dementia, it is important to implement an individualised nutrition care plan both for patient comfort and to ease family concerns. The Peterborough Palliative Care in Dementia Group (2010) devised a useful tool to help practitioners and carers to ensure that patients with advanced dementia are still able to enjoy food and drink (Box 6).

Some of the initiatives in Box 6 may seem difficult to implement in a hospital setting. However, engaging with families and providing open visiting facilities makes them more feasible. This will also ensure relatives' concerns about their loved ones are seen to be taken seriously, helping to build mutual trust and respect while improving the quality of care for the patient.

#### Complete time out activity 5



**4** Who do you think would attend a best interest meeting for a patient in your care? Does your organisation have a safeguarding policy and do you know where to find it?

**5** Using information from this article, devise a plan of nutritional care for Mike, the patient in case study 2 (Box 5). How will you engage with his family? What can they do to help Mike enjoy his mealtimes? What questions could you ask to ensure Mike has food that he enjoys?

**BOX 6**

**Peterborough Palliative Care in Dementia Group tool**

- ▶ Ensure the individual is on the correct diet that is appropriate for him or her – refer to the speech therapist if there is a swallowing problem.
- ▶ Encourage the individual to consume highly flavoured foods and drinks, for example cranberry juice or lemon juice, and food and drinks that are hot or ice cold, but not tepid. Hot or cold foods can stimulate a stronger swallow response because they provide more stimulation to the brain than bland and tepid food and drinks.
- ▶ Alternate temperature and taste in a meal. For example, alternate sweet and savoury spoonfuls of food to stimulate the swallowing reflex.
- ▶ Use frequent verbal prompts about the food or drink and to encourage the person to swallow.
- ▶ Check that the person has swallowed before offering another mouthful.
- ▶ Use gentle and physical prompts to encourage self-feeding, for example put the utensil or cup in the person's hand.
- ▶ If the person crams food into his or her mouth or eats too quickly, then use verbal prompts to encourage him or her to finish each mouthful before taking another bite.
- ▶ Hand-over-hand feeding may be appropriate to control the rate of eating.
- ▶ Offer food and drink at times of day when the person is at his or her most alert.
- ▶ Encourage small amounts of appropriately textured food and fluids frequently throughout the day.
- ▶ Try to keep the eating environment as calm and free from distractions as possible.
- ▶ Prepare and present food to stimulate the appetite.
- ▶ If someone needs soft or puréed food, provide him or her with the correct texture of food. Ensure foods are served separately, not all mixed together, unless the person prefers them this way.

Peterborough Palliative Care in Dementia Group (2010)



**6** Now that you have completed the article, you might like to write a reflective account. Guidelines to help you are on page 61

**Conclusion**

Dementia is an irreversible disease and, once the ability to eat and drink safely is affected, it is unlikely to improve. Changes in the environment, habits, noise levels and social interactions resulting from admission to hospital may increase confusion and agitation for the person with dementia. Providing the appropriate level of

support and care for these individuals is essential to maintain safe oral intake. If nurses take the time to assess and implement suitable care plans and provide food and drink in ways that assist with safe consumption, this can potentially have a positive effect on both patient and nurse **NS**  
**Complete time out activity 6**

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