# Oral and enteral nutrition in dementia: an overview

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# Oral and Enteral Nutrition in Dementia: An overview of the literature

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## Abstract

The number of people currently living with dementia in the UK is estimated to be 850,000 and this is expected to rise to over 1 million by the year 2025. Dementia is a progressive terminal disease and the rate of decline is unique to each person, however cognitive deterioration can be accelerated by undernutrition. The aim of this paper is to discuss evidence-based approaches in the use of oral and enteral nutrition interventions for people living with dementia and to support their caregivers. Discussion of interventions to improve oral nutrition will include: changes to the environment, support with feeding difficulties, nutritional supplements and education and training for caregivers.

## Introduction

The number of people with living with dementia in the UK is currently estimated at 850,000 and this is expected to rise to over 1 million by the year 2025 (Prince et al. 2014a). Dementia is a progressive terminal disease which results in a person’s cognitive decline so they are unable to maintain their own activities of daily living (World Health Organisation 1992). The rate of decline is different for each person, although a number of factors can increase the likelihood of an accelerated decline such as undernutrition (Prince et al. 2014b).

Undernutrition in older people is common and results in a decline in muscle function, bone mass, immune functioning, wound healing, and cognitive functioning, with an increase in hospital admission, readmissions, and mortality (Chapman 2006). The cause of undernutrition in the older person is multifactorial including biological and physiological changes in the digestive system (Ahmed and Haboubi 2010). An older person with a diagnosis of dementia is at a higher risk of undernutrition, due to the added difficulties and challenges that may result from the individual manifestations of dementia.

Undernutrition and clinically significant weight loss occurs in nearly half of all people with dementia (Gillette-Guyonnet et al. 2000), leading to reduced mobility, ability to complete activities of daily living and quality of life (White et al. 1998, Ball et al. 2014). Weight loss in dementia can occur due to the imbalance of nutrition/energy intake and physical needs; this may be due to increased energy expenditure by the person with dementia such as wandering (Knopman 2008). The effect of dementia on brain structures that regulate appetite control and the energy/need balance including mesial temporal cortex, hypothalamus and cingulate gyrus may also impact on weight loss (Grundman et al. 1996, Buchman et al. 2005, Schultz et al. 1999). A positive correlation between weight loss and the progression of dementia has been acknowledged (Albanese et al. 2013).

Lack of nutritional intake due to the development of eating difficulties also impacts on weight loss in dementia. In the early stages of dementia eating difficulties include changes in taste, difficulties in executive planning, development of attention deficits, dyspraxia, agnosia, behavioural problems, lack of recognition of food and hunger (Volkert 2014). In the later stages of dementia, eating difficulties including oral and pharyngeal phase dysphagia leading to the risk of aspiration may be present (Dodds et al. 1990).

An estimated half of the people diagnosed with dementia will lose the ability to feed themselves, placing extra burden on family caregivers (LeClerc et al. 2004). Carergiver strain has been demonstrated to negatively impact on eating behaviours of people with dementia (Riviere et al. 2002), and is an independent risk factor for weight loss in people with Alzheimer's disease (Gillette-Guyonnet et al. 2000).

A comprehensive nutritional status assessment of a patient with dementia is crucial including: dietary assessment, weight history, anthropometric indicators, nutritional biomarkers, energy expenditure and body composition assessment (Prince et al. 2014b). However, an assessment of eating and feeding behaviour is also required and can be completed by the use of a validated tool, such as the Edinburgh Feeding Evaluation in Dementia Scale (Watson 1994). The scale allows an evaluation of the person with dementia in terms of assistance required with eating and their nutritional needs and also highlights when it is necessary to refer the person with dementia to a speech and language therapist due to the identification of swallowing difficulties. In addition, an indication of poor nutritional status in patients with dementia should elicit nutritional interventions.

Therefore, the aim of this paper is to discuss evidence-based approaches in the use of oral and enteral nutrition interventions for people living with dementia and to support their caregivers. The main body of this paper will explore interventions for improved oral intake including changes to the environment, support with feeding difficulties, nutritional supplements and education and training for caregivers. The paper will conclude by exploring the use of enteral nutrition in people living with dementia.

## Oral Nutrition

The National Institute for Health and Care Excellence (NICE) clinical guideline 42 (2006, updated March 2015) identify the need for health and social care staff to be competent in recognising eating difficulties in people with dementia, including issues with oral health. NICE recommend that health and social care staff should encourage people with dementia to eat and drink by mouth for as long as possible, but do not clarify any interventions for staff or caregivers to support this recommendation. Research studies exploring strategies and interventions to increase oral nutrition of people with dementia are limited (Ball et al. 2014). The majority of research studies focus on one of the following elements; the environment, nutritional supplements, or education and training for informal family caregivers or formal carers (Burgener et al. 2008). Each of these elements and relevant research will be discussed separately, however all elements need to be evaluated simultaneously when providing care for people living with dementia.

### *Environment*

The influence of the environment on a person with dementia cannot be over emphasised (Watson 2002). Four core principles relating to improving the environment for people with dementia have been identified by Cooper et al. (2008) and more recently Yates-Bolton et al. (2012). These include elements relating to the:

- Fabric of the environment
- Ambience of the environment
- Psychological impact of the environment
- Sociological impact of the environment

The four core principles outlined relate to all environments in health and social care settings, but will be discussed here with relevance to the dining experience of people with dementia. An important element throughout the core principles is recollection versus recognition. Recollection is a memory that has been triggered by a memory aid. Whereas recognition is recalling information without a memory aid which becomes more and more difficult as the dementia progresses (Timlin and Rysenbry 2010).

The fabric of environment for improving oral nutrition is the use of a dining room, rather than the person sitting by their bed in the same chair they sit in all day, as this does not promote a recollection of a dining room or mealtime. If a dining room space is not possible, the use of a tablecloth or the laying of the table with placemats and cutlery may assist recollection (Perivolaris et al. 2006). The use of coloured crockery for people with dementia may support their perceptual difficulties; the importance of the colour is that it is in contrast to the food and table. Rossiter et al. (2014) found blue crockery was associated with increased oral intake in patients in an acute elderly ward, whereas Dunne et al. (2004) found red or blue crockery of high-contrast colouring significantly increased oral intake compared to red or blue crockery of low-contrast colouring.

In addition to contrasting coloured crockery, good lighting in dining rooms or during the dining room experience is essential. The importance of good lighting is the avoidance of shadows being cast, as people with dementia may have difficulty interpreting shadows due to perceptual difficulties. Good quality lighting has improved levels of food consumption and independence of feeding amongst residents in care homes in a US study (Brush et al. 2002).

The ambience of the dining room experience should be quiet, relaxed and not overly crowded. Mealtimes should be unhurried and free from distractions, as people with dementia may be easily distracted by noise and over stimulation (Prince et al. 2014b). The dining room environment could be enhanced with relaxing music, which may reduce agitation (Thomas and Smith 2009) or if possible the use of the smell of freshly baked bread, which may stimulate the appetite of older people with dementia (Cleary et al. 2008).

Lastly, the dining environment where possible should include tables where residents/patients may eat together and for optimal social interaction tables for four people are recommended (Timlin and Rysenbury 2010). Prince et al. (2014b) recommend a complex intervention to support the dining experience with the aim of returning to 'family-style' eating environment to support nutrition intake in people living with dementia.

### ***Support with feeding difficulties***

People with dementia may need support with feeding difficulties. However, feeding difficulties may be the result of other conditions, including reduction in physical activity, constipation and the person being unable to communicate due to depression, pain, tiredness or the impact of medication (Alzheimer's Society 2013). Feeding behaviour difficulties need a holistic assessment to avoid diagnostic overshadowing, where other underlying conditions are labelled as symptoms of dementia (Kerr et al. 2006).

A review of interventions to promote eating and to reduce undernutrition in people with dementia was completed in 2011 by Jackson et al. Effective interventions included aspects relating to the change of the dining environment, including table settings, education of staff, increased dietetic input with enhanced nutritional screening and changes to the food provided (Jackson et al. 2011).

However, due to different outcome measures in each study, the effectiveness of the different interventions could not be compared (Jackson et al. 2011). Only one study reported supporting people with dementia in practical feeding interventions, which included the use of volunteer assistance with feeding. Jackson et al. (2011) recommended complex interventions which included grazing, staggered mealtimes, menus providing enhanced energy dense foods, the provision of a texture-modified diet and mid-morning supplements to improve nutritional intake in people with dementia.

Non evidence-based suggestions to support feeding difficulties have been documented in various factsheets including the provision of finger food, offering small portions of food throughout the day, providing one course or item of food at a time and offering of additional snacks (Guys and St Thomas' NHS Foundation Trust 2014, Ragdale 2014).

### ***Nutritional supplements***

Macronutrient supplementation includes the provision of nutritional components that are required in relatively large amounts in the diet such as: proteins, carbohydrates and fats. Oral protein supplements in older people with poor nutritional intake increases weight gain and reduces mortality risk (Milne et al 2009). In people with dementia, high calorie supplements have been shown to promote weight gain, although were unlikely to impact on cognitive functioning or mortality risks (Hanson et al. 2011).

On the other hand, micronutrient supplementation includes the provision of nutritional components that are required in minute amounts in the diet.  In dementia this includes Vitamin B12, Folate and Vitamin E. Oral B vitamins in patients with mild cognitive impairment has been demonstrated to lead to a reduction in the rate of brain atrophy over a period of 2 years (Smith et al. 2010). However, this study did not investigate the impact of the treatment on cognition. Currently, there is limited evidence regarding the use and effectiveness of Vitamin B12 and Folate in any stage of dementia (Prince et al. 2014b).

The impact of Vitamin E and Memantine have been explored in mild to moderate Alzheimer's disease, and it was observed that patients taking Vitamin E had a slower cognitive decline over a 2 year period than those taking Vitamin E and Memantine or Memantine alone, suggesting the benefit of Vitamin E in mild to moderate Alzheimer's disease (Dysken et al. 2014). However, a further study found participants receiving Vitamin E, Vitamin C and a-lipoic acid had an accelerated cognitive decline compared to those who did not receive these supplements (Galasko et al. 2012). This study raised concerns about the safety of providing these supplements for people with dementia over an extended period of time (Galasko et al. 2012). Therefore the risks and benefits of providing micronutrient supplementation need to be evaluated on an individual basis (Prince et al. 2014).

### *Education and training*

Evidence suggests that education and training for formal and informal caregivers on reducing eating difficulties with people with dementia has a moderate impact (Liu et al. 2014). However, studies in this field are limited, although a common outcome is that caregivers appreciated the education and training (Salva et al. 2011), demonstrating the need for support in this area.

One way of providing support to formal and informal carers is through an 'Eating and Drinking' factsheet by Alzheimer's Society (2013). This factsheet provides important information on maintaining adequate nutrition in people with dementia. In addition, it discusses in lay terminology common problems such as poor appetite, cognitive impairment, and physical and sensory disabilities. The factsheet is appropriate for both family members and healthcare professionals and can inform future care needs and support available when provided to family caregivers prior to changes in patients eating behaviours.

Education and training programmes on nutrition for family caregivers tend to be conducted by a dietician and include elements that address the importance of dietary changes and challenges in dementia, tools to monitor nutritional intake, how to provide a protein rich diet and strategies to address eating difficulties (Salva et al. 2011, Riviere et al. 2001, Pivi et al. 2011). The aforementioned studies were reviewed by Prince et al. (2014b) who concluded that overall the studies did not significantly demonstrate an increase in nutritional intake in the person with dementia or a reduction in caregiver burden.

Table 1: Evidence-based interventions to improve nutritional intake in people with dementia

| | Recommendation | Evidence |
|---|---|---|
| Environment | - Use of tablecloths, placemats and laying of cutlery<br>- Coloured crockery, such as dark blue or red<br>- Good quality lighting<br>- Music<br>- Smell of freshly baked bread<br>- Tables to seat 4 people | - Perivolaris et al. (2006)<br>- Rossiter et al. (2014), Dunne et al. (2004)<br>- Brush et al. (2002)<br>- Thomas and Smith (2009)<br>- Cleary et al. (2008)<br>- Timlin and Rysenbry (2010) |
| Support with feeding difficulties | - Grazing, staggered mealtimes, menus providing enhanced energy dense foods, texture-modified diet, mid-morning supplements<br>- Provision of finger food, offering small portions of food regularly, offering one course or item of food at one time, additional snacks | - Jackson et al. 2011<br>- Guys and St Thomas' NHS Foundation Trust, Ragdale 2014 |
| Nutritional Supplements | - Macronutrient supplementation, such as high protein, high calorie supplements | - Milne et al. (2009), Hanson et al. (2011) |
| Education and Training | - To support family caregivers<br>- Dietary changes in dementia, tools to monitor nutritional intake, how to provide a protein rich diet, strategies to address eating difficulties | - Salva et al. (2011)<br>- Salva et al. (2011), Riviere et al. (2001), Pivi et al. (2011) |

## Enteral Nutrition

Enteral nutrition provided through a feeding tube, such as a Percutaneous Endoscopic Gastrostomy (PEG) tube is an intervention to provide complete nutrition and improve a patient's quality of life (Llyod et al. 2004) and is implemented in a wide range of health conditions. A number of systematic reviews have been completed exploring the use of enteral nutrition for patients with dementia (Finucance et al. 1999, Dharmarajan et al. 2001, Sampson et al. 2009, Brooke and Ojo 2015). The first review by Finucane et al. in 1999 concluded with the recommendation of actively discouraging the use of enteral nutrition for patients with dementia. The following review by Dharmarajan et al. in 2001 recommendations were rather more conservative and advised caution in providing nutrition in older people with dementia. Sampson et al. in 2009 explored the data and concluded there was insufficient evidence to support the use of enteral nutrition in patients with advanced dementia. Lastly, Brooke and Ojo in 2015 challenged the traditional view that enteral nutrition increases mortality in patients with dementia, but suggested an holistic assessment of each patient is required in the decision making process. All reviews found little to no data exploring the impact of enteral nutrition on quality of life and all evidence were related to health outcomes such as; mortality, pressure ulcers, aspiration pneumonia, and decreased or decreasing serum albumin levels.

National and International guidelines support the use of enteral nutrition in dementia for short periods of time to enable the reversal of an acute condition but do not recommend enteral nutrition in the end stages of dementia, when the condition is terminal. For example, NICE guidance (2006, updated March 2015) recommend enteral nutrition if the diagnosis of dysphagia in a patient with dementia is considered transient, but is not recommended for patients with dementia who are disinclined to eat or have permanent dysphagia. European Society of Parenteral and Enteral Nutrition (ESPEN) support the use of enteral nutrition in a person with dementia if the cause is a predominantly reversible condition and only for a limited time frame (Volkert 2014). ESPEN suggest revisable conditions may include infection, depression, over use of sedatives, poor oral health or pain. ESPEN provide a clear recommendation that enteral nutrition is not appropriate in end stage dementia. However, all decisions regarding the use of enteral nutrition are unique to each patient and include the patient’s current prognosis and wishes.

Discussions and decisions regarding enteral nutrition are important and should be facilitated by healthcare professionals with the person with dementia and their families in the early stages of the disease so conversations can be legally documented through Advance Care Directives and Advanced Care Plans, but this is not currently or consistently provided in the care of people with dementia and their families (Brooke and Kirk 2014). Decision-making at the point of need adds further stress and burden on family members, especially as enteral nutrition in advanced dementia remains controversial (Cullen 2011). Any introduction or commencement of enteral nutrition in a person with advanced dementia should be in concurrence with clear discussions with family members that the intervention is to support the person through an acute episode of illness and will then be discontinued and not a long term solution for nutritional issues (Parker and Power 2013).

An example of poor decision making regarding enteral nutrition use in dementia is documented in the Parliamentary and Health Service Omudusman report (2011). This case report challenges the beliefs of healthcare professionals regarding the use of enteral nutrition in patients with dementia. The case concerns Mr W who was admitted to hospital with a chest infection, dementia and depression, and who was treated with intravenous fluids and antibiotics. On completion of the treatment Mr W remained frail, neither eating nor drinking, but was discharged to a care home. Three days later Mr W was readmitted to hospital with severe dehydration and pneumonia, where the decision was made to insert a PEG tube for treatment and nutrition. Following the completion of treatment Mr W's condition improved and he was able to enjoy life in the care home, such as playing his favourite game of dominos. An element of the decision to discharge Mr W to a care home, was the belief by healthcare professionals he was as well as could be expected. The difficulty for healthcare professionals working in an acute environment is understanding the level of functioning and capabilities of a person with dementia prior to their admission, this is where the importance of listening to family members is vital.

## Conclusion

Due to the increase in the number of people living with dementia an understanding of supporting their nutritional needs is essential. There is a growing evidence-base for practical interventions across a range of domains including: changes to the environment, changes to food provided, the provision of nutritional supplements and education and training for both informal (family and friends) and formal (health and social care professionals) caregivers. A collective approach involving the person with dementia, informal and formal caregivers is required to support and address the individual nutrition needs of each person with dementia.

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