

Nutritional Care of Patients with Dementia in the Acute Setting

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Background

Dementia describes a number of conditions in which there is a progressive loss of brain function. The symptoms exhibited depend on the part of the brain affected and on how the individual attempts to compensate with this loss. As dementia progresses so does an individual's ability and desire to eat and drink resulting in decline in nutritional status. Admission to an acute hospital ward can exacerbate an individual's confusion, leading to behavioural symptoms and reduced nutritional intake. Many staff will not be trained in how to care for people with dementia, thus compounding the problem for the individual with dementia, their family, ward staff and other patients.

This article has three aims:

1. To outline the principles of a new model of care (developed by The Royal Wolverhampton Hospitals NHS Trust, sponsored by NHS West Midlands and supported by the University of Worcester's Association for Dementia studies) aimed at improving dementia care in general hospitals.
2. To discuss the physiological basis and manifestations of dementia from a dietetic perspective.
3. To consider the potential for gastrostomy feeding in some dementia patients. Although the case summary presented is atypical of the usual approach to nutrition support in this group, it highlights the need for individualised treatment planning.

The article concludes with some learning points which may be helpful to dietitians working with dementia patients in an acute hospital.

A new model of care

The aims of this model of care are to improve clinical outcomes and to provide cost effective care for patients with dementia. It has three elements:

1. A new ward (D22) specifically for the care of acute medical patients with dementia. The ward has been designed to foster a calm and quieter environment. There are day rooms with dining tables and music is usually being played. The nurses' stations and notes trolley are within the bays to facilitate contact between patients and staff. Nursing staff volunteered to be moved from elderly care wards, that is, they are interested in the person with dementia and readily develop an insight into their physical and psychological needs and triggers to behavioural symptoms, e.g. personal care, pain, not being able to locate the toilet.
2. The dementia out-reach team (consultant nurse, dementia specialist nurse, occupational therapist who undertake assessments and dietitian) who support patients and healthcare professionals on other wards and implement the care bundle approach for those individuals.

3. Training and staff development.

This composite approach to improving the quality and safety of dementia care is facilitated by the New Cross Hospital care bundle which, when applied, help the individual to feel more secure, optimise their nutritional (and fluid) intake and maintain their usual regime and degree of independence. It focuses on three elements of care: communication, nutrition and hydration and environment.

Background to dietetic involvement

Nutrition is implicated in the development of dementia. There is evidence that antioxidants are protective in the development of cognitive decline and dementia^{1,2,3} and that sub-optimal levels of folic acid and vitamin B12 are associated with cognitive decline in the elderly.¹ However, this article focuses on the problems of optimising the nutritional status of acute hospital patients with dementia. The project has provided two sessions of dietetic time to undertake direct patient work, facilitate catering developments and to support the multi-disciplinary team (MDT) and dementia

out-reach team. **Table One** outlines the causes of common dietary problems seen in dementia patients and suggests some strategies for overcoming them.

Enteral feeding

There is little, if any, evidence that tube feeding is beneficial to patients with advanced dementia.^{5,6,7,8} However, the decision making process is complicated when patients with mild to moderate dementia present with co-morbidities which are independent indications for enteral feeding, for example, stroke, Parkinson's disease and head and neck cancer. Another indication may be Down's syndrome, a risk factor for dementia, particularly as life expectancy is improving in this group. There is evidence that the ageing process is associated with dysphagia in people with Down's syndrome.⁹ The implication is that we may expect an increasing number of people with Down's dementia presenting with dysphagia and aspiration pneumonia at an earlier stage of their disease than would be expected in other forms of dementia.

Table One: Considerations for Providing Dietetic Input/Nutrition Support to People with Dementia

(adapted from Association for Dementia Studies course material⁴)

Part of Brain Affected by Dementia	Effect and Typical Symptoms/Signs	Impact on Nutrition	Hints and Tips
Temporal lobe	Memory, speech and understanding	Communicating dietary needs and factors which influence intake, e.g. pain	Seek information from family/carers. Orientating a patient to meal time. Assistance to eat and drink, providing food which can be eaten with fingers if patients can't use cutlery. Anticipating and treating pain or discomfort
Occipital lobe	Making sense of vision	Recognising food and drink, and identifying food from non food. May take food from other patients	Assistance at mealtimes, telling patient what they are eating. Clear non food clutter from table. Identify most appropriate drinking cup (beaker with spout may be difficult)
Frontal lobe	Reasoning, social behaviour, stopping and starting	Voracious appetite (e.g. Pick's dementia). Lack of inhibitions can be associated with behavioural problems, including the stealing of food from other patients	If voracious appetite is complicated by diabetes and obesity ensure low calorie foods and drinks are available between meals. Consider the need for supervision at meal times
Parietal lobe	Making sense of surroundings and how I fit into it	Patients who are disorientated and confused may be especially so in hospital, and this is likely to have a negative impact on appetite	Reassurance and reminding patients where they are and what time it is. Clock with a clear dial on their table. Familiar objects to help them locate their bed space
General			
Cognitive decline	Memory and communication problems, confusion, co-ordination difficulties	Ability to remember how to eat. Inability to recognise hunger and thirst	Patience when patient asks the same question repeatedly. Prompts and assistance, consider soft and possibly single textured food
Underlying illness	Investigate through U&Es, WCC, temp, chest, urine checks	Impact of illness on appetite may be compounded in dementia. Underlying illness can cause delirium to worsen existing symptoms associated with dementia	If there is a possibility patient may be in pain they need regular analgesia, not PRN
Sensory decline	Visual impairments, hearing loss	May compound confusion and communication problems and identification of food from non-food items	Check hearing aids and glasses worn and working if normally used
Nocturnal activity	Not sleeping at night and wandering around	May sleep during the day and mealtimes and/or have higher calorie requirements because of activity	Snacks and milky drinks for night time snacks when patient is most alert. High calorie snacks
Depression	Withdrawn, lack of interest	Reduced appetite and intake	Treat depression. Small meals with high calorie snacks or sip feeds
Medication	Various (e.g. antibiotics, digoxin toxicity)	GI disturbances may affect appetite	Review medications and how administered (discuss with team or ward pharmacist)

A case of successful PEG placement in a dementia patient?

Mr M is a 61 year old gentleman with Down's syndrome and moderate to severe learning disability and epilepsy, living in his own home with 24-hour carers. He was diagnosed with dementia in August 2009 and at that time was 62kg, 1.54m BMI 26.1kg/m² and eating and drinking well.

Mr M was admitted to New Cross Hospital in September 2011, suffering from aspiration pneumonia, deemed nil by mouth (NBM) and prescribed intravenous (IV) antibiotics. He was referred to speech and language therapy (SALT) and dietetics and commenced on naso-gastric (NG) feeding. Weight 60.3 kg. He failed to respond to IV antibiotics until the middle of October. During this period his resuscitation status was reviewed as per protocol, and his carers and next of kin were informed of the severity of Mr M's condition. However, NG

feeding, aside from some loose stools which resulted in some changes of rate and fibre content of feed, was otherwise well tolerated and meeting Mr M's estimated requirements. At the end of October, there was sufficient improvement for there to be consideration of discharge planning and methods of long-term nutrition. He was now trying small amounts of pureed diet and weighed 52.3kg (BMI 22.1kg/m²).

Mr M was transferred to ward D22 at the beginning of November, still receiving regular respiratory physiotherapy. He was receiving 1200kcal and 48g protein from his NG feed; 400kcal and 24g protein from semi-solid oral nutritional supplements and approximately 350kcal and 10g protein from pureed diet. His weight had stabilised at 52kg. The SALT recommended a trial of syrup thick fluids. The dietitian, following discussion with consultant, discussed the implications of gastrostomy tube feeding with Mr M's own carers, who continued to stay with him throughout his admission. They

agreed that, with appropriate training, they would be able to undertake care of the gastrostomy (if placed) and administer feeds as necessary. Accordingly, Mr M was discussed at the enteral feeding multidisciplinary team (MDT) meeting and assessed by the gastroenterologist who agreed that percutaneous endoscopic gastrostomy (PEG) placement was appropriate but that he was not yet fit enough for the procedure. By the third week of November, Mr M was taking pureed diet and semi-solid sip feeds well and his weight had increased to 55.7kg. Therefore, when his NG tube was dislodged the decision was made to leave it out, but continue to monitor weight and oral intake.

At the beginning of December, Mr M's weight had increased further to 58.9kg (BMI 24.8kg/m²). His oral fluid intake was between around 450mls and 750mls. A case conference was held to discuss discharge and future care needs, including issues around gastrostomy placement. In attendance were a senior member

of his own care team, next of kin (niece and advocate), consultant geriatrician (with a special interest in dementia care) and members of his team, nursing staff, representatives from the community learning disabilities service (Mr M was already known to them), SALT, physiotherapist and dietitian. The aims of future care for Mr M were agreed as:

- To maintain patient's quality of life in his own home for as long as possible
- To prevent further aspiration pneumonia
- To avoid another hospital admission.

Discussion points and actions agreed at the case conference are presented in **Table Two**.

PEG placement was arranged for two weeks time, during which period the care team underwent training on PEG care and Mr M underwent further occupational therapy assessment in preparation for discharge home. His fluid intake continued to be monitored and discussions held between his consultant and dietitian to be absolutely sure that PEG placement (with its inherent risks) was justified right up to the day of placement. Finally, the decision was swung by there being further episodes when it had been difficult to get Mr M to take his oral anti-epileptic medications. His weight was 61.7kg (BMI 26.0kg/m²) and oral fluid intake 450-960 mls.

Written information was provided to carers on tube care and water regime, 300mls plus flushes with medications. Guidance was also provided on providing a nutritious pureed diet and details for obtaining commercial meals if required. Mr M was recommended to continue with two semi-solid sip feeds/day.

Mr M was finally discharged on 23 December, three months after being admitted with aspiration pneumonia, which the admitting medical team felt he would be unlikely to survive. He was reviewed by the dietitian at the beginning of January. Although it was not possible to establish a weight for Mr M (avidly watching Rihanna on the TV) carers indicated that he was taking thickened fluids and diet extremely well, taking medications by mouth and was once again enjoying a quality of life. A review of his swallowing by SALT was requested, and this was undertaken at the beginning of February, the recommendations were to continue with pureed diet and thickened fluids and Mr M was subsequently discharged from their care.

While it could be argued that since the PEG (up to the end of February) has only been used to boost Mr M's fluid intake, its placement cannot be justified. However, while there is no indication that Mr M's swallow will improve, enough is known of

Down's syndrome in older adults to suggest that it is likely to deteriorate. Only time will tell, if the MDT decision really was the right one.

Conclusions

Nutritional problems are common in dementia patients but there are things that can be implemented even on a busy acute ward:

- Establish patient's normal eating preferences and find something that can be replicated on the ward. Consider therapeutic visiting to allow a relative to feed a patient
- Remove non-food clutter from tables
- Do not assume that dysphagia or food refusal in a patient with dementia is an indication of advanced disease, consider other causes, e.g. oesophageal stricture, cerebral event, infection.
- Enteral feeding is contraindicated in patients in end stage dementia, who are refusing food. However, do not exclude tube feeding for all patients with dementia, consider the stage of their dementia vs the impact of comorbidities on their nutritional status. Individuals with dementia are individuals. They need consideration of their own specific needs and this extends to nutrition support, and in some cases, even to tube feeding.

Table Two: Decision Making by the MDT for PEG Placement in the Context of an Ethical Framework

Ethical Principle	Action to Address this Ethical Issue	Outcome of Discussion with MDT
Autonomy	Patient did not have capacity to understand the potential risks and benefits of having a PEG – as decided by the learning disability service, consultant, carers and niece as power of attorney	The MDT believed a PEG was in Mr M's best interests in achieving the agreed aims of future care. Mr M's niece explained in a way he understood and he subsequently agreed to the principle of having a feeding tube
Beneficence	Supplementation of fluid intake	Oral fluid intake averaged around 600 mls/day. Although Mr M had apparently never drunk much there was concern that a further drop associated with taking thickened fluids or illness could risk dehydration for Mr M
	Reliable route for medication, especially anti-epileptics	Seizures often made it difficult while an in-patient to give oral medication, thus increasing the risk of further fits
	Minimise aspiration risk if swallow deteriorated	Avoid the need to administer oral fluids and/or fluids if patient's swallow deteriorated
	Facilitate the management of the patient in his own home as his condition progresses	If patient became unwell, hospital admission would be avoided. A PEG would facilitate the administration of medication, nutrition and fluids
Non maleficence	Would having a PEG prevent return to own home with carers he trusted?	Team were willing and motivated to be trained on PEG care
	Ensure patient is physically well enough to tolerate PEG placement	4 weeks recovery from aspiration pneumonia. Medical teams agreed fit for PEG at the time that the procedure was undertaken, representing a window of opportunity to place PEG when patient was at least risk of aspiration pneumonia
	Concerns that patient may be distressed by the tube, and/or pull the PEG tube and that if in pain this was more likely	Niece explained to patient who agreed. Had tolerated NG tube well. Prescribed regular analgesia post procedure
Justice	Mr M was considered for a PEG despite his diagnosis of dementia because it was believed to be in his best interests and would help to maintain his quality of life at home. He was not at the end stage of his dementia, was well supported at home and was considered to be able to regain a quality of life once discharged.	

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