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Nutrition & Hydration – Issues in Dementia Palliative Care

Eating and drinking can be difficult

Dementia alters dietary habits and a person with dementia may develop problems eating, drinking and swallowing. Challenges may also arise from forgetfulness and food habits that can disrupt dietary intake, eating and drinking routines. As the condition progresses, people with dementia may experience:

- Visual agnosia (e.g. difficulty recognising utensils and their function)
- Oral tactile agnosia (e.g. reduced recognition of or sensitivity to food/drink in the mouth)
- Apraxia for eating or swallowing (e.g. difficulty bringing food/fluid to the mouth & initiating chewing & swallowing)
- Behavioural difficulties with eating/drinking (e.g. holding food in the mouth, overfilling the mouth)
- Dysphagia (difficulty swallowing) & aspiration (food/drink 'going down the wrong way' and entering the airway)
- Need for assistance at mealtimes
- Weight loss and cachexia
- Malnutrition
- Dehydration
- Problems with oral health (e.g. dry mouth, ill-fitting dentures)

The person with dementia will communicate hunger and thirst in different ways and this is often subtle and needs people to know the person well to read these communicative signals. Continuity of care and consistency is a key part of good dementia care.

Aversive feeding behaviours

Dyspraxia/agnosia
Unable to use utensils, inability to distinguish food from non-food, walks away from table.

Resistance
Turns head away, blocks mouth with hands, bites assistant, spits or throws food.

Oral neuromuscular incoordination
Will not open mouth, continuous tongue or mouth movements preventing ingestion, chews without swallowing

Selective behaviours
Prefers or will only eat particular types of food, flavours or consistencies, including, sometimes, fluids only.

Sources: Prince, M., Albanese, E., Guerchet, M., & Prina, M. (2014). Nutrition and Dementia: a review of available research (Doctoral dissertation, N/A Ed. London: Alzheimer's Disease International).
https://www.alz.co.uk/nutrition-report
http://www.kcl.ac.uk/ioppn/depts/hspr/research/cgmhpcr/Projects/GlobalObservatoryforAgeingandDementiaCare.aspx

The Irish Hospice Foundation

This factsheet has been developed based on Irish Hospice Foundation Dementia Palliative Care Guidance Document No 4. Management of Hydration and Nutrition. Available from www.hospicefoundation.ie

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Think Food First

- Find out what the person's food preferences were and encourage these foods and fluids. Some people with dementia develop a marked preference for sweet foods so these may be more appetising to the person than savoury foods.
- Ensure appropriate food and fluids are easily available throughout the day and night so that the person with dementia can be encouraged to eat and drink whenever he/she is most alert.
- If a person with dementia frequently wakes at night it is worth considering whether he/she is waking because of hunger.
- Encourage food and fluids little and often. Many elderly people (with or without dementia) do not have a large appetite, and nutritional needs are more likely to be met via six or so small meals and snacks per day rather than three bigger meals.
- Encourage higher calorie foods and drinks. Avoiding high fat and high sugar foods at this stage is unlikely to be beneficial to health and may increase the risk of malnutrition. People at risk of malnutrition should therefore generally avoid low fat, low sugar, low calorie and diet foods and drinks.
- Consider food fortification (e.g. dried milk powder can be added to milk for cereal or drinks, custard, porridge, yogurt, milk puddings, cream soups, mashed potato etc.) There are many other simple ingredients which can be used to fortify food and drinks.

An individualised plan of care, endorsed by the person with dementia, a key family member or advocate, with twin objectives of providing adequate food and fluid intake and maintaining self-feeding ability is recommended best practice

What about Clinically Assisted Nutrition and Hydration?

Where a person has advanced dementia, he/she may have problems swallowing (dysphagia). In such cases, the goals of care change to a focus on comfort.

The research is in clear agreement that the long-term use of artificial hydration and nutrition in people with end-stage dementia is not appropriate.

Ethical and legal principles should be applied when making decisions about withholding or withdrawing nutritional and hydration support.

Good communication with the person with dementia and their family is imperative. It is important that information is provided in a coordinated manner ensuring that the person's preferences are elicited and respected as an important target for improving the quality of care of persons with advanced dementia.

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Hydration and Nutrition for the end-of-life care of a person with dementia

Regular multidisciplinary assessment and reassessment is vital

- People with dementia may communicate hunger or thirst differently.
- The person may have reduced appetite and may prefer smaller volumes more often.
- Various assessment methods can inform the hydration and nutritional status.
- Nurses have a key role in the provision and monitoring of nutrition and hydration.

Hydration can be assessed by:

- Variation in blood pressure measurements.
- Dryness of the tongue and mucous membranes.
- Complaints of persistent tiredness, nausea, confusion, back pain, rapid breathing, dry mouth, lethargy, heartburn, muscle weakness, dizziness, headaches, dry eyes or constipation.
- Substantial decrease in urinary volume and thirst

Nutrition can be assessed by:

- Dietary evaluation methods (e.g. 24 hour dietary recall, food frequency questionnaire and food records).
- Body measurements such as weight or BMI
- Biochemical, laboratory methods (e.g. full blood count, electrolytes, urea and creatinine, fasting glucose, albumin and ferritin).
- Clinical methods (e.g. detailed history, assessment tools such as fluid balance chart, MUST, MNA).

Refer if necessary to

- Speech & Language Therapy for assessment of swallow and advice on appropriate food and drink consistencies.
- Occupational Therapy for assessment and recommendation of environmental changes and equipment.
- Clinical Nutrition for dietary advice.
- Physiotherapy for advice on seating and posture when eating.

Review the environment for these four negative environmental influences at mealtimes

1. Visual overstimulation in a crowded room.
2. Poor lighting.
3. Lack of visual contrast when objects/food are close together or on top of each other.
4. Auditory confusion secondary to background noise.

Oral feeding assistance can be enhanced by altering the environment and creating person-centred approaches to eating and drinking, with the aid of multi-disciplinary assessment. Careful hand feeding assistance should continue when a person accepts and appears to gain pleasure from oral intake.

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Oral Health

Often at the end of life care of a person with dementia may develop dental disease indirectly as a result of his/her dementia, this is associated with a loss of awareness of oral health measures. Subsequently, when a person is not eating or drinking, or has no appetite, it is important for the person's mouth to feel comfortable.

6 steps to maintain oral health of a person with dementia.

1. Conduct an assessment of the mouth in a good light (for example, using a hand-held pen torch) to provide a baseline for routine oral care.
2. Clean the mouth with water-moistened gauze and protect with a lubricant to minimise the risk of dry, cracked and uncomfortable lips.
3. Some people will need assistance in brushing and denture care.
4. If person has dentures, ensure dentures are stored in optimal solution and fit appropriately.
5. Clean dentures with individual brush under running water over a sink of cold.
6. Adequate oral health care is carried out preferably after every meal and before bedtime every night.

Assessment and management of eating difficulties in people with dementia is aimed at optimising oral intake as safely as possible in order to preserve the pleasure and necessity of eating and drinking.

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Hydration and Nutrition for the end-of-life care of a person with dementia

Eating, Drinking & Swallowing Difficulties in Dementia Advice for Healthcare Professionals

As we age, our swallow changes.

- We may experience reduced smell and taste, which can affect appetite.
- Reduced saliva makes it more difficult to chew food.
- Reduced muscle strength means food takes longer to swallow.

What is dysphagia?

Dysphagia is the medical term used to describe difficulty with eating, drinking and swallowing. This includes swallowing food and fluids, as well as swallowing saliva and medications.

Dysphagia may range from a mild problem (difficulty only with certain foods, for example) to a more severe problem (inability to safely swallow any food or fluids).

Is dysphagia common in dementia?

Research shows that dysphagia is very common in dementia, especially in the later stages. 90% of people with dementia experience swallowing difficulties in the final three months of their life.

Dementia can affect many different aspects of mealtimes.

- **Memory and concentration:** A person with dementia may forget to eat, or forget that there is food in their mouth and that they need to swallow. The person may forget to chew, or may hold food in their mouth. The person may talk with food still in their mouth – this puts them at risk of choking (having the food 'go down the wrong way').
- **Perception/agnosia:** The person may have difficulty recognising food or drink, or utensils such as plates and cutlery.
- **Motor difficulties:** The person may have difficulty with coordination and being able to use cutlery.

Medications may also cause dry mouth, making swallowing more difficult.

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Eating, Drinking & Swallowing Difficulties in Dementia Advice for Healthcare Professionals

Signs/Symptoms of Dysphagia

Drooling
Difficulty chewing food
Coughing
Choking
Facial Grimacing
Red face
Watery eyes
Increased 'chestiness' after eating/drinking
Wet/gurgly/husky voice
Food residue remaining in mouth
Increased respiratory rate during/after eating & drinking
Unexplained weight loss
Temperature spikes
Repeated chest infections
Pneumonia

Feeding behaviors which may increase risk of aspiration in dementia

Tendency to eat rapidly/impulsively

Talking while eating

Agnosia – difficulty visually recognising food

Pica – eating non-food items

Biting on utensils

Tongue thrusting

Pocketing food in cheeks or holding food in mouth

Spitting out food, difficulty dealing with 'lumps' in food

Essentials when feeding a person with dementia and dysphagia

- Always following the individualised advice given by a Speech & Language Therapist
- The person should be awake and fully alert for all oral intake.
- The person should ideally be seated 90° upright, in midline position, as much as possible.
- Try to minimise distractions to help the person concentrate on their meal. Turn off the television or radio.
- Tell the person what is happening, and what food/drink the person is having. *('Hello Mary, it's breakfast time. Let's try some of your porridge').*
- If feeding the person, give small sips/ spoonfuls/ bites, one at a time.
- Never try to force-feed a person who is refusing oral intake.
- Check that the person has swallowed before giving the next sip/spoonful/bite.
- Stop feeding if the person becomes drowsy, slower to swallow or short of breath.
- Always check the person's oral cavity for residue after eating.
- Perform oral hygiene after all intake to minimise the risk of aspirating bacteria in oral secretions.
- Ensure the person remains upright for a minimum of 30 minutes after oral intake, to decrease the risk of reflux and potential aspiration of same.

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