

GUIDANCE DOCUMENT 4

Management of Hydration and Nutrition



Palliative Care for the Person with Dementia

Guidance Document 4: Management of Hydration and Nutrition.

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This is a guidance document provided for information and educational purposes only. It has been designed to assist healthcare providers by providing an evidence-based framework for decision-making strategies. It has been published in accordance with available evidence at the time of publication.

This guidance document is not intended as a sole source of guidance for decision making for the management of hydration and nutrition of people with dementia.

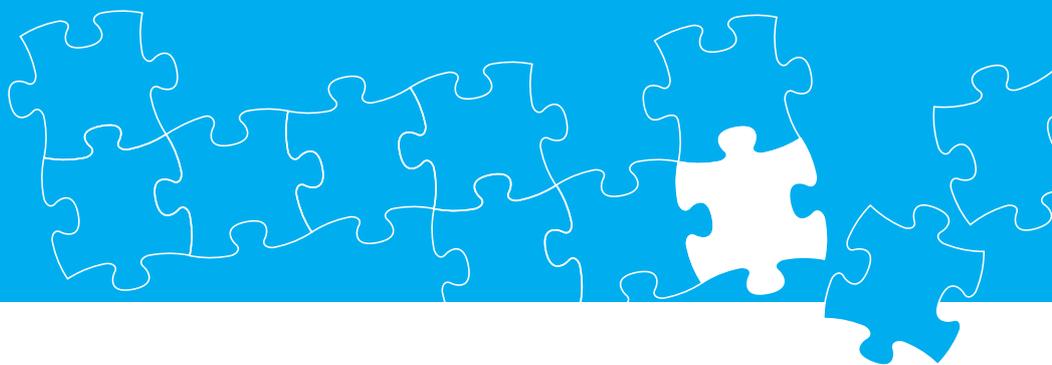
This guidance is not intended to replace clinical judgment or establish a protocol for all individuals with this condition. Guidance documents do not purport to be a legal standard of care. The guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of individual patients in consultation with the patient and/or family. Adherence to this guidance will not ensure successful patient outcomes in every situation.

The Irish Hospice Foundation, 2016

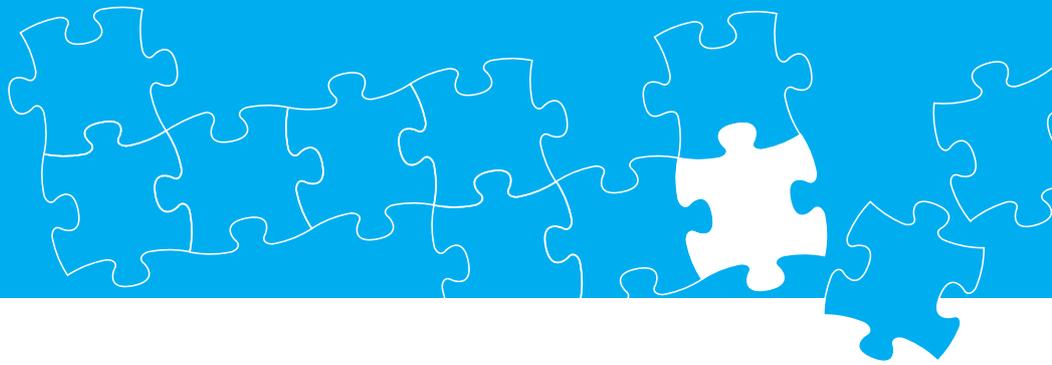


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Contents



1. Background	5
2. Introduction to this guidance document	6
3. Themes from the literature	9
4. Overarching principles to guide good practice	11
5. Guidance and resources	12
Guidance 1. Common Eating, Drinking and Swallowing Difficulties in People with Dementia	12
Guidance 2. Assessment of Hydration and Nutrition	16
Guidance 3. Management of Hydration and Nutrition	22
Guidance 4. Decision-Making – Balancing Different Views	26
6. Additional Resources	35
6.1 Understanding the progression of dementia	35
6.2 Factsheets to accompany this document	37
7. Conclusion	43
APPENDIX 1 - Steering and project group membership	44
APPENDIX 2 - Methodology	45
References	49



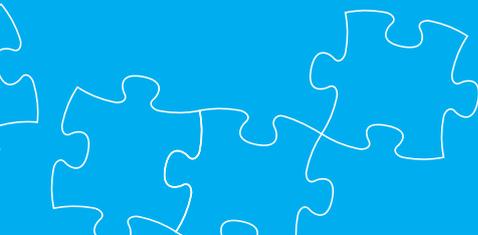
WHAT IS PALLIATIVE CARE?

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO (2016) Definition of Palliative Care <http://www.who.int/cancer/palliative/definition/en/>



GLOSSARY OF TERMS

Agnosia: An inability to recognise and identify objects or persons. Agnosia can be limited to one sensory modality such as vision or hearing. For example, a person may have difficulty in recognising an object as a cup or identifying a sound as a cough. Agnosia can result from strokes, dementia, developmental disorders, or other neurological conditions.¹

Apraxia: Disruption to the selection, motor programming and online control of voluntary movements². Apraxia may affect different patterns of movement, such as apraxia of speech, apraxia of swallow, or apraxia for self-feeding.

Aspiration: Entry of secretions, food, or any foreign material into the airway that travels below the level of the true vocal folds. Aspiration may occur before, during, or after the pharyngeal phase of swallowing. It can also occur from reflux of gastric contents³.

Dysphagia: Eating and drinking disorders which may occur in the oral, pharyngeal and oesophageal stages of deglutition². Dysphagia includes difficulty swallowing food, fluids, medications and a person's own saliva.

Oral Intake: Placement of food in the mouth; oral gestures used to prepare food for the swallow and gain pleasure from eating; and tongue movement to initiate the oral stage of the swallow. This sometimes refers to the amount of food or liquid the individual is able to take in by mouth³.

Oral care: The effective removal of plaque and debris to ensure the structures and tissues of the mouth are kept in a healthy condition.

Xerostomia: Dry mouth resulting from reduced or absent saliva flow. Xerostomia may be a symptom of various medical conditions, a side effect of radiation to the head and neck, or a side effect of a wide variety of medications. It may or may not be associated with decreased salivary gland function⁴.



BACKGROUND

Dementia is an umbrella term used to describe a condition which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function including; decline in memory, reasoning, communication skills and in the ability to carry out daily activities⁵. The number of people living with dementia in Ireland today is estimated to be around 48,000 and this number is set to treble by 2045⁶. Dementia is a chronic, life limiting condition⁷⁻⁹.

People with dementia have a unique set of care needs which include: a progressive cognitive impairment; diminishing capacity; communication difficulties; possible responsive behaviours and a prolonged illness trajectory leading to uncertainty in relation to prognosis^{5,10}. People dying with and or/from dementia require staff to have knowledge, skills, competence and confidence in both dementia and palliative care¹¹. Palliative dementia care involves supporting the person with dementia and their family to address and relieve the pain, distress and discomfort associated with advancing dementia and inviting them to participate in making decisions about future care needs¹². Providing this care and comfort presents services with a significant challenge as each person's journey through dementia is unique with huge variability in the length of the final phase, difficulties in communication and a lack of awareness about the terminal nature of dementia^{9,13}. This is often compounded by staff lacking basic knowledge, awareness and skills in supporting people with dementia^{5,9}. It is recommended that palliative care principles are introduced in the person's care early on, ideally soon after diagnosis when the person can meaningfully engage in discussions about their future care^{7,12,13}.

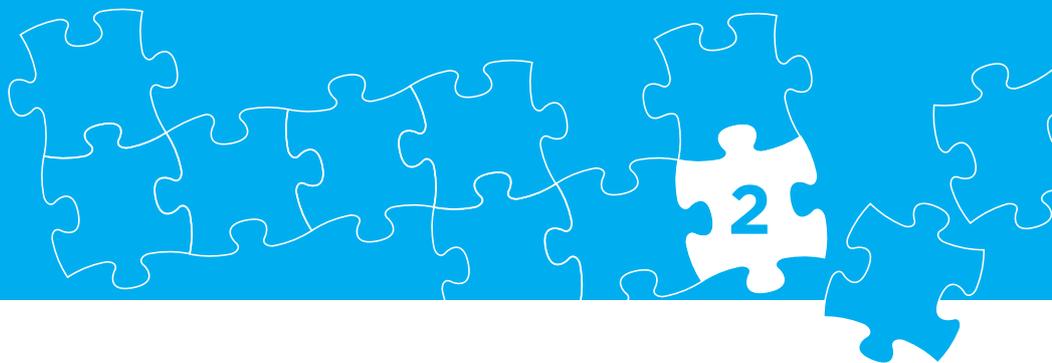
As illustrated, there has been growing recognition of the complexities involved in providing end-of-life care for people with dementia in the literature; however, there is a notable void of practice guidelines to support healthcare staff in delivering excellence in end-of-life care for people with dementia. In order to support staff in meeting the palliative care needs of people with dementia, there was a call for the development of practice guidelines for the Irish context^{12,14,15,16}.

The following series of guidance documents has been developed as part of the Irish Hospice Foundation's Changing Minds Programme:

1. Facilitating discussions about end-of-life care with the person with dementia
2. Advance healthcare directives and advance care planning
3. Loss and grief in dementia
4. Management of hydration and nutrition
5. Pain assessment and management
6. Ethical decision-making
7. Medication management

Irish Hospice Foundation (IHF) have taken the lead for the development of guidance documents 1 – 3 with assistance from relevant experts. University Collge Cork (UCC) successfully tendered for the development of the guidance documents 4-7.

The steering group and project team overseeing the development of this guidance document are listed in Appendix 1.



INTRODUCTION TO THIS GUIDANCE DOCUMENT

“Over the course of the dementia trajectory, maintaining oral intake of food and fluids can be challenging. Oral health and dysphagia are two issues that can impact upon both adequate oral intake and comfort in severe dementia. Weight loss may cause concern and can become inevitable as death draws near. Artificial nutrition and hydration are not generally considered a helpful option in severe dementia”.

Australian Government Initiative¹⁷

Dementia is a progressive, life-limiting and incurable condition with a varying trajectory depending on both the type of dementia and the stage of its severity (see Section 6 – Additional Resources). People living with dementia may experience problems with eating, drinking and swallowing and have a reduced appetite. This can result in potential nutrient deficiencies¹⁸, significant weight loss and vitamin deficiency^{19,20} which in turn can lead to sub-optimal health, increased risk of fractures following falls, poor concentration and behaviours which further negatively impact on eating and drinking. As a person’s dementia progresses, maintaining oral intake of food and fluids may be challenging and guidance regarding evidence-based approaches to care is required.

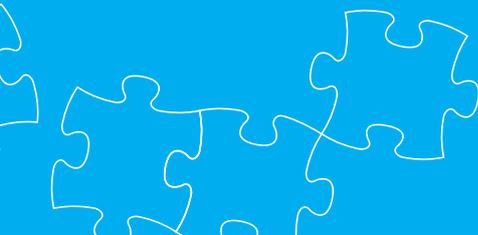
Aim

The aim of this guidance document is to provide evidence-based guidance for healthcare workers on best practice in relation to the assessment and management of hydration and nutrition for a person with dementia throughout their dementia journey. This in turn will support healthcare professionals in their decision-making and communication with the person with dementia and their families/carers.

Despite the presence of evidence-based guidance, ethical dilemmas and difficult decision-making situations may arise in practice and readers should also consult Guidance Documents 1, 2 and 6 in this series.

Who is this document for?

Clinical and non-clinical healthcare staff working in any setting who care for a person with dementia.



How to use this document

This guidance was developed after careful consideration of the evidence available at time of publication and is provided for information and educational purposes. It has been designed to assist healthcare providers by providing an evidence-based framework for decision-making strategies.

This guidance document is not intended as a sole source of guidance for decision-making for the management of hydration and nutrition of people with dementia and is not intended to replace clinical judgment or establish a protocol for all individuals with this condition. It does not purport to be a legal standard of care and does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of individual patients in consultation with the patient and/or family.

The factsheets have been developed to summarise key points that may be useful in practice and can be displayed in the clinical area for reference.

Links to resources considered useful for people with dementia and/or family caregivers are included where appropriate at the end of the guidance document.

Scope of guidance document

Existing guidance is available to support healthcare staff in ensuring that people receive good nutritional care, adequate hydration and a positive mealtime experience^{21,22,23,24}. However, such documents lack specific reference to maintaining hydration and nutrition when a condition, such as dementia, progresses. This document is intended to address this identified deficit and should be read in conjunction with such existing guidance.

This guidance document will:

1. Outline common eating, drinking and swallowing (EDS) difficulties for people with dementia, with a particular focus on the end of life.
2. Consider a systematic approach to the assessment and screening of EDS difficulties for people with dementia at the end of life
3. Outline the appropriate management of hydration and nutrition issues in end-of-life care of a person with dementia.
4. Consider decision-making and balancing different views with regard to hydration and nutrition at end of life for people with dementia.



Development of guidance document

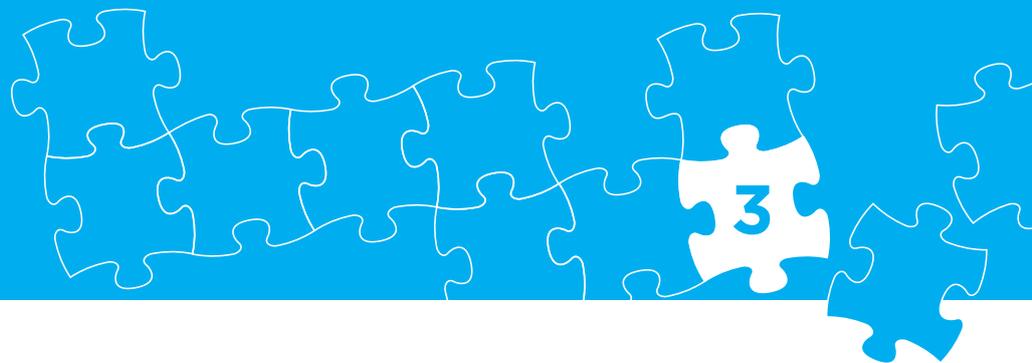
This guidance document was developed by a project team and overseen by a steering committee (*please see Appendix 1 for membership of both groups*) using the process below.

1. Completion of scoping review.
2. Collation of key review themes to inform the guidance and principles of assessment and management of hydration and nutrition.
3. Preparation of Draft 1 of guidance document for comment by the project steering committee and national/international experts in the field.
4. Preparation of Draft 2 for external consultation.
5. Assimilation of feedback from external consultation to final draft. Final version published.

Structure of guidance document

The guidance provided in this document focuses on four key areas, based on the agreed key themes emerging from the scoping review considered most beneficial for professional and non-professional caregivers, together with the expert advisor's feedback (who indicated specific areas that staff may benefit from guidance on based on their experience in practice). These areas are examined in detail in the following sections, together with the underlying principles that guide the management of nutrition and hydration in people with end-stage dementia. Where applicable, we have signposted available resources and tools to assist professional and non-professional caregivers.

This document should be read in conjunction with the other guidance documents in this series produced by the Irish Hospice Foundation available via www.hospicefoundation.ie



THEMES FROM THE LITERATURE REVIEW

Dementia palliative care incorporates the qualities of person-centred dementia care and the holistic focus of palliative care. Both models share a person-centred philosophy and a set of underlying principles that focus on quality of life, whole person care, a respect for autonomy and care of the person and their family⁴. Person-centred care seeks to support and maintain personhood through relationships and recognises the need for attachment, comfort, identity, occupation and inclusion^{24,25}. These are the core values that underpin and inform this guidance document in order to support people with dementia to live well and die with dignity. The need to support a person with dementia to plan their future care early in the trajectory of their condition has been well documented^{3,8,26,27,28,29}.

A scoping study was undertaken to inform the development of this specific guidance document. The review of literature yielded a number of themes:

Literature review themes

1. Challenges associated with hydration and nutrition at end-of-life in dementia.
2. The role of the multi-disciplinary team and the environment in the management of hydration and nutrition at end-of life in dementia.
3. Care planning and advance discussions.
4. Clinically Assisted Nutrition and Hydration (CANH) at end-of-life in dementia.

The key themes were presented to the project team. These themes were grouped into four overarching principles to guide optimal hydration and nutrition at the end of life for people with dementia (Figure 1). In addition, four areas of specific guidance staff considered key to informing good practice for the management of hydration and nutrition at the end of life for people with dementia are outlined in this document.

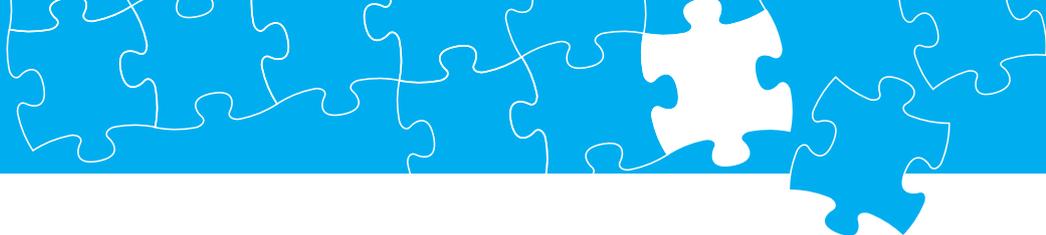
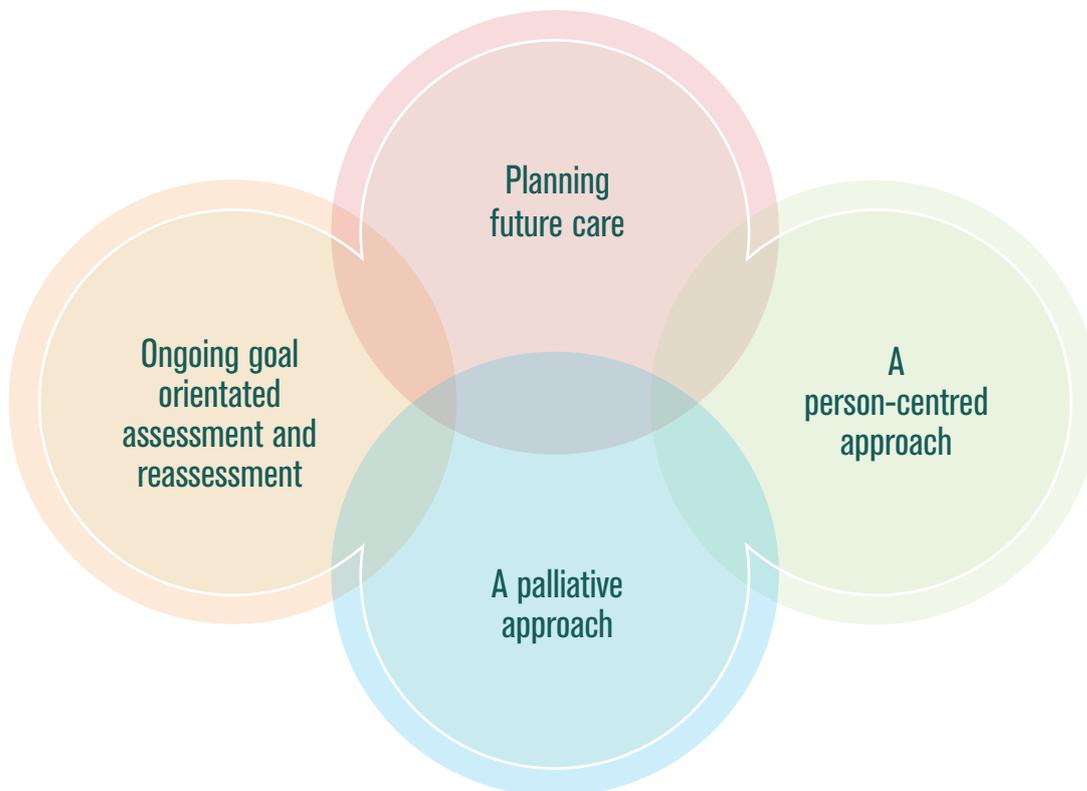
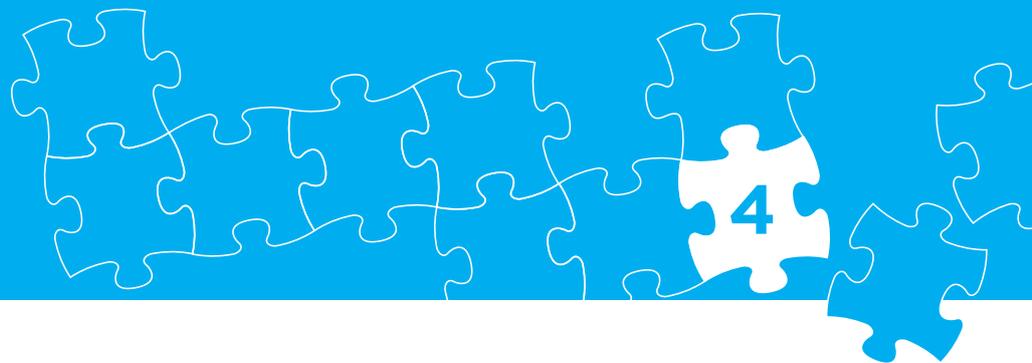


Figure 1: Four overarching principles for for optimal hydration and nutrition for people with dementia.





OVERARCHING PRINCIPLES TO INFORM GOOD PRACTICE

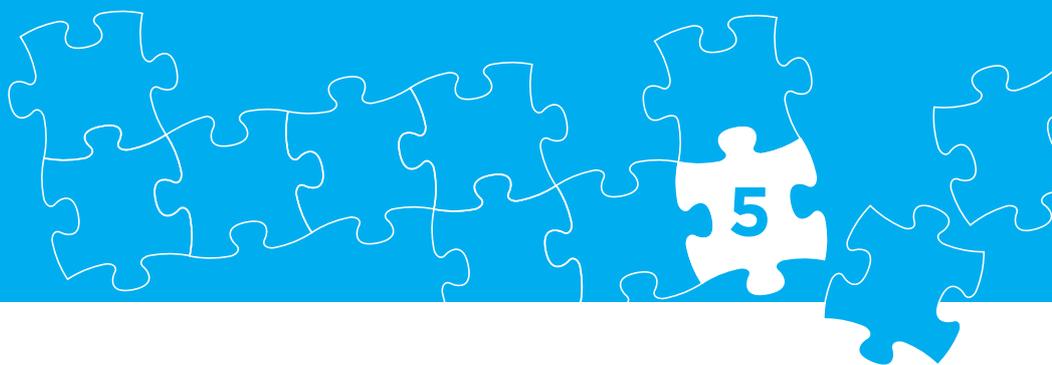
A set of four overarching principles for optimal hydration and nutrition for people with dementia have been agreed by the project team, based on the themes emerging from the literature. These should guide best practice when working with people with dementia.

Planning future care should occur at an early stage for a person with dementia³⁰. A discussion should take place with the person about their preferences and wishes in relation to hydration and nutrition as soon after the diagnosis as possible³¹ (also see Guidance Document 1 and 2). These conversations should be revisited and reviewed on a regular basis with the person. Every effort should be made by staff to find out the person's preferences relating to food and drink on an ongoing basis, and this should be shared with the team to ensure good quality care. The person with advanced dementia will often communicate this in subtle ways such as body language, using their eyes, turning their head, facial expression, acceptance or rejection of oral intake etc and staff need to be reminded that it is essential to be 'tuned in' to this. It should also be noted that these interactions/wishes should be documented and shared with all key staff working with that person.

A **palliative approach from diagnosis to death** to support the *quality of life* of people with dementia should be adopted.³¹⁻³⁶ This approach should extend to the proper assessment and management of hydration and nutrition. Where a person appears to get enjoyment from eating or drinking, this activity should continue³⁷. Even though a person with dementia has a cognitive impairment, that person may retain capacity to make some decisions, especially when care is taken to maximise the person's communication abilities. The person's autonomy can still be promoted through adherence to his/her advance plans/directives and continued respect for his/her current wishes regarding hydration and nutrition where possible.

A **person-centred approach to care** seeks to support and maintain personhood through relationships and recognises the need for attachment, comfort, identity, occupation and inclusion²⁴. With regard to hydration and nutrition, it is important to know about the person with dementia's relationship with food and drink throughout their lifespan, their taste preferences and consider how the condition of dementia might change these. The loss of neurocognitive and motor skills can make a person's relationship with food and drink difficult and this can reduce the enjoyment they may obtain from the experience of eating and drinking whilst impacting on their optimum hydration and nutrition. Therefore a person-centered approach to meals and nutrition is founded on getting to know the individual, their needs and preferences³⁸.

Ongoing goal orientated assessment and reassessment of hydration and nutrition, with MDT input as necessary, is essential for optimal hydration and nutrition of people with dementia. Assessment is holistic including physiological data, together with psychological, sociocultural, spiritual and life-style domains. A thorough assessment and reassessment of the person with dementia will identify their needs and inform management strategies as their condition progresses. People with dementia often lose the ability to recognise hunger and thirst and therefore various strategies should be implemented to ensure that the person with dementia is able to eat and drink comfortably and is provided with food and drink at times and in quantities adequate for his/her needs. Identifying an individual's goals at various stages of dementia will address factors associated with poor hydration and nutrition. The individual's ability to set goals may be compromised, therefore the assessment typically should include consideration of the person's experience and/or their will and preference together with caregiver reports.



GUIDANCE AND RESOURCES

Guidance Area 1

Common Eating, Drinking and Swallowing Difficulties in People with Dementia

Dementia alters dietary habits and a person with dementia may develop problems eating, drinking and swallowing. Challenges may also arise from forgetfulness and eating habits that can disrupt dietary intake, eating and drinking routines (Box 1). 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 independent feeding or swallow (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) and 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)

BOX 1

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.

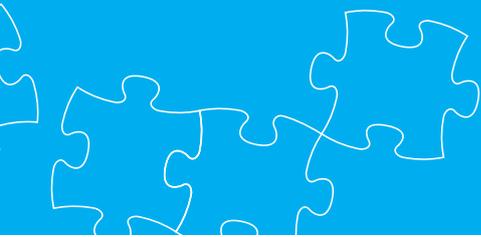
Oral neuromuscular incoordination

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

Evidence suggests that difficulty eating and drinking is a marker of advanced dementia and the appearance of dysphagia is often a sign of further disease progression^{39,40}. People who have difficulty with eating and drinking are at risk of nutritional decline, thereby at significant risk of death during the following year, regardless of the underlying diagnosis⁴¹. Whilst weight loss in advanced dementia can sometimes be stabilised through nutritional support, it also is a strong predictor of impending mortality⁴¹. As people approach the end of their lives, decreased interest in food is normal³⁶. The body's increasing inability to absorb nutrients is often accompanied by loss of appetite, thirst and difficulty swallowing^{39,42}. However, the body adapts at the end of life and this prevents people from suffering as a result of the absence of food⁴³. Cachexia, where an individual is unable to absorb adequate nutrients from food, even when intake is sufficient, may be viewed as a way of the body preparing itself for death, with the person no longer wanting food and becoming very tired and weak⁴⁴.

Almost 90% of people with dementia experience problems with eating, drinking and swallowing (EDS) in the final three months of life⁴⁵. Challenges encountered in EDS in advanced dementia as a person comes to the end of their life include:

- oral versus clinically-assisted nutrition and hydration (CANH)
- maintaining nutrition and hydration
- carer concerns regarding ongoing risk of aspiration
- balancing different views

The Peterborough Guide for Hydration and Nutrition in Advanced Dementia (Box 2) recognises the importance of a 'Food First' approach from the time of diagnosis for those at risk of malnutrition. Food is the first choice to correct or prevent under-nutrition in a person with dementia. This should include understanding the preferences of the person, ensuring that high calorie food and drink is available throughout the day and night and that food is fortified as necessary⁴⁶.

The principles outlined in Box 2 are appropriate to follow in late stage dementia, even if the person's food and fluid intake is very poor.

Assisting someone who is sick to eat and drink is a 'powerful instinctive act' and the human contact provided by the act of assisting with food and drink may be of therapeutic benefit^{47,48}.

A palliative approach with careful assistance to eat and drink is considered to be the most appropriate option of care for people with dementia at end-of-life. When interest in food is negligible, the individual should not be forced to receive nutrition⁴⁹.

BOX 2: Peterborough Guide⁴⁶

- Find out what the person's food preferences were and try encouraging these foods and fluids. However it is also important to remember that for some people with dementia food preferences can change, and some people with dementia start to prefer foods or fluids that they did not previously like. 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.

As a person's condition progresses, he/she may spend longer periods of time in bed and become dependent on others for all care, and have limited ability to communicate⁵⁰. He/she may also present with other co-morbidities (e.g. intellectual disability, previous cerebrovascular accident, chronic obstructive pulmonary disease) which of themselves can impact on swallowing, and the person's overall functional baseline. The person with end-stage dementia is likely to present with aspiration pneumonia and dehydration/malnutrition as a result. Appropriate assistance is offered in a discreet and sensitive manner to enable the person to eat and drink safely when necessary.

Food has an emotional, symbolic and social importance which should not be underestimated. When a person with dementia is no longer able to eat and drink in the way that they would have, this is yet another loss and change in the landscape for the person and for their family/carers. Grief is a natural response to this loss and may evoke a range of responses from the person with dementia and their family (see Loss and Grief in Dementia Guidance Document 3).

Clinically Assisted Nutrition and Hydration

The research is in clear agreement that the long-term use of artificial hydration and nutrition in patients with end-stage dementia is not appropriate^{23, 24, 25 – 27, 30,31,34,50,51}

Artificial feeding should not be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity³¹ (p. 42).

This is further discussed in Section 4.

Guidance – Knowledge of hydration and nutrition issues for the end-of-life care of a person with dementia.

1. Ensure all members of multi-disciplinary team understand hydration and nutrition issues at end-of-life in dementia.
2. Access to education on end-of-life care in dementia and palliative care should be available to those who care for the person with dementia in hospital, residential care settings or at home so that care is provided by health professionals and caregivers with appropriate knowledge and skills.
3. Regular review of hydration and nutrition is undertaken involving appropriate formal and informal carers. Healthcare professionals are aware of review principles and tools which may assist in the review in this process.
4. A Food First approach is important throughout the trajectory of care for a person with dementia.
5. Artificial feeding should not generally be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity³¹ (p. 42).
6. Long-term use of artificial hydration and nutrition in people with end-stage dementia is not appropriate



Guidance Area 2:

Assessment of Hydration and Nutrition

Advanced dementia is characterised by dependence on another person to assist with eating and drinking to achieve optimal nutritional intake. The risk of being malnourished and dehydrated increases due to the nature of dementia as a progressive illness, coupled with increasing age. It is therefore essential that adequate systems are in place to assess and monitor hydration and nutrition for persons with dementia⁵² together with assessment of issues that may impair a person eating, swallowing or drinking. There is little evidence that people in end-stage dementia experience significant levels of hunger or thirst⁵³. A holistic assessment by a skilled multi-disciplinary team is recommended in order to provide an individually tailored plan of care⁵⁴.

The assessment and management of hydration and nutrition for persons with dementia entails a multi-disciplinary systematic approach informed by the use of a decision-making pathway, tailored to the person's cognitive and related communication abilities. The National Consent Policy⁵⁵ states that the health professional who is providing the particular health and social care service is ultimately responsible for obtaining the informed consent of the person for any proposed intervention. The onus is on the healthcare professional to communicate in a way that maximises the person's participation and ability to understand the information presented and express their will and preferences.

See Discussion on CANH below and guidance documents 1, 2 and 6 for more information on communication and decision-making.

Guidance on nutritional assessment for persons with dementia is available from a number of organisations^{21,22,31,34,40,56,57}

The Health Information and Quality Authority (HIQA) in 2008, produced the National Quality Standards for Residential Care Settings for Older People⁵⁸, to help improve and insure the quality and safety of residential care. They have also recently launched guidance regarding nutrition and hydration specific to residential care services for older people and acute hospitals^{21,22}

Multi-disciplinary evaluation of eating, drinking and swallowing needs is an integral part of a comprehensive approach to end-of-life care⁵⁹. A careful multidisciplinary approach to nutritional assessment is necessary for both the successful diagnosis of dehydration and nutrition difficulties and appropriate management. The assessment process should consider all situations and behaviours which might impact on food intake and should take a whole person approach, considering relevant psychosocial and spiritual factors.

Care planning should therefore have a multi-disciplinary focus, including:

- The person with dementia and/or family/carers
- Medical team
- Nursing staff
- Dietitian
- Speech and Language Therapist
- Physiotherapists and Occupational Therapists
- Healthcare assistants and catering staff

The purpose of hydration and nutrition assessment is to:

- Identify individuals who are at risk of becoming dehydrated.
- Identify individuals at risk of undernutrition or who are malnourished.
- Develop a care plan that is appropriate and attainable to meet the person's needs, as defined by the assessment.

Direct methods of assessment of dehydration include:

- 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, constipation, or darker coloured urine. Substantial decrease in urinary volume and thirst.

Direct methods of nutritional assessment are often summarised as ABCD

- Anthropometric methods (e.g. body measurements such as weight, 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 MUST).
- Dietary evaluation methods (e.g. 24 hour dietary recall, Food Frequency Questionnaire (FFQ) and food records).

Hydration Assessment

Optimal hydration in older adults is a common yet complex problem, requiring a comprehensive approach. Timely recognition of dehydration is essential. Dehydration occurs as a result of a low fluid intake, excess fluid loss (excessive sweating, vomiting or diarrhoea), or a combination of both^{21,22} Dehydration in older adults can result in reduced cognitive performance, constipation, delirium, infections, renal failure, shock, seizures, brain damage and death⁶⁰

Popkin et al⁶¹ assert that a consensus on a “gold standard” for hydration markers, particularly for mild dehydration is non-existent. Terminal dehydration in people who are close to death is beneficial in the sense that it reduces respiratory and gastrointestinal secretions³⁹. Classical dehydration symptoms such as diminished skin turgor, increased thirst, oliguria, low blood pressure and orthostatic hypotension are less sensitive and less specific in elderly people. There is no ratified dehydration assessment tool that we are aware of at the time of print⁶².

Nutrition Assessment

Undernutrition, insufficient calories, protein or other nutrients¹² can lead to serious health consequences such as weight loss, dehydration, poor wound healing and pneumonia¹⁴. The cause of malnutrition is usually multifactorial⁶³. Clinical assessment utilises a number of physical signs, (specific and nonspecific), that are known to be associated with malnutrition. In conjunction with a

nutritional history, a general clinical examination – with special attention to hair, angles of the mouth, gums, nails, skin, eyes, tongue, muscles, bones and thyroid gland should be conducted. A nutritional assessment is an essential feature of all nutritional surveys as it is the simplest and most practical method of ascertaining the nutritional status. A nutritional assessment is non-invasive and inexpensive to perform; however, it can fail to detect early signs of malnutrition.

Nutritional assessment tools include the Mini-Nutritional Assessment (MNA)^{64,65} and the Malnutrition Universal Screening Tool (MUST)⁶⁶, which were developed and validated to identify malnutrition or those at risk of malnutrition. Self report is always preferable, however this may be a significant challenge for the person with dementia so therefore, food recall questionnaires are often administered. Dietary assessment can also be assessed by other methods. These include:

- 24 hours dietary recall
- Food Frequency Questionnaire
- Dietary history
- Food diary
 - Observed food consumption
 - Addressing difficulties with chewing, swallowing or self-feeding
 - Assessment of behavioural and psychological symptoms
 - Assessment of visuo-spatial and perceptual abilities

For the person with dementia, food recall questionnaires are usually administered to family carers or care home staff. The choice of the most appropriate dietary method depends on clinical and cognitive factors as well as on the information required for clinical purposes (See Guidance Area 2 for consideration of cognitive and physiological assessment with regard to hydration and nutrition).

Poor hydration and nutrition can inevitably lead to bladder and bowel problems. To maintain bladder and bowel health, persons with dementia should be encouraged or assisted to have their preferred drinks regularly. Adequate time should be given to consume food and drinks, and/or relatives encouraged to assist if available. There are a number of continence tools that can be used to help in the assessment of bladder and bowel function (and many clinical settings have these in place as part of routine/standard care). Monitoring a person's fluid balance to prevent dehydration should be completed using a fluid balance chart. It is the responsibility of the nurse caring for a patient to ensure observations and fluid balance are recorded in a timely manner, with any abnormal findings documented and reported to the nurse in charge/medical team⁶⁷. The colour of the urine should not be relied on as a marker of fluid balance as some medication can alter urine colour and give a false indication of urine concentration⁶⁷. Whilst it is suggested that analysis of blood chemistry may be useful in the assessment of hydration status, the evidence surrounding this is equivocal⁶⁷. The frequency of bowel elimination varies considerably from individual to individual. Often persons with dementia may experience faecal incontinence or constipation or both. Appropriate assessment and documentation of bowel elimination can inform management strategies. Persons with dementia may exhibit changes in weight, either weight gain or weight loss, because of changes in their eating habits. Therefore a record of their weight should be documented and reviewed regularly in accordance with local policy.

Oral Care

Good oral health is important to maintain the enjoyment of eating and drinking. If the person with dementia is able, continue oral intake if compatible with the overall goals of care and comfort. Poor oral hygiene can increase a person's risk of developing pneumonia and has an impact on a person's ability to eat and drink⁶⁸. Issues such as xerostomia, infection, oral infection or ulceration and poor dentition can cause or contribute to swallowing difficulties⁵⁹. The provision of effective oral care is fundamental to nursing practice and can greatly influence a person's comfort and quality of life. When a person is not eating or drinking, or has no appetite, it is important for the person's mouth to feel comfortable. Maintaining good oral hygiene is essential to improve comfort⁶⁹. The person's lips should be kept moist and clean and appropriate oral care products applied if needed. To alleviate symptoms of dry mouth and thirst, mouth care should be administered.

Assessment to inform a decision regarding CANH

As outlined in Guidance Area 1 long-term use of artificial hydration and nutrition in people with end-stage dementia is not appropriate^{23, 24, 25 – 27, 30, 31, 34, 50, 51} and artificial feeding should not be used where dysphagia or disinclination to eat is a manifestation of disease severity³¹. However, consideration of artificial hydration and nutrition may be appropriate only if dysphagia is thought to be a transient phenomenon.

Decisions pertaining to the use of artificial nutrition vs. hydration may arise separately and the merits of these interventions may need to be evaluated individually taking into account the person's values and preferences. Health professionals commonly associate several signs and symptoms with dehydration (e.g. hypernatremia, thirst, anorexia, nausea and vomiting, fatigue and irritability) or hypovolemia (e.g. diminished skin turgor, orthostatic hypotension, and dizziness); however these may not be highly specific in people who are terminally ill⁷⁰⁻⁷⁵. Many symptoms such as thirst, dry mouth, and fatigue are not specific to dehydration and artificial hydration is not likely to be of any benefit⁷⁵. There is no evidence that hydration reduces the risk of (or worsening of) fatigue, sedation, myoclonus, or hallucinations⁷⁶. There is a lack of data demonstrating the benefit of artificial hydration at the end of life and this should be explained to people with dementia and their families.

An advance healthcare directive is an expression made by a person who has capacity (in writing, to include voice, video recording and speech recognition technologies) of their will and preferences concerning treatment decisions (including CANH) in the context of an anticipated deterioration of their condition with loss of decision-making capacity to make these decisions and communicate them to others. An advance healthcare directive is legally binding when a person writes down what treatments they would refuse in the future and the circumstances in which the refusal is intended to apply.

An advance healthcare directive may also designate authority to a healthcare representative to interpret the will and preferences of the directive-maker and consent or refuse treatment based on their known will and preferences.

The National Consent Policy (2014)⁵⁵ together with the Assisted Decision-Making (Capacity) Act 2015⁷⁷ recognise that a person may have capacity to make some decisions and need support with other decisions.



Capacity: Legal decision-making capacity refers to a specific decision about a particular medical treatment that is to be made at the time it is made.

A person with capacity:

- understands in broad terms the reasons for, and nature of, the decision to be made and is able to retain this knowledge long enough to make a voluntary choice.
- has sufficient understanding of the principal benefits and risks of a medical intervention and relevant alternative options, after these have been explained to them in a manner and in a language appropriate to their individual level of cognitive functioning.
- can communicate their choice (sometimes with the support of augmentative communication strategies [See Guidance 1]).

According to the Assisted Decision-Making (Capacity) Act 2015⁷⁷, a person lacks capacity to make a decision to consent or refuse medical treatment if they are unable to –

- (a) understand the information relevant to the decision;
- (b) retain the information long enough to make a free choice;
- (c) weigh the information as part of the decision-making process;
- (d) communicate their decision

It should not be presumed that, simply because a person lacks the capacity to make a specific decision about a particular medical treatment or care, they do not have the capacity to make other decisions. Their autonomy can still be promoted through adherence to their advance plans/directives and continued respect for their current wishes where possible.

Swallowing and Medication

Please see Guidance document 7 for guidance regarding assessment of swallowing and medication.

At the end of life

As end of life approaches, and eating and drinking difficulties become more pronounced, comprehensive nutritional screening and assessment may not be appropriate. At this stage it is important to ensure that nutritional assessment and screening is not overly burdensome for the individual and that assessment focuses on symptom management and prioritising comfort.

Guidance – Assessment of hydration and nutrition

1. A comprehensive assessment is essential on which to base management plans so that the goals of care are appropriate and attainable.
2. Health professionals should identify the specific needs, arising from difficulties with hydration and nutrition, for the person with dementia and their carers. Care plans should record and address these needs.
3. Refer to Dietitian for dietary advice as clinically indicated or guided by standardised assessment tool.
4. Specialist assessment and advice concerning swallowing and assistance to eat in dementia should be available. Speech and Language Therapy assessment of eating, drinking and swallowing is recommended for people presenting with signs/symptoms of dysphagia.



Guidance Area 3:

Management of Hydration and Nutrition

As outlined in Guidance Area 1, a 'Food First' approach is appropriate for people with dementia at all stages of the illness trajectory. Existing guidance is available to support healthcare staff in ensuring that people with dementia receive good nutritional care, adequate hydration and a positive mealtime experience^{21,22}. The information below is specific to people with advanced dementia.

Assistance with Mealtimes

The American Geriatrics Society⁵⁰ and NICE guidelines^{30,31,34} recommend 'careful hand feeding' for persons with advanced dementia. This includes efforts to enhance the experience by altering the environment and creating person-centred approaches to eating and drinking, with the aid of multi-disciplinary assessment (e.g. Speech and Language Therapist, Occupational Therapist, Dietitian).

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.

Managing Dysphagia and the Risk of Aspiration

As discussed earlier, the vast majority of people with end-stage dementia will experience dysphagia.

The person with advanced dementia usually presents with a combination of both physiological changes to the swallow (dysphagia), and behavioural issues secondary to cognitive deficits. Although the progression of swallowing difficulties may vary from person to person, the following recommendations from the Alzheimers Society UK⁷⁸ are advocated:

- Referral to a dietitian who will work with the multi-disciplinary team to advise on the application of nutritional interventions or best course of action based upon evidence and careful medical, dietary and lifestyle assessment.
- Referral to a Speech and Language Therapist is a priority when people experience any difficulty with swallowing, holding food in the mouth, continuous chewing, or leaving harder-to-chew foods (e.g. hard vegetables) on the plate.
- It is important to ensure that the person is alert, comfortable and sitting upright or, if in bed, are well positioned, before offering food and drink. People who are lying down or drowsy will struggle to swallow safely. Advice on positioning techniques should be obtained from a Physiotherapist and/or advice from an Occupational Therapist on aids for eating and drinking.

- A multi-disciplinary team ought to address any potentially reversible causes of dysphagia and/or decreased oral intake, such as constipation, pain, depression, delirium, medications and poor oral health⁵⁴.
- For an in-depth understanding of the roles of these disciplines in the palliative care context please see the HSE Palliative Care Competencies Framework 2014⁷⁹

The person with end-stage dementia may be unable to tolerate any consistency of food or fluids orally without risk of aspiration, and may be unable to meet hydration and nutrition requirements orally. Careful monitoring of swallowing is therefore important. It is essential to seek Speech and Language Therapy assessment and advice to determine safe swallowing strategies, tailored to the individual. This may include advice on the most appropriate food and fluid consistencies, as well as strategies for providing assistance with eating and drinking to minimise (but not necessarily eliminate) the risk of aspiration.

CANH

The research is in clear agreement that the long-term use of artificial hydration and nutrition in patients with end-stage dementia is not appropriate^{23, 24, 25–27, 30, 31, 34, 50, 51}. Finucane et al.'s²³ seminal and often-cited paper set out to answer a number of clinical questions around the benefits or otherwise of tube feeding practices for people with dementia. The authors found no evidence for benefit of feeding tubes practices in preventing aspiration, prolonging survival, improving pressure sore outcomes, reducing infection, improving functional status or improving comfort.

“There is no clear evidence that placing a PEG tube will allow patients to live longer, be healthier, do more or suffer less. The desire to place a feeding tube in a demented elderly person with feeding difficulties who is losing weight is based on a reasonable misunderstanding, but in most cases it is not medically defensible...”

(Finucane, 2001:702)²³

Indeed, provision of artificial nutrition and hydration can lead to increased risks/burdens, such as increased infections, blockages, sensory deprivation of food and increased risk for restraint use^{53, 80}. Some widely assumed benefits of CANH, such as alleviation of thirst, may be achieved by less invasive measures including good mouth care or providing ice chips^{53, 81}. Hoefler⁵³ states that effective dehydration (i.e. by avoidance of artificial hydration) can lessen unpleasant symptoms such as nausea, vomiting, abdominal pain, continence issues and pulmonary secretions.

Consideration of artificial hydration and nutrition may be appropriate only if dysphagia is thought to be a transient phenomenon^{30, 36, 39}. It is again essential that the multi-disciplinary team is involved in discussing the likely cause of dysphagia and prognosis for recovery. There should be clear goals and a defined time-frame for use of artificial nutrition and hydration in these circumstances. It is important that nutritional support goals are documented in a management care plan and regularly reviewed.

Most often in people with end-stage dementia, dysphagia is more likely to represent a marker of disease severity, rather than a transient difficulty. Ethical and legal principles should be applied when making decisions about withholding or withdrawing nutritional and hydration support^{30, 31, 34, 59}. In such cases, the goals of care change to a focus on comfort.



Focus on Comfort

Carefully assisting with eating and drinking should continue in the case of a person who accepts and appears to gain enjoyment from oral intake³⁷. It also allows the person with advanced dementia to experience continued human contact when eating and drinking. The focus on 'comfort' means that food and fluid consistencies recommended may not be those which are safest for the person with dementia in terms of minimising aspiration. For example, it may be more appropriate to recommend normal fluids, even if there is a risk of aspiration, if the person with dementia appears to enjoy eating and drinking without overt signs of distress. Such recommendations should be discussed by the multi-disciplinary team and clearly documented. A person may accept oral intake at some stages and not at others. Appropriate, accurate documentation to ensure accurate reflection of the person's circumstances should be maintained (e.g. regular updating of fluid balance charts, prescriptions etc).

Palachek recommends that the use of the term "Comfort Feeding Only" should be adopted⁸², however the term 'Tastes for Comfort' may be more appropriate, placing the person's comfort/enjoyment as the focus of any decision-making. Research has also shown that family members are more satisfied when comfort is the primary goal of end-of-life care⁸³.

Tastes for comfort, through careful hand feeding, if possible, offers a clear goal-oriented alternative to tube feeding and eliminates the apparent care-no care dichotomy imposed by current orders to forgo artificial hydration and nutrition.

Mouth Care

1. Rinsing the mouth with water and cleansing teeth with a soft toothbrush and toothpaste is an effective oral cleansing routine that is cost-efficient and reduces the risk of oral mucositis (mouth ulcers)¹⁷
2. Access to the mouth may be improved by stimulating the root reflex – that is, stroking the cheek in the direction of the mouth⁸⁴.
3. Modified dental equipment, such as a backward bent toothbrush may also be helpful in improving mouth access.
4. Dry mouth products are more therapeutic than moistened swabs to hydrate the mouth. However, substances with a PH lower than 5.5 (acid condition; for instance, lemon and glycerine) or alcohol as an ingredient are not recommended and should be avoided⁸⁴.

An Individualised Plan of Care

An individualised plan of care, endorsed by the person with dementia (concurrently or in an advance directive), a key family member or legally designated healthcare representative or advocate, with twin objectives of providing adequate food and fluid intake and maintaining self-feeding ability is recommended best practice⁸⁵. Such a plan may be developed by any member of the multi-disciplinary team. It is best practice to consult as widely as possible with the person with dementia, other clinical and non clinical team members, carers and family members or friends, as appropriate, who may provide insight into the person's specific values and treatment preferences with regard to hydration and nutrition management. Where a person appears not to comply with the plan of care the plan should be reviewed in light of their current and past expressed wishes, their capacity to understand what is happening and their overall benefit.

Guidance – Management of hydration and nutrition in the end-of-life care of a person with dementia.

1. Continue careful hand-feeding assistance if the person is accepting and appears to gain enjoyment from same. Use of the term 'Tastes for Comfort' when discussing and documenting same.
2. Seek Speech and Language Therapy assessment advice on the most appropriate food and fluid consistencies, as well as feeding assistance strategies to minimise (but not necessarily eliminate) the risk of aspiration.
3. Caregivers should have access to education and training on how best to assist with careful handfeeding.
4. Long-term use of artificial hydration and nutrition is not recommended for people with end-stage dementia



Guidance Area 4

Decision-Making – Balancing Different Views

Advanced or end stage dementia is characterised by profound cognitive impairment and inability to communicate verbally. Persons with dementia often encounter weight loss, dehydration, or aspiration, while family members struggle with the emotionally difficult decision to continue assisting the person to eat and drink or consider alternatives⁸⁶. Families often feel unprepared and unsupported when discussing treatment choices for persons with dementia^{87,88}. Furthermore, many nurses and care home staff do not feel well prepared to deal with issues related to end of life⁸⁹. Health professionals are often faced with dilemmas in helping people with dementia meet their nutrition and hydration needs⁹⁰. It is important that clear, consistent and independent evidence-based advice is provided to support decision-making with regard to hydration and nutrition for people with dementia. Advanced eating and swallowing difficulties need to be considered in the context of holistic palliative end-of-life care²⁰. Communication and assisted decision-making are key factors, and having trust in doctors and surrounding staff is essential for people with dementia and caregivers^{20,91}.

CANH is a medical treatment⁴⁸ and, like other medical treatments, it is associated with both burdens and benefits, depending on an individual person's circumstances. This can lead to ethical dilemmas and difficult decision-making situations in practice. Decisions therefore regarding the introduction of clinically-assisted nutrition should always be considered on an individual basis³⁵.

The role of CANH in advanced dementia is often misunderstood. Arguments founded on obligations of maintaining optimum hydration and nutrition are thrust against arguments around the perceived benefits, risks and burdens of CANH in this group⁹². Furthermore criticisms arise not only from the risks associated with dysphagia but also on the lack of evidence of favourable outcomes from enteral nutrition⁹³.

Important issues to address in a multi-disciplinary discussion include:¹⁰²

- Severity of the person's dysphagia
- The person's current nutrition and hydration status
- The person's food/fluid/ mealtime preferences (including any previously expressed wishes around nutrition and hydration at end of life)
- Discussion of the benefits and risks/burdens of artificial nutrition and hydration
- Discussion of the benefits and risks/burdens of continued oral feeding and assistance
- Treatment plan in case of further deterioration in medical status (e.g. aspiration pneumonia)
- The person's ceiling of care, including the issue of transfer to acute hospital

When tube feeding replaces oral feeding on a long-term basis, people are deprived of the taste of food and the opportunity for contact with caregivers while eating^{39,83}. Although healthcare professionals may be aware of the risks associated with tube feeding, they may feel compelled by institutional, societal or legal pressures to intervene^{94,95}. Nasogastric (NG) tubes are usually used for very short periods of time (1-3 days). However, such tubes are often quite uncomfortable and can be complex to manage, therefore where a longer duration of artificial nutrition is indicated,

Percutaneous Endoscopic Gastrostomy (PEG) or jejunostomy feeding tubes (J-tubes) are preferred⁴⁷.

Whilst there are a number of perceived benefits associated with artificial nutrition, existing evidence suggests that artificial nutrition rarely achieves its intended clinical goals in people with advanced dementia⁴⁸, and tube feeding (enteral nutrition) is not effective in terms of prolonging survival, improving quality of life, providing better nourishment or decreasing the risk of pressure sores^{40,96}.

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^{23, 24, 25-27, 30,31,34,50,51}.

Guidance: Decision-making on the appropriate management of hydration and nutrition issues in the end-of-life care of a person with dementia.

1. Develop and agree a decision-making pathway to ensure multi-disciplinary assessment and discussion takes place.
2. Information must be given to the person with dementia (if appropriate)/ family/caregivers in a balanced manner, outlining feeding practices and benefits/burdens of each method.
3. Ensure all members of multi-disciplinary team, including person with dementia if appropriate/family/carers, receive verbal and written documentation regarding decision made and implications of same.





CASE STUDY 1

Chioma Matthews lives in a residential care setting for older people. She has vascular dementia and has been admitted to hospital with aspiration pneumonia.

Chioma is dependent on staff in the residential care setting to assist with all her activities of daily living. She requires assistance to eat a smooth purée diet and drink thickened fluids, and has little verbal communication. Chioma has been attending the Speech and Language Therapist (SLT) in the community clinic for the last four months.

Following her admission, Chioma was assessed by the SLT in hospital and found to be at high risk of aspiration on all consistencies of food and fluid. After a multi-disciplinary team (MDT) discussion it was concluded that Chioma's swallowing problems could be attributed to advancing dementia. Further to a functional assessment of Chioma's capacity to make a decision about oral intake and artificial nutrition, the MDT confirmed that Chioma lacked the capacity at that time to make such a decision and agreed that artificial nutrition would not be appropriate.

The reasons for Chioma's swallowing problems were explained to her daughter and the risks and benefits of artificial nutrition discussed. It was decided by all that Chioma should receive food and fluids at the safest possible consistency when she was awake and alert enough to receive them, acknowledging that this was not likely to meet her nutritional and fluid requirements and she would remain at high risk of aspiration. Chioma's family are very concerned that she is not eating.

Planning future care

Upon recognition of her eating difficulty, a physician completes a medical evaluation of Chioma in consultation with members of the MDT (e.g. Nurses, Occupational Therapist, Physiotherapist, SLT (community and inpatient) and Dietitian). This evaluation includes a careful history, obtained from staff and family if necessary to include physical examination, swallowing observation and medication review. Evaluation focuses on therapeutic interventions that may alleviate Chioma's swallowing difficulties. Specific interventions include altering the texture, cohesiveness, viscosity, temperature, and density of Chioma's food⁹⁷; changing her posture while eating^{98,99}; environmental modifications⁹⁹⁻¹⁰⁰; denture adjustment and medication adjustment. These interventions should be reviewed regularly'. This assessment informs the care plan for Chioma's management of hydration and nutrition.

CASE STUDY 1

When artificial nutrition is ruled out, the alternative option is a risk-managed approach. This means that every effort is made to minimise the risk of aspiration - however, due to the severity of the eating and/or swallowing problem, it is not possible to eliminate these risks entirely. Palacek et al⁸² refer to this approach as 'comfort feeding only', (CFO) which means that the person with dementia is helped to eat and drink orally but this stops when it becomes distressing for the individual. We refer to this as 'tastes for comfort'. Eating and drinking should be comfort orientated and based on a personalised eating and swallowing care plan for that individual. CFO is envisioned as functioning foremost as a care order, detailing the care received during mealtimes and documenting the decision not to use a feeding tube, 'tastes for comfort' allows for greater patient or surrogate empowerment in advance care planning. Ideally, this discussion should take place in the context of a previously established advance care plan, in which the person with dementia's condition and prognosis have been addressed before discussion of 'tastes for comfort' occurs.

A person-centred approach

In the case of Chioma it is important to review her previously stated wishes regarding tube feeding, if any, and to discuss the benefits and burdens of tube feeding with her family, any legally designated healthcare representative or other carers. If Chioma has an advance healthcare directive that clearly applies to the current circumstances, then the MDT are legally bound to respect her wishes.

Where there is an advance directive but there is ambiguity as to its meaning or application; then health professionals should consult Chioma's designated healthcare representative (if any) or those who are significant in her life who may be able to interpret the advance directive and/or offer insights as to her values and beliefs. Where ambiguity persists, the opinion of a second health professional should be sought. Throughout these deliberations Chioma should be the focus of concern:

'[A]ct at all times in good faith and for the benefit of the relevant person.' (Assisted Decision-Making (Capacity) Act 2015 Pr.2 S.8(7)(e))⁷⁷

A palliative approach

As part of the advance care planning discussion, healthcare professionals educate family members about the burdens and benefits of feeding tubes, ascertain whether the person with dementia has preferences for the use of artificial hydration and nutrition, and make recommendations. Written guidelines to support healthcare professionals in making decisions about artificial nutrition in people with advanced dementia enables those without specialist knowledge of dementia to access information on best practice and the resources available locally to support them.

CASE STUDY 1

Once a diagnosis of advanced dementia has been confirmed and an acute reversible cause of the swallowing problem ruled out, a meeting with the MDT, significant family members and community representatives, for example, care home staff, where appropriate, should be held to formulate a written plan for future care. This plan should include the ceiling of treatment and intervention for eating or swallowing problems, including a plan of care in case of aspiration. Such a plan can be developed by any member of the multidisciplinary team.

Open communication and shared decision-making are key factors essential for people with dementia and caregivers^{20,92}. Families can place pressure on professionals around the need to feed and hydrate a person out of their sense of care. The professional must always address family concern in the context of the person's will and preferences as well as best evidence in practice and judge accordingly, moving to a palliative focus of care if appropriate.

Ongoing goal orientated assessment and reassessment

According to an individualised care plan, Chioma should be 'tastes for comfort' regularly, with cessation of oral feeding when she begins to show signs of distress (e.g. choking, coughing). Feeding assistance is comfort oriented in that it is the least invasive and potentially most satisfying way of attempting to maintain nutrition through careful hand feeding. As designed, 'tastes for comfort' provides an individualised care plan stating what nursing home staff will do to ensure the comfort of the person with dementia during assistance with feeding, if possible. Her individualised care plan should document unique signs of distress, which behaviours indicate it is safe to offer food, what types of foods are preferable, effective feeding techniques, and at what times of day food is preferable.

When Chioma no longer tolerates oral feeding, the nursing home staff provide an alternative means of positive human interaction, in lieu of comfort feeding, for the remainder of the meal period. Interaction may involve speaking to her and therapeutic touch, which carry a range of benefits for people with dementia.



Useful Resources

1. NICE Guidance

The NICE Guideline (www.nice.org.uk) modified March 2015, summarises the key recommendations as follows:

- People with dementia should be encouraged to eat and drink by mouth for as long as possible.
- Specialist assessment and advice concerning swallowing and feeding assistance in dementia should be available.
- Dietary advice may also be beneficial. Nutritional support, including artificial (tube) feeding practices, should be considered if dysphagia is thought to be a transient.
- Artificial feeding should not generally be used in people with severe dementia for whom oral or oropharyngeal dysphagia or disinclination to eat is a manifestation of disease severity.

2. GSF Prognostic Indicator Guidance (UK)

This guidance aims to clarify the triggers that help to identify people who might be eligible for inclusion on the supportive/palliative care/ GSF/ locality registers. Once identified and included on the register, such people may be able to receive additional proactive support, leading to better co-ordinated care that also reflects people's preferences.

<http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>

3. Alzheimer's Society (2012). My life until the end: Dying well with dementia.

This report provides a broad overview of the key issues relating to end of life planning and end of life care as experienced by people with dementia. The report summarises existing evidence and presents new evidence from current carers, bereaved carers and people with dementia. It makes recommendations about planning for end of life and to improve co-ordinated care through to the end of life.

http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1537

4. Royal College of Physicians and the British Society of Gastroenterology. (2010). Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life. London: Royal College of Physicians⁵⁹.

This report summarises the mechanism of oral feeding, its assessment and the modification of food and liquid to facilitate maintenance of oral nutrition as well as the consequences of cessation of intake of nutrition. Feeding difficulties can arise in patients with dementia at an earlier stage or at end of life. These difficulties are discussed and principles of practical management are provided.



5. A summary of healthcare organisations with similar views on feeding tube placement at end of life is available in Schwartz et al¹⁰¹.

This resource presents the use of a patient-centred interdisciplinary process by applying core ethical principles to a case study involving nutrition support.

6. Alzheimer's Association Campaign for Quality Residential Care: Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes. Phase 3: End-of-Life Care.

These practice recommendations are designed to improve the dying experience for people with dementia and build upon recommendations developed by the Alzheimer's Association in Phases 1 and 2 of *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes*. The earlier recommendations focus on many relevant areas of care, including the basics of good dementia care, food and fluid intake, social engagement, pain management, falls, wandering and restraints. The recommendations included in Phase 3 offer suggestions for addressing issues unique to people with dementia at the end of life

https://www.alz.org/national/documents/brochure_dcprphase3.pdf

7. Fact Sheet: Irish Nutrition and Dietetic Institute

This information is designed to help people understand the effects of dementia on appetite, eating and drinking, and to help people manage some of these difficulties.

<https://www.indi.ie/fact-sheets/fact-sheets-on-nutrition-for-older-people/516-feeding-strategies-in-dementia.html>

8. Food fortification and variation on methods of assessment are provided by the Buckinghamshire Healthcare NHS Trust, Aylesbury Vale CCG, Chiltern CCG.

This link provides Healthcare professionals/care guides to end of life & nutrition, food first-eating well for small appetites, food first-fortifying food for care homes, MUST How to complete, MUST How to complete alternative measurements, MUST How to treat, Sips and Food Comparison.

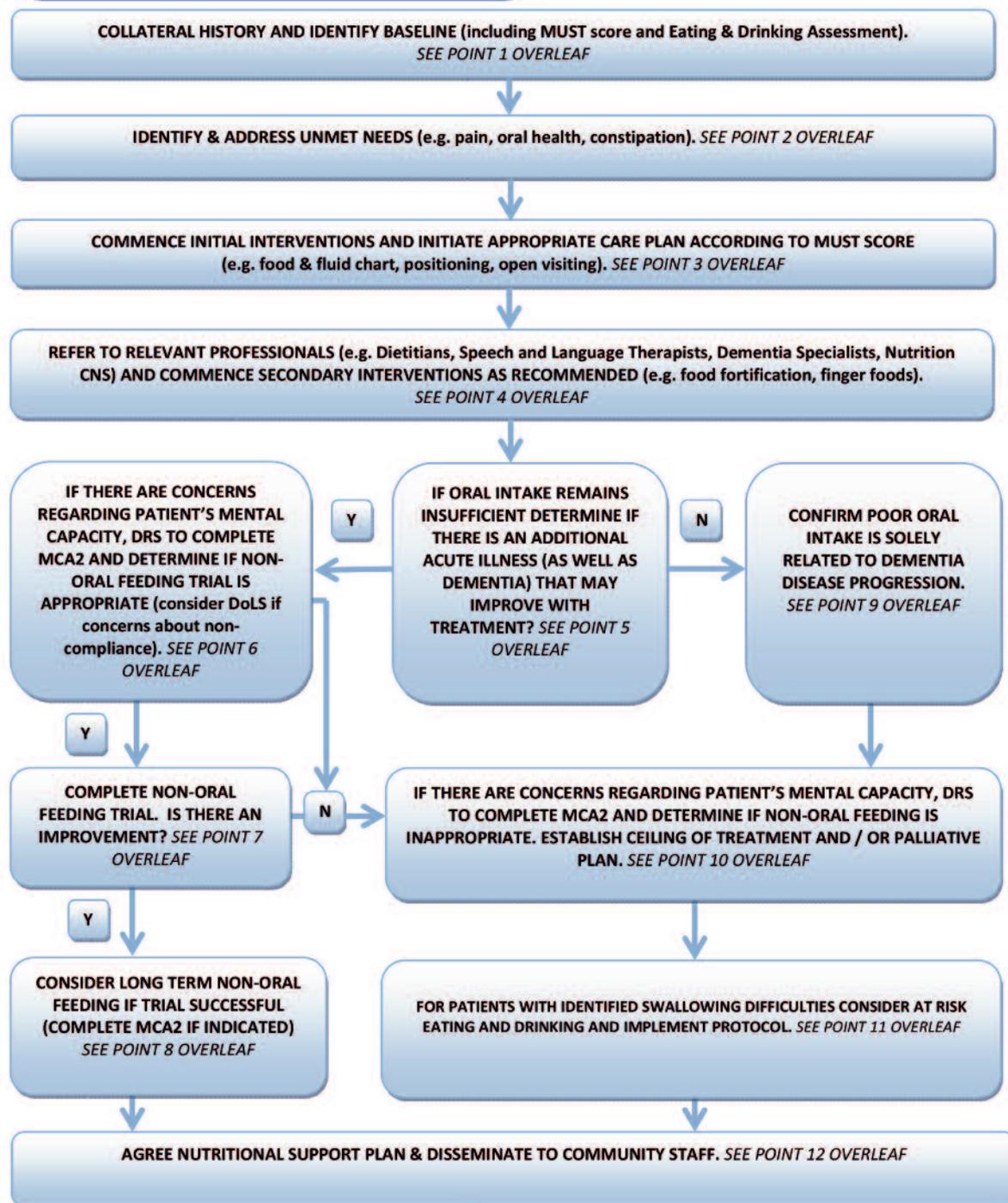
<http://www.bucksformulary.nhs.uk/docs/avc/>

9. Care of Patients with Dementia Policy-A Flowchart for Patients with Dementia.

This Nutritional Flowchart for Patients with Dementia from Mid Essex Hospital is included to guide the management for people with dementia who are not eating and drinking adequately.

Flowchart for People with Dementia who are not eating and drinking adequately

Mid Essex Hospital Services 
NHS Trust



POINT 1 - COLLATERAL HISTORY AND IDENTIFY BASELINE:

- Malnutrition Universal Screening Tool (MUST) assessed within 12 hours of admission to hospital and completed weekly or more frequently for those at risk. Eating and Drinking Assessment.
- Research background nutritional history; e.g. 'This Is Me', weight history, dietary habits, likes/dislikes, usual food portions, assistance required with meals, *religious beliefs/needs? *Consider patient's ability to communicate.

POINT 2 - IDENTIFY & ADDRESS UNMET NEEDS:

Rule out constipation, impact of Medication, pain, surgery, nausea, oral health, infection, dentures, positioning, minimise distractions, depression. Treat delirium (refer to Delirium Pathway for Guidance).

POINT 3 - COMMENCE INITIAL INTERVENTIONS:

Monitor food/fluid intake accurately. Monitor amount of weight loss (weekly weights). Offer relatives mealtimes with the patient & open visiting. Consider food fortification, snacks and finger foods. Use 'Red Tray System'. Use coloured cups and plates. Review medication. Encourage to eat meals sitting in chair.

POINT 4 – REFER TO RELEVANT PROFESSIONALS AND COMMENCE SECONDARY INTERVENTIONS:

Consider referrals to Dietitian, Dementia Specialist, Nutrition CNS Consultant Geriatrician with specialist interest in Dementia. Consider oral nutritional supplements. Consider if there may be a swallowing problem & if so refer to SALT and identify if texture modification is indicated.

POINT 5 – IF ORAL INTAKE INSUFFICIENT AND THERE IS AN ADDITIONAL ACUTE ILLNESS THAT MAY IMPROVE WITH TREATMENT?

Determine if IVI required. Consider if there is any potential for recovery i.e. does the patient have an illness that may improve with treatment?

POINT 6 - COMPLETE MCA2 AND DETERMINE IF NON-ORAL FEEDING TRIAL IS APPROPRIATE:

Best Interests decision should include all relevant members of MDT (Drs, Nurses, SALT, Dietitian, Dementia Specialist and Nutrition CNS), relatives and the patient's current and previous wishes, spiritual wishes & consider re-feeding syndrome. Please note that a MDT meeting is not necessary (particularly if this delays decision making) as the decision maker can ascertain the views of others individually. Consider DoLS if it is anticipated the patient may struggle to tolerate NG feeding. Consider mittens and 1:1 nursing.

POINT 7 - COMPLETE NON-ORAL FEEDING TRIAL AND MONITOR FOR IMPROVEMENT:

Refer to Nutrition CNS and Dementia Specialist. If patient's condition continues to deteriorate consider MCA2 to withdraw active treatment if no reversible illness.

POINT 8 - CONSIDER LONG TERM NON-ORAL FEEDING IF TRIAL SUCCESSFUL:

Only applicable if the patient consents or if she/he lacks capacity and it can be evidenced this is deemed to be in the patients' best interests. Refer to Nutrition CNS.

POINT 9 - CONFIRM POOR ORAL INTAKE IS SOLELY RELATED TO DISEASE PROGRESSION:

If it can be evidenced that there are no reversible illnesses and there are concerns regarding mental capacity, complete MCA2 regarding withdrawal of treatment and inform patient and family of poor prognosis. Consider palliative discharge. Refer to Dementia Specialist. Establish and agree new baseline with MDT, patient and family - if there are concerns regarding mental capacity consider MCA2 regarding ceiling of treatment if inadequate oral intake.

POINT 10 - COMPLETE MCA2 AND DETERMINE IF NON-ORAL FEEDING IS INAPPROPRIATE:

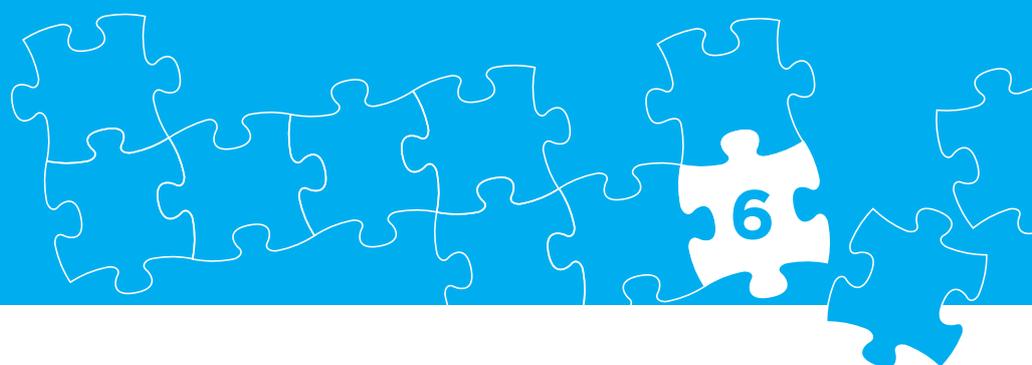
Best Interests decision should include all relevant members of MDT (Drs, Nurses, SALT, Dietitian, Dementia Specialist and Nutrition CNS), relatives and the patient's current and previous wishes, spiritual wishes. Ceiling of treatment established.

POINT 11 - FOR PATIENTS WITH IDENTIFIED SWALLOWING DIFFICULTIES CONSIDER AT RISK EATING AND DRINKING AND IMPLEMENT PROTOCOL:

Consider safest 'at risk' feeding recommendations & optimise intake, e.g. finger foods, food fortification, full fat milk

POINT 12 - AGREE NUTRITIONAL SUPPORT PLAN & DISSEMINATE TO COMMUNITY STAFF:

Ensure all decisions made (including MCA2 if appropriate) are recorded on discharge summary and a copy of MCA 2 is provided to community SALT, Dietitian, Matron and District Nurse.



ADDITIONAL RESOURCES

6.1 Understanding the progression of dementia

When considering hydration and nutrition for a person with dementia, it is important to understand the progression of the condition and consider its effect on the person's memory, ability to make decisions and to eat and drink independently.

Whilst many classification systems exist to grade the severity of the dementia such as the Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS) (also known as the Reisberg Scale)¹⁰³ and the FAST - Functional Assessment Staging¹⁰⁴ the Clinical Dementia Rating (CDR) Scale^{105,106} is considered to be the most widely used staging system in dementia research. Here, the person with suspected dementia is evaluated by a health professional in six areas: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care and one of five possible stages (0-3) of dementia is assigned (see below).

CDR-0	No dementia
CDR-0.5	Mild Memory problems are slight but consistent; some difficulties with time and problem solving; daily life slightly impaired
CDR-1	Mild Memory loss moderate, especially for recent events, and interferes with daily activities. Moderate difficulty with solving problems; cannot function independently in community affairs; difficulty with daily activities and hobbies, especially complex ones
CDR-2	Moderate More profound memory loss, only retaining highly learned material; disoriented with respect to time and place; lacking good judgment and difficulty handling problems; little or no independent function at home; can only do simple chores and has few interests.
CDR-3	Severe Severe memory loss; not oriented with respect to time or place; no judgment or problem solving abilities; cannot participate in community affairs outside the home; requires help with all tasks of daily living and requires help with most personal care. Often incontinent.

The Clinical Dementia Rating Scale^{105,106}

Progression of Dementia

Three important influences on the life-span of dementia are the type of dementia, the stage of dementia, and whether the course of deterioration is rapid or slow.^{58,107}

Life expectancy of the person with dementia

Although dementia is a progressive, life limiting and an incurable condition, it is not possible to clearly predict a person's life expectancy and this uncertainty can be very challenging for the person with dementia and their relatives/friends.

Although, specific life expectancy cannot be provided, there are some indicators below that healthcare staff can provide on the probable life expectancy of the person:

- 4.5 years post diagnosis is the average survival time for a person living with dementia¹⁰⁸. However, some people can live for 20 years post diagnosis.
- Half of the people with late stage dementia will die within 1.3 years⁵⁸.



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>



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



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.

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.

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.

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.

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



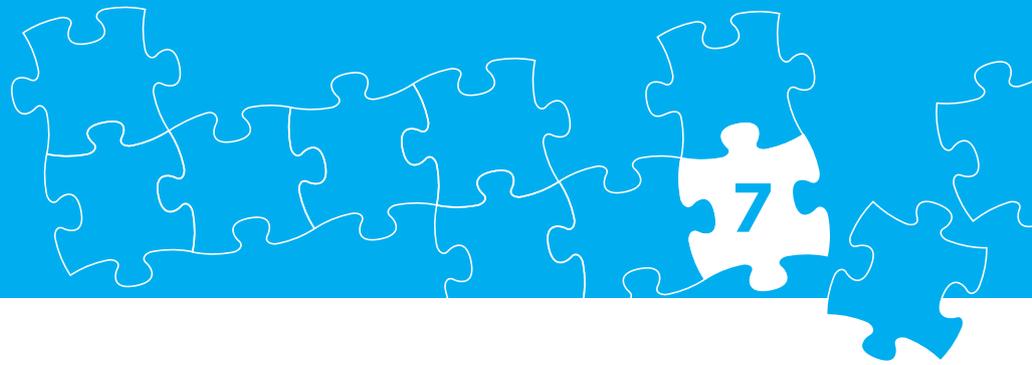
Essentials when feeding a person with dementia and dysphagia

- ✔ 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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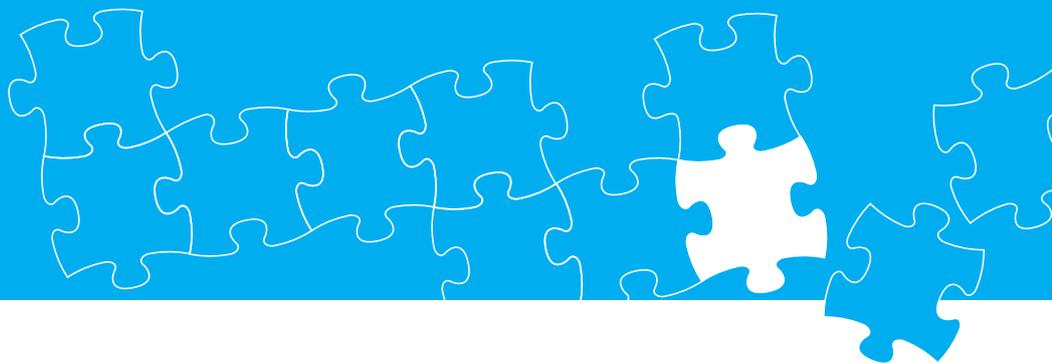


CONCLUSION

This document seeks to provide professional caregivers of people with dementia, regardless of care setting, with evidence-based guidance on best practice in relation to the assessment and management of hydration and nutrition for a person with dementia throughout their dementia journey.

The management of hydration and nutrition for persons with dementia is complex. Therefore, it should entail a multi-disciplinary systematic assessment and the use of a decision-making pathway. Strategies to support a person to eat and drink should be considered based on the needs, preferences and wishes of the person with dementia. End stage dementia frequently leads to triad of conditions involving anorexia, dysphagia and weight loss. Finucane et al²³ and others show that this 'triad of conditions' is not addressed by insertion of a PEG.

Studies on the effect of parenteral nutrition in people with dementia are limited¹⁰⁸. There are conflicting results from systematic reviews pertaining to treatment decisions around CANH and people with dementia. The decision to start artificial nutrition is often a difficult, emotional and controversial decision. Divergent views exist in relation to CANH in people facing the end of life, including those with dementia. Advocates for and against CANH often agree that the most compassionate and humane option is hospice and palliative care. Such divergence in views can lead to ethical dilemmas and difficult decision-making situations in practice. It is therefore useful for a decision-making framework, as proposed in this guidance document, to be utilised and the overarching principles of advance care planning, maintaining comfort, engaging in assisted decision-making and on-going assessment considered. Communication and education are vital in the area of hydration and nutrition and the MDT should be utilised to its full potential in decision-making as necessary whilst taking due consideration to the wishes of the person with dementia.



APPENDIX 1

STEERING AND PROJECT GROUP MEMBERSHIP

Guidance Documents Project Lead: Dr. Alice Coffey

Guidance Documents Project Researcher: Dr. Kathleen McLoughlin

Principal Investigator for Hydration and Nutrition Document: Dr. Irene Hartigan

Authors:

- Dr. Irene Hartigan, Lecturer in Nursing, Catherine McAuley School of Nursing & Midwifery, University College Cork.
- Sheila Robinson, Senior Speech & Language Therapist, Cork University Hospital.
- Mary P. O'Sullivan, Clinical Development Co-Ordinator affiliated to Nurse Practice Development Unit, Cork University Hospital.
- Dr. Kathleen McLoughlin, Research Project Associate, University College Cork.
- Dr. Paul Gallagher, Consultant Geriatrician & Senior Lecturer, School of Medicine, University College Cork.
- Dr. Suzanne Timmons, Senior Lecturer Clinical Gerontology & Rehabilitation, University College Cork.

Draft documents were reviewed by the following international and national subject experts:

International Reviewer:

Professor David H Alpers, M.D. Washington University School of Medicine

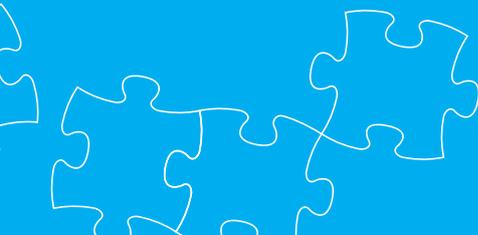
National Reviewer:

Claire Molloy, MINDI, Senior Dietitian, Department of Nutrition and Dietetics Milford Care Centre Limerick.

Steering Committee

The outputs from the Project Group were overseen by a Steering Committee convened by The Irish Hospice Foundation comprising of:

1. Prof. Geraldine McCarthy, Emeritus Professor, University College Cork and Chair South/South West Hospitals Group.
2. Dr. Ailis Quinlan, former member of National Clinical Effectiveness Committee (NCEC).
3. Ms. Marie Lynch, Head of Healthcare Programmes, Irish Hospice Foundation.
4. Prof. Cillian Twomey, Geriatrician (Retired).
5. Ms. Kay O'Sullivan, Lay Representative, Marymount Hospice, Volunteer Support.
6. Ms. Mary Mannix, Clinical Nurse Specialist Dementia Care, Mercy University Hospital, Cork.
7. Prof. Philip Larkin, Director of the Palliative Care Research Programme, School of Nursing and Midwifery, University Collge Dublin.
8. Dr. Bernadette Brady, Consultant in Palliative Medicine, Marymount Hospital & Hospice, Cork.



APPENDIX 2

METHODOLOGY

The process for developing this guidance document is outlined as follows:

1. The IHF project advisory group issued a tender for the development of a suite of four guidance documents. A project team, led by Dr. Alice Coffey, UCC, successfully tendered to develop this guidance document (See Appendix 1 for membership of the team). A Steering Committee was established by the IHF to oversee the development of this guidance document (See Appendix 1 for membership of the group). Drafts of the guidance document were reviewed by international/national subject experts (See Appendix 1 for details).
2. A literature review was conducted using scoping review methodology.^{109,110}

DATABASES SEARCHED

EBSCO Database

Medline

CINAHL Plus with Full Text

Academic Search Complete

Psychology and Behavioural Sciences Collection

SocINDEX

PsycINFO

PsycARTICLES

EMBASE

The Cochrane Library

SEARCH STRATEGY

The following key word strategy was agreed by the project team and used in EBSCO, adapted variations were developed for the other databases:

S1: palliative OR dying OR “end of life” OR “end-of-life” OR hospice OR terminal* OR “end-stage” OR “end stage” OR chronic OR “advanced illness” OR “advanced life limiting illness” OR “advanced life-limiting illness” OR “advanced life limited illness” OR “advanced life-limited illness” OR “late stage”

S2: Dementia OR Alzheimer* OR demented

S3: Guideline* OR guidance OR algorithm* OR “decision aid” OR pathway* OR policy OR policies OR protocol* OR standard* OR checklist* OR Decision N3 (aid OR aids OR support OR tool OR tools OR system OR systems OR making) OR Standard N3 (care OR clinical OR treatment) OR care N3 model OR framework OR flowchart

S4: Appetite OR Aspirat* OR ‘Body weight’ OR ‘Body mass index’ OR ‘Biochemical markers’ OR Calori* OR Dehydrat* OR Diet* OR Drink* OR Dysphagia OR Enteral OR gastrostomy OR ‘Energy Intake’ OR feed* OR Food* OR Fluid* OR Nutrition* OR malnutrition OR hydrat* OR ‘Naso gastric tube’ OR nourish* OR Insufficien* OR modif* OR parenteral OR ‘Percutaneous feeding’ OR PEG OR Starv* OR Swallow* OR Thirst* OR ‘Weight loss’ OR ‘Water’ OR ‘Voluntary refusal’

S5: S1 AND S2 AND S3 AND S4

References from relevant papers were scanned to identify additional papers as necessary.

INCLUSION CRITERIA

English language

Peer reviewed publication

Focus on adult populations (patients /family caregivers) with dementia

Studies published between 2005-2015

EXCLUSION CRITERIA

Written in a language other than English

Conference abstracts, thought pieces, reflective articles, dissertations, book chapters and book reviews.

Focus on populations under 18 years of age

Studies with a purely biochemical focus

Animal/lab based studies

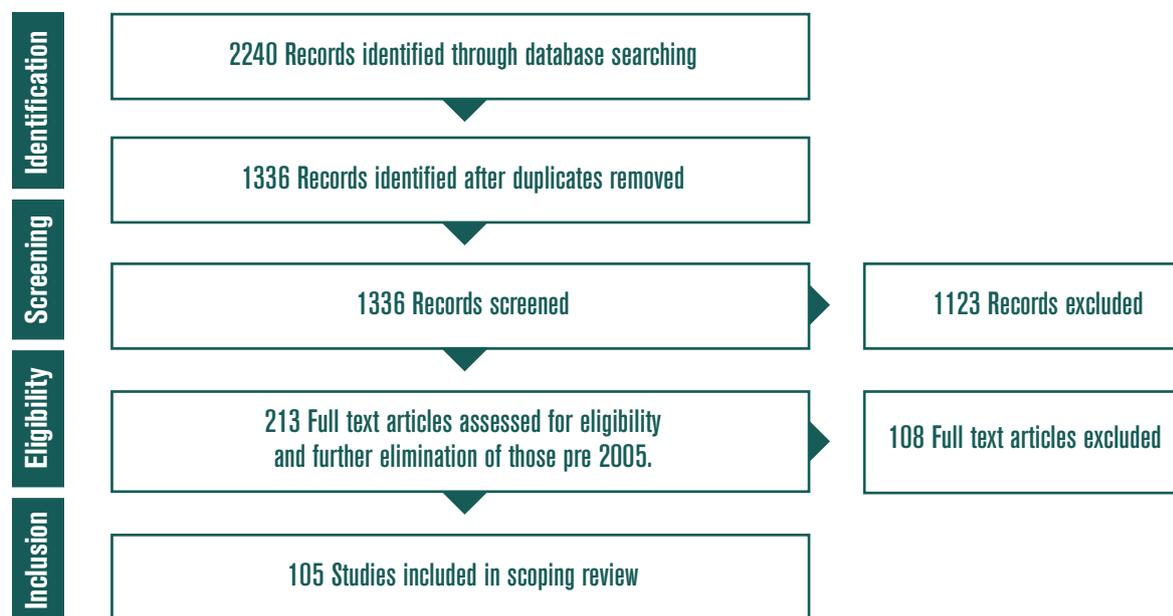
Papers generic to older people

Mixed Populations e.g. Parkinson’s and Dementia where data/ themes relating to dementia could not be separated from other diseases

Not in English.

Records retrieved were divided into three groups “Yes”, “Maybe” and “Reject”. A second and third screening of the “Yes” and “Maybe” folders was conducted to produce a final list for full-text review. Only papers satisfying the criteria above were included for data extraction. Where there was a disagreement regarding inclusion of a record, a third reviewer was consulted.

OUTCOME OF LITERATURE SEARCH



LITERATURE WAS REVIEWED TO CONSIDER:

The volume and level of evidence available.
 Theoretical models or principles proposed.
 Instruments and procedures to assess manage and review patients with regard to assessment and management of hydration and nutrition in dementia palliative care.
 Evidence specific to a variety of care settings.
 Recommendations for practice.
 Gaps in current knowledge, relevant research in progress and key emerging issues.

Based on the review of full text papers, data was extracted onto a table, organised under the following headings, to aid thematic analysis:

- (1) Title of Paper
- (2) Authors
- (3) Year of Publication
- (4) County of Origin
- (5) Level of Evidence
- (6) Aim
- (7) Setting (Primary Care / Residential Care Setting / Hospital / Hospice/Other (specify))
- (8) Population – Patients - to include age profile; comorbidities; classification of stage of dementia (against the CDR scale) / Family caregivers / Healthcare Providers
- (9) Focus on: Assessment / Treatment / Review / Other
- (10) Reference to other pre-existing guidance
- (11) Key findings / arguments
- (12) Key recommendations for practice

CLEARING HOUSES AND PROFESSIONAL BODIES

Searches of the following major clearing houses to identify pre-existing guidance documents, relevant to the domains above were also conducted:

Australian Government NHMRC
 NHS Quality Improvement Scotland
 Department of Health Australian Government
 WHO
 US: Institute of Medicine
 Institute for Healthcare Improvement
 United States National Guideline Clearinghouse
 The Guidelines International Network
 New Zealand Guidelines Group, NLH
 National Library of Guidelines (UK) Includes NICE
 Scottish Intercollegiate Guidelines Network
 Health technology Assessment
 NICE

Where specific guidance documents were sourced, these were critically assessed using the AGREE tool.

3. Collation of key themes to inform the guidance and principles of medication management and assessment by the Project Team.

LITERATURE REVIEW THEMES

1. Challenges associated with hydration and nutrition at end-of-life in dementia.
2. The role of the multi-disciplinary team and the environment in the management of hydration and nutrition at end-of-life in dementia.
3. Care planning and advanced discussions.
4. Artificial tube feeding at end-of-life in dementia.

4. Hand search of international and national policy and best practice guidelines - ongoing throughout the process in order to inform and populate the resources.

Limitations

Evidence on effectiveness and cost effectiveness was not explored due to time and resource constraints. It is challenging to include representatives from all relevant professional associations and people with dementia in the initial phases of development. It is hoped that the targeted external consultation will include as many groups as possible in order to get feedback from all relevant stakeholders in this area.

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