

GUIDANCE DOCUMENT 6

Management of Hydration and Nutrition



UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh



The Irish Hospice Foundation
Striving for the best care
at end of life for all

Palliative Care for the Person with Dementia

Guidance Document 6: Management of Hydration and Nutrition.

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DISCLAIMER AND WAIVER OF LIABILITY

This guidance was developed after careful consideration of the evidence available at time of publication. Whilst every effort has been made by the authors to ensure the accuracy of the information and material contained in this document, errors or omissions may occur in the content.

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.

Contents

1. Background	2
2. Introduction to this guidance document	4
3. Themes from the literature	7
4. Overarching principles to guide good practice	9
5. Guidance and resources	10
5.1 A systematic approach to the assessment and screening of hydration and nutrition in the end-of-life care of a person with dementia.	11
5.2 Difficulties with eating, drinking and swallowing in the end-of-life care of a person with dementia.	17
5.3 Decision-making on the appropriate management of hydration and nutrition issues in the end-of-life care of a person with dementia.	20
5.4. Management of hydration and nutrition in the end-of-life care of a person with dementia.	26
6. Additional Resources	29
6.1 Understanding the progression of dementia	29
6.2 Factsheets to accompany this document	31
7. Conclusion	37
APPENDIX 1 - Steering and project group membership	38
APPENDIX 2 - Methodology	39
References	43

BACKGROUND

Dementia is a chronic, degenerative, life-limiting illness that impacts on mental capacity and communication. The end-of-life care needs of people with dementia may be complicated by cognitive impairment, communication difficulties and responsive behaviours^{1,2}. The National Dementia Strategy³ recommended that people with dementia should be supported and cared for in the place of their choice, as far as is possible, including at the end of life. Whilst there has been growing recognition of the complexities involved in providing end-of-life care for people with dementia,^{3,4} there remains a notable dearth of practice guidelines to support healthcare staff and there has been a call for their development.^{4,5}

In 2013, the Irish Hospice Foundation (IHF) embarked on a three-year programme entitled **Changing Minds: Promoting Excellence in End-of-Life Care for People with Dementia**. The aim of this programme is to enable more people, particularly those living with dementia to live and die with dignity in all care settings. The programme seeks to achieve the following:

- To ensure that palliative care for people with dementia is prioritised and developed in all care settings and more people are supported to be able to die well at home.
- To improve end-of-life care in residential care settings for older people, with a particular focus on people with dementia.
- To increase public discourse on death and dying, with a focus on those with dementia engaging in early advance planning.

The programme consists of six projects, one of which centres on the development and adaptation of practice tools and service models with a dementia specific focus. This project is committed to developing a suite of guidance documents to support healthcare staff working with people with dementia from all care settings in addressing specific aspects of dementia palliative care. These documents will consider all stages of dementia and will include consideration of all people experiencing dementia (e.g. people with young onset dementia, people with intellectual disabilities and dementia etc).

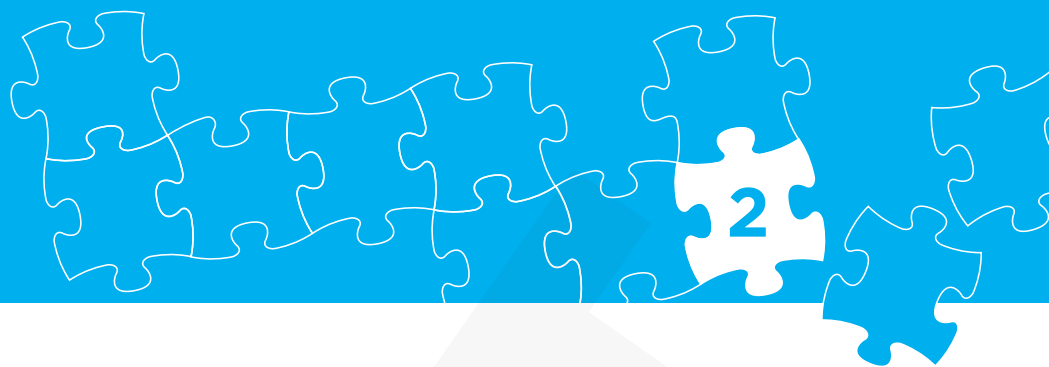
In order to determine the focus for the guidance documents, a desktop review of Irish literature on the topic of dementia and palliative care was completed and compared against an Irish review of the educational needs of staff working with dementia. An Expert Advisory Group was convened to develop each guidance document which had links to a Project Advisory Group (see Appendix 1 for membership of both groups for this document).

Following a process of consultation and feedback with the Expert Advisory Group, the following care domains were agreed upon as a focus for the suite of guidance documents:

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

When completed, it is envisaged that a final composite guidance document will be prepared based on key findings from those developed.





INTRODUCTION TO THIS GUIDANCE DOCUMENT

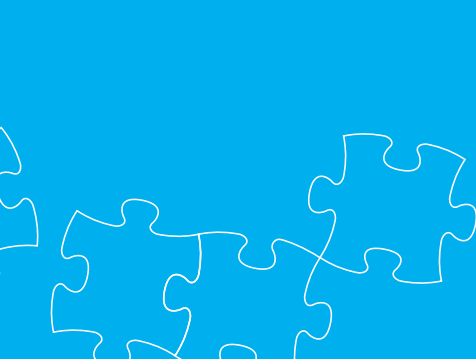
As the condition of dementia increases in severity, one of the first activities to fail is the ability to independently maintain oral hydration and nutrition (Heuberger, 2010).

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 6.1). Difficulties with eating, drinking and swallowing are a recognised challenge for people with dementia since the condition may impact negatively on a person's ability to eat or drink and may alter a person's appetite resulting in potential nutrient deficiencies⁶. This can result in significant weight loss and vitamin deficiency^{7,8} which in turn can lead to general deterioration in health, increased risk of fractures following falls, poor concentration and behaviours which further negatively impact on eating and drinking.

As the condition progresses, people with dementia may experience dysphagia (difficulty swallowing) and other difficulties associated with eating and drinking (e.g. swallowing without chewing, overfilling the mouth, holding food in the mouth, prolonged chewing, drooling saliva, agnosia and oral dyspraxia)⁶. The weight loss, malnutrition, dehydration, and dysphagia observed in people with dementia, are widely recognised as the entrance into the end stages of the disease⁹. Evidence suggests that 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 diagnosis¹⁰. Whilst weight loss in advanced dementia can sometimes be stabilised through nutritional support, it also is a strong predictor of impending mortality¹⁰.

Existing guidance is available to support healthcare staff in ensuring that people receive good nutritional care, adequate hydration and a positive mealtime experience.^{11,12} 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.

Food has an emotional, symbolic and social importance which should not be underestimated; feeding someone who is sick is a 'powerful instinctive act' and the human contact provided by the act of feeding may be of therapeutic benefit^{13,14}. Food is the first choice to correct or prevent under-nutrition in a person with dementia. Only when ordinary food or nutritional sip feeds do not meet the nutritional requirements and all attempts to maximize and promote independence have failed, should the provision of clinically-assisted nutrition and hydration (CANH) be considered. The research is in clear agreement that the long-term use of artificial hydration and nutrition in patients with end-stage dementia is not appropriate¹⁵⁻²⁴.



A palliative approach with careful hand feeding is considered to be the most appropriate option of care for patients with dementia at end of life.

CANH is a medical treatment¹⁴ 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 basis²⁵. Consideration of artificial hydration and nutrition may be appropriate if dysphagia is thought to be a transient phenomenon. Enteral nutrition should only be prescribed for people with dementia who are malnourished or at risk of malnutrition and have inadequate or unsafe oral intake and a functional, accessible gastrointestinal tract¹¹.

The management of hydration and nutrition for persons with dementia entails a multi-disciplinary systematic assessment, appropriate screening of eating and drinking difficulties and attention to feeding assistance strategies. The use of a decision-making pathway should be included to inform the management approach, tailored to the person's cognitive and related communication abilities. Under current Irish legislation, only the lead clinician has the legal authority to make healthcare decisions for a person who lacks capacity. However, these decisions should not be taken in isolation, since best practice is to consult as widely as possible with other healthcare 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.

The aim of this guidance document is to provide professional and non-professional caregivers of people with dementia with evidence based information and guidance to support their care practices. It also highlights how assistance can be provided to persons with eating and drinking difficulties to help reduce the incidence of unplanned weight loss and dehydration.

Despite the presence of evidence based guidance, ethical dilemmas and difficult decision-making situations may arise in practice and readers should also consult the ethics guidance document in this series.

Scope of guidance document

This guidance document will:

1. Consider a systematic approach to the assessment and screening of hydration and nutrition for the end-of-life care of a person with dementia.
2. Outline difficulties with eating, drinking and swallowing in the end-of-life care of a person with dementia including the potential for ethical conflict between the person's family and healthcare professionals.
3. Explore decision-making on the appropriate management of hydration and nutrition issues in end-of-life care of a person with dementia.
4. Consider the management of hydration and nutrition in the end-of-life care of a person with dementia.

Due to the extent and type of evidence currently available, limited inferences can be made in relation to hydration and nutrition and therefore recommendations presented in this document should be considered in tandem with the circumstances of the individual patient and in consultation with the person and/or family.

The term feeding assistance is used in this guidance document to describe assistance with eating and drinking for a person with dementia. The term 'feeding' alone contributes to negative connotations associated with ageing and stereotypes older persons.

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. This draft (June 2015) is at stage 4 of this process.

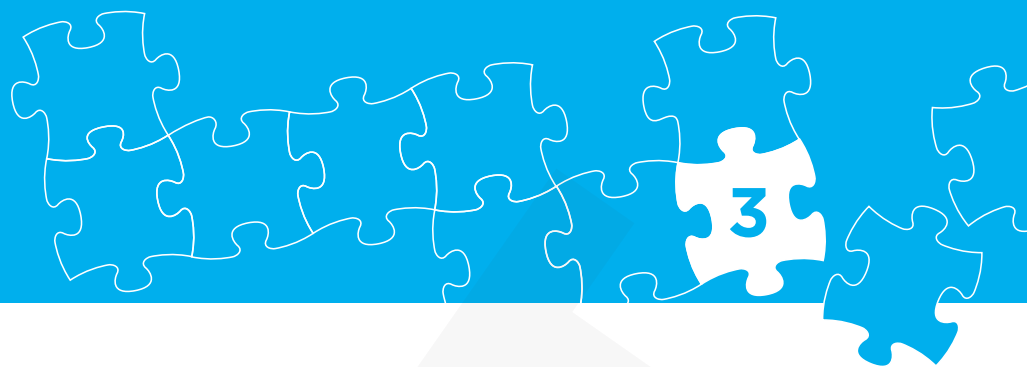
1. Completion of scoping review.
2. Collation of key review themes to inform the guidance and principles of medication management.
3. Preparation of Draft 1 of guidance document for comment by the project steering committee and national/international experts in the field.
4. Preparation of Draft 2 for 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 advisory group'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 principles of relational autonomy and the holistic focus of palliative care. Both models share a person-centred philosophy and a set of underlying principles focusing 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 inclusion²⁸. These are the core values that underpin and inform the suite of guidance documents 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^{3,4,29,30}.

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 advanced discussions.
4. Clinically Assisted Nutrition and Hydration 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 in dementia palliative care (Figure 1) and four areas of specific guidance staff considered key to informing good practice around the management of hydration and nutrition for people with dementia (see page 10).

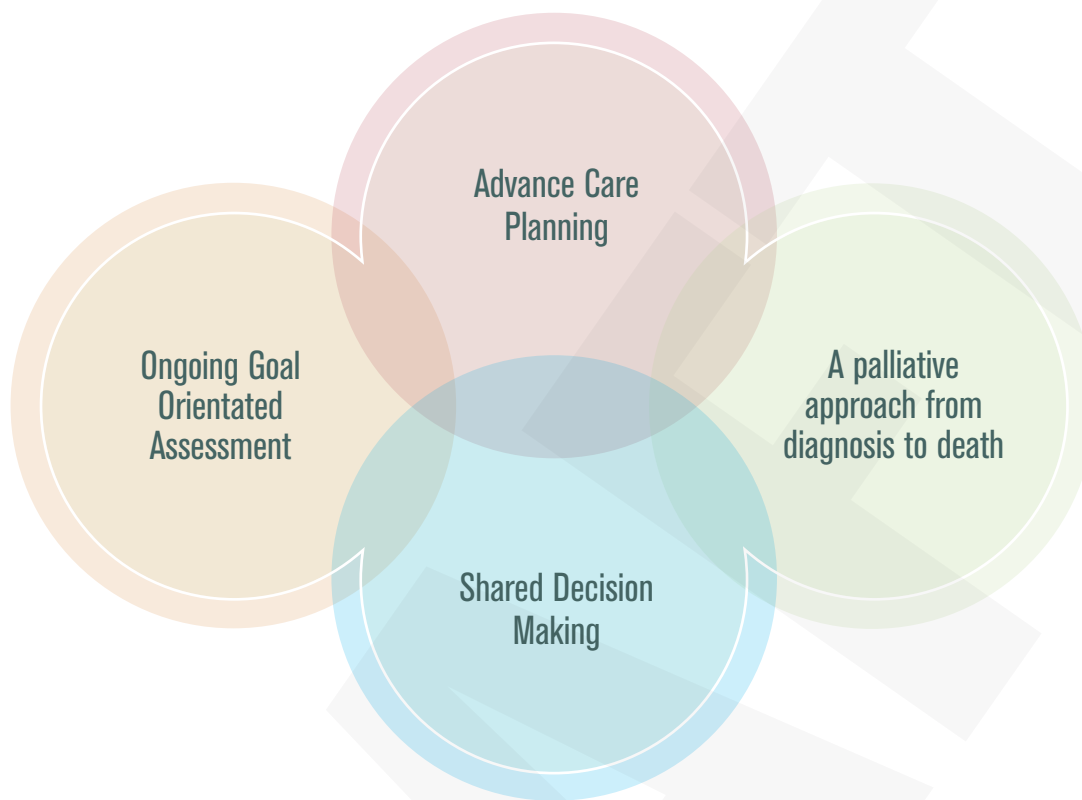
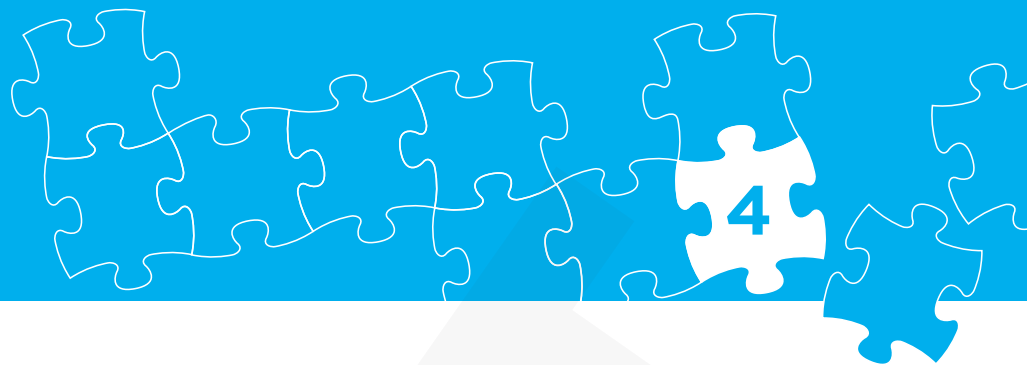


Figure 1: Four overarching principles for for optimal hydration and nutrition for people with dementia.





OVERARCHING PRINCIPLES TO INFORM GOOD PRACTICE

A common 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 as follows:

1. Advance care planning should occur at an early stage for a person with dementia³¹ and a discussion regarding hydration and nutrition wishes should take place early, before a decision is needed with regard to feeding practices.³²

2. A relational autonomy centered perspective from diagnosis to death to support the *quality of life* of people with dementia should be adopted.³³⁻³⁵ This approach should extend to the proper assessment and management of hydration and nutrition.

A relational autonomy centred perspective should emphasise the following:

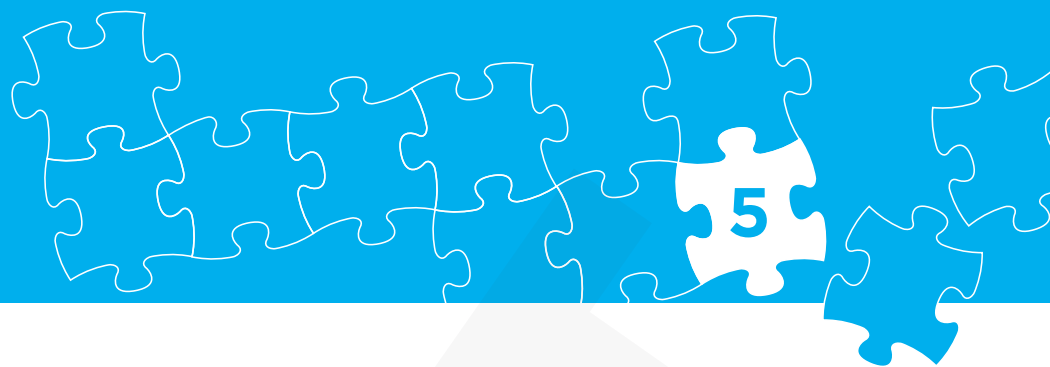
- focus on the experiences of the person receiving care and on what matters most to them
- attune to the way in which people make sense or meaning out of the world
- help the person to express themselves
- meet the person where they are at in themselves and in their environment of care
- enable and foster relationships that are important to the person
- recognise and meet the needs of carers.

It should be kept in mind that, even though a person's decision-making capacity may be impaired, their autonomy can still be promoted through adherence to their advance plans/directives and continued respect for their current wishes regarding hydration and nutrition where possible.

This approach should extend to the management of hydration and nutrition and where a person appears to get pleasure from eating or drinking, this activity should continue³⁶.

3. Shared decision-making based on the person with dementia and their families' values regarding quality of life goals, should take place between healthcare professionals, people with dementia and their families³¹.

4. Ongoing goal orientated assesement of hydration and nutrition with MDT input as necessary, is essential for optimal hydration and nutriton of people with dementia, as needs and management strategies will change as dementia progresses. People with dementia often lose the ability to recognise hunger and thirst and therefore will need strategies implemented to ensure that they are able to eat and drink comfortably and thus maintain their nutritional status^{37,38}.



GUIDANCE AND RESOURCES

The four areas where healthcare professionals, carers and people with dementia would benefit from guidance with regard to hydration and nutrition are stated below and are outlined in further detail in subsequent four sections of this document. These are as follows:

1. **A systematic approach to the assessment and screening of hydration and nutrition in the end-of-life care of a person with dementia.**
2. **Outline difficulties with eating, drinking and swallowing in the end-of-life care for a person with dementia.**
3. **Decision-making on the appropriate management of hydration and nutrition issues in the end-of-life care of a person with dementia.**
4. **Management of hydration and nutrition in the end-of-life care of a person with dementia.**





5.1 Guidance Area 1

A systematic approach to the assessment and screening of hydration and nutrition for the end-of-life care of a person with dementia.

Dementia alters dietary habits and leads to eating and drinking difficulties. As people approach the end of their lives, decreased interest in food is normal²⁶. The body's increasing inability to absorb nutrients is often accompanied by loss of appetite and thirst and difficulty swallowing^{27,39}. However, the body adapts physiologically at the end of life and this prevents people from suffering as a result of the absence of food⁴⁰.

Maintaining adequate hydration and nutrition for people with dementia represents a significant challenge^{41,42}. People with dementia are particularly vulnerable to undernutrition and weight loss due to memory difficulties, visual agnosia and dysphagia⁴³. Therefore, it is essential that adequate systems are in place to assess and monitor hydration and nutrition for persons with dementia⁴⁴.

Weight loss is strongly associated with advanced dementia, which is attributed to the neurodegenerative process and dietary changes⁴⁵. Advanced dementia is characterised by dependence on another person to achieve optimal nutritional intake, and 86% of persons with advanced dementia develop eating and drinking difficulties^{46,47}, resulting in a high prevalence of malnutrition particularly undernutrition⁸. The risk of being malnourished increases due to the nature of dementia as a progressive illness, coupled with increasing age.

Undernutrition, insufficient calories, protein or other nutrients⁸ can lead to serious health consequences such as weight loss, dehydration, poor wound healing and pneumonia¹⁰. The cause of malnutrition is usually multifactorial⁴⁸. 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.

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.^{11,12} Dehydration in older adults can result in reduced cognitive performance, constipation, delirium, infections, renal failure, shock, seizures, brain damage and death.⁴⁹

Popkin et al⁵⁰ assert that a consensus on a "gold standard" for hydration markers, particularly for mild dehydration is non-existent. Terminal dehydration in patients who are close to death is beneficial in the sense that it reduces respiratory and gastrointestinal secretions²⁷. 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 print⁵¹.

Decisions regarding artificial nutrition and hydration should take into account the person's values and preferences. In addition, decisions pertaining to the use of artificial nutrition and hydration may

arise separately and the merits of these interventions may need to be evaluated separately. 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 ill⁵²⁻⁵⁷.

Many symptoms such as thirst, dry mouth, and fatigue are not specific to dehydration and artificial hydration is not likely to be of any benefit⁵⁸. There is no evidence that hydration reduces the risk of (or worsening of) fatigue, sedation, myoclonus, or hallucinations⁵⁹. 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.

Good oral health is important to maintain the pleasure of oral feeding. If the patient is able, continue oral intake if it is compatible with the overall goals of care and comfort. When a person is not eating or drinking, or has no appetite, it is important for the person's mouth to feel comfortable⁶⁰. 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. Maintaining good oral hygiene is essential to improve comfort⁶¹. Moreover, oral hygiene has a reciprocal relationship with dysphagia. Issues such as xerostomia, infection, oral infection or ulceration and poor dentition can cause or contribute to swallowing difficulties⁶². The provision of effective oral care is fundamental to nursing practice and can greatly influence a person's comfort and quality of life.

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. Multi-disciplinary evaluation of eating, drinking and swallowing needs is an integral part of a comprehensive end of life approach.⁶² 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. Care planning should therefore have a multi-disciplinary focus, including:

- The person with dementia and/or family/carers
- Medical team
- Nursing staff
- Speech and Language Therapy
- Clinical Nutrition
- Physiotherapists and Occupational Therapists

Nutritional assessment tools include the Mini-Nutritional Assessment (MNA)^{63,64} and the Malnutrition Universal Screening Tool (MUST)⁶⁵, which were developed and validated to identify malnutrition or those at risk of malnutrition. 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 that is required for clinical purposes (See Guidance Area 2 for consideration of cognitive and physiological assessment with regard to hydration and nutrition).

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 on nutritional assessment for persons with dementia is available from a number of organisations^{11,12,23,24,66,67,68}. The Health Information and Quality Authority (HIQA) in 2008, produced the National Quality Standards for Residential Care Settings for Older People⁶⁹, to help improve and to assure 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.^{11,12}

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, FFQ and food records).

Guidance - A systematic approach to the assessment and screening of hydration and nutrition in the end-of-life care of a person with dementia.

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 Clinical Nutritionist for dietary advice as clinically indicated or guided by standardised assessment tool.
4. Specialist assessment and advice concerning swallowing and feeding assistance in dementia should be available. Speech and Language Therapy assessment of swallow is recommended for persons presenting with signs or symptoms of dysphagia.



Resources for Healthcare Professionals

1. Alzheimer's Disease International Nutrition and Dementia Report⁷⁰

The '*Nutrition and dementia*' report investigates how the right nutrition can help make life better for people affected by dementia. The report reviews dietary factors across the life course that might increase or decrease the risk of onset of dementia in later life. It also details what actions could be taken to improve the nutrition of people with dementia, through diet and external factors such as modifying the mealtime environment and supporting and training carers.

<http://www.alz.co.uk/sites/default/files/pdfs/nutrition-and-dementia.pdf>

2. Royal College of Speech and Language Therapists: Speech and Language Therapy Provision for People with Dementia. RCSLT: 2014⁷¹

The paper intends to provide guidance on the provision of speech and language therapy services that meet the needs of people with dementia, their families and their carers.

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

3. National Quality Standards for Residential Care Settings for Older People in Ireland, Health Information and Quality Authority (HIQA) 2008⁶⁹

The Standards set out what a quality, safe service for an older person living in a residential care setting should be. For service providers, these Standards provide a road map of continuous improvement to support the continued development and provision of person-centred, accountable care.

<http://www.hiqa.ie/publications.asp>

4. Care Homes for Older People National Minimum Standards 2002 (Department of Health UK)⁷²

This document sets out National Minimum Standards for Care Homes for Older People, which form the basis on which the new National Care Standards Commission will determine whether such care homes meet the needs, and secure the welfare and social inclusion, of the people who live there. The national minimum standards set out in this document are core standards which apply to all care homes providing accommodation and nursing or personal care for older people. The standards apply to homes for which registration as care homes is required.

<http://www.dh.gov.uk>

5. Caroline Walker Trust - Eating well for older people (revised 2004)⁷³

The aim of this practical guide is to support all those who help older people and older people with dementia to eat well. It provides practical guidance about the types of food and drinks that can be served to ensure that everyone has healthy, nutritious and enjoyable meals, snacks and drinks.

www.cwt.org.uk

6. ESPEN Guidelines 2006⁶⁷

The European Society for Clinical Nutrition and Metabolism promotes experimental and clinical research, fosters high ethical standards of practice and investigation, and promotes contact between investigators and clinicians in related fields.

<http://www.espen.org>

7. FSAI - Recommendations for a national food and nutrition policy for older people (2000)⁷⁴

This report provides information on the status of nutrition in our older population and on the common risk factors affecting this status. It relates nutrition to diseases and conditions experienced in the older population and outlines the benefits of adequate diet. In order to be of practical use to health professionals and those caring for older people, the report sets out nutritional requirements and dietary guidelines as well as highlighting barriers that impede proper eating patterns.

www.fsai.ie/publications/reports/recommendations_nutrition_older_people.pdf

8. Mulvihill, M. and Pyper S. (2001)⁷⁵ Managing Nutrition for older people in longstay care - a guide for health care staff Midland Health Board. Menu Planning and Special Diets in Care Homes www.thenacc.co.uk

9. Eating and Feeding Issues in Older Adults with Dementia: Part I: Assessment.⁷⁶ Shares The Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q) as a valid and reliable observational instrument for nurses to use to identify eating and feeding difficulties and determine the level of assistance needed.

10. Mouth care guidance and support in cancer and palliative care⁷⁷ developed by the UK Oral Mucositis group to support healthcare professionals involved in the care and treatment of cancer patients. Available online <http://ukomic.co.uk/new-om-guidelines.html>

Resources for Person with Dementia and Caregivers

From Campbell⁵¹

Helping a person drink requires time and patience. The following list offers an insight into some of the challenges associated with this "simple task":

- Gaining the person's consent and concordance
- Assessing individual physical and cognitive abilities
- Correct and safe positioning (often requiring two people)
- Encouragement and assistance
- Time spent at the bedside

5.2 Guidance Area 2:

Outline difficulties with eating, drinking and swallowing at the end-of-life care for a person with dementia.

The person with advanced dementia is likely to be bed-bound, dependent on others for all care, and have limited ability to communicate¹⁵. He/She may also present with other co-morbidities (e.g. previous Cerebrovascular Accident, Chronic Obstructive Pulmonary Disease) which can impact on their swallowing, and overall functional baseline. People with intellectual disabilities present with an increased incidence of dementia compared to the general population⁷⁸. Dementia may also progress more quickly in those with learning disabilities⁷⁹. Difficulties with eating, drinking and swallowing are a recognised challenge for people with dementia, especially in the later stages⁷¹.

Mitchell et al.⁴⁷ note that almost 90% of people with dementia experience problems with eating, drinking and swallowing (EDS) in the final three months of life. The person with end-stage dementia is likely to present with aspiration pneumonia and dehydration/malnutrition as a result. They may become dehydrated as a direct consequence to their cognitive impairment⁸⁰. Challenges arise from forgetfulness and aversive feeding behaviours that can disrupt dietary intake, eating and drinking routines. The person may have difficulty with performing specific tasks related to food and fluid (e.g. removing plate covers, recognition of the utensils and their use, moving food or fluid to their mouth, chewing, and swallowing). People with dementia may not be able to alert anyone to their hunger, or the need for assistance or extra time for chewing and swallowing. Therefore 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 practice⁸⁰. Such a plan may be developed by any member of the multidisciplinary team, however only the lead clinician has the legal authority to make healthcare decisions for a person who lacks capacity. It is best practice to consult as widely as possible with other healthcare 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 management.

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 UK⁷⁹ are advocated:

- 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 (eg 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 health⁸¹.

The person with end-stage dementia, as in other terminal conditions, will eat and drink less as part of the natural progression towards the end of life⁸². There is little evidence that people in end-stage dementia experience significant levels of hunger or thirst⁸³. A holistic assessment by a skilled multi-disciplinary team is recommended in order to provide an individually tailored plan of care⁸¹. Where a person has no interest in eating / drinking and, for example pulls out tubes or decides in some other way to go against advice, and the professionals have done all they can to advise regarding the importance of maintaining hydration / nutrition – the person's autonomy must be considered.

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 should be available to those who care for the person with dementia in hospital, residential care settings or at home so that persons with dementia are cared for 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 process.



Resources for Healthcare Professionals

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

5.3 Guidance Area 3

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

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, family members struggle with the emotionally difficult decision to continue feeding assistance or consider alternative feeding practices⁸⁴. Family surrogate decision-makers often feel unprepared and unsupported when making treatment choices for persons with dementia^{85,86}. Furthermore, many nurses and care home staff do not feel well prepared to deal with issues related to end-of-life³⁷. Health professionals are often faced with dilemmas in helping people with dementia meet their nutrition and hydration needs⁸⁷. It is important that clear, consistent and independent evidence-based advice is provided to support decision-making with regard to hydration and nutrition for persons with dementia. Advanced eating and swallowing difficulties need to be considered in the context of holistic palliative end-of-life care⁸. Communication and shared decision-making are key factors, and having trust in doctors and surrounding staff is essential for patients and caregivers^{8,88}.

Controversy exists around the role of CANH in advanced dementia. 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 group⁸⁹. Furthermore criticisms arise not only from the risks associated with dysphagia but also on the lack of evidence of favourable outcomes from enteral nutrition⁹⁰. 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^{82,27}. 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^{91,92}. 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, PEG or J-Tubes are preferred¹³.

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 patients with advanced dementia¹⁴, and it does not establish that tube feeding (enteral nutrition) is effective in terms of prolonging survival, improving quality of life, providing better nourishment or decreasing the risk of pressure sores^{67, 94}. 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^{15,22,24}.

Consideration of artificial hydration and nutrition may be appropriate if dysphagia is thought to be a transient phenomenon^{22,26,27}.

Decision aids provide structured information and are effective to increase knowledge and reduce decisional conflict⁹⁵⁻⁹⁸. The use of a decision-making pathway is recommended to enable clear and timely decision-making on the part of the multi-disciplinary team. There should be clear documentation acknowledging that discussion has taken place and that all parties are aware of the implications thereof (e.g. continued aspiration, inability to meet nutrition and hydration needs). Ideally, discussion

regarding feeding difficulties and practices should take place long before a decision is needed, involving the person with dementia and their family³². This allows the person and their family time to consider these potentially difficult decisions. Discussions should not be delayed until a crisis develops¹⁵.

Good communication with the person with dementia and their family is imperative. It is important that information is provided in a coordinated manner^{99,100}, 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. The team should establish whether the person has capacity to consent, has made an advance decision outlining their wishes, or has appointed someone to make healthcare decisions on their behalf should they lose capacity (lasting power of attorney)¹⁰¹. Where no previous wishes are documented, relatives or the primary caregiver should be consulted and an informed decision be made in conjunction with the MDT with consideration given to rights and needs of the person with dementia.

The Royal College of Physicians* recommends the following approach to team discussions and ethical decision-making:

1. Each member of the team must state their opinion.
2. The underlying reason for each decision is then determined.
3. The concerns of each team member are discussed and common themes identified.
4. An action plan is agreed the best solution adopted.

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.
4. Ensure documentation of multi-disciplinary discussions and outcome of same (e.g. in person's medical record notes/ care plan).



* <http://shop.rcplondon.ac.uk/collections/books-1/products/oral-feeding-difficulties-and-dilemmas-a-guide-to-practical-care-particularly-towards-the-end-of-life>

Resources for Healthcare Professionals

1. CASE STUDY

These case studies have been specifically chosen since they reflect challenges addressed in the literature and/or experienced in practice.



CASE STUDY 1

Mrs B is a care home resident with vascular dementia admitted to hospital with aspiration pneumonia. She is dependent on care home staff for all her activities of daily living, requires assistance to eat a smooth puréed diet and drink thickened fluids, and has little verbal communication. She has been attending the Speech and Language Therapist in the clinic for the last four months. Mrs B was assessed by the SLT in hospital and found to be at high risk of aspiration on all consistencies of food and fluid. The SLT recommended she should be placed Nil By Mouth.

After a multidisciplinary team (MDT) discussion it was concluded that her swallowing problems could be attributed to advancing dementia. Further to a cognitive assessment, the MDT confirmed that Mrs B did not have capacity to make decisions about eating and that artificial nutrition would not be appropriate, therefore risk-managed eating began. The reasons for Mrs B's swallowing problems were explained and the risks and benefits of artificial nutrition discussed. It was decided by all that Mrs B 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. Mrs B's family are very concerned that she is not eating.

Advance care planning

Upon recognition of her eating difficulty, a physician completes a medical evaluation of Mrs. B in consultation with members of the MDT (e.g. Nurses, Occupational Therapist, Physiotherapist, SLT (community and inpatient), Dietitian). This evaluation includes a careful history, obtained from staff and family if necessary; physical examination;

CASE STUDY 1

swallowing observation; and medication review. Evaluation focuses on therapeutic interventions that may alleviate Mrs. B's swallowing difficulties and should be reviewed regularly. Specific interventions include altering the texture, cohesiveness, viscosity, temperature, and density of Mrs. B's food;¹⁰² changing her posture while eating;^{102,103} environmental modifications;¹⁰³⁻¹⁰⁵ denture adjustment or addressing other dental concerns; and medication adjustment. This assessment informs the care plan for Mrs. B's management of hydration and nutrition.

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. Palecek 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.

Eating 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 oral feedings and documenting the decision not to use a feeding tube, CFO allows for greater patient or surrogate empowerment in advance care planning. Ideally, this discussion should take place in the context of a previously established physician–surrogate relationship, in which the patient's condition and prognosis have been addressed before discussion of CFO occurs.

A relational autonomy centred approach

In the case of Mrs. B 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 the appropriate surrogate decision-maker. It is easy to see how a surrogate may agree with the physician that tube feedings do not sound consistent with the resident's wishes, but faced with a "care" or "no care" decision, he or she is unable to choose the "no care" option. Such a decision should be based on the person with dementia and their families' values regarding quality of life goals and should take place between healthcare professionals, people with dementia and their families³¹.

Shared decision-making

As part of the advance care planning discussion, healthcare professionals educate the proxy about the burdens and benefits of feeding tubes, ascertain whether the nursing home resident has preferences for the use of artificial hydration and nutrition, and make

CASE STUDY 1

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.

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. 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^{8,88}. 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 balance family concern with best evidence in practice and judge accordingly. Only the lead clinician has the legal authority to make healthcare decisions for a person who lacks capacity. However, these decisions should not be taken in isolation by an individual healthcare professional, since best practice is to consult as widely as possible with other healthcare team members, carers and family members or friends, as appropriate, all of whom may provide insight into the person's specific values and treatment preferences.

Ongoing goal orientated assessment and reassessment

According to an individualised care plan, Mrs. B should be CFO 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, CFO provides an individualized care plan stating what nursing home staff will do to ensure the comfort of the patient during hand feeding, if possible. Her individualized care plan should document unique signs of distress, which behaviors indicate it is safe to feed, what types of foods are preferable, effective feeding techniques, and at what times of day feeding is preferable. When Mrs. B no longer tolerates oral feeding, the nursing home staff provides an alternative means of positive human interaction, in lieu of 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.¹⁰⁶

2. Example Algorithms for Decision-Making

Mid-Essex pathway (to be confirmed)

Schwartz et al., (2014)¹⁰⁷ Smith et al., (2009)¹⁰¹

3. Guide to Professional Conduct and Ethics for Registered Medical Practitioners (Irish Medical Council, 2009)

<https://www.medicalcouncil.ie/News-and-Publications/Publications/Information-for-Doctors/Guide-to-Professional-Conduct-and-Ethics-for-Registered-Medical-Practitioners.pdf>

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

http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1537 (see page 20 for overview)

Important issues to address in a multi-disciplinary discussion include (Back and Arnold¹⁰⁸):

- 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

5.4 Guidance Area 4

Management of hydration and nutrition for the end-of-life care of a person with dementia.

As discussed in Guidance Area 2, the vast majority of people with end-stage dementia will experience dysphagia. Management thus often involves a decision on the most appropriate method of achieving hydration and nutrition. The person with end-stage dementia may be unable to tolerate any consistencies of food or fluids orally without risk of aspiration, and may be unable to meet hydration and nutrition requirements orally. It is essential to seek Speech and Language Therapy assessment and 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. The American Geriatrics Society¹⁵ and NICE guidelines²²⁻²⁴ recommend careful hand feeding for persons with advanced dementia. This includes efforts to enhance oral feeding assistance by altering the environment and creating patient centred approaches to eating and drinking, with the aid of multi-disciplinary assessment (e.g. Speech and Language Therapist, Occupational Therapist, Clinical Nutrition). The use of the term “Comfort Feeding Only” should be adopted⁸², placing the person’s comfort/pleasure 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 care¹⁰⁹.

“Comfort refers to the stopping point in feeding, emphasising that the patient will be fed so long as it is not distressing. Second, comfort refers to the goals of the feedings. The feedings are comfort oriented in that they are the least-invasive and potentially most-satisfying way of attempting to maintain nutrition through careful hand-feeding.”
(Palacek et al., 2010)⁸²

Therefore, careful hand feeding assistance should continue in the case of a person who accepts and appears to gain pleasure from oral intake³⁶. 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 minimizing aspiration. For example, it may be more appropriate to recommend normal fluids if the person with dementia appears to enjoy eating and drinking without overt signs of distress, even if there is a risk of aspiration. Such recommendations should be discussed by the multi-disciplinary team and clearly documented. 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).

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^{15, 16-24}. Finucane et al.’s¹⁷ 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)¹⁷

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^{83,110}. 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^{111,83}. Hoefler⁸³ 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 if dysphagia is thought to be a transient phenomenon^{22,26,27}. 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.

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^{22-24,62}.

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 of, and appears to gain enjoyment from, same. Use of the term ‘Comfort Feeding’ when discussing and documenting same.
2. Speech and Language Therapy assessment for 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 feed a person with dementia
4. Long-term use of artificial hydration and nutrition is not recommended for people with end-stage dementia



Resources for Healthcare Professionals

1. Clinical Guidelines

American Geriatrics Society (2013) – Feeding Tubes in Advanced Dementia Position Statement
<http://www.americangeriatrics.org/files/documents/feeding.tubes.advanced.dementia.pdf>

2. NICE Guidelines (2006a, 2006b, 2013)

The NICE clinical guideline on nutrition support in adults covers the care of patients with malnutrition or at risk of malnutrition, whether they are in hospital or at home.
<https://www.nice.org.uk/guidance/cg32>

This guideline makes recommendations for the identification, treatment and care of people with dementia and the support of carers. Settings relevant to these processes include primary and secondary healthcare, and social care. <http://www.nice.org.uk/guidance/CG42>

3. 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 Physicians⁶².

4. A summary of healthcare organisations with similar views on feeding tube placement at end of life is available in Schwartz et al¹⁰⁷.

5. 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.

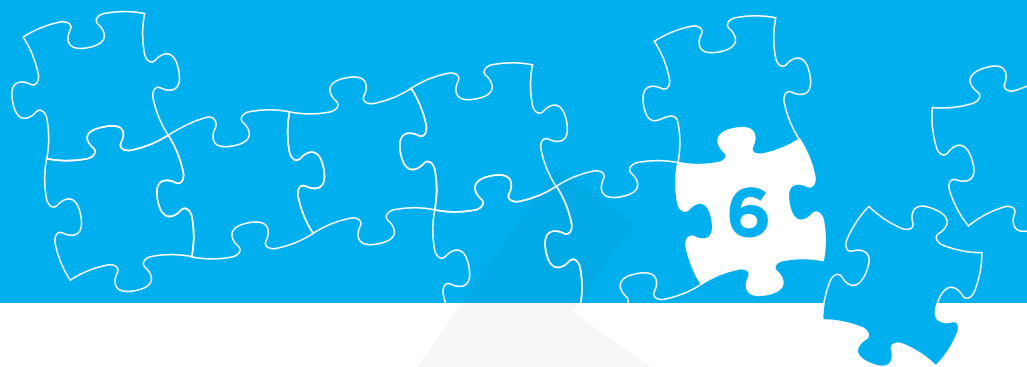
These practice recommendations are designed to improve the dying experience for people with dementia and build upon recommendations developed by the Alzheimer's Association in Phases 1 and 2 of *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes*. The earlier recommendations 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>



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 (e.g. Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS) (also known as the Reisberg Scale)¹¹² and the FAST - Functional Assessment Staging¹¹³ the Clinical Dementia Rating Scale¹¹⁴ 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 is assigned.

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 at 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

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.^{69,70.}

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 dementia⁷⁰. However, some people can live for 20 years post diagnosis.
- Half of the people with late stage dementia will die within 1.3 years⁶⁹.



FACT SHEET 6A

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



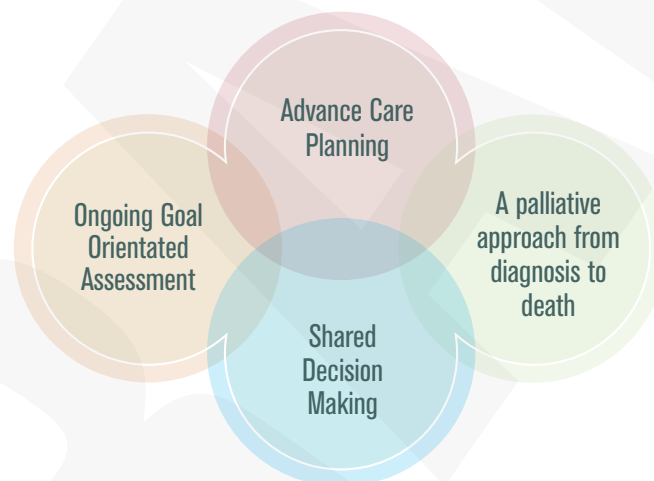
Principles for optimal hydration and nutrition



As dementia progresses, people may experience dysphagia (difficulty swallowing) and other difficulties associated with eating and drinking.



Four overarching principles are recommended for optimal hydration and nutrition for people with dementia.



Ethical challenges often arise in healthcare at the end of life, decisions regarding artificial nutrition and hydration should take into account the person's values and preferences.

An individualised plan of care, endorsed by the patient, 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.

The long-term use of artificial hydration and nutrition in patients with end-stage dementia is not appropriate.

A palliative approach with careful hand/ oral feeding is considered to be the most appropriate option of care for patients with dementia at end of life.



Striving for the
best care at end
of life for all



FACT SHEET 6B

Management of Hydration and Nutrition



Maintaining adequate hydration and nutrition is a complex problem requiring a comprehensive approach and advance care planning.

The management of hydration and nutrition for persons with dementia entails

- A multi-disciplinary systematic assessment
- Appropriate screening of eating and drinking difficulties
- Attention to feeding assistance strategies
- The use of a decision-making pathway should be tailored to the patients' cognitive and related communication abilities.

Treatment of eating difficulties in patients with dementia is aimed at optimising oral intake as safely as possible in order to preserve the pleasure of eating and drinking, while attempting to counteract malnutrition, dehydration, and aspiration pneumonia for as long as possible.

Strategies to enhance hydration and nutrition



- **offer** a variety of liquids at regular times
- **enhance** the visual appeal of food and fluids
- **discuss** safe methods of delivery of food and fluids
- **encourage** food-related activities

In the later stages of dementia aversive feeding behaviours (Box 1¹) can disrupt dietary intake, necessitating supervision and extensive assistance at mealtimes.

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.

¹ 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).

FACT SHEET 6C

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



Regular multidisciplinary assessment and reassessment is vital



- People with dementia often lose the ability to recognise hunger and thirst.
- Nurses have a key role in the provision and monitoring of oral and clinically-assisted nutrition and hydration.
- Various assessment methods can inform the hydration and nutritional status.

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

Nutrition can be assessed by:

- ✓ 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, MNA).
- ✓ Dietary evaluation methods (e.g. 24 hour dietary recall, food frequency questionnaire and food records).

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 patient 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.

² Vitale, C. A., Monteleoni, C., Burke, L., Frazier-Rios, D., & Volicer, L. (2009). Strategies for improving care for patients with advanced dementia and eating problems. *Ann Long-Term Care*, 17, 32-33.

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.




7 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 Nursing staff should be aware that some people would need assistance in brushing and denture care.
- 4 Provide additional plaque control if needed using mouthwash, spray or gel.
- 5 If person has dentures, ensure dentures are stored in optimal solution and fit appropriately.
- 6 Clean dentures with individual brush under running water over a sink of cold.
- 7 Adequate oral health care is carried out preferably after every meal and before bedtime every night.



FACT SHEET 6E

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



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



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.

There are also changes in the swallow that occur with normal ageing, such as reduced taste and smell, reduced saliva which makes it more difficult to chew food adequately, reduced muscle strength, and taking longer to swallow.

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

If you notice a person with dementia presenting with any of the difficulties listed below, ensure the person is referred to a Speech & Language Therapist for assessment of swallow.



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FACT SHEET 6F

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.

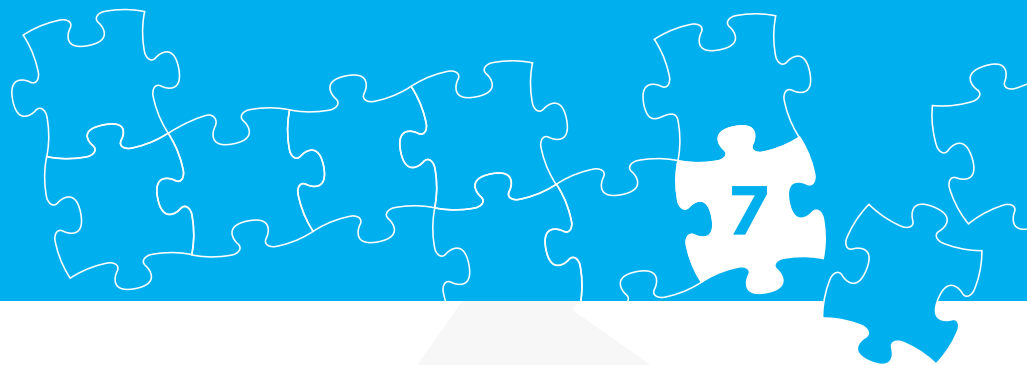


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Colaiste na hOllscoile Corcaigh

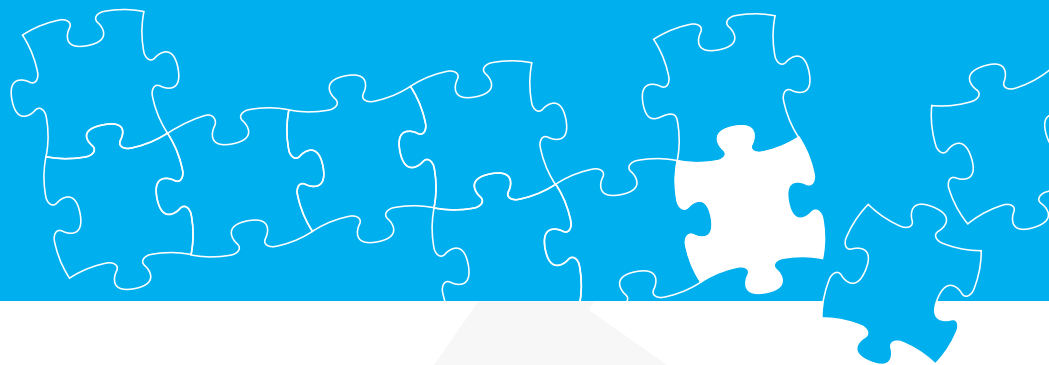


CONCLUSION

This document seeks to provide professional caregivers of people with dementia, regardless of care setting, with guidance to support optimal hydration and nutrition for people living with dementia.

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 to inform the management of hydration and nutrition at the end of life for a person with dementia. Alternative feeding assistance strategies should be considered along with consideration of the needs, preferences and wishes of the person with dementia. End stage dementia is a common disorder that frequently leads to triad of conditions involving anorexia, dysphagia and weight loss. Finucane et al¹⁷ and others show that this 'triad of conditions' is not addressed by insertion of a PEG.

Studies on the effect of parenteral nutrition in patients with dementia are limited¹¹⁶. There are conflicting results from systematic reviews pertaining to treatment decisions around CANH and patients with dementia. The decision to start artificial nutrition in people with dementia 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 for patients near the end of life is hospice and/ or 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 shared 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.



APPENDIX 1

STEERING AND PROJECT GROUP MEMBERSHIP

Guidance Documents Project Lead: Dr. Alice Coffey

Guidance Documents Project Researcher: Dr. Kathleen McLoughlin

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

Partners:

Sheila Robinson, Senior Speech & Language Therapist, Cork University Hospital.

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Dr Suzanne Timmons, Senior Lecturer Clinical Gerontology & Rehabilitation, University College Cork.

Dr Paul Gallagher, Consultant Geriatrician & Senior Lecturer, School of Medicine, University College Cork.

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

International

Professor David H Alpers, M.D.

William B Kountz Professor of Medicine

Washington University School of Medicine

National

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. Professor Geraldine McCarthy (Chair), Health Service Executive.
2. Dr. Ailis Quinlan, Public Health Doctor.
3. Ms. Marie Lynch, Irish Hospice Foundation.
4. Prof. Cillian Twomey, Geriatrician
5. Ms. Kay O'Sullivan, Lay Representative, Marymount Hospice, Volunteer Support.
6. Ms. Mary Mannix, CNS Dementia Care, Mercy Hospital, Cork.
7. Professor Phil Larkin, Director of the Palliative Care Research Programme, School of Nursing and Midwifery, UCD.
8. Dr. Bernadette Brady, Temporary 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 Irish Hospice Foundation to establish an Expert Advisory Group 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.^{75,76}

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

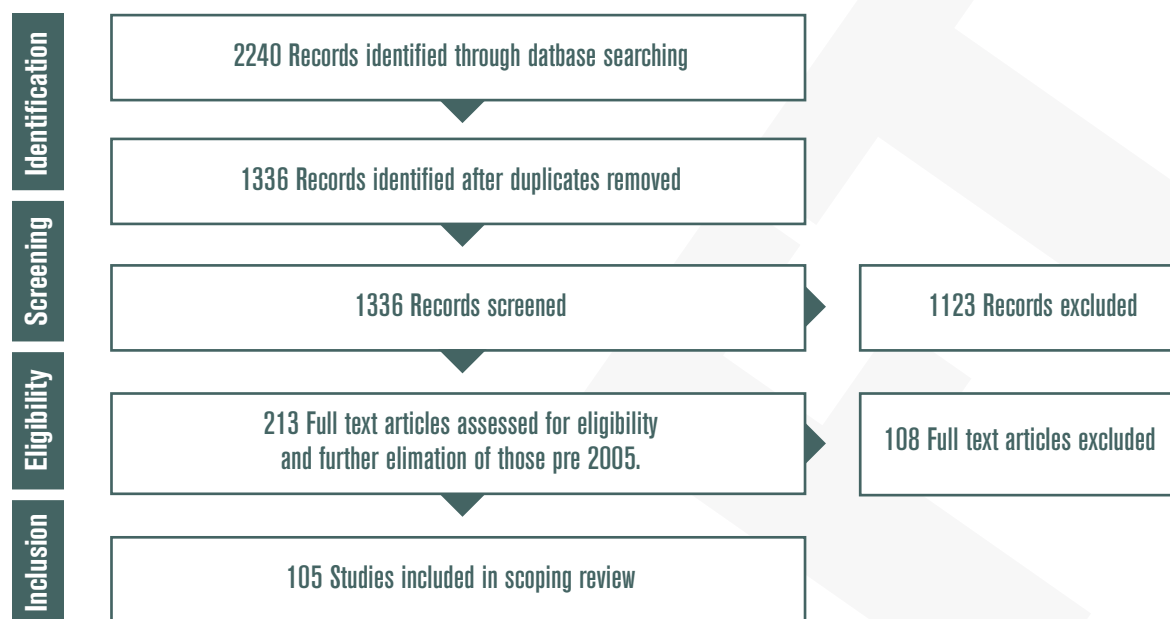
Papers generic to older people

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 pain 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) Country 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

These tables are available from the project lead on request n.cornally@ucc.ie

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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