Ethical decision making in end-of-life care for the person with dementia
Palliative Care for the Person with Dementia


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Guidance Documents Project Lead: Dr. Alice Coffey

Guidance Documents Project Researcher: Dr Kathleen McLoughlin

Principle Investigator for Ethics Guidance Document: Dr. Joan McCarthy

Authors: Joan McCarthy, Louise Campbell, Caroline Dalton-O’Connor, Tom Andrews, Kathleen McLoughlin

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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.

This guidance document is not intended as a sole source of guidance for ethical decision making in dementia palliative care and healthcare professionals should also refer to professional codes of ethics and relevant national policies and laws.

This guidance is not intended to replace ethical and clinical judgment or to 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.
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BACKGROUND

Dementia is a chronic, degenerative, life-limiting illness that affects mental capacity and communication. The end-of-life care needs of people dying from and/or with dementia may be complicated by cognitive impairment, communication difficulties and responsive behaviours\(^1\)\(^2\). The Irish National Dementia Strategy\(^3\) recommends that people with dementia should be supported to be cared for in the place of their choice, as far as this 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 project team 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

‘It is clearly imperative that key elements of the palliative care approach – in particular the focus on caring for the ‘whole person’, the importance of advance planning, the provision of adequate pain relief, the avoidance of inappropriate treatment, and support for family – should be made available in an appropriate way to people who are dying with dementia.’

(Nuffield Council 2009, p.556)

Dementia is associated with borderline capacity, dependence and behavioral changes and it prompts profound ethical questions about individual autonomy, selfhood and relationship. Specific ethical challenges that arise in relation to the care of individuals with dementia include: respecting autonomy and assessing capacity to consent to treatment, truth-telling and covert administration of medication, ensuring the overall well-being of individuals as well as their family/carers, making decisions about pain management and withholding and withdrawing treatment. These concerns are all the more pressing at the end of life where they may arise in tense and emotionally fraught circumstances and serve as a source of stress, for health professionals, care providers and families, who report feeling isolated and unsupported in making ethical decisions.

Many of the well-known ethical and legal cases involving end-of-life decision-making and questions about competency concern patients in a persistent vegetative state, e.g. Karen Quinlan\textsuperscript{10} and Nancy Cruzan\textsuperscript{11} in the US, Tony Bland\textsuperscript{12} in the UK and In re Ward of Court\textsuperscript{13} in Ireland. However, ethical challenges that arise in relation to individuals with dementia have unique features that need to be taken into account. Authors such as Golan\textsuperscript{14} and Jaworska\textsuperscript{15} draw attention to the following distinctive dimensions of dementia:

1. Dementia involves a slow deterioration and irreversible decline of cognitive capacities – as distinct from a sudden loss of consciousness and transformation of a previously competent person to a permanently incompetent person. During the transformation, the person may have periods during which they are able to communicate their wishes regarding their treatment.

2. Developments in neuroscience and neuropsychology indicate that individuals with dementia retain emotional and practical abilities long after they have suffered severe cognitive losses. This means that they may continue to hold ethical values which should be respected and they may continue to have an interest in the continuation of their lives.

3. The person with dementia undergoes a long process of personality change – so much so that the validity and applicability of their prior wishes and advance directives may be in doubt.

4. The final stage of the dementia process is sometimes associated with difficulties in swallowing and this often prompts consideration of administering Clinically-Assisted Artificial Nutrition and Hydration (CANH).
A guidance document can provide a framework to support ethical decision-making in relation to dementia care but will not tell a caregiver exactly what to do. It is important to acknowledge that there is rarely one over-arching ethical principle or value that can be used to solve an ethical problem. Critical judgment is required based on the individual’s rights and interests, the situation, the risks and the context in which the decision is made. There is rarely a single right solution for what should be done, and in fact reasonable disagreement can be expected and even encouraged. An approach to decision-making where solutions emerge in the course of dialogue, disagreement and negotiation often works best\(^8,9,16,17\).

The aim of this guidance document is to provide caregivers of people with dementia, regardless of care setting, with a framework to support ethical decision making for people living with dementia at the end of life.

**Scope of Guidance Document**

This guidance document will:

- Explain core ethical principles as they apply to individuals with dementia at the end of life
- Provide a decision-making tool that supports ethical decision-making for individuals with dementia at the end of life
- Offer guidance on key ethical challenges that arise in dementia care at the end of life.

**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 (October 2015) is at stage 4 of this process.

1. Completion of scoping review.
2. Collation of key review themes to inform the ethical principles and decision-making tool.
3. Preparation of Draft 1 of guidance document for comment by the project steering committee and national/international experts in the field.
5. Assimilation of feedback from external consultation to final draft.
6. Final version published.

**Structure of Guidance Document**

The guidance provided in this document focuses on core ethical principles and values, a decision-making tool and four key ethical topics, based on the key themes emerging from the scoping review which were considered most beneficial for caregivers. These areas are examined in detail in the following sections. Where applicable, we have signposted available resources and tools to guide ethical decision-making for people with dementia.
THEMES FROM THE LITERATURE REVIEW

A scoping study was undertaken to inform the development of this specific guidance document (see Appendix B for overview of associated methodology). It found that ethical concerns in relation to dementia are inconsistently addressed in national dementia guidelines around the world\textsuperscript{17,18,19,20,21}.

Knuppel\textsuperscript{18} identified a need for further research to specify how detailed ethical issues and related recommendations can and should be addressed in dementia guidelines. Knuppel\textsuperscript{18}’s systematic review of dementia guidelines in general indicates that Ireland does not have any such guidance, nor does it have any specific guidance on ethical challenges that arise in relation to dementia at the end of life.

Given the dearth of research in this area, a literature review identified the following three themes:

1. Common ethical and legal principles and values underpinning ethical decision-making for dementia care at the end of life.
2. Existing ethical decision-making frameworks for dementia care at the end of life.
3. Specific concerns that arise in end-of-life dementia care, e.g. advance care planning, truth-telling, assessment of capacity to consent or refuse treatment, enabling and protecting the person with dementia, withholding/withdrawing life prolonging treatment.

Drawing on the key themes, the Project Team agreed a set of Ethical Principles that inform an Ethical Decision Making Tool. The Decision Making Tool is, in turn, applied to four specific ethical challenges that arise in relation to the care of individuals with dementia at the end of life.

Four Areas for Ethical Guidance

1. Promoting relational autonomy and the capacities of the individual to consent or refuse treatment and care.
2. Decision-making for individuals with diminished capacity.
3. Meeting the Ethical Goals of Treatment and Care – Do Not Attempt Resuscitation (DNAR).
4. Disputing the Ethical Goals of Treatment and Care – Clinically Assisted Nutrition and Hydration (CANH).
Persons with dementia have the same rights as all persons, e.g., the right to life, autonomy, dignity, bodily integrity, freedom from inhuman and degrading treatment as well as the right to information, to consent and to confidentiality.  

To ensure that these rights are respected and protected, the project team has agreed that the following core ethical principles should underpin any decision-making process in dementia care at the end of life.

**4.1 Ethical principles**

**A. Relational Autonomy**

Autonomy is the capacity for self-determination; a person’s ability to make choices about their own life based on their values and beliefs about what is important. The notion of ‘relational autonomy’ draws attention to the embodied nature and social interdependence of human beings - our embeddedness in a family, a language group, or a cultural context.

In healthcare, both our embodiment and social interdependence provide the context within which treatment and care options are made available and within which our ability to choose amongst them is facilitated and enabled. The focus of a relational autonomy approach is on the person with dementia and those who care for them. It recognises the unique values, priorities and preferences of individuals and enables them to participate as fully as possible in decisions about their care. However, it also
recognises that a person does not make decisions or develop a value system entirely independently of the influence of others. The relational dimension of autonomy requires that health professionals also consider everything that surrounds the person – how they sit in their family, culture etc.

A relational autonomy-centred perspective obliges health professionals to:
- focus on the experiences of the person receiving care and on what matters most to them
- be attuned 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 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 where possible.

Individuals with dementia may well lose their understanding of who they are and the connection between their past and future, but nevertheless retain core preferences and ethical values.

B. Avoiding harm and doing good

Promoting the well-being of the person with dementia

Avoiding harm and doing good can be applied to all interactions with a person who has dementia. It can range from very ordinary and everyday interactions - e.g. simply doing good by saying ‘Hello’ to, or sitting with, someone with dementia - to making complex decisions on a person’s behalf.

When making decisions for individuals who lack decision-making capacity or whose capacity may be compromised, caregivers must act to promote the person’s overall well-being.

Promoting a person’s well-being goes beyond weighing the clinical burdens and benefits of proposed actions: it also involves taking the person’s past and current wishes and preferences into account and identifying the beliefs and values that may influence the decision in question (these include the values of patients, family members and staff).

It should not be presumed that, simply because a person lacks the capacity to make an autonomous decision, their views should simply be disregarded. To provide active support, the caregiver must try to understand what the person with dementia is currently feeling, wanting and experiencing, whilst enabling and maintaining relationships and interests of importance.

A balance must be struck between enabling a person with dementia to live their life in the way they wish, promoting their well-being, protecting their safety and protecting the safety and interests of others.
C. Personhood and value of life

The life of a person with dementia should be valued just as much as that of a person without dementia, with a particular focus on the person’s capabilities, rather than on presumed deficits.

Given proper individualised, holistic and respectful care, the quality of a person’s life with dementia can be positive. This holistic approach emphasises the following:

- Recognising the human value and dignity of people with dementia, regardless of age or cognitive impairment.
- Respecting the individuality of people with dementia, with their unique personality, life stories, experiences, familial and social relationships.

Treatment and care should meet the physical, psychological, spiritual and social needs of each individual throughout the course of their illness.

D. Solidarity

Our interdependence as human beings means that any of us may be touched by dementia and all of us will certainly touched by end-of-life issues. As such, we are ‘fellow travellers’ who have faced, or will at some point face, dependency in our lives. This understanding prompts an empathic response:

The quality of care provided should reflect the standard of care we would expect for ourselves and the people we love.

This interconnectedness is reflected in the relationship between the person with dementia, their caregivers and healthcare professionals, all of whose interests should be considered. On this view, our dependency on each other is the norm, not the exception.

‘Our dependency is not …. an exceptional circumstance. To view it as such reflects an outlook that dismisses the importance of human interconnectedness, not only for purposes of survival, but for the development of culture itself.’ (Kittay 1999)

E. Justice

Distributive Justice

In healthcare, distributive justice involves the fair or equitable distribution of finite resources. Problems of distributive justice arise when there is a scarcity or shortage of resources within a society. Advances in health technologies and care practices raise expectations that result in ever-increasing demands on the health allocation of a state’s budget. This increased demand may lead to allegations of injustice when these limited resources are not equally accessible to all who might benefit from them.

Access to treatment and care, while constrained by the availability of resources, should not be restricted on the basis of age, disability, psychological or intellectual impairment.

(Syrett, 2014)
Resource allocation in dementia care becomes particularly challenging at end of life. Uncertainty about when a person with dementia enters the dying phase raises questions about the need for hospitalisation and the appropriateness of providing potentially burdensome life-prolonging treatment.

**Social Justice**

- recognises that different groups in society may be advantaged/disadvantaged, e.g. on the basis of socio-economic status, gender, ethnicity, and this leads to diminished health and well-being.
- requires that particular attention be paid to the way in which group differences can place individuals and families at a disadvantage, and to the need to develop strategies/processes/practices to ameliorate inequities.

These five principles; Relational Autonomy, Avoiding Harm and Doing Good, Personhood and Value of Life, Solidarity and Justice encompass the key features of an emerging and significant theme in healthcare and in dementia care in particular – Person-Centered Care (PCC). PCC requires recognition of the dignity and uniqueness of each person and of what is important to them. It obliges health professionals and carers to form and foster therapeutic relationships that put the person with dementia – their needs, wishes, experiences and personalities – at the centre of concern.30-32

**Conclusion**

The principles employed in this Guidance Document are secular in origin and support a view of what is good or worthwhile from an intersubjective perspective. For example, we can agree that the idea of promoting a person’s well-being is a good thing, although we may disagree about what ‘well-being’ might mean in a given context.

Justifying an action by appealing to ethical principles means having to defend that choice of action over others in a manner which goes beyond one’s own perspective, bias, values and interests. By choosing an action based on principles, we remove our own partial viewpoint from the decision and appeal to a more general sense of what is the right thing to do.
4.2 Ethical decision making tool

Drawing on existing frameworks and mindful of the five core ethical principles that we have adopted above, we have developed an ethical decision-making tool for addressing ethical challenges involving persons with dementia:

<table>
<thead>
<tr>
<th>Actions</th>
<th>Responsibilities</th>
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</thead>
<tbody>
<tr>
<td>1. Articulate the ethical problem(s) and identify relevant facts</td>
<td>Be ethically sensitive and communicate clearly</td>
</tr>
<tr>
<td>2. Identify stakeholders’ interests, needs, values</td>
<td>Be respectful and inclusive</td>
</tr>
<tr>
<td>3. Weigh the merits and demerits of available courses of action</td>
<td>Be informed and fair</td>
</tr>
<tr>
<td>4. Select the action which can best be supported by ethical principles</td>
<td>Be impartial and transparent</td>
</tr>
<tr>
<td>5. Review</td>
<td>Check: Have I been sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent?</td>
</tr>
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Campbell and McCarthy
Actions and Responsibilities

1. Articulate the ethical problem(s) and identify relevant facts
   - Make an initial assessment of the situation in order to identify the main ethical issue(s) and the facts deemed relevant to the decision which needs to be made.
   - Although the issue(s) may have legal, clinical or organisational aspects, be sensitive to and focus on the ethical dimensions of the problem.
   - Clarify the ethical issue(s) in question in order to identify the interests and values of those who are affected by the decision and bring into focus the perceived harms and benefits associated with making a decision.

2. Identify stakeholders’ interests, needs, values
   - Ensure that all persons who have a stake or interest in the decision being made are consulted or represented and their needs and values identified. Inclusiveness is a vital part of good decision-making, so no person affected by the decision should be excluded from the decision-making process without adequate justification.

3. Weigh the merits and demerits of available courses of action
   - Explore available options and compare their relative merits and demerits fairly. Consider the perceived harms and benefits associated with each available course of action.
   - Make any underlying values, assumptions, motivations explicit and promote clarity, fairness and transparency in the decision-making process.

4. Select the action which can best be supported by ethical principles
   - Defend your choice of action over other possible choices by appealing to ethical principles and argument. This should go beyond your own perspective or bias, values and interests and appeal to a more general sense of what is the right thing to do. Different principles, e.g. relational autonomy, justice, solidarity etc., may be more or less relevant and applicable in different situations.

5. Review
   - A decision which is ethically sound is one which is sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent.
GUIDANCE AND RESOURCES

The four areas that healthcare professionals, carers and people with dementia would benefit from guidance with regard to ethical decision-making are introduced below and are outlined in further detail in subsequent sections of this document. These are as follows:

5.1 Guidance Area 1

Promoting relational autonomy and the capacities of the individual to consent or refuse treatment and care.

The autonomy of the person with dementia may be promoted by engaging in a process of Advance Care Planning (ACP) while he or she still has the capacity to make decisions about future treatment. Even if an ACP is in place, a relational autonomy-centered approach requires healthcare professionals to pay attention to what the experience of his or her condition means to the person who is now living with dementia and his or her carers. It requires that healthcare professionals and carers actively support the person with dementia so that they are encouraged to retain and express their sense of self and maintain the relationships that are important to them, rather than simply being protected from harm.

5.2 Guidance Area 2

Decision-making for individuals with diminished capacity

When making decisions for individuals who lack decision-making capacity or whose capacity may be compromised, caregivers must act to promote the person’s overall well-being. Promoting a person’s well-being goes beyond weighing the clinical burdens and benefits of proposed actions: it also involves taking the person’s past and current wishes and preferences into account and identifying the beliefs and values that may influence the decision in question (these include the values of patients, family members and staff). Under current Irish legislation, only the lead clinician has the legal authority to make healthcare decisions for a patient 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.
5.3 Guidance Area 3

Meeting the Ethical Goals of Treatment and Care – Do Not Attempt Resuscitation (DNAR)

Meeting the ethical goals of treatment and care may sometimes require limiting medical treatment in cases where individuals have refused it or in situations where it offers no overall benefit. Omitting to administer a particular treatment such as CPR for a particular patient is generally viewed as morally justified if it is considered futile (ineffective/without benefit) or unnecessarily burdensome. When discussing judgments of futility, it should be made clear that it is not people’s lives that are judged futile. In making judgments of futility, a clinician (often in company with patient or family) should not be making a value judgment about the significance or worth of this person’s life or implying that a life with dementia is not worth living. Rather, the judgment relates to the expectation that the treatment will not provide any benefit for this particular person at this stage of their dementia and/or related illnesses.

5.4 Guidance Area 4

Disputing the Ethical Goals of Treatment and Care – Clinically Assisted Nutrition and Hydration

As persons with dementia approach the end of their lives, the body’s increasing inability to absorb nutrients is often accompanied by loss of appetite and thirst and difficulty swallowing. However, food has an emotional, symbolic and social importance which should not be underestimated; assisting to feed someone who is sick is a ‘powerful instinctive act’ and the human contact provided by the act of feeding assistance may be of therapeutic benefit.

Deciding whether or not the administration or continuation of Clinically Assisted Nutrition and Hydration (CANH) is clinically indicated requires careful consideration of its burdens and benefits in the context of the specific goals of care for the person with dementia. Such considerations include the person’s illness trajectory, the potential impact of the intervention on the person’s condition, the expected clinical outcomes, the impact of a potential inpatient admission on the person, and the preferences/values of the person with dementia or proxy decision-maker.

Readers are advised to also refer to Guidance Document No 6 in this series, focusing on hydration and nutrition.
5.1 Guidance Area 1

Promoting relational autonomy and the capacities of the individual to consent or refuse treatment and care.

The autonomy of the person with dementia may be promoted by engaging in a process of Advance Care Planning (ACP) while he or she still has the capacity to make decisions about future treatment. The Advance Care Plan might include an advance statement of wishes and preferences (Advance Directive), and/or an Advance Decision to Refuse Treatment (ADRT) in a predefined future situation. The ACP may also include the appointment of a representative responsible for interpreting the stated wishes of a patient if they lose capacity (See Guidance Document No. 2 for further explanation and discussion of Advance Care Planning. Legislation on decision-making for individuals with diminished capacity, the Assisted Decision-Making (Capacity) Bill 2013, is at government committee stage in Ireland47).

Even if an ACP is in place, a relational autonomy-centered approach requires healthcare professionals to pay attention to what the experience of his or her condition means to the person now living with dementia and his or her carers. It requires that they actively support the person with dementia so that they can be encouraged to retain and express their sense of self and maintain the relationships that are important to them, rather than simply being protected from harm.6

This approach obliges health professionals and organisations to create the conditions that foster capacity including the development of relational skills and practices:

‘[T]he capacity to communicate, to engage in meaning-sending and meaning receiving relationships... with others, and to evince understanding and evaluation of such communication.’ e.g. touch, gesture, facial expression, posture, eye contact, sitting together, may endure long after speech, memory, functional capacities for daily living are compromised (Jennings 20043).

One of the most pressing ethical challenges that arises in caring for people with dementia is the fact that their understanding of their situation and ability to make decisions is affected by their illness. Depending on the nature and stage of their illness, their capacity may fluctuate or be seriously compromised.

Assessing Capacity

The fact that the person with dementia may currently not have sufficient understanding or appreciation regarding a decision should in the first instance signal a requirement for the provision of supports in order to ensure that their decision-making capacity is enhanced to the greatest degree possible, rather than signalling that they lack capacity to make that decision (adapted from National Consent Policy 2014; Section 5.544).

Where a person with dementia, having been given all appropriate help and support:

• is unable to communicate a clear and consistent choice or
• is obviously unable to understand and use the information and choices provided,

the possibility of incapacity and the need to assess capacity formally should be considered. (National Consent Policy 2014, 5.444)
Assessing whether a patient has capacity can be complex, difficult and uncertain. A responsible capacity assessment should prevent two possible mistakes: “first, the unjustifiable overruling of patient autonomy in order to safeguard patient well-being; and second, the unjustifiable respecting of patient autonomy at the cost of the patient’s well-being.”

It is important to choose the best time and best circumstances for assessing a person’s capacity. Consideration should be given to the person’s environment and the method of communication used. See Guidance Document 1 in this series for more about communication skills.

When assessing the capacity of a person with dementia, it must be determined whether:

- The person understands in broad terms and believes the reasons for, and nature of, the decision to be made.
- The person has sufficient understanding of the principal benefits and risks of an 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.
- The person understands the relevance of the decision, appreciates the advantages and disadvantages in relation to the choices open to them and is able to retain this knowledge long enough to make a voluntary choice.
Guidance Area 1:

Promoting relational autonomy and assessing capacity to consent or refuse treatment and care

Plan for end-of-life care: Encourage individuals to plan for end-of-life care while they have the capacity to do so. Good communication and (appropriate) reassurance is essential to ensuring that people with dementia can make decisions which are informed and which represent their considered views.

Presume capacity: When in doubt, the process of assessing capacity should be fair and free from prejudices based on old age, mental illness, dementia or intellectual disability.

Provide supports: Ensure that the decision-making capacity of the person with dementia is enhanced to the greatest degree possible. Seek to support people who have borderline capacity in making decisions for themselves insofar as this is possible. Listen for what matters to them, attend to the relationships that are important to them and talk to the person with dementia in a way that they can understand. Use augmentative communication strategies (see Guidance Document Number 1).

Inform yourself and seek advice: Be familiar with the legal criteria for capacity, as this is the relevant test for determining whether or not a person has legal authority to make decisions. If in doubt, seek a second opinion from another colleague with expertise in the area of capacity assessment (e.g. a psychologist or geriatrician). If doubts remain, seek legal advice.

Consider the context. Choose the best time and best circumstances for assessing a person’s capacity.

Respect the person’s values: Where a person is considered to lack capacity for decision-making, a relational approach requires an understanding of, and respect for, what is of value and importance to an individual. Therefore, when engaging with persons with dementia:

Instead of asking: ‘Can this person reason and come to a rational decision?’ and ‘Can this person grasp what is best for their life as a whole?”

We might ask: ‘Does this person still value and can they live in accordance with their values?’ (Jaworska 1999).
CASE STUDY 1

Karolina Husarek is a 55-year old woman who has Down syndrome and a mild intellectual disability. Karolina was diagnosed with Alzheimer’s disease just over three years ago. Prior to her recent admission to the local community nursing home she lived independently in a supported living environment. She was independent in all activities of daily living with access to support services if required.

Recently, Karolina has developed epilepsy and had initially agreed to take her anticonvulsant medication. Despite this, her epilepsy is not fully controlled and she continues to have some seizures although the duration and frequency of her seizures has significantly reduced. However, Karolina has begun to refuse to take her anticonvulsants as she feels she is taking too much medication. Owing to her intellectual disability and Alzheimer’s diagnosis, some staff are of the opinion that Karolina lacks insight into her condition and the importance of taking her medication. Despite staff having discussed this at length with Karolina, she is adamant that she is not going to take ‘all those tablets’. She has informed staff that, since the anticonvulsants have not stopped her seizures, ‘those tablets are no good’.

In the past month, Karolina also began to appear to be hypersensitive to auditory and visual stimuli. She complained of severe headaches and was observed holding her head in her hands and appeared to be in considerable pain. A CT scan revealed a large mass, which was diagnosed as an inoperable brain tumour. A number of palliative options have been prescribed, including analgesics and steroids. Palliative radiotherapy has also been discussed. It is clear that the decline in Karolina’s health is accelerating at pace. Staff are concerned that she will continue to refuse to take any more medications which will impact on symptom management as part of her palliative care. They are considering other options such as telling her that the oral medication is a health supplement, because in the past she has taken vitamin supplements.
Consider the case by applying the Ethical Decision-Making Tool

1. Articulate the ethical problem(s) and identify relevant facts

**Ethical problem(s)**

Nursing staff are unclear as to impact of Alzheimer’s disease on Karolina and are unsure of her ability to participate in decision-making about her treatment and care. A decision needs to be made about Karolina’s immediate and long term care given her refusal to take the medication prescribed for her. Some staff are of the opinion that Karolina’s decision to refuse medication and other therapeutic interventions should be respected. Other staff are unsure if Karolina has the capacity to fully understand the implications of her decision. These staff are of the opinion that the administration of her medication in a disguised form (covert medication) is justified to manage the symptoms she is experiencing (See examples of international guidelines relating to the use of covert medication in vulnerable populations in Additional Resources and Guidance Document 5 on the administration of covert medication)

**Relevant facts**

Karolina is diagnosed with Alzheimer’s disease, which is progressing rapidly. She also has a mild intellectual disability and Down Syndrome.

A decision needs to be made about Karolina’s refusal to take medication or avail of other therapeutic interventions prescribed for her. These are considered essential to minimise the symptoms which Karolina is currently experiencing and will experience as her health deteriorates in the future.

Karolina’s medical condition has further deteriorated since she developed epilepsy and was diagnosed with an inoperable brain tumour.

Karolina strongly believes that she should not take her medication as she feels the medication is not doing her any good.

Karolina has been living independently, predominately without supports. As such, a strong therapeutic relationship has not been established between her and the nursing staff.

Nursing staff are committed to supporting Karolina to remain within the supported accommodation setting within her community. However, they feel under pressure to act and they are concerned that her refusal to take medication and other therapeutic interventions will compromise their ability to support her in this setting.

There is no end-of-life policy in the support service that addresses situations like this.

2. Identify stakeholders’ interests, needs, values

**Karolina Husarek**

Karolina’s independence is vital to her quality of life; to maintain this to the greatest extent possible, she needs to remain in her current supported living accommodation (quality of life, relational autonomy, solidarity).

Karolina’s own views should be central to how this situation is addressed (relational autonomy).
Karolina’s health and continued well-being depends on good medication management and symptom control (doing good, avoiding harm).

**Nursing Staff**

Nurses are morally obligated to support Karolina to live in accordance with her own beliefs and values and to help her to maintain the relationships that are important to her (relational autonomy).

They are also obligated to avoid harming Karolina and to act in ways that benefit her (avoiding harm, doing good).

Nurses may experience moral distress when unable to fulfill their obligations to Karolina, for example if they are unable to continue to support her to stay in her home (avoiding harm, personhood, solidarity).

Nurses may experience moral distress when faced with a situation in which respecting Karolina’s wishes impacts on their ability to provide good quality patient care and symptom management (doing good, avoiding harm, solidarity).

**Organisation**

Nursing home management and health services are obligated to put in place policies and procedures to ensure that safe, respectful, quality care is provided to service users (doing good, avoiding harm).

Organisations are obligated to provide quality services which respect the human rights of service users and ensures their needs are met (relational autonomy, doing good, avoiding harm, solidarity).

Organisations are obligated to ensure staff are supported and empowered to deliver that care (doing good, avoiding harm, justice, solidarity).

Organisations are obligated to work closely together to ensure the best quality care and to conserve scarce resources (justice).

3. Weigh the merits and demerits of available courses of action:

1. Respect Karolina’s decision to refuse to take medication and potentially avail of other therapeutic interventions.

**Merits**

Respecting Karolina’s wishes may reduce her distress and anxiety given the changes in her circumstances. It may support the development of a therapeutic relationship between Karolina and nursing staff.

**Demerits**

Exposes Karolina to the risk of accelerated deterioration of her condition. Respecting Karolina’s wishes at this point may compromise her autonomy in the future, should her condition deteriorate more rapidly without medication. It may also impact negatively on her living situation.
2. **Respect Karolina’s decision while continuing to discuss her refusal to take medication and potentially avail of other therapeutic interventions with her.**

**Merits**
Respects Karolina’s wishes without abandoning her to harms which she may not fully understand or appreciate. It may reduce her distress and anxiety given the changes in her circumstances. Facilitates the development of a therapeutic relationship between Karolina and nursing staff.

**Demerits**
Delays the anticipated benefits of taking the medication. Exposes Karolina to the risk of accelerated deterioration of her condition. Respecting Karolina’s wishes at this point may compromise her autonomy in the future should her condition deteriorate more rapidly without medication.

3. **Administer medication in the form of ‘covert medication’ informing Karolina they are vitamin tablets**

**Merits**
Immediate administration of medication will clinically benefit Karolina. Overriding Karolina’s wishes at this time may afford nurses the opportunity to promote her autonomy at a later date as the situation progresses.

**Demerits**
Deceiving Karolina violates her right to autonomy and dignity. Subterfuge undermines the therapeutic relationship.

Administering the medication covertly may not be clinically appropriate and staff worry that doing so may contravene best practice guidelines.

4. **Select the option which can best be supported by ethical principles**

**Respect Karolina’s decision while continuing to discuss her refusal to take medication and potentially avail of other therapeutic interventions with her.**

Karolina’s capacity to participate in decisions about her care may be formally assessed. If she has capacity to make her own decision regarding medication, her reasons for refusing medication should be explored. Health professionals supporting Karolina are obligated to communicate honestly with her in relation to their clinical concerns and the possible impact of her decision on her living situation. However, advice should not be allowed to become manipulative. Options should be clearly stated, Caroline’s own views should be elicited and encouraged and she should not be in any doubt that decisions are hers to make. If, following discussion, she continues to indicate that she does not want to take medication, her wishes should be respected.

If an assessment reveals that Karolina’s capacity to make healthcare decisions is impaired then her wishes should be respected in as far as possible. Karolina should be facilitated to
participate in the decision-making process cognisant of her level of intellectual ability and the co-existing diagnosis of Alzheimer’s disease.

When engaging with Karolina, nursing staff must first identify what is of importance and of value to her. Karolina’s values should be central to decisions made about her care. Her refusal to take medication may be informed by a number of factors and these should be explored. It is also important to explore her understanding of different concepts, such as serious illness, death and her understanding of time. It would also be important to explore how Karolina links concepts together, i.e. linking serious illness to dying.

There is no moral pressure to satisfy whimsical wishes (unless to do so comforts and reassures). However, consistent and unwavering wishes are to be given respect. Karolina has consistently stated she wishes to remain within her supported living accommodation and this request must be respected also.

**Communicate clearly and sensitively**

Continued efforts should be made to develop a therapeutic relationship with Karolina, to facilitate open, respectful communication. Appropriate communication can alleviate a person’s concerns and can sometimes prevent confrontational situations developing between the individual involved and health professionals. Efforts should be made to maintain open lines of communication with Karolina and to continue to explore her reasons for refusing medication. It would also be important to have such a discussion each time there is a change in her health status, i.e. if she experiences an increase in pain or nausea.

**Make reasonable adjustments**

Reasonable adjustment requires that health professionals within the health services are prepared to adapt and/or revise their usual or routine practices in order to ensure that those with an intellectual disability are not disadvantaged. These adjustments should reflect a reasonable effort to accommodate the specific needs of those with disabilities. Karolina may require access to easy read material and medical jargon should be avoided. Providing longer appointment times and follow up appointments to address queries will also facilitate good communication. Since Karolina does not appear to have any next of kin, an independent advocate, friend or key worker from her supported living accommodation might be in a position to support her.

**5. Review**

Have I been sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent?
Additional resources

Amazon Kindle http://amzn.to/1KnaCyH  

McCarthy J, Donnelly M, Dooley D, Campbell L, Smith D (2011) Ethical Framework for End of Life Care (8 Modules and 8 Study Sessions). Available to download at:  
http://hospicefoundation.ie/publications/ethics/


Covert Medication (See Guidance Document 7)

The resources listed below are some examples of international guidelines relating to the use of covert medication in vulnerable populations.


5.2 Guidance Area 2

**Decision-making for individuals with diminished capacity**

When making decisions for individuals who lack decision-making capacity or whose capacity may be compromised, caregivers must act to promote the person’s overall well-being.

Promoting a person’s well-being goes beyond weighing the clinical burdens and benefits of proposed actions: it also involves taking the person’s past and current wishes and preferences into account and identifying the beliefs and values that may influence the decision in question (these include the values of patients, family members and staff).

Legislation on decision-making for individuals with diminished capacity, the Assisted Decision-Making (Capacity) Bill 2013, is at government committee stage in Ireland.47

In the absence of legislation, the National Consent Policy44 advises that

‘in making decisions for those who lack capacity, the health and social care professional should determine what is in their best interests, which is decided by reference to their values and preferences if known. The health and social care professional should:

- Consider whether the service user’s lack of capacity is temporary or permanent. In those with fluctuating cognitive impairment, it may be possible to make use of lucid periods to obtain consent.
- Consider which options for treatment would provide overall clinical benefit for the service user.
- Consider which option, including the option not to treat, would be least restrictive of the service user’s future choices.
- Support and encourage service users to be involved, as far as they want to and are able, in decisions about their treatment and care.
- Seek any evidence of the service user’s previously expressed preferences, such as an advance statement or decision, and of the service user’s previous wishes and beliefs.
- Consider the views of anyone the service user asks you to consult.
- Consider the views of people who have a close, ongoing, personal relationship with the service user such as family or friends.
- Consider involving an advocate to support the service user who lacks capacity to participate in the decision making process around consent. This may be particularly helpful in difficult situations such as when service users with no family or friends have to make a complex decision; or when there is significant disagreement regarding the best course of action.’ (National Consent Policy44 Part 1, 5.6)

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 patient’s specific values and treatment preferences.
Professionals have an ongoing duty to respect the right to life of a person who lacks decision-making capacity. However, this duty must be balanced against the duty to protect the patient from inhuman or degrading treatment and the duty to respect the patient’s right to dignity and bodily integrity. Sometimes ethical dilemmas concerning competing obligations - such as preserving human life and avoiding harm - can arise as a result of hospital admissions.

**Unnecessary hospitalisation**

When a person with dementia is approaching the end of life, a palliative approach to care should be adopted and, where possible, acute episodic illness should be managed in the community.

*Current or previously-expressed preferences with regard to place of care should be honoured as a principle, but best interest, safety and family caregiver burden issues should also be given weight in decisions on place of care (van der Steen et al 2014: 200)*21.

The most frequent causes of hospitalisation among people in the end stages of dementia are pneumonia and urinary tract infections, even though being in hospital is not necessary for optimal treatment48. People with dementia can deteriorate when they move to an unfamiliar environment and admissions are often distressing and disorientating for them49. A recent audit of dementia in acute care highlights that approximately 1 in 12 people admitted to an acute hospital with a diagnosis of dementia will die during that admission50. Unnecessary hospital admissions can be avoided through advance care planning and liaison with the medical team51. Generally most people with dementia and their families prefer to remain in their usual place of care, rather than be admitted to hospital. To maximise the potential for this to occur it is important to recognise that:

- There is a need for knowledge and expertise on end-of-life care in long term care setting.
- The duration of the end stage of dementia and the dying process can be uncertain and this can be difficult for families.
- There is a need for teams to anticipate needs and changes; best practice is not to bombard families with information.
- Advance care planning issues need to be addressed. (MacConville et al.)5

Where admission to hospital is unavoidable, staff working in acute settings should be familiar with best practice for the care of people with dementia in such an environment, as outlined in the Irish National Audit of Dementia Care in Hospitals 2014 report50.
Guidance Area 2

Decision-making for individuals with diminished capacity

**Plan for end-of-life care:** Individuals should be encouraged to plan for end-of-life care while they have the capacity to do so. In this respect, early communication and (appropriate) reassurance is essential to ensuring that persons at the early stages of dementia can make decisions which are informed and which represent their considered views (See Guidance Document Nos 1 and 2).

**Maintain good communication:** It is essential to maintain good communication with family members. This does not mean that family members’ views should take precedence over the legal and ethical obligation of the healthcare professional to provide care that aims to promote the overall benefit of the person with dementia. Identifying overall benefit may involve weighing up claims of the family or others, but the person with dementia perspective and well-being should be at the centre of the deliberations. Appropriate communication may also alleviate family concerns and can sometimes prevent confrontational situations developing.

**Time and place are important:** Professionals should think about the time at which they talk to family members and the environment in which discussions take place. Rushed conversations in public places may lead to misunderstanding, cannot provide the kind of reassurance needed and may lead to feelings of resentment and anger among family members. This may create further difficulties for the person with dementia, the family and the health professionals involved.

**Inform about the dying process:** Where possible, health professionals should inform families about what to expect in the dying process. Many families will not know what to expect and informing them of what is likely will make the process easier and reduce the possibilities of conflict between families and health professionals. This may also involve reassurance about pain relief and distress.

**Inform yourself and seek advice:** If in doubt about the legal rights implicated in a particular decision, professionals and carers should seek advice as to how to proceed. This is especially important in the event of disputes between family members or between professionals and family members. Where health care professionals have difficulty dealing with the expressed wishes of people with dementia and the expectation of their loved ones, then they should seek advice from their peers.
CASE STUDY 2

RESPECTING PRIOR WISHES

*Pat O’Brien is a 63-year old male with late stage Alzheimer’s disease and he has no decision-making capacity.* While in the early stages of Alzheimer’s disease, Pat needed to have a pacemaker inserted for 3° heart block. This has been very successful and he remains symptom free. As the pacemaker has been in situ for some years, it is anticipated that the battery will become depleted in the coming months. This will require a replacement procedure, meaning a minor operation and short stay in hospital. A recent interrogation of the device showed that Pat’s cardiac rhythm is completely dependent on the device. In this instance, the device is life prolonging.

At the initial insertion, Pat clearly stated that, should he deteriorate to late stage Alzheimer’s, he did not want a replacement battery and wrote an advance directive to this effect. His wife, Helen, is in full agreement with this decision since they have discussed it at length over the course of a number of years. Her concern is that the device is prolonging the dying process. Pat’s cardiologist, who is monitoring the pacemaker, fully intends to replace it when the time comes. Helen has expressed her wish for this not to happen, but the cardiologist is uncomfortable with this and is adamant that it should. He is concerned that not replacing the pacemaker battery may be tantamount to killing and would leave him open to litigation. (Adapted from Bharadwaj and Ward52)
Consider the case by applying the Ethical Decision-Making Tool

1. Articulate the ethical problem(s) and identify relevant facts

**Ethical problem**

Helen, respecting Pat’s previously expressed wishes as set down in his advance directive, does not want the cardiologist to change the battery on a pacemaker which is keeping Pat alive. If the battery is not replaced, Pat may die. The cardiologist is adamant that the battery should be replaced.

**Relevant facts**

1. Pat has late stage Alzheimer’s disease.
2. The disease is burdensome to Pat and to Helen.
3. Pat wrote an advance directive requesting that the battery should not be changed if his condition deteriorated to a late stage of the disease.
4. His wife, Helen, is in agreement and believes that the device is prolonging death.
5. Pat’s cardiac rhythm is completely dependent on the device.
6. The cardiologist believes that not changing the battery is equivalent to killing Pat and that it may expose him to litigation.

2. Identify stakeholders’ interests, needs, values

**Pat O’Brien**

1. Respect for Pat’s overall interests, including his autonomy interests, requires that his views should inform what happens to him. (*relational autonomy*)
2. The act of dying should not be unnecessarily prolonged. (*avoiding harm*)
3. Pat should not be subjected to futile and unnecessarily burdensome treatment. (*avoiding harm*)
4. If Pat is dying, he should be supported to die in comfort and dignity surrounded by those he loves. (*doing good, relational autonomy, solidarity*)
5. Pat’s life is profoundly valuable; ending it harms Pat and the community as a whole (*value of life, avoiding harm, solidarity*)

**Helen**

1. Helen fully agrees with the advance directive and believes that the device is merely prolonging death. (*avoiding harm; relational autonomy*)
2. She wants what is best for Pat. (*doing good*)
3. She has been very close to Pat and they have discussed the situation over many years. (*relational autonomy, solidarity*)
**Cardiologist**

1. The cardiologist feels morally and professionally obligated to respect Pat’s wishes and values if known. *(relational autonomy)*
2. He is also obligated to preserve and protect Pat’s life, to avoid harming him and his family and to act in ways that benefit him. *(value of life, avoiding harm, doing good)*
3. Even though Helen seems to support Pat’s Advance Directive, the cardiologist is afraid of being sued at a later stage because of his uncertainty about the status of ADs in Ireland and about whether or not Pat’s AD applies to this situation.
4. At the same time, he is not obligated to provide futile and/or burdensome care to Pat. *(avoiding harm)*
5. The cardiologist may experience moral distress when he is unable to fulfill these competing obligations. *(value of life, avoiding harm, doing good)*

**3. Weigh the merits and demerits of available courses of action**

1. **Replace the battery**
   
   **Merits**
   The device will continue to work and provide Pat with a life-saving intervention. The battery is fairly easy to replace and the procedure does not place an excessive burden on Pat. It will also alleviate the cardiologist’s discomfort. The operation is quick and relatively painless. It has very few risks.

   **Demerits**
   Replacing the pacemaker battery explicitly violates Pat’s documented wishes. In this instance, the pacemaker is prolonging the dying process. This is burdensome to Pat and Helen. Pat will need to be hospitalised for a short period and this may cause him to be more disorientated than usual. A hospital admission may also cause Pat and Helen distress and may be a ‘trigger’ for admission into residential care, thus forcing Pat and Helen to make important decisions about the future at a point of crisis, instead of in their own time.

2. **Do not replace the battery**
   
   **Merits**
   Respects Pat’s autonomy by adhering to his AD. Gives consideration to Helen’s concerns about Pat’s well-being. Avoids burdensome treatment

   **Demerits**
   Pat is likely to die as soon as the pacemaker fails to keep his heart beating.
4. Select the option which can best be supported by ethical principles:

**Do not replace the battery**

Pat has a right to life. The right to life is one of the most fundamental rights and it is protected by the Irish Constitution, the European Convention on Human Rights as well as under United Nations human rights instruments. Pat cannot be deprived of his right to life because he is may lack capacity. It would be both unlawful and unethical to deny treatment to anyone on this basis.

However, the right to life is not absolute. It is generally accepted that treatment is not required where treatment would be futile because it offers no reasonable hope of benefit or in situations in which the expected benefit would be outweighed by burdens such as excessive pain and discomfort.

Pat has a right to dignity and a right to freedom from futile treatment. There is no ethical or legal distinction between withholding a pacemaker and not replacing the battery. Not replacing the battery is ethically and legally equivalent to withdrawing other forms of life-sustaining treatment, a position which is widely regarded as ethically permissible.

In this case, there is clear evidence in the form of an AD as to Pat’s wishes. There is a need to respect his wishes and those of his wife. Patients are entitled to refuse treatment, and physicians must respect this even if it conflicts with their own values.

In situations like this, it is possible to refer Pat to a cardiologist who is willing to uphold the wishes of Pat and Helen. The feelings of the cardiologist should not take priority over what is best for Pat. There is an advance directive in existence and this should take precedence. The AD is an ethically but not yet legally binding document, which provides a comprehensive statement of Pat’s values and previously expressed wishes.

Patients are members of families and, given Pat’s relationship with Helen and wider family, it is right that they should be consulted. Respect for Pat’s rights requires family involvement.

5. Review

Have I been sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent?
Resources for Healthcare Professionals/ Family Caregivers

In many cases, there will be clear continuity between the way people with dementia approach their life now and in the past. However, in the event that there is a divergence, the Nuffield report advises that

“neither past nor present can automatically take precedence, but that the relative strength of the person’s wishes, the degree of importance of the decision, and the amount of distress being caused should all be important factors to consider”.

There are arguments in favour of prioritising the person’s past or present preferences, based on the assumptions made about the person’s beliefs, values and behaviour. Nuffield recommend that the following factors are considered:

- How important is the issue at stake? For example, maintaining a person’s religious practice or moral beliefs (e.g. with regard to what they eat) is likely to have been much more important to them than issues of aesthetics, taste, or smartness of dress.
- How much distress or pleasure is it causing now? If maintaining a past belief is causing major distress, then it is likely that the person’s current well-being and not their previous autonomy interests should take precedence.
- Consider the underlying values or beliefs on which the earlier preferences were based. Have they genuinely changed or can they be interpreted in a new light? It may be the case that the person is expressing ‘old’ views or preferences in a different way.
- Explore whether the apparent changes in preferences or values result from psychosocial factors (such as fear) or directly from the dementia (such as sexually disinhibited behaviour), or whether on the other hand they are linked with a genuine pleasure in doing things differently?
- Early (and continuing) discussions on these issues shortly after diagnosis will clearly help caregivers to obtain a greater understanding of the strengths of the beliefs and values held by the person with dementia at that time. This will enable an appropriate balance to be made between potentially conflicting interests if this later becomes necessary.

Also see the National Consent Policy.
Meeting Ethical Goals of Treatment and Care – Do Not Attempt Resuscitation (DNAR)

If healthcare decision making is to be truly respectful of a person’s wishes, then the goals of care must be clarified. Determining the goals of care entails considering the stage of a person’s disease or prognosis and uncertainties related to this. The goals of care for any person are not set in stone. They are dynamic and can change rather quickly. On-going reassessment of goals and on-going documentation is necessary to ensure quality of care that is clinically judged feasible and in keeping with the particular person’s preferences.

Meeting the ethical goals of treatment and care may sometimes require limiting medical treatment where individuals have refused it or in situations where it offers no overall benefit is sometimes appropriate. Withholding or withdrawing life prolonging treatments such as cardiopulmonary resuscitation (CPR), ventilators, or dialysis machines, are ethically and legally accepted practices that should ideally be specified in advance care plans or directives (See Guidance Document No. 2)

Omitting to administer a particular treatment such as CPR for a particular person is generally viewed as morally justified if it is considered futile (ineffective/without benefit) or unnecessarily burdensome. In discussing judgments of futility, it should be made clear that it is not people’s lives that are judged futile. In making judgments of futility, a clinician (often in company with patient or family) should not be making a value judgment about the significance or worth of this person’s life or that a life with dementia is not worth living. Rather, the judgment relates to the benefit or otherwise of the treatment for this particular person at this stage of their dementia and/or related illnesses. This point is most important to stress with family members where a DNAR has been signed.

‘Decisions about CPR must always be made on the basis of an individual assessment of each case and not, for example, on the basis of age, disability, the subjective views of healthcare professionals regarding the individual’s quality of life or whether he/she lives in the community or in long term care. The individual’s own views and values are centrally important.’

(National Consent Policy, Part 4, 3.24)

Decisions to withhold CPR usually require the consent of the person with dementia. However, when CPR is, on the basis of clinical evidence, considered to be futile then it does not need to be offered. If a person with dementia is unable to participate in discussions about CPR,

‘those with a close, on going, personal relationship with the individual may have insight into his/her previously expressed preferences, wishes and beliefs...[The] role of those close to the individual is not to make the final decision regarding CPR, but rather to help the senior healthcare professional to make the most appropriate decision. Where CPR is judged inappropriate, it is good practice to inform those close to the patient, but there is no need to seek their ‘permission’ not to perform CPR in these circumstances’

(National Consent Policy, Part 4, Section 3.34).
When people with dementia and their families are consulted, decisions about attempting CPR raise sensitive and potentially distressing issues for patients and people emotionally close to them. Initially it is most important to determine the capacity of people with dementia who are deciding on DNAR or CPR.

When the wishes of a person with diminished capacity are not known, treatment decisions must be based on the person’s overall benefit. This judgment is not solely a clinical or legal judgment that lacks reference to the particular patient. Quite the contrary - it needs to take into account:

a) The person’s known values and preferences.
b) Information received from those who are significant in the person’s life and who could help in determining his or her best interests.
c) Aspects of the person’s culture and religion that would influence a treatment decision.
d) The person’s diagnosis and prognosis.

Documenting decisions carefully will ensure that they are understood and implemented particularly if staff who are not familiar with the patient are on duty when a crisis does arise. However, staff should be clear; the documentation is secondary and gives effect to the decision, it is not the decision itself. A valid DNAR is one that is reached following an appropriate decision-making process.

A decision not to attempt CPR applies only to CPR. It does not apply to any other aspect of treatment and all other treatments and care that are appropriate for the individual should continue. However, many DNAR decisions and discussions will occur in a broader context of decisions and discussions about end of life care, and it is often appropriate that documentation should reflect that broader context and refer to any additional decisions. (National Policy On Do-Not-Attempt-Resuscitation Decisions: Recommendations on Implementing the Policy).

Respect for the person’s well-being and dignity also means that, if a person with dementia has a DNAR in their chart, they and, where appropriate, their family, need reassurance that all pain management and supportive physical, psychological, social and spiritual care will continue.

It is important that unduly restrictive policies do not have the effect of preventing appropriate DNAR decisions from being made in urgent situations such as where attempting CPR is clearly inappropriate because death is imminent and unavoidable and starting or continuing resuscitation measures will be ineffective and/or harmful. (National Policy On Do-Not-Attempt-Resuscitation Decisions: Recommendations on Implementing the Policy).

In general, according to the National Consent Policy, the most senior healthcare professional is responsible for making such decisions. However, it is acknowledged that:

‘Situations may arise where a decision regarding CPR has to be made quickly and the most senior healthcare professional is unavailable. In such circumstances, decision making responsibility can be delegated to other less senior healthcare professionals, who should notify and discuss with their senior colleague as soon as possible’

(National Consent Policy, Part 4, Section 3.6)
Guidance Area 3
Meeting Ethical Goals of Treatment and Care

Do Not Attempt Resuscitation (DNAR)

Make resuscitation status clear: DNAR decisions should be clearly and accurately documented, dated and signed by a health care professional in the individual’s healthcare record. Information should be provided about:

1. The rationale for the decision, including whether or not there is an advance care directive or plan.
2. Who was involved in discussions about the decision, including any discussion with the person themselves.
3. Whether a DNAR decision is to continue indefinitely or will be subject to review for example within a particular time or in the event of clinical change.
   (National Consent Policy 2014, Part 44)

Resuscitation status should be made clear to family members and the reason why a DNAR is considered appropriate should be made clear. The meaning and limits of a DNAR should be explained in full to family members.

Explain the risks and benefits: Many people, patients, families and even some health professionals have unrealistic expectations about the likely success and potential benefits of CPR and lack detailed understanding of what is involved. In the clinician-family conversation, it is important to find out whether the family understands what is actually involved in CPR, what likely outcomes can be anticipated, and what possible suffering might be involved for the patient if it is attempted.

Be informed: Be aware of the national and local policies on DNAR and its requirements as it applies to your professional role. Act in accordance with the policy with respect to the making, documentation and communication and implementation of DNAR decisions.

Put systems in place: Healthcare providers should have systems in place to ensure that the fact that a DNAR decision has been made is readily available to staff who may not always be familiar with the individual patient to ensure that it is complied with in the event of an emergency.

DNAR and other end-of-life decisions: A decision not to attempt CPR applies only to CPR. It does not apply to any other aspect of treatment and all other treatments and care that are appropriate for the individual should continue. However, many DNAR decisions and discussions will occur in a broader context of decisions and discussions about end-of-life care, and it is often appropriate that documentation should reflect that broader context and refer to any additional decisions.
CASE STUDY 3

NOT FOR RESUSCITATION STATUS AND FUTILE TREATMENT

Noel Dabrowski is a 78-year old widower who emigrated to Ireland from Poland many years ago and speaks very good English. He has been cared for in a nursing home for the past two years, since he suffers from the early stages of Alzheimer’s and was not coping very well at home. In the past six months he has also been diagnosed with end stage chronic bronchitis and heart failure. Despite this condition, Noel is actively interested in what is happening around him. He has two sons and one daughter, who visit him frequently and take a keen interest in his care. His children have accepted that nothing more can be done for their dad though he is seen regularly by his GP for symptom management and monitoring.

Early one evening Noel’s condition suddenly deteriorates and he is breathless and increasingly confused. The nursing staff feel that since his resuscitation status has not been discussed or determined, they have no choice but to begin resuscitation efforts, call an ambulance and his family and seek his admission to hospital. One of the nurses hesitates and asks her colleagues; ‘Would Noel or his family want us to resuscitate him in these circumstances and move him to hospital?’ ‘Will resuscitation and further treatment benefit Noel?’
Consider the case by applying the Ethical Decision-Making Tool

1. Articulate the ethical problem(s) and identify relevant facts

**Ethical problem**
A decision needs to be made about resuscitating Noel and admitting him to hospital but there is no DNAR order, care plan or advance directive that could guide the nurses as to how to proceed.

**Relevant facts**
1. Noel seems to be in the final phases of his illness.
2. It is likely that CPR will be painful and burdensome and the move by ambulance from familiar to unfamiliar surroundings will cause discomfort. It also seems likely that these efforts will be futile i.e. that Noel will not survive the intervention.
3. It is unclear how much the patient understands what is happening to him because of his Alzheimer’s and his breathlessness.
4. Noel's family seem to have believed that their father was for palliative care only and they indicated that they had accepted this, but there was no documentation to support this understanding.
5. The nursing staff feel under pressure to make a decision due to perceived lack of time. In the absence of any clarity around Noel’s resuscitation status, they feel compelled to provide CPR and to call the emergency services.
6. There is no end-of-life policy in the nursing home that addresses situations like this.

2. Identify stakeholders’ interests, needs, values

**Noel Dabrowski**
1. Respect for Noel's overall interests, including his autonomy interests requires that his views should inform what happens to him. *(relational autonomy)*
2. Noel’s life should be saved if possible. *(value of life)*
3. Noel should not be subjected to painful, futile, unnecessarily burdensome or undignified treatment. *(avoiding harm, dignity)*
4. If Noel is dying, he should be supported to die in comfort and dignity surrounded by those he loves. *(doing good, dignity)*

**Noel’s family**
1. Noel’s family have accepted that further treatment for Noel’s overall condition would be futile. *(avoiding harm)*
2. They indicate that they want high quality care for Noel. *(doing good)*
3. They demonstrate that they are very close to Noel and would want to be with him in his final days and hours. *(solidarity)*
### Nursing Staff

1. Nurses are morally, legally and professionally obligated to respect Noel’s wishes and values if known and to support his family. *(relational autonomy)*
2. They are also obligated to avoid harming Noel and his family and to act in ways that benefit them. *(value of life, avoiding harm, doing good)*
3. Nurses are not obligated to provide futile and/or burdensome care to patients. *(avoiding harm)*
4. Nurses may experience moral distress when they are unable to fulfil these obligations. *(avoiding harm, solidarity)*

### Organisation

1. The nursing home management and health services in the region are obligated to provide necessary policies and procedures to ensure safe, respectful, quality care is provided to patients and that staff are supported and empowered to deliver that care. *(value of life, avoiding harm, doing good, relational autonomy, justice, solidarity)*
2. They are also obligated to conserve scarce resources. *(justice)*

### 3. Weigh the merits and demerits of available courses of action

#### 1. Transfer Noel to hospital

**Merits:**

Resuscitation efforts can be maximized and they may temporarily prolong Noel’s life. The move reassures nurses that they are doing everything they can to save Noel’s life and addresses any worries about their obligations under the law.

**Demerits:**

The move risks increasing Noel’s discomfort and suffering. He may become disorientated and confused and the move may hasten his death. The move is likely to cause the nursing staff moral distress if they believe that resuscitation efforts are actually futile.

#### 2. Telephone Noel’s GP to clarify Noel’s resuscitation status. Telephone Noel’s family to seek their understanding of Noel’s wishes for his end-of-life care.

**Merits:**

This ensures that any decision made is consistent with what Noel would want. It also provides the nurses with the ethical and legal reassurance to act.

**Demerits:**

Any delay may risk Noel’s life. Staff may experience moral distress if they believe that they are doing the wrong thing in delaying treatment for Noel. They may also worry about their legal obligations.
4. Select the option which can best be supported by ethical principles:

**Contact Noel’s GP and family**

The attempt to avoid the perceived risk of litigation should not take priority over what is best for Noel. If the nursing staff are unable to reach Noel’s GP and his family, and they are in doubt about their ethical and legal obligations, they should seek advice from senior staff in the nursing home. Currently, the section on DNAR orders of the Irish National Consent Policy (2014) supports the nursing staff to make whatever decision (1. or 2.) they believe respects Noel’s wishes and is in his best interests.

Noel has a right to life. The right to life is one of the most fundamental rights and it is protected by the Irish Constitution, the European Convention on Human Rights as well as under United Nations human rights instruments. Noel cannot be deprived of his right to life because he is may lack capacity. It would be both unlawful and unethical to deny treatment to anyone on this basis.

Yet, the right to life is not absolute. It is generally accepted that treatment is not required where treatment would be futile because it offers no reasonable hope of benefit or because, even though it does, the expected benefit would be outweighed by burdens such as excessive pain and discomfort.

Noel has a right to dignity, a right to freedom from inhuman and degrading treatment and a right to bodily integrity. If resuscitation involves severe trauma such as cracking of his ribs, this would be an invasion of Noel’s bodily integrity that would not be justified if it is unlikely to benefit Noel. Noel’s right to dignity would also be compromised because his last moments life would be spent in this way.

Telephoning the GP is supported by the principle of beneficence

Nursing staff caring for Noel may have had an opportunity to discuss his care with him during periods when he was most lucid. Where possible, every effort should continue to be made to explain to Noel what is happening.

Any indications from Noel as to what he wanted prior to the incident can inform their decision-making process.

This case also arose in part because the resuscitation process was neither clarified nor documented on the ward and the family’s wishes or family expectations were not documented. Ongoing communication with Noel’s family maximizes the chances of agreement and appropriate resolution of difficult situations and it ensures that, even if the participants fail to reach agreement, the discussion takes place in the best possible way for the patient, the family and the health professionals. Patients are members of families and, given Noel’s relationship with his children, it is right that they should be consulted. Respect for Noel’s rights requires family involvement.

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5. Review

Have I been sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent?
Additional resources

Available at: http://www.hse.ie/eng/about/Who/qualityandpatientsafety/qpsfocuson/consentfocuson.html


![Image of IMPORTANT NOTICE form]
Section 5

5.4 Guidance Area 4

Disputing the Ethical Goals of Treatment and Care – Clinically Assisted Nutrition and Hydration

Poor appetite and weight loss are often associated with dementia. Difficulties with eating experienced by people with dementia may be caused by physiological problems associated with the disease or by psychological problems, such as depression. It may also be the case that a person’s routine has been disrupted or that their food preferences are simply not met. In situations in which patients with dementia are no longer able or willing to take food orally, the option of administering clinically-assisted nutrition and hydration (CANH) must be carefully considered (See Guidance Document 6).

Food has an emotional, symbolic and social importance which should not be underestimated; offering feeding assistance to someone who is sick is a ‘powerful instinctive act’ and the human contact provided by the act of assisting to feed someone may be of therapeutic benefit. CANH is a medical treatment, and, like other medical treatments, it is associated with both burdens and benefits, depending on an individual patient’s circumstances.

‘Deciding whether or not the administration or continuation of CANH is clinically indicated requires careful consideration of its burdens and benefits in the context of the specific goals of care for the patient. Such considerations include the patient’s illness trajectory, the potential impact of the intervention on the patient’s condition, the expected clinical outcomes and the preferences/values of the patient or proxy decision-maker.’

(ASPEN, 2014)

CANH may be very useful in providing nutrition and hydration to people who are temporarily unable to swallow or have dysfunctional gastrointestinal tracts. It may also benefit people with chronic disabling conditions who value their quality of life. However, there is insufficient evidence to suggest that CANH can provide meaningful clinical benefit to patients who are terminally ill or approaching the end of their lives.

In people with dementia, CANH most commonly takes the form of feeding assistance via a PEG tube. Supposed benefits of PEG feeding include prolonged survival, prevention of malnutrition and weight loss, reducing the incidence of aspiration pneumonia and reducing the development of pressure ulcers. However, existing evidence suggests that tube feeding rarely achieves its intended clinical goals in people with advanced dementia, 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.

Rather than preventing suffering, tube feeding may actually cause it in a person with dementia. NG tube feeding is associated with numerous complications, including diarrhea, nausea, vomiting and oesophageal perforation. Intravenous feeding is associated with risk of infection, phlebitis and electrolyte imbalances, while the burdens of PEG feeding (enteral nutrition) include risk of infection around the site of PEG and increased risk of aspiration pneumonia in advanced dementia.

*NB: 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 a negative connotations associated with ageing and stereotypes older persons.
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\textsuperscript{60,61}. 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\textsuperscript{54,59}.

As people with dementia approach the end of their lives, decreased interest in food is normal\textsuperscript{56}. The body’s increasing inability to absorb nutrients is often accompanied by loss of appetite and thirst and difficulty swallowing\textsuperscript{61,63}. However, the body adapts physiologically at the end of life and this prevents people from suffering as a result of the absence of food\textsuperscript{57}. Terminal dehydration in people who are close to death is beneficial in the sense that it reduces respiratory and gastrointestinal secretions\textsuperscript{61}.

Decisions about whether or not to feed people with advanced dementia may be better managed by reframing the discussion in terms of ‘comfort feeding only’ and devising an individualised care plan which focuses on the person’s treatment goals. Careful hand feeding assistance is the least invasive and potentially most satisfying way of maintaining nutrition for the person with dementia\textsuperscript{59}.

Health professionals should set aside ample time early in the process of end-of-life care planning to discuss treatment options with people with dementia and family members - including the possibility of foregoing CANH - rather than waiting until the person is at the end of his or her life\textsuperscript{64}.

Where a person is at a moderate - advanced stage in their illness and admission to acute hospital is required for the purposes of administering CANH, this should be considered with regard to the potential benefit for the person. As indicated in Guidance Area 2, evidence suggests that acute admission can cause significant (and often avoidable) distress at the time to people with dementia and their carers: there is also evidence to suggest that the disorientation and distress that people with dementia often experience in hospital have a long-term and permanent effect on the person’s cognitive abilities and capacity to continue coping on their own\textsuperscript{65}. Indeed, a hospital admission will often be a ‘trigger’ for admission into residential care, thus forcing the person with dementia and those close to them to make important decisions about the future at a point of crisis, instead of in their own time.
Guidance Area 4
Disputing the Ethical Goals of Treatment and Care

Clinically Assisted Nutrition and Hydration

CANH is a medical treatment with benefits and burdens: In situations in which people with dementia are no longer able or willing to take food orally, the option of administering clinically-assisted nutrition and hydration (CANH) must be carefully considered. CANH is a medical treatment, and, like other medical treatments, it is associated with both burdens and benefits, depending on an individual patient’s circumstances. While it may help some people with dementia, there is insufficient evidence to suggest that CANH can provide meaningful clinical benefit to patients who are terminally ill or approaching the end of their lives.

Consider the goals of care: Deciding whether or not the administration or continuation of CANH is clinically indicated requires considering the nature and severity of the person’s illness, the specific goals of care for the person, the expected impact of the intervention, the person’s current preferences, if available, and the views of family members and carers about what the person with dementia would have wanted if he or she no longer has decision-making capacity.

Devise and individualized care plan: As people with dementia approach the end of their lives, the body’s increasing inability to absorb nutrients is often accompanied by loss of appetite and thirst and difficulty swallowing. However, the body adapts physiologically at the end of life and this prevents people from suffering as a result of the absence of food. An individualised care plan which focuses on the person’s treatment goals, including the option of comfort feeding assistance, may allow better management of decisions about whether or not to provide feeding assistance to people with advanced dementia.

Make a plan in advance: Set aside ample time early in the process of end-of-life care planning to discuss the possibility of foregoing CANH, rather than waiting until the person with dementia is at the end of his or her life.

Listen to people with dementia and their families: Recognise the pressures which families can place on people in end-of-life contexts. While recognising the importance of communication and engagement with family members, professionals should make efforts to ensure that the person is not pressured into making decisions about end-of-life care which do not accord with what he or she wants or needs in order to keep family members happy.

Reassure both the person with dementia and the family that the primary duty is owed to the person with dementia. While this needs to be done sensitively, it is essential that this primary duty is maintained and that all parties involved are aware of it.
CASE STUDY 4

Mary is a 92-year-old woman who has been living in a residential care setting for older people, for the last 10 years. About two years ago, she fell out of bed and broke her hip. Since then, her health has been in gradual decline, with reduced mobility over time. A year ago, she was diagnosed with mild to moderate dementia.

When Mary broke her hip, her family was very angry, suggesting that this may have occurred due to a lack of supervision in the care setting. Since the fall, they have constantly questioned the care provided. Staff are concerned that the family may attempt to take legal action against the care centre and feel that the family no longer trust them.

A few weeks ago, Mary was diagnosed with a chest infection and was admitted to hospital at her family’s request. She spent 24 hours in A&E and was admitted to a ward for one night and was then discharged back to the nursing home. Since then, Mary’s health has declined and it is clear that she is now approaching the end of life.

Mary is weak and spends all of her time in bed. Six days ago, Mary refused to eat. Since then she has declined all food and drink, although on two occasions she requested egg white, which she was given when she asked for it. Staff have talked to Mary and she continues to communicate both verbally and non-verbally that she does not want to eat or drink anything. Previously Mary had said that she would not want to be admitted to hospital or to have any type of a feeding device inserted if she were at the end of her life.

Mary’s family is very concerned. They question everything the nursing home staff do. They believe that, since Mary is requesting such nourishing food, she wants to live and is fighting for life. They want Mary to be taken to hospital to be fed artificially using a PEG tube.
Consider the case by applying the Ethical Decision-Making Tool

1. Articulate the ethical problem(s) and identify relevant facts

**Ethical problems**

A decision needs to be made about Mary’s care, but this process is complicated by tensions in the relationship between Mary’s family and those providing her care.

Mary has indicated her wishes but her family disagree with them.

**Relevant facts**

1. Mary’s physical and mental health have declined over the course of the past two years; this decline has accelerated rapidly during the past month and she has lost interest in food, although she requests a small amount of food every couple of days.
2. Mary’s family members want her to be taken to hospital and fed via a PEG or nasogastric tube.
3. Although Mary doesn’t have an Advance Care Directive, there is clear documentation of her wish (consistent over time) not to be hospitalised or fed artificially.
4. As a result of Mary’s fall and her subsequent decline, her family members have lost faith in the quality of care provided by staff in the nursing home.
5. Nursing home staff believe that members of Mary’s family may be prepared to take legal action if their request to transfer Mary to hospital isn’t complied with.

2. Identify stakeholders’ interests, needs, values

**Mary**

1. Mary is able to express her preferences on some level. She is refusing food for a reason and this needs to be explored. *(relational autonomy)*
2. Mary has explicitly stated on previous occasions that she does not want to go into hospital. Even if she no longer has capacity to make decisions, this expressed preference should be central to the decision-making process. *(relational autonomy, avoiding harm)*
3. Mary’s capacity to understand the consequences of not eating should be assessed. *(relational autonomy, avoiding harm)*
4. Her nutrition status should be assessed and her needs determined in the context of promoting her autonomy and well-being *(relational avoiding harm, doing good)*

**Mary’s family members**

1. Mary’s family value keeping her alive for as long as possible, and to this end they may not be able to appreciate that her own wishes must also be considered in this situation. *(avoiding harm, doing good, relational autonomy, solidarity)*
2. Because she is elderly and has dementia, Mary’s family may see her refusal of food as the result of a lack of capacity and they may believe that her wishes should be overridden in the interests of keeping her alive. \textit{(value of life)}

3. Mary’s family may see food as symbolic of their love and attachment and possibly as the only thing they can still do for Mary, hence their insistence on the provision of artificial nutrition and hydration. \textit{(avoiding harm, solidarity)}

4. Mary’s family may believe that clinically-assisted nutrition and hydration may prolong Mary’s life or improve its quality. \textit{(value of life, avoiding harm, doing good)}

**The healthcare professionals and staff caring for Mary**

1. Healthcare professionals caring for Mary may not have reached a consensus about what is best for her. Some members of staff may be reluctant to transfer Mary to hospital against her express wishes; others may perceive withholding food as tantamount to allowing Mary to starve. \textit{(relational autonomy, avoiding harm, doing good)}

2. While those caring for Mary may need an opportunity to explore the rationale underlying their own perspectives, the conversation between members of the care team should focus on devising appropriate goals of care for Mary, in the context of her own wishes, her illness and current clinical status. \textit{(relational autonomy, avoiding harm, doing good)}

**Nursing home management**

1. The management team should be presumed to have put Mary’s overall benefit at the centre of the decision-making process. \textit{(avoiding harm, doing good, relational autonomy)}

2. However, because they may be concerned that Mary’s family may take legal action against the nursing home or complain publicly, management may feel compelled to go along with the family’s request for hospitalisation.

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3. **Weigh the merits and demerits of available courses of action**

1. \textit{Continue to care for Mary in the nursing home, giving her food by mouth if and when she requests it.}

   **Merits:**
   
   This course of action seems to be in accordance with Mary’s wishes, and as such it prioritises her autonomy. Careful assistance with hand or comfort feeding assistance would allow Mary to taste small amounts of food and experience the social aspects of eating. Comfort feeding assistance accompanied by oral hydration may have a therapeutic benefit for Mary.

   **Demerits:**
   
   Mary may be malnourished and may be in need of more comprehensive nutrition support than oral intake can provide. Members of Mary’s family may be concerned that she may be suffering from hunger and thirst or may feel that she is starving to death, even though the body naturally loses interest in food as death approaches. Mary may eventually become completely unable to eat, meaning that she is entering the dying phase.
2. Transfer Mary to hospital where clinically-assisted nutrition and hydration will be administered.

**Merits:**
Clinically assisted nutrition and hydration may improve Mary’s nutritional status and may temporarily improve her quality of life.

**Demerits:**
This is against Mary’s previously expressed wishes and her current preferences, and as such it violates her autonomy. If a capacity assessment indicates that Mary is capable of making a voluntary decision to stop eating and drinking, she has a legal right to do so; as such, administering artificial nutrition and hydration against her wishes violates this legal right and is akin to providing treatment without consent. If Mary’s refusal of food is an indication that she is approaching the end of her life, prolonging the dying process may be burdensome for her. Mary may need to be restrained to prevent her resisting the insertion of, or pulling out, the gastrostomy tube; this is a direct violation of her autonomy.

4. Select the action which can best be supported by ethical principles

**Promote Mary’s ability to participate in decisions about her care.**
Mary’s capacity to participate in decisions about her care should be formally assessed. If she has the capacity to make her own decision about eating, her reasons for refusing food should be explored. If, after discussing her situation, she indicates that she does not want to be fed unless she requests food, her wishes should be respected.

If they can be elicited, Mary’s values should be central to the decision-making process. Mary’s refusal to eat may be prompted by a number of factors and these should be explored. Members of her family should also be encouraged to express their perspectives, but if Mary is found to have capacity in relation to the decision about assistance, her preferences should be prioritised.

**Provide care which balances Mary’s autonomy and her well-being.**
If an assessment reveals that Mary’s capacity to make healthcare decisions is impaired, her ability to participate in decision-making at a level appropriate to her cognitive ability should be promoted and her wishes respected as far as possible. If she refuses to communicate or if she is judged to lack decision-making capacity completely, her previously expressed wishes should be taken into account in the decision-making process and balanced against what is best for her clinically, psychologically and emotionally. Because a refusal to eat may be the result of a number of causes, Mary should be given a thorough medical assessment incorporating an examination of her mouth, teeth and dentures (including an analysis of her medication regimen for side-effects). Mary should also be screened for depression.

**Explore the burdens and benefits associated with available treatment options.**
Assess the benefits and burdens of administering clinically-assisted nutrition and hydration to Mary in accordance with the best available evidence.
Communicate clearly and sensitively

Efforts should be made to open the lines of communication between those caring for Mary and her family. A meeting between all family members and staff caring for Mary should be arranged and the goals of care for Mary should be clearly established. The perspectives of the family members should be sensitively elicited and explored. The family members’ reasons for requesting that Mary be hospitalized should be identified and the burdens and benefits of providing clinical-assisted nutrition and hydration to Mary should be fully explained to them. Her family members may be experiencing emotions which are common when confronted with the ending of a loved one’s life, such as anxiety, distress and possibly grief and guilt – emotions which are often masked by anger and mistrust. They may see giving Mary food as the one last thing they can do for her and may be unwilling to forego this. They may be unaware of the evidence indicating that enteral feeding does not benefit patients at the end of life and may in fact cause harm.

Staff may need to revisit the fall incident and acknowledge the distress and anxiety experienced by Mary’s family, if necessary acknowledging any systemic flaws responsible. The person who chairs the meeting should keep the conversation focused on the need to determine appropriate goals of care. Staff should make it explicit to Mary’s family that they are giving Mary the best care they can and should emphasise the importance of focusing on their shared goal of doing what is best for her.

5. Review

Have I been sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent?

Additional resources

National Institute for Clinical Excellence (UK)

American Academy of Nutrition and Dietetics

American Society for Parenteral and Enteral Nutrition (ASPEN)
Ethics Position paper (2010): http://ncp.sagepub.com/content/25/6/672.full.pdf+html
6.1 Understanding the progression of dementia

When considering the assessment and management of medication 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 communicate.

Whilst many classification systems exist to grade the severity of the dementia (e.g. Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS)66 (also known as the Reisberg Scale) and the FAST - Functional Assessment Staging)67, the Clinical Dementia Rating Scale68 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.

<table>
<thead>
<tr>
<th>CDR</th>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDR-0</td>
<td>No dementia</td>
<td></td>
</tr>
<tr>
<td>CDR-0.5</td>
<td>Mild</td>
<td>Memory problems are slight but consistent; some difficulties with time and problem solving; daily life slightly impaired</td>
</tr>
<tr>
<td>CDR-1</td>
<td>Mild</td>
<td>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</td>
</tr>
<tr>
<td>CDR-2</td>
<td>Moderate</td>
<td>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.</td>
</tr>
<tr>
<td>CDR-3</td>
<td>Severe</td>
<td>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.</td>
</tr>
</tbody>
</table>

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.\textsuperscript{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 dementia\textsuperscript{70}. However, some people can live for 20 years post diagnosis.
- Half of the people with late stage dementia will die within 1.3 years\textsuperscript{69}.

6.2 Alternative ethical decision making frameworks

The Nuffield Council on Bioethics\textsuperscript{6} present a framework based on a number of core commitments:

- That individuals with dementia, with good care and support, can expect to have a good quality of life throughout their illness;
- That promoting both the interests of the person with dementia and those who care for them is important;
- That we need to act in solidarity with people with dementia, to acknowledge their citizenship and our mutual interdependence;
- That we should recognise the personhood, identity and value of people with dementia who remain the same equally valued persons throughout the course of their lives.
A Case Based Approach to Decision Making

Nuffield Offers a three-step process to approach ethical decisions, taking the reader through case studies focusing on a number of key areas relevant to dementia care at the end of life.

1. Identifying and clarifying the relevant factual considerations Carefully consider the background factors e.g. degree and duration of danger and distress to the person, the effect on the caregiver, what the person may have wanted before illness, currently able to understand.

2. Interpreting and applying appropriate ethical values considering the person with dementia, caregivers and healthcare professionals

3. Comparing with other similar situations to find ethically relevant similarities or differences.

The Nuffield document presents a care pathway for people with dementia within which a person-centered, supportive and palliative approach to care is recommended at all stages of the illness trajectory. With regard to end of life and palliative care specifically for a person with dementia, the report notes the importance of the palliative philosophy of caring for the ‘whole person’, advance care planning, the provision of adequate pain relief, the avoidance of inappropriate treatment, and support for family. Considerable attention is given to decision making, an inevitable aspect of end of life care, focusing on when it may not be appropriate to provide a particular treatment for the dying person and how best to manage symptoms at the very end of life.

The Nuffield report presents several case studies highlighting specific dilemmas in practice with a focus on decision-making, particularly with regard to nutritional support. The area of advance planning and proxy decision-making is discussed in detail, with reference to UK law, noting how a person’s earlier wishes and decisions about their healthcare should be considered and balanced with any preferences conveyed (for example through behaviour or gesture) after the person has lost the legal capacity to make such decisions. The document makes it very clear, that by focusing on the value of the person with dementia, the importance of autonomy and quality of life, clinical decisions should be made based on the benefits and burdens for the individual. Considerable attention is given to ethics and dementia in a societal context and one of the key recommendations of the report is the need for training to be developed with an emphasis on skills and knowledge, to enable informed ethical decisions to be made.

The need for such education has also been recognised and addressed by McCarthy et al with regard to ethics and end of life care specifically. The Ethical Framework for End-of-Life Care is a set of educational resources that aims to foster and support ethically and legally sound clinical practice in end-of-life treatment and care in Irish hospitals, specifically, but can be adapted for use across other settings.
A Consensus Approach

Karlawish\textsuperscript{16} offers the following core principles to plan the palliative care for people who lack the capacity to make decisions using a model of consensus based decision-making:

- **Identify potential decision makers** – these may be friends or family of the person with dementia or people who have been involved in the person’s care over a period of time.
- **Clarify the person with dementia’s diagnosis and prognosis**
- **Determine whether the person has an advanced directive or other advanced planning documentation to outline their care preferences.**
- **Engage with the potential decision makers, asking them to describe how things have changed over time. The purpose of this dialogue is both to achieve a consensus among decision makers about the patient’s current disease state, prognosis, quality of life, and previously stated values and to hear and clarify where necessary, the meaning of emotionally charged terms, such as “starvation,” “suffering,” “quality of life,” “feeding,” and “dying.”**
- **Teach the potential decision makers about the expected clinical course of the disease, providing guidance based on clinical data and experience.**
- **Advocate for the person’s quality of life and dignity.**
- **Decisions should be based on:**
  1) the patient’s preferences and
  2) a balance of the burdens and benefits of each option in terms of its ability to relieve suffering and maximize dignity and quality of life.

- **Palliative care should be offered whether life-prolonging measures are initiated or the patient is treated with comfort measures only.**
- **In the event that a consensus is not reached:**
  - Postpone the decision-making where appropriate and recommend that the participants take time to think about and discuss key issues.
  - Understand and separate from each person’s perspective the goals of medical care and the treatment choices to achieve these goals.
  - Invent new solutions (for example, a time-limited trial rather than an all-or-nothing solution).
  - Avoid power struggles or personalising the conflict.
  - Call in a third party (e.g. clergy, ethicist, palliative care as appropriate).
6.4 Approaches to care

PERSON-CENTRED CARE

The predominant philosophy of care for people with dementia in recent years has been person-centred care. Brooker has suggested the acronym VIPS to encapsulate the broader meaning of person-centred care: people with dementia and their carers must be Valued; they must be treated as Individuals; the Perspective of the person with dementia must inform our understanding; and the person’s Social environment must be attended to because of the fundamental importance of relationships in sustaining personhood. Towards the end of his book, Dementia Reconsidered, Kitwood (who conceived the notion of person-centred care in dementia) suggested a new culture of care which:

‘…brings into focus the uniqueness of each person, respectful of what they have accomplished and compassionate to what they have endured. It reinstates the emotions as the well-spring of human life, and enjoys the fact that we are embodied beings. It emphasizes the fact that our existence is essentially social’ (Kitwood p.135).

Person-centred care is underpinned by a philosophy of personhood, which Kitwood characterised as follows:

‘It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being’ (Kitwood p.8).

The notion of person-centred care was born out of opposition to a narrow biomedical view (‘the medical model’) and it is firmly based on a psychosocial and spiritual paradigm. As articulated by Kitwood, person-centred care places little emphasis on the medical management of patients.

PALLIATIVE CARE

If dementia is a terminal condition, individuals with dementia should have access to a palliative approach from the time of diagnosis.

‘Dementia can realistically be regarded as a terminal condition. It can also be characterized as a chronic disease or in connection with particular aspects, as a geriatric problem. However, recognizing its eventual terminal nature is the basis for anticipating future problems and an impetus to the provision of adequate palliative care.’

(van der Steen et al 2014: 200)

Key aspects of palliative care relevant to dementia care can be summarised thus:

- Life is affirmed: people should be encouraged to live as well as they can even whilst accepting the inevitability of death, which should neither be hastened nor postponed;
- Distressing symptoms of whatever sort should be actively treated whilst maintaining quality of life;
- Care must be holistic: biological, psychological, social and spiritual, which necessarily means the family and significant friends must be included and care must extend to bereavement.
6.5 Dementia, Palliative Care And Intellectual Disability

The resource listed below is an example of an international guideline relating to promotion of access to palliative care for people with an intellectual disability.


The resources listed below are some examples of national and international guidelines and empirical research relating to the accurate and comprehensive assessment of Alzheimer’s disease in people with an Intellectual Disability.

The resources listed below are some examples of international guidelines relating to the provision of community supports for people with an Intellectual Disability and Alzheimer’s disease.


The resource listed below is an example of international guidelines which seek to enable caregivers, whether family members or staff, to prepare for and advocate during health visits.

**FACT SHEET 7A**

**Ethical decision making in end-of-life care for the person with dementia**

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**Core ethical principles to underpin decision making**

- Justifying an action by appealing to ethical principles means having to defend that choice of action over others in a manner which goes beyond our own perspective, bias, values and interests. By choosing an action based on principles, we remove our own partial viewpoint from the decision and appeal to a more general sense of what is the right thing to do.

- There is rarely one overarching ethical principle or value that can be used to solve an ethical problem. Critical judgment is required based on the individual’s rights and interests, the situation, the risks and the context in which the decision is made.

- There is rarely a single right solution for what should be done, and in fact reasonable disagreement can be expected and even encouraged.

- An approach to decision-making where solutions emerge in the course of dialogue, disagreement and negotiation often works best.

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5 Core Ethical Principles Underpin Ethical Decision Making in Dementia Palliative Care.
FACT SHEET 7B

CORE ETHICAL DECISION MAKING PRINCIPLES

Relational Autonomy
- Focus on the experiences of the person and on what matters most to them
- Be attuned to the way in which they make sense or meaning out of the world
- Help the person to express themselves
- Meet the person where they are 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

Avoiding Harm and Doing Good
- Promoting a person's well-being goes beyond weighing the clinical burdens and benefits of proposed actions: it also involves taking the person's past and current wishes and preferences into account and identifying the beliefs and values that may influence the decision in question (these include the values of people with dementia, family members and staff).

Personhood and Value of Life
- The life of a person with dementia should be valued just as much as that of a person without dementia, with a particular focus on the person’s capabilities, rather than on presumed deficits.

Justice
- Requires that access to treatment and care should not be restricted on the basis of age, disability, psychological or intellectual impairment.
- Requires that attention be paid to the way in which group differences (e.g. gender, ethnicity) can place individuals and families at a disadvantage, and to the need to develop strategies/practices to ameliorate inequities.

Solidarity
- Our interdependence as human beings means that any of us may be touched by dementia and all of us will certainly be touched by end-of-life issues. The quality of care provided should reflect the standard of care we would expect for ourselves and the people we love.
FACT SHEET 7C

Ethical decision making in end-of-life care for the person with dementia

Ethical decision making tool

- Articulate the ethical problem and identify the facts
  - Be ethically sensitive and communicate clearly
- Identify stakeholders’ interests, needs and values
  - Be respectful and inclusive
- Weigh up the merits and demerits of available courses of action
  - Be informed and fair
- Select the action best supported by ethical principles
  - Be impartial and transparent
- Review
  - Check: Have I been respectful, inclusive, sensitive, clear, informed, fair, impartial and transparent?

See Guidance Document No 7 for more Information and Case Studies

Persons with dementia have the same rights as all persons
  e.g. the right to life, autonomy, dignity, bodily integrity, freedom from inhuman and degrading treatment as well as the right to information, to consent and to confidentiality
Guidance Area 1
Promoting relational autonomy and the capacities of the individual to consent or refuse treatment and care

The autonomy of the person with dementia may be promoted by engaging in a process of Advance Care Planning (ACP) while he or she still has the capacity to make decisions about future treatment. Also, a relational autonomy-centered approach requires that healthcare professionals and carers actively support the person with dementia so that they can be encouraged to retain and express their sense of self and maintain the relationships that are important to them, rather than simply being protected from harm.

Guidance Area 2
Decision-making for individuals who have diminished capacity

Under current Irish legislation, only the lead clinician has the legal authority to make healthcare decisions for a patient 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 patient’s specific values and treatment preferences.

Guidance Area 3
Meeting the Ethical Goals of Treatment and Care – Do Not Attempt Resuscitation (DNAR)

Meeting the ethical goals of treatment and care may sometimes require limiting medical treatment in cases where individuals have refused it or in situations where it offers no overall benefit. Omitting to administer a particular treatment such as CPR for a particular patient is generally viewed as morally justified if it is considered futile (ineffective/without benefit) or unnecessarily burdensome. When discussing judgments of futility, it should be made clear that it is not people’s lives that are judged futile - judgments relate to the expectation that the treatment will not provide any benefit for this particular person at this stage of their dementia and/or related illnesses.

Guidance Area 4
Disputing the Ethical Goals of Treatment and Care – Clinically Assisted Nutrition and Hydration

As a persons with dementia approaches the end of their life, the body’s increasing inability to absorb nutrients is often accompanied by loss of appetite and thirst and difficulty swallowing. However, food has an emotional, symbolic and social importance which should not be underestimated; assisting to feed someone who is sick is a ‘powerful instinctive act’ and the human contact provided by the act of feeding assistance may be of therapeutic benefit. Deciding whether or not the administration or continuation of Clinically Assisted Nutrition and Hydration (CANH) is clinically indicated requires careful consideration of its burdens and benefits in the context of the specific goals of care for the person with dementia. Such considerations include the person’s illness trajectory, the potential impact of the intervention on the person’s condition, the expected clinical outcomes, the impact of a potential inpatient admission on the person, and the preferences/values of the person.

Please see Guidance Document Number 7 for more Information.
CONCLUSION

Individuals with dementia may well lose the thread of their lives as a whole, but still retain the ability to hold on to core moral values. Add to this, the fact that over the course of a slow deterioration, their cognitive capacity may fluctuate; it is imperative that individuals with dementia are viewed as subjects, not objects, of care and that focus is placed on their abilities to participate in decision-making and communication and not simply on the preservation of their comfort and safety. In addition, whether they have or lack memories or the capacity to communicate, they remain persons with unique life histories and relationships that we are obliged to honour and maintain.

The aim of this guidance document is to provide caregivers of people with dementia, regardless of care setting, with a framework to support ethical decision making for people living with dementia at the end of life. It:

- explains core Ethical Principles as they apply to individuals with dementia at the end of life
- provides a Decision-making Tool that supports ethical decision-making for individuals with dementia at the end of life
- offers guidance on key ethical challenges that arise in dementia care at the end of life (preserving relational autonomy, decision-making for individuals with diminished capacity, ethical goal setting in treatment and care [DNAR and CANH]).

The case studies included all place emphasis on advance planning, individualised plans, the inclusion and support of loved ones where appropriate, and honest, ethical and evidence-based goal setting. They also prioritise the development of relational skills and practices in order to preserve an enabling environment within which individuals with dementia are consulted on factors that affect their lives and are supported to make meaningful choices in the face of their impairment. We believe that this kind of approach and these skills can best serve the needs of individuals with dementia at the end of their lives and, in turn, remind us all that even though we may be frail and dependent we may also hold on to our dignity and even flourish.
GLOSSARY

Cardiopulmonary resuscitation (CPR): is a group of treatments used when someone’s heart and/or breathing stops. It was developed as a treatment intervention for cases of sudden unexpected cardiac or respiratory arrest. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing; chest compression, bag-and-mask positive-pressure ventilation, intubation and defibrillation. Drugs are also frequently used to stimulate the heart.

Do Not Attempt Resuscitation (DNAR): A DNAR order may generally be described as a request primarily written and signed by a medical practitioner but which could involve the patient, health care team and family, stating that in certain circumstances should the patient suffer from cardiopulmonary failure, cardiopulmonary resuscitation (CPR) should not be attempted. Such an order is only relevant to not attempting CPR and not to the withholding of any other treatment. This request should always be documented and kept in the patient’s record.

Life Prolonging Treatment (LPT): is any medical intervention, technology, procedure or medication that is administered to provide benefit for a patient and to forestall the moment of death. These treatments may include, but are not limited to, mechanical ventilation, artificial hydration and nutrition, cardiopulmonary resuscitation, haemodialysis, chemotherapy, or certain medications including antibiotics.
APPENDIX 1
STEERING AND PROJECT GROUP MEMBERSHIP

Guidance Documents Project Lead:
Dr. Alice Coffey

Guidance Documents Project Researcher:
Dr. Kathleen McLoughlin

Principle Investigator for Ethics Document: Dr. Joan McCarthy

Partners:
Dr. Louise Campbell,
Dr. Tom Andrews,
Caroline Dalton-O’Connor
Dr. Kathleen McLoughlin

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

National Reviewer:
Dr. Dolores Dooley
Senior Lecturer Healthcare Ethics (P/T)
Department of General Practice
Royal College of Surgeons in Ireland
Beaux Lane House
Mercers Street Lower
Dublin 2

International Reviewers:
Professor Julian Hughes
Honorary Professor of Philosophy of Ageing and Consultant in Old Age Psychiatry
PEALS (Policy, Ethics and Life Sciences) Research Centre
Newcastle University
4th Floor Clarendon Bridge
Newcastle upon Tyne
NE1 7RU
UK

Professor Ann Gallagher
Professor of Ethics and Care
Director, International Care Ethics (ICE) Observatory
www.surrey.ac.uk/fhms/research/centres/ICE/
Editor, Nursing Ethics
Member, Nuffield Council on Bioethics
School of Health Sciences
Faculty of Health and Medical Sciences
University of Surrey
Guildford, Surrey GU2 7TE
UK

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. Aislis Quinlan, Public Health Doctor.
4. Prof. Cillian Twomey, Geriatrician
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. Joan McCarthy, 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

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<tr>
<th>DATABASES SEARCHED</th>
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The following key word strategy was agreed by the project team and used in EBSCO, adapted variations were developed for the other databases:

S1: TI (Belie* OR value* OR principle* OR ethic* OR moral* OR virtue*) OR AB (Belie* OR value* OR principle* OR ethic* OR moral* OR virtue*)
S5: S1 AND S2 AND S3 AND S4

S2: TI (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”) OR AB (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 limited illness”)

S3: TI (Dementia OR Alzheimer* OR demented) OR AB (Dementia OR Alzheimer* OR demented)

S4: TI (Guideline* OR guidance OR pathway* OR policy OR policies OR protocol* OR standard* OR framework) OR AB (Guideline* OR guidance OR pathway* OR policy OR policies OR protocol* OR standard* OR framework)

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

**INCLUSION CRITERIA**
- English language
- Peer reviewed publications
- Focus on adult populations (patients/family caregivers) with dementia
- Book Chapters and Books
- Thought pieces and reflective articles

**EXCLUSION CRITERIA**
- Written in a language other than English
- Conference abstracts, dissertations, 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
- 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 – TO BE FINALISED

Identify 579 Records identified through database searching

Screen 330 Records identified after duplicates removed

330 Records screened

Eligibility 52 Full text articles assessed for eligibility

278 Records excluded

4 Records excluded

Inclusion 48 Studies included in scoping review

LITERATURE WAS REVIEWED TO CONSIDER

The volume of evidence available.
Theoretical models proposed.
Evidence specific to a variety of care settings.
Recommendations for practice.
Gaps in current knowledge, relevant research in progress and key emerging issues.
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

3. Collation of key themes to inform the guidance by the Project Team.

LITERATURE REVIEW THEMES

1. **Common ethical and legal principles and values underpinning ethical decision making for dementia care at the end of life**

2. **Existing ethical decision making frameworks for dementia care at the end of life**

3. **Specific concerns that arise in end-of-life dementia care e.g. advance planning, truth-telling, assessment of capacity to consent or refuse treatment, enabling and protecting, withholding/withdrawing life prolonging treatment.**

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

The search was broad and highlighted key areas for guidance development. These areas e.g. hydration then required additional searches. Well known documents, e.g. Nuffield Framework did not emerge from the academic search and were subsequently sourced online.
REFERENCES

12. Airedale NHS Trust v Bland [1993] 1 All ER 821 HL
21. van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., ... & European Association for Palliative Care (EAPC. (2013). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. Palliative medicine, 026921631493685.
References


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66. Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS) (also known as the Reisberg Scale).


73. For Prof. Hughes’ presentation on Models of Dementia Care, see: https://www.youtube.com/watch?v=-ROF_sSylAc


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DRAFT FOR PUBLIC CONSULTATION

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Simard, J (2007). “Silent and invisible: nursing home residents with advanced dementia”. The Journal of Nutrition, Health and Aging 11:6, 484-


