

GUIDANCE DOCUMENT 2

Advance care planning and advance healthcare directives with a person with dementia



This guidance document is a product of The Irish Hospice Foundation's Changing Minds Programme. Changing Minds is a three year project which is co-funded by The Irish Hospice Foundation and The Atlantic Philanthropies. This document entitled: "Advance care planning and advance healthcare directives with a person with dementia" is the second in a series of 7 guidance documents for health and social care staff in promoting and enabling excellence in end-of-life care for people with dementia.

ACKNOWLEDGEMENTS:

This guidance document has been produced in a collaborative manner with significant input from a number of key individuals. The writing and editing was carried out by Deirdre Shanagher and Marie Lynch. The appraisal of literature and editing was overseen by the Expert Advisory Group.

The group would like to acknowledge Ronan Smith, Kathy Ryan, Olga Price, Dr. Morgan Crowe, Dr. Graham Hughes, Dr. Suzanne Timmons, Dr. Joan McCarthy and Dr. Karen Harrison Denning for their feedback during the development of this document (Appendix 1).

The Irish Hospice Foundation would like to thank all of those who gave feedback as part of the consultation process (Appendix 4).

DISCLAIMER AND WAIVER OF LIABILITY:

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.

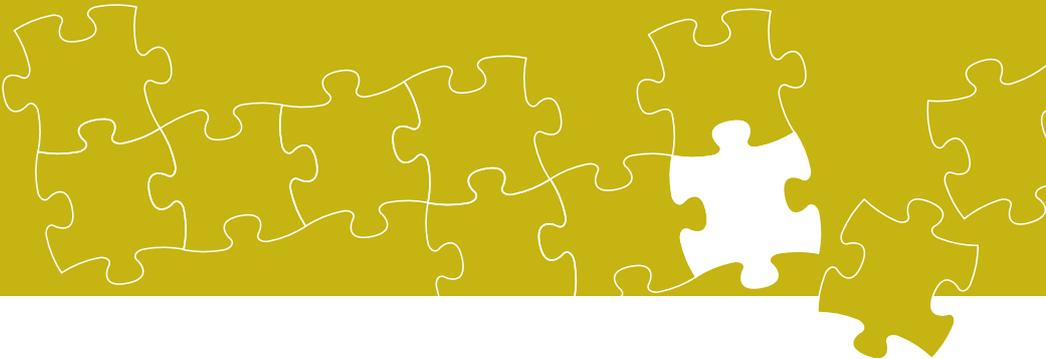
This guidance document is not intended as a sole source of guidance on advance care planning and advance healthcare directives with a person with dementia. It is not intended to replace ethical and clinical judgement or to establish a protocol for people living with dementia. Guidance documents do not purport to be a legal standard of care. Adherence to this guidance will not ensure successful outcomes for the person with dementia in every situation.

REFERENCE:

This guidance document should be cited as follows:

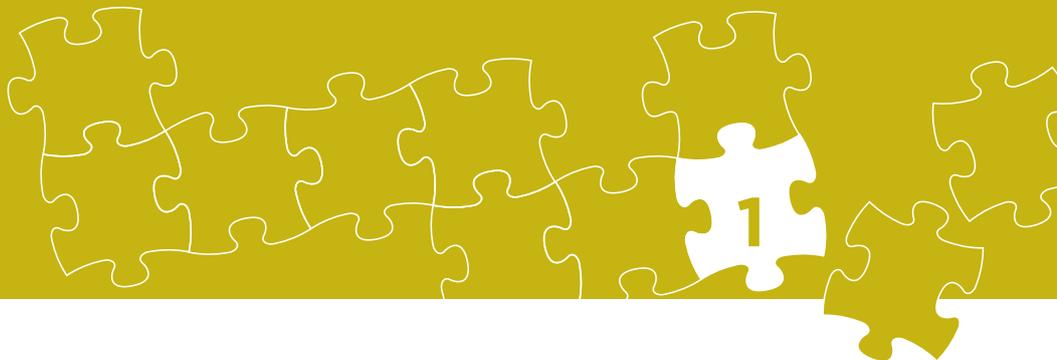
The Irish Hospice Foundation (2016). Dementia Guidance Document 2: Advance care planning and advance healthcare directives with a person with dementia: The Irish Hospice Foundation; 2016.

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GLOSSARY

Advance Care Planning

Advance care planning refers to a process of discussion and reflection about goals, values and preferences for future care in the context of an anticipated deterioration in a person's condition with loss of capacity to make decisions and communicate these to others. Adapted from (1). This process usually takes place with the person receiving health and social care and their health and social care team. Unlike an advance healthcare directive, an advance care plan is not legally binding. The process of advance care planning may lead to the development of an advance healthcare directive but does not necessarily have to.

Advance Healthcare Directive

An advance healthcare directive is an expression made by a person who has capacity (in writing, to include voice, video recording and speech recognition technologies) of their will and preferences concerning specific treatment decisions in the context of an anticipated deterioration in their condition with loss of decision making capacity to make these decisions, to give consent to or refuse treatment and communicate them to others. An advance healthcare directive is legally binding (therefore certain formalities must be followed) when a person writes down what treatments they would refuse in the future and the circumstances in which the refusal is intended to apply. The Assisted Decision Making (Capacity) Act 2015 provides that a request for a specific treatment is not legally binding but should be followed if relevant to the medical condition for which treatment is required. Adapted from (2).

Decision Making Capacity

Decision making capacity is the ability of a person to understand at the time a decision is to be made, the nature and consequences of the decision in the context of the available choices at that time. This means that decision making is time and issue specific. Every adult is presumed to have capacity to make decisions about their own healthcare; this is enabled by focusing on the person's will, preferences, beliefs and values; addressing both their autonomy and protection. Adapted from (2,3).

End of Life Care

End of life care refers to all aspects of care relating to dying, death and bereavement. In this context "end of life" can be from time of diagnosis, the months before death, the last hours of a person's life or the experience of loss and grief (4).

Enduring Power of Attorney

An enduring power of attorney is a document, drawn up with a person who has capacity, which gives another person(s) the power to make general and/or specific decisions. This comes into effect when a person lacks decision making capacity in relation to one or more of the relevant decisions outlined in the enduring power of attorney and when their enduring power is registered with the Wards of Court Office¹. Adapted from (2,5).

¹. When the Assisted Decision Making (Capacity) Act is commenced the enduring power of attorney will be registerable with the Decision Support Service

Family Members

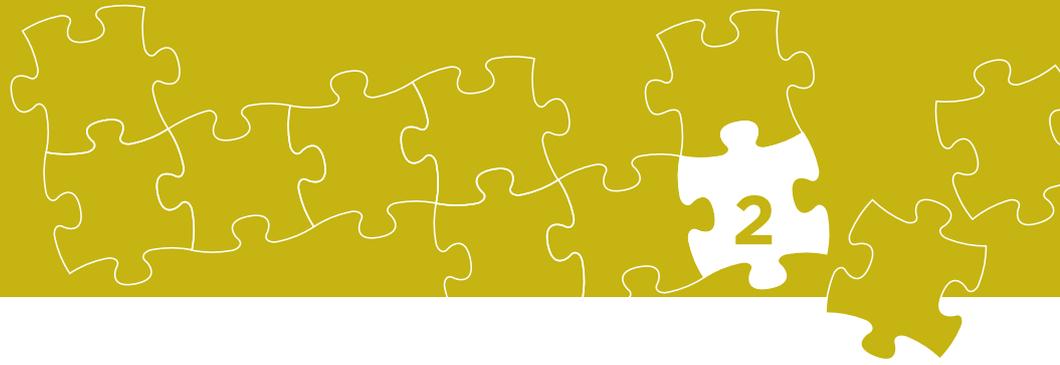
Family members are those people closest to the person in knowledge, care and affection. It is more than biological relatives or people related by marriage and can include those identified by people as being key in their lives. Adapted from (6–8).

Palliative Care

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

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help people live as actively as possible until death;
- offers a support system to help the family cope during a person's illness and in their own bereavement;
- uses a team approach to address the needs of people and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. Adapted from (9).





BACKGROUND AND CONTEXT

Dementia is an umbrella term which is used to describe a condition which may be caused by a number of illnesses in which there is progressive decline in memory, reasoning, communication skills and in the ability to carry out daily activities (10). The number of people living with dementia in Ireland today is estimated to be around 48,000 and this number is set to treble by 2045 (11). Dementia is a chronic, life limiting condition (12–14).

People with dementia have a unique set of care needs that arise from progressive cognitive impairment and includes fluctuating capacity, communication difficulties, possible responsive behaviours and a prolonged illness trajectory leading to uncertainty in relation to prognosis (10–15). People dying with or from dementia are therefore a particularly vulnerable group who require health and social care staff to have knowledge, skills, competence and confidence in dementia, end of life and palliative care (16). Palliative care for the person with dementia involves supporting the person with dementia and their family, (if the person with dementia wishes), to address and relieve the pain, distress and discomfort associated with advancing dementia and inviting them to participate in making decisions about future care needs (17). Providing this care and comfort can uncover significant challenges as each person’s journey through dementia is unique with huge variability in the length of the final phase, difficulties in communication and a lack of awareness about the terminal nature of dementia (14,18). This is often compounded by health and social care staff lacking basic knowledge, awareness and skills in supporting people with dementia (10,13). It is recommended that palliative care principles are introduced in the person’s care early on, ideally soon after diagnosis when the person can meaningfully engage in discussions about their future care (12,13,17,18). See section 6.1 “Additional Resources for more information on the progression of dementia.

As illustrated, there has been a growing recognition of the complexities involved in providing palliative and end-of-life care for people with dementia in the literature; however, there is a notable void of practice guidelines to support health and social care staff in delivering excellence in end-of-life care for people with dementia. In order to support health and social care staff in meeting the palliative care needs of people with dementia, there was a call for development of practice guidelines for the Irish context (17,19–21).

In 2013, the Irish Hospice Foundation (IHF) embarked on a three year work 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 Changing Minds programme seeks to achieve the following:

- 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 in a place of their choosing.
- Better end-of-life care in residential care settings for older people, with a particular focus on all people with dementia.
- Increased public discourse on death and dying, with a focus on those with dementia engaging in early advance care planning.

The Changing Minds programme has six projects, one of which has a dementia specific focus. The overall aim of this dementia specific project is to develop and adapt practice tools and service models for people with dementia. The project committed to develop a suite of guidance documents in order to support health and social care staff working with people with dementia across all care settings in addressing specific aspects of palliative care for people with dementia. This work was overseen by a Project Advisory Group (see Appendix 1 for membership). These documents aim to consider all stages and types of dementia and include consideration of all people impacted by dementia (e.g. people with young onset dementia, people with intellectual disabilities, their carers and family members 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 health and social care staff working with dementia. An Expert Advisory Group was convened to develop each guidance document which had links to a Project Advisory Group (see Appendix 1 for membership of both groups). Following a process of consultation and feedback with the Project Advisory Group, the following care domains were agreed upon as a focus for the suite of guidance documents:

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



INTRODUCTION

Advance care planning is increasingly regarded as a feature of good clinical care in Ireland and an important part of overall care (22). It has been found to be helpful in addressing the needs of people with dementia (23) and particularly those in long-term care homes (24). Advance care planning can support the provision of excellent end-of-life care by promoting dignity, choice and support to address a person's physical, personal, social and spiritual needs (25). The benefits of engaging in advance care planning with people with dementia are documented to include an improved quality of life at the end of life, less aggressive medical care, reduced inappropriate hospital admissions and increased hospice admissions. It has also been shown to reduce the decision making burden on others by ensuring that wishes can be carried out at a future time when people can no longer decide for themselves (26–29). Although challenges, to include a lack of knowledge and skills about advance care planning (10,13,30–35) and a lack of understanding about the 'right' time to initiate advance care planning discussions exist (30,35–38), literature indicates that advance care planning discussions can take place with those with advanced dementia (39–42). More significantly, most people, including those with dementia, want to have conversations, are willing to record their end of life preferences and feel relieved when issues have been discussed (39,43–45).

Over the last two decades the area of advance care planning and advance healthcare directives has increasingly received attention and has gained momentum with countries, including Ireland, signing the United Nations Convention on the Rights of Persons with Disabilities in 2006. This United Nations Convention calls for states to facilitate people with disabilities to exercise their right to make choices and express preferences in relation to their care on a similar basis, equal to those who do not have any disability (46). Subsequent to this, in December 2009 the Council of Europe issued a recommendation to Member States, to promote self-determination for adults in the event of their future incapacity (47).

Advance care planning and advance healthcare directives are respected within common law in Ireland and are supported by the Constitution of Ireland that outlines the fundamental right of bodily integrity and the right of a person to decide for themselves (48). Although the Council of Europe recommendations are incorporated into Irish law by virtue of the European Convention on Human Rights Act 2003, for the purposes of legal certainty as to their status, there was a need for a legislative framework. The Assisted Decision Making (Capacity) Act was enacted in December 2015 and includes a legislative scheme for advance healthcare directives. This legislation replaces the 1871 Regulation of Lunacy (Ireland) Act and proposes a modern statutory framework to support decision making by adults who, when they have capacity, wish to plan for the eventuality when they may lack capacity and for those whose decision making capacity is at issue (49). In doing so, this legislation promotes the autonomy of people in relation to their treatment choices and will enable all people to be treated according to their will and preferences and/or beliefs and values. At the time of publication, (July 2016), the Minister for Health has appointed a multi-disciplinary Working Group to make recommendations to the Director of Decision Support Service in relation to a code of practice. In the interim, this guidance document aims to inform and guide health and social care staff in engaging with advance care planning and advance healthcare directives.

3.1 Scope of this guidance document

This guidance document will:

- List three key considerations to inform good practice with regard to advance care planning and advance healthcare directives.
- Provide guidance for health and social care staff with regard to completing advance care plans and advance healthcare directives.

This Guidance document should be read in conjunction with Guidance documents 1 and 7 “Facilitating discussions on future and end-of-life care with a person with dementia” (41) and “Ethical decision making in end-of-life care for the person with dementia” (50).

3.2 Who is this document for?

This document has been written for **all health and social care staff** who work with and support people with dementia **across all settings** e.g. in the home, in long term care units, in hospitals etc.

Engaging people with dementia and their family members, (if the person with dementia wishes), in the process of advance care planning and inviting them to participate in making decisions about their future care needs at a time when decision making capacity is not an issue is of utmost importance. Within healthcare, a whole person approach needs a whole team approach: all people supporting those with dementia will interact and engage with the person with dementia in different ways dependent on their roles. Each of these roles is interconnected and is key to delivering good person centred care. Therefore, all people involved in the care of a person with dementia need to develop competence and confidence in engaging in advance care planning and with advance healthcare directives within their own scope of practice and with regard to professional guidelines and standards. They also need to be aware of their roles and responsibilities when supporting a person to engage in advance care planning or making an advance healthcare directive.



This may occur in the context of the difficulties those with dementia face with regard to thinking about what might happen as dementia progresses and about what future care needs may be required. However, taking early steps to plan can enable people to be prepared for various situations that might arise, reduce the practical and emotional burden on family and friends and address some other fears and concerns.

3.3 How to use the document

Giving a person with dementia the opportunity to engage in sensitive discussion and reflection about their goals, values, wishes and preferences is an integral part of good palliative care. However, advance care planning and completing an advance healthcare directive is a process that a person may or may not choose to engage with. It is important to note that completing an advance care plan and/or advance healthcare directive may not address every eventuality that may occur at the end of life. If a person chooses not to engage in these processes, other options, as outlined in section 5, exist to support a person in decision making as their illness progresses.

This guidance document should be considered as an adjunct to The Assisted Decision Making (Capacity) Act 2015, (yet to be commenced), and supporting documentation which will include a statutory code of practice, existing best practice guidelines in dementia care, best practice guidelines in end-of-life care, and national and local policies and procedures which relate to working with people with dementia and older people.

It is recommended that if a person is not familiar with the subject matter outlined in this document, they take the time to read it in its entirety, as each section builds on the knowledge and information shared in the previous section. The factsheet that accompanies the document should serve as a visual reminder to people who have read the whole document. It is not recommended as a stand-alone item.

This document provides some guidance to health and social care staff on introducing advance care planning to people with dementia with an overall aim being to enhance the healthcare experience of people with dementia and their family members with regard to advance care planning and use of advance healthcare directives. Changing attitudes, cultures and practices takes time. How you choose to use this guidance document will depend on your situation. Within healthcare you may choose to incorporate it into policies, deliver it as part of an education programme, hold information sessions on it, refer to it as a person's dementia progresses or discuss it with individual people.

3.4 Structure of the guidance document

This guidance document is based on key themes which emerged from 5 literature reviews and a process of consensus building by the Expert Advisory Group (see Appendix 2 for methodology). It is compiled of the following sections:

Section 1: Glossary

Section 2: Background and Context

Section 3: Introduction

Section 4: Key Considerations to Inform Good Practice

The three key considerations should be applied as foundation knowledge when addressing the topic of advance care planning and advance healthcare directives.

Section 5: Guidance and Resources

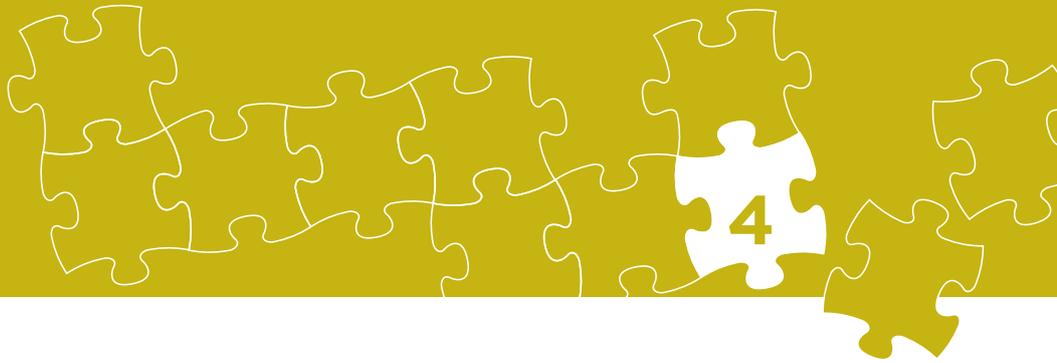
There are three areas where guidance is provided to the reader on aspects of advance care planning and advance healthcare directives. Each guidance area is followed by resources and signposting to further information.

Section 6: Additional Resources

These resources may serve as supplementary information for health and social care staff.



▶ Section 4



KEY CONSIDERATIONS TO INFORM GOOD PRACTICE

This section explores three key considerations which inform good practice with regard to advance care planning and advance healthcare directives with a person with dementia. They should be applied as foundation knowledge when supporting a person with dementia and should be read in conjunction with guidance document 7 “Ethical decision making in end-of-life care for the person with dementia” (50).

The three key considerations to inform good practice are as follows:

1. **Develop understanding of dementia**
2. **Become familiar with aspects of the Assisted Decision Making (Capacity) Act 2015, specifically in relation to the functional approach to decision making capacity**
3. **Become familiar with Guidance Document 1 “Facilitating discussion on future and end-of-life care with a person with dementia” (41)**



4.1 Develop understanding of dementia

Before advance care planning and advance healthcare directive discussions take place it is important that people have a good understanding of the clinical progression of dementia (51). Having this knowledge will enable people to anticipate discussions and respond appropriately and sensitively when opportunities for discussions arise. It is also important to acknowledge that many people living with dementia may also have other illnesses to include cerebrovascular disease, cardiac, musculoskeletal or respiratory illnesses that may impact on the signs and symptoms of dementia. As dementia is an individual journey associated with gradual loss of memory and function, an individual response is required (52). Understanding and sensitive communication is needed to guide the person and family members through the potential scenarios which can arise as dementia progresses and where particular decisions may need to be made to ensure optimum comfort for the person (53). Section 6.1 “Additional Resources” outlines more information on the progression of dementia.

4.2 Become familiar with aspects of the Assisted Decision Making (Capacity) Act 2015, specifically in relation to the functional approach to decision making capacity

European and Irish legislation exists to protect the fundamental rights of all people (See Appendix 3). With regard to medical care, legislation indicates that when a person does not have the decision making capacity to consent to an intervention, in particular because of a mental disability or disease, the intervention may only be carried out with the authorisation of his or her representative, an authority or a person or body provided by law (54). This means that a person has the right to make decisions,

(even unwise decisions), on their own behalf and is assumed to have decision making capacity to do this, unless proven otherwise. The responsibility for proving otherwise rests with the person challenging decision making capacity. See section 5.1.4 for more on this. Enshrined in this is the concept of consent. Consent is giving permission or agreeing that an intervention, receipt or use of a service or participating in research can take place following a process of communication (55). Consent is valid if a person participates freely and is not acting under duress or pressure from anyone (55).

Many health and social care professionals are uncertain about their responsibilities and are unclear about the legal standing of advance healthcare directives (37). The Assisted Decision Making (Capacity) Act 2015² promotes the autonomy of people in relation to treatments that they do not want in the future and provides a framework that will enable all people to be treated according to their will, preferences, beliefs and values. For health and social care professionals, this legislation will require a change in current norms and practices with regard to ascertaining a person's will and preferences and will require them to have a clear understanding of the requirements of the legislation. The Assisted Decision Making (Capacity) Act (2015) sets out a clear legislative scheme and also provides for the development of a statutory code of practice³ concerning advance healthcare directives. Of particular importance within health and social care is the functional approach to decision making capacity which is outlined below.

4.2.1 The functional approach to decision making capacity:

Decision making capacity is the ability of a person to understand at the time a decision is to be made, the nature and consequences of the decision in the context of the available choices at that time. This means that decision making is time and issue specific. Every adult is presumed to have capacity to make decisions about their own healthcare; this is enabled by focusing on the person's will, preferences, beliefs and values; addressing both their autonomy and protection. Adapted from (2,3). An adult is presumed to have capacity unless the contrary is clearly indicated and, having been given all appropriate help and support, it is clear that he/she cannot understand, retain, use or weigh up the information needed to make a particular decision at a specific time or to communicate his/her wishes (2,56). It is the obligation of any person, (which will include a health and social care professional), who is interacting with a person whose decision making capacity is at issue to assist the person to maximise their decision making capacity (55).

The "functional" approach to decision making capacity recognises that decision making is complex and that cognitive deficits are only relevant if they actually impact on decision making (55). Dementia impacts upon a person's ability to remember, learn new information, make decisions and solve problems leading to problems with thinking, observing, behaviour and reasoning (26,52). Depending on the decision being made, a person with dementia's decision making capacity may vary (57). See case study 2, section 5.3 for example. It is necessary for health and social care staff to understand this functional approach to decision making capacity and establish ways to ascertain what a person's decision making capacity is in relation to a decision that is being made at the time the decision is being made with care not to use undue influence. However, in line with the least intrusive approach, it is important that no assessment of decision making capacity is undertaken unless it is necessary to do so having regard to the individual circumstances. See section 5.1.3 for more information on assessing decision making capacity.

² Commencement of the Assisted Decision Making (Capacity) Act (2015) is pending.

³ Working groups have been established by the Dept. of Health to prepare the code of practice that will support implementation of this legislation. The Director of the Decision Support Service has the function of preparing and publishing the code of practice when finalised.

4.3 Become familiar with guidance document 1 “*Facilitating discussion on future and end-of-life care with a person with dementia*”

Communication skills are key to enabling a person with dementia express their will, preferences, beliefs and values and are essential when assisting a person to maximise their decision making capacity. Guidance document 1 “Facilitating discussion on future and end-of-life care with a person with dementia” outlines key considerations to inform good practice and offers guidance with regard to having conversations with a person with dementia (41). Of particular importance is that communication with a person with dementia is *always* possible and that future wishes should be recorded when they are expressed. Guidance document 1 offers direction and resources on how to maximise communication opportunities with a person with dementia. One of the resources recommended is the AFIRM approach which is a framework that supports health and social care staff to deal with informal conversations and use these conversations as an opportunity to pick up on underlying apprehensions or queries that a person might have (58). This and other guidance with regard to having conversations about future and end-of-life care with a person with dementia are outlined in guidance document 1 and should be accessed and used in conjunction with the information outlined in this guidance document.



GUIDANCE AND RESOURCES

Three areas for guidance were identified in the literature as a way to support people with dementia with advance care planning and advance healthcare directives. These areas are introduced below and are outlined in further detail in the subsequent sections. They are:

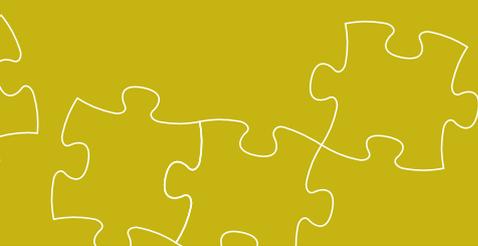
1. **Develop understanding of advance care planning**
2. **Develop understanding of advance healthcare directives**
3. **Develop understanding of decision making supports**



5.1 Develop understanding of advance care planning

Advance care planning is an integral part of care provided by all health and social care professionals and is of significant importance for people with dementia. Yet two main barriers to the initiation of advance care planning discussions within dementia care exist: 1. Lack of knowledge and skills about advance care planning (10,13,30–35) and 2. Lack of understanding about the ‘right’ way to initiate advance care planning discussions (30,35–38). A lot of research indicates that advance care planning discussions should take place early in the dementia illness, when the person is well, so that when they are no longer able to make decisions that affect them, their previously stated wishes can be respected (39,59–62). However, it is important to remember that regardless of what stage a person’s dementia is at they can still make decisions (41,63). Subsequently, health and social care professionals need to be fully aware of their responsibilities and duties relating to advance care planning as this is a key aspect to the provision of person centred end of life dementia care. The area of advance care planning is steeped in ethical dilemmas and challenges. This is explored in greater detail in guidance document 7 “Ethical Decision making in end-of-life care with the person with dementia” (50).

Advance care planning refers to a process of discussion and reflection about goals, values and preferences for future care in the context of an anticipated deterioration in a person’s condition with loss of capacity to make decisions and communicate these to others (1). This indicates that ascertaining a person’s will and preferences with regard to future wishes may occur over a number of occasions and may take several conversations. The process of advance care planning usually takes place between the person and a member of their health and social care team. However, the person with dementia should be consulted with regarding the inclusion of others, (e.g. family members), in such conversations. The health and social care professional should be cognisant of potential familial tensions and difficulties that can be experienced when having conversations about the future. An advance care plan is written when a person with dementia and their health or social care professional wish to record the outcome of the advance care planning discussion. Although an advance care plan often emphasises treatment decisions such as Cardio Pulmonary Resuscitation (CPR), antibiotics, and tube feeding; advance care planning discussions can also extend to wider issues such as appointing an attorney under an enduring power of attorney, wills, environmental comforts, spiritual issues and anything else important to the person (64).



Advance care planning can serve to enhance the provision of end-of-life care by ensuring a person's voice is heard. This correlates with person centred care that involves building a relationship with people, getting to know fears and anxieties and listening to hopes and aspirations. This type of relationship supports open conversations and enables people to express their will and preferences for the present but also for the future while also understanding a person's beliefs and values. What is important is that people, including those with dementia, want to have conversations about their future and often feel relieved when issues have been discussed (23,39,43–45). Because of the uncertainty of making decisions for the future, some people may prefer to describe their overall values or goals of treatment, rather than make any specific decisions (22). Additionally, some people are reluctant, simply not ready or willing to engage in the advance care planning process and may also fear death (26,30,35–38). Good end-of-life care for the person with dementia involves responding to and meeting a person's physical, social, spiritual and psychological needs, while honouring and respecting their will and preferences. If a person does not wish to engage in the process of advance care planning then this should be respected. However, they must be offered opportunities to revisit discussions and be given appropriate information to assist them in understanding their options with regard to advance care planning. People should also be assured that regardless of their decision about engaging in advance care planning that the quality of end-of-life care will not be affected.

If a person does choose to engage in the process of advance care planning, it is important to remember that over time, their will and preferences for the future may change because of increasing effects of illness, change in circumstances or another life event (57). Consequently it is important that expressed and documented will and preferences are routinely revisited and re-evaluated with people to ensure that future wishes can be carried out when a person with dementia is no longer able to decide for themselves and that recorded preferences for the future are accurate and reflect a person's current beliefs and values (65). This is particularly important in the care of a person with dementia as subtle issues occur where a person's understanding and decision making capacity may affect their views on what was previously stated. These changes or response shifts can impact on a person's health related quality of life (66) and therefore indicate the need for ongoing assessment. Within healthcare, advance care planning should be discussed regularly and as the person with dementia wishes (65). Unlike an advance healthcare directive (outlined in section 5.2), an advance care plan is not legally binding. The process of advance care planning may lead to the development of an advance healthcare directive but does not necessarily have to.

Below is some guidance with regard to advance care planning with a person with dementia. More information is then provided in the following subsections.

1. Always presume decision making capacity
2. Help the person to maximise their decision making capacity
3. Remember that the person with dementia can choose to not take part in the advance care planning process
4. Be aware of how to assess a person's decision making capacity if required to do so
5. Gain knowledge on what steps to take if decision making capacity is an issue
6. Check existing advance care plans with the person regularly for validity and applicability

5.1.1 Always presume decision making capacity:

As indicated in section 4.2, all adults, including those diagnosed with dementia, can take part in the decision making process and are presumed to have decision making capacity unless the contrary is clearly indicated and, having been given all appropriate help and support, it is clear that he/she cannot understand, retain, use or weigh up the information needed to make a particular decision at the time the decision has to be made or to communicate his/her wishes (56). As stated in the Health Service Executive (HSE) National Consent Policy (2014), decision making capacity should be assumed in all circumstances focusing on the person's will and preferences to address both their autonomy and protection (55). Making an unwise or irrational decision does not prove lack of decision making ability. All adults retain the right to make unwise decisions. What matters is the ability to make the decision, not the outcome (67).

5.1.2 Help the person to maximise their decision making capacity:

Maximising decision making capacity involves taking every practicable step to support individuals to make their own decisions before it is decided that decision making capacity is an issue. Consequently, all health and social care professionals should take every practicable step to help a person with dementia to, as fully as possible, take part in the decision making process. For example, consideration should be given as to whether an individual's decision making capacity is affected by the time of day or medication regimes. The aim is to ensure that individuals who are capable of making decisions for themselves, though may need some support, are not inappropriately assessed as lacking decision making capacity (67).

Guidance on how to maximise decision making capacity in those with dementia includes the following:

1. Discuss treatment options in a place and at a time when the person with dementia is best able to understand and retain information.
2. Ask the person with dementia if there is anything that would help them remember information or make it easier to make a decision; such as:
 - Bringing another person to healthcare meetings
 - Having audio or pictorial information about their illness
 - Writing things down
 - Staff using simple language
 - Staff finding out how the person usually communicates
 - Having space to think quietly
 - Staff involving others where necessary such as speech and language therapists or psychologists
3. (See guidance document 1 "Facilitating discussion on future and end-of-life care with a person with dementia for more guidance in relation to effective communication).
4. Document steps taken to maximise a persons decision making capacity

Adapted from (55,68).



5.1.3 Remember that the person with dementia can choose to not take part in the advance care planning process:

It is not obligatory for a person with dementia to take part in the advance care planning process. If a person declines to participate in the process this should be respected. However, they must be offered opportunities to revisit discussions and be given appropriate information to assist them in understanding their options with regard to advance care planning in a sensitive manner.

5.1.4 Be aware of how to assess a person's decision making capacity if required to do so:

The HSE National Consent Policy indicates that there is an issue with a person's decision making capacity in situations where, having been given all appropriate help and support, a person is unable to communicate a clear and consistent choice and is obviously unable to understand and use the information and choices provided (55).

Four elements of decision making capacity have also been outlined and are included in specific guidance below. They are: the ability to understand information relative to the decision, retain the information long enough to make a voluntary choice, use or weigh the information as part of the process of making the decision and being able to communicate a decision which may include the assistance of a third party (2,48,69). If one of these four elements is absent a person's decision making capacity is deemed to be at issue (67). All those involved in the care of person with dementia should be aware of these four elements and what steps to take if an assessment of decision making capacity is required.

It is important to remember that any assessment of decision making capacity being carried out is done so only in relation to the specific decision being made and at the time a person is being asked to make that decision. (See also guidance document 7 “Ethical Decision making in end-of-life care for the person with dementia” (50)). When engaging in advance care planning in relation to end-of-life care decisions with a person with dementia it is important to record what steps have been taken to maximise decision making capacity and also record how decision making capacity was assessed in relation to the specific decision being made. Indicated below is some guidance on assessing decision making capacity:

1. Consider what decision has to be made.
2. Decision making capacity must not be established by referring to a person’s age, appearance, illness or behaviour. Engage with the person and assess them as an individual. Do not discriminate.
3. Is there something currently happening that may temporarily affect the person’s decision making capacity? Consider a delirium or anything else that might be upsetting the person. It may be possible for those with fluctuating capacity to make decisions during lucid periods.
4. Can the decision be made at a later time?
5. Can the person:
 - a. Understand information relative to the decision
 - b. Retain the information long enough to make a voluntary choice
 - c. Use or weigh the information as part of the process of making the decision
 - d. Communicate their decision?
6. Consider what supports have been provided to help the person make the decision for himself or herself.
7. Consider if decision making capacity is absent even with all practicable support.
8. Document the assessment process and outcome.

Adapted from (55,68)

5.1.5 Gain knowledge on what steps to take if decision making capacity is an issue:

If decision making capacity in relation to a specific decision is, or consistently remains an issue for a person with dementia the following steps should be taken:

1. Support the person to be involved in the decision making process by engaging in capacity building and maximising as outlined in section 5.1.2.
2. Consider the level of support that the person requires to make the decision in question.
3. Seek evidence of previously expressed will and preferences.
4. Consider which option, including not to treat, would be least restrictive of the person's future choices.
5. Consider the views of anyone indicated by the person. These people may be those appointed by the person to support them when making decisions. This may include:
 - a. A decision making assistant
 - b. A co-decision maker
 - c. A decision making representative
 - d. An attorney created under an enduring power of attorney
 - e. A designated healthcare representative appointed under an advance healthcare directive. (These roles are explained in section 5.3)
6. Consider involving advocacy support.
7. Seek a second opinion if required.

If there is nobody appointed by the person whose decision making capacity is at issue and/or an urgent decision is required, an application can be brought to the circuit court seeking the appointment of one or more persons to act as a decision making representative.

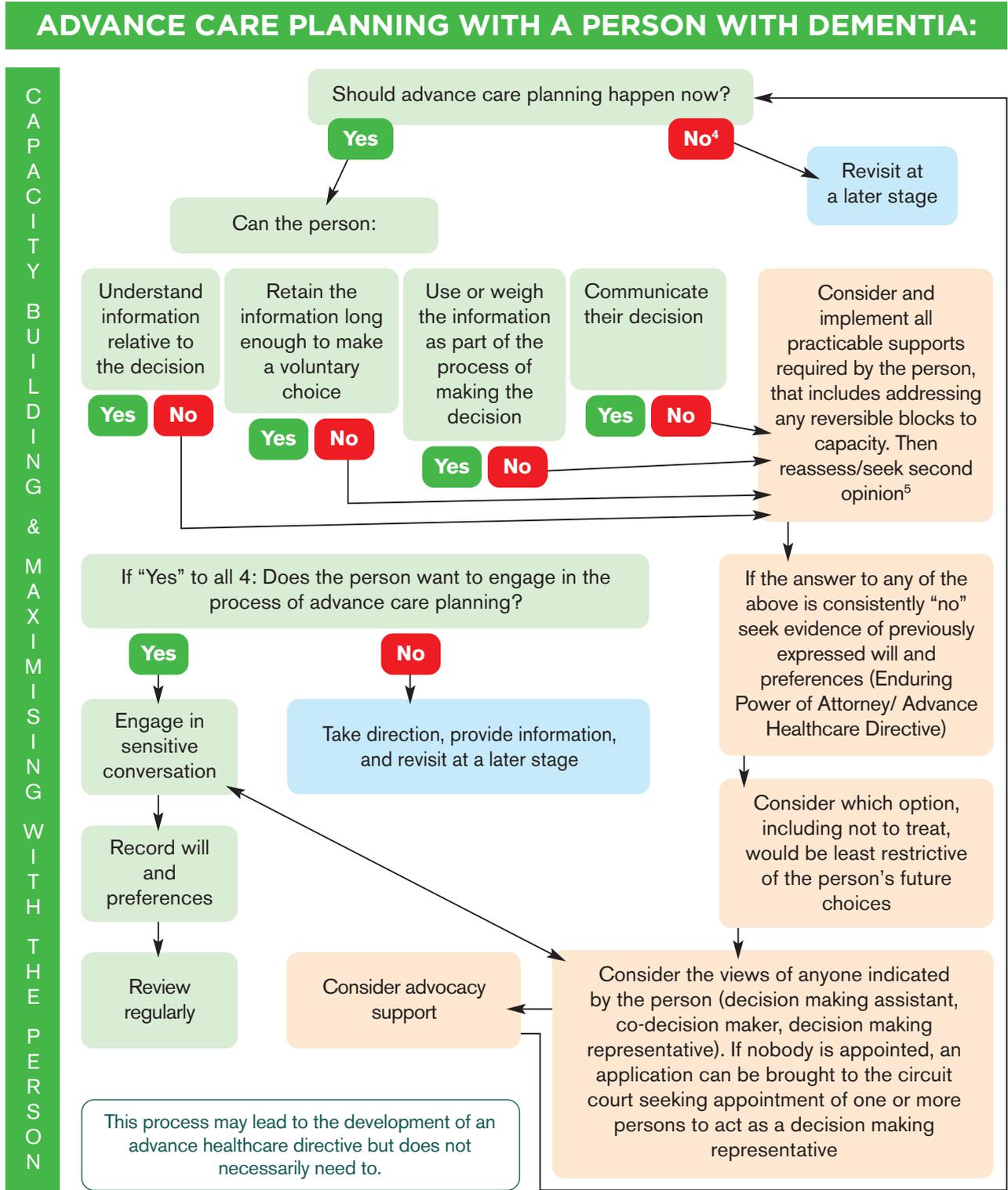
Adapted from (2,55).

5.1.6 Check existing advance care plans with the person regularly for validity and applicability:

It is important that expressed and documented will and preferences are routinely revisited and re-evaluated with people; this is to ensure that future wishes can be carried out when a person with dementia is no longer able to decide for themselves and that recorded preferences for the future are accurate and reflect a person's current beliefs and values (65).

The following advance care planning algorithm (overleaf) has been prepared for the purpose of this document in an attempt to illustrate engaging in the advance care planning process with a person with dementia. It is based on the Assisted Decision Making (Capacity) Act 2015 (2,49) and the HSE National Consent Policy (2014) (Ireland) (55) and will be applied to the case studies at the end of section 5.3. It is merely a guide. Each person should be cared for on an individual basis with due regard taken for applicable legislation in that jurisdiction.

Advance care planning algorithm



4. It may be inappropriate to engage in advance care planning if there is a temporary issue with a person's decision making capacity, for example an acute delirium.

5. The person/persons that may be called upon to provide a second opinion have not yet been outlined. It is the responsibility of the Director of Decision Support Service to provide guidance and information with regard to this.

5.1.7 Resources

The resources outlined below may be useful when engaging in advance care planning with a person with dementia. These resources should be used with cognisance of relevant legislation and with consideration for personal scope of practice.

1. The "I have dementia... How do I plan for the future?" booklet, developed by the Alzheimer Society of Ireland and Irish Hospice Foundation outlines five steps to planning for the future with dementia:

- Planning financial affairs
- Planning legal affairs
- Planning health and care needs
- Planning for what happens after death
- Talking to family about plans (70).

The 28 page booklet also provides some phrases to assist people with dementia having conversations about their plans for the future (70).



2. Understanding late stage dementia is an information leaflet developed by the Alzheimer Society of Ireland and the Irish Hospice Foundation. It provides information about what to expect as dementia progresses to late stage. The topics outlined in this information leaflet are as follows:

- How does dementia progress?
- What is late stage dementia?
- Caring during the final stages of dementia
- Who is responsible for making medical care and treatment decisions? (71)



3. HSE National Consent Policy (2014) (55).

4. Tips that may be useful when assisting a person to engage in the advance care planning process (Adapted from (72)).

- a. Initiate the conversation if it has not occurred already

"I know this is hard, but it would be helpful to discuss these matters now."

- b. Convey to the person that they are in charge, they are making the decisions but you are there to help

"What would you like to happen in the future if you are not able to tell me at the time?
I'd like to know your wishes so you will still have an input later on."

c. Respect, dignity, choice and independence should be upheld during the talking process

- Give the person time to express him/herself
- Explore the different options for various scenarios that might arise
- Offer the opportunity to come back to the conversation at a later time

d. Promote hoping for the best but planning for all eventualities

“I may not need to do anything with this information but if at some point you will not be able to make decisions I would like to know what you would wish me to do.”

e. Look for opportunities within conversations to find out likes and dislikes

“What would you like if that were you?”
“How would you feel if ...? What do you think about ...?”

f. Use a resource, such as "Think Ahead" to help with the conversation (72).

5. The Alzheimer Society of Ireland Dementia Carers Campaign Network is an advocacy group for those who have experience of caring for a person with dementia (73).
6. Citizens Information provide information about advance care planning and advance healthcare directives (74).
7. Inclusion Ireland website hosts information on capacity and the Assisted Decision Making (Capacity) Act 2015 (75).
8. SAGE Support and Advocacy Service for Older People works to promote and protect the rights, freedoms and dignity of older people by developing support and advocacy services wherever ageing poses a challenge for individuals (76).
9. “Planning for your future care: A Guide” is a UK based, Dying Matters, National Council for Palliative Care information booklet about advance care planning and provides readers with key points when engaging with advance care planning (77).
10. “Difficult Conversations for Dementia” is a UK, National Council for Palliative Care information booklet that is aimed at anyone to open up conversations about end of life wishes and preferences (78).

5.2 Develop understanding of advance healthcare directives

The Assisted Decision Making (Capacity) Act, 2015 provides a framework to support advance healthcare directives within Ireland. It is important that health and social care professionals understand the role of advance healthcare directives and understand how they work in practice. An advance healthcare directive is an expression made by a person who has capacity (in writing, to include voice, video recording and speech recognition technologies) of their will and preferences concerning specific treatment decisions in the context of an anticipated deterioration in their condition with loss of decision making capacity to make these decisions, to give consent to or refuse treatment and communicate them to others. An advance healthcare directive is legally binding (therefore certain formalities must be followed) when a person writes down what treatments they would refuse in the future and the circumstances in which the refusal is intended to apply⁶. The Assisted Decision Making (Capacity) Act 2015 provides that a request for a specific treatment is not legally binding but should be followed if relevant to the medical condition for which treatment is required. (2).

Although Codes of Practice⁷ are required to support full implementation of the legislation there are a number of things that health and social care professionals can do in the interim. Subsequently the guidance in relation to advance healthcare directives is as follows:

1. Become familiar with what an advance healthcare directive can include
2. Become familiar with what makes an advance healthcare directive legal
3. Check existing advance healthcare directives regularly for validity and applicability

More information is outlined in the following subsections:

5.2.1 Become familiar with what an advance healthcare directive can include:

Issues that may be covered in an advance healthcare directive include:

- Treatments that a person would not want in the future – this is legally binding provided the following conditions are met:
 - At the time in question the person lacks decision making capacity to give consent to the treatment
 - The treatment to be refused is clearly identified in the advance healthcare directive
 - The circumstances in which the refusal of treatment is intended to apply are clearly identified in the advance healthcare directive
- A request for a specific treatment. This is not legally binding but must be taken into consideration during any decision making process which relates to treatment for the person in question if that specific treatment is relevant to the medical condition for which the person may require treatment. If a health and social care professional does not comply with a request for a specific treatment, he or she must record the reasons for not complying with the request and give a copy of those reasons as so recorded to the person's designated healthcare representative (if there is one appointed) (79).

⁶. The Assisted Decision Making (Capacity) Act 2015 indicates that a record of advance healthcare directives will be held by the Decision Support Service. At the time of writing this service has not been established. It is recommended that a record also be stored with relevant others to include the G.P, family members and medical specialist.

⁷. Multi-disciplinary Working Groups have been established to make recommendations for a code of practice. The Director of the Decision Support Service has the function of preparing and publishing the code of practice when finalised.

Within an advance healthcare directive, a person can refuse treatment up to and including life sustaining treatments but cannot refuse what is termed “basic care”. The legislation on advance healthcare directives defines basic care as including, (but is not limited to), warmth, shelter, oral nutrition, oral hydration and hygiene measures but does not include artificial nutrition or artificial hydration (which would be termed as medical treatment) (2). This is particularly important throughout the care of a person with dementia as those with dementia may refuse food and drinks at various times throughout their journey with dementia. A person has the legal right to refuse life sustaining treatment in an advance healthcare directive even if it means that their life is at risk. This promotes individual autonomy and respect for a person’s will and preferences. A health and social care professional will be obliged to follow a person’s valid advance healthcare directive even if he/she disagrees with such a decision.

5.2.2 Become familiar with what makes an advance healthcare directive legal:

An advance healthcare directive comes into effect when a person loses decision making capacity, and the circumstances in their advance healthcare directive arise. Doctors will be obliged to give effect to an advance healthcare directive under the following circumstances:

1. The person had decision making capacity at the time they made the advance healthcare directive.
2. The advance healthcare directive was made voluntarily.
3. The advance healthcare directive was not altered or revoked.
4. The person who made the advance healthcare directive did not do anything inconsistent with the terms of the advance healthcare directive while they had decision making capacity.

If all the legal requirements are in place, the healthcare team have a statutory obligation to comply with the terms of the advance healthcare directive (2).



5.2.3 Check existing advance healthcare directives regularly for validity and applicability

It is important that expressed and documented will and preferences are routinely revisited and re-evaluated with people with dementia. This will help to ensure that future wishes can be carried out when a person with dementia is no longer able to decide for them-self and that recorded preferences for the future are accurate and reflect a person's current beliefs and values. As indicated in section 5.1, future wishes should be discussed regularly and as the person with dementia wishes (65). These conversations are a good opportunity to check that an existing advance healthcare directive, if in place, is still appropriate, valid and applicable. In situations where an advance healthcare directive is not in place, the regular care plan review also provides health and social care staff with an opportunity, if appropriate, to propose that a person might consider making an advance healthcare directive pointing out that it is helpful to the health and social care professional to know the person's will and preferences. It is also good practice for health and social care professionals to check with other relevant professionals about their being an advance healthcare directive in place.

5.2.4 Resources

Below are some resources that might be useful when engaging with advance healthcare directives with a person with dementia. Some of the Irish resources require updating since enactment of The Assisted Decision Making (Capacity) Act 2015 and should therefore be used with caution and with consideration for personal scope of practice.

1. Developed by the Irish Hospice Foundation, Think Ahead (2016) is an initiative that guides people to discuss and record their care preferences in the event of an accident, serious illness or death. Recording wishes can help family members know preferences if a person is unable to speak for themselves. The Think Ahead form is divided into five main sections:

- Key information
- Care preferences (see the following 5 pages)
- Legal matters
- Financial matters
- When I die (80)



Think Ahead encourages people to:

- Think about how well (or not) those close to a person would know or understand wishes and preferences if a time came when a person could not speak for themselves.
- Talk about preferences, with family members or key professionals (such as a GP, solicitor or accountant)
- Tell the most relevant people about wishes and to record them using the Think Ahead form.
- Record their wishes
- Review the document regularly

Once wishes are recorded on the Think Ahead form, they will be available if at some stage, for whatever reason, including illness or accident, a person cannot communicate with family members or carers, or make their wishes known. Think Ahead contains provision for an advance healthcare directive (79,80). The care preferences section from "Think Ahead" is available on the following 5 pages.

Care preferences excerpt from “Think Ahead”



SECTION 2. Care Preferences

This section provides key information about you that can be used to inform your treatment and care in case of emergency.

This information should be shared with: (Please tick all that apply)

Family Loved Ones GP, Nurse, Carer Other

- How would you like to be cared for if you were ill?
- Who would you like included in discussions about your medical condition or care?
- Are there cultural preferences or religious beliefs that you would like the healthcare staff to consider in caring for you?

These are important questions and can be answered here so that you are given the best possible care and consideration by the staff at a hospital or in another care setting. This part of the form has three separate sections.

1. The first section deals with your care preferences should you become ill and unable to communicate your wishes.
2. The second section is an Advance Healthcare Directive. This allows you to set out your preferences about medical treatments you **do not want** to receive in the future in case you cannot communicate your wishes for yourself. It also allows you to nominate someone, called a **Designated Healthcare Representative**, who you have authorised to interpret or make your healthcare decisions. If you have appointed an attorney under an Enduring Power of Attorney to make healthcare decisions on your behalf, it is important to state what authority you have given your attorney
3. The final section is an emergency summary sheet containing important information. **Remove it from the rest of the form and store it in an easily accessible place for use in an emergency situation.**

We recommend that you speak to a healthcare professional before completing this section of the form as he or she may be the person best placed to give you the information you need when deciding about the care and treatment you would like.

2.1 Care Preferences Communication/Information

There may be some instances when your medical condition may prevent you from being involved in discussions about your health. You might be unconscious, or you might be conscious but unable to understand some information or you might simply lack capacity to make decisions. With this in mind:

Would you like a relative or friend to be present with you for conversations with the medical team, or at key events in your care?

Yes No

...
* See Glossary

?
Need Help?

If at any point you need help completing this form, please visit the Think Ahead website: www.thinkahead.ie

Care preferences excerpt from “Think Ahead”



Speak for Yourself



If yes, please give the name and relationship of that person:

Name:	Relationship:
_____	_____

Phone:	Email:
_____	_____

Care Preferences

If your condition is deteriorating and is life-limiting, who should talk to any children, or other close family and friends, about the extent of your illness and the possibility of your death?

Please Specify...

Cultural preferences/Religious beliefs

Are there any cultural preferences or religious beliefs or rituals that you would like to be considered as part of your care? If so please list these below:

Is there someone from your cultural community or religious community that you would like to be informed if you are seriously ill? If so please give that person’s name and contact details.

Name:

Role:

Phone:

Email:



You may change your mind over time and you may also find that when the time comes your preferred place of care may not be available.

Care preferences excerpt from “Think Ahead”




Care Preferences 10

Other wishes

Thinking about the place you would most like to be cared for if you were nearing death.

Please indicate your first preference by putting the number ‘1’ beside that option. Likewise, please put the number ‘2’ beside your second preference, ‘3’ beside your third preference and so on.

- Home
- Hospice
- Hospital
- Nursing Home
- Other (please specify)

Name of preferred Hospital/Hospice/Nursing Home:

You may change your mind over time and you may also find that when the time comes your preferred place of care may not be available.

Is there anything in particular you would or would not like in your final days of life? (e.g. photos, favourite music, rituals, prayers etc.) **Please list preferences:**

What I would like.

What I would not like.

Besides those wishes already expressed, I would like the following requests or preferences to be considered.

Care preferences excerpt from “Think Ahead”



Speak for Yourself



Care Preferences 11

2.2 My Advance Healthcare Directive

An Advance Healthcare Directive (AHD) is a written statement made by a person who has reached the age of 18 years with capacity (the ability to understand, retain and use or weight up the information in order to make a decision). It sets out will and preferences about treatment decisions that they **do not want** to receive in the future, if a time comes where they lack capacity to make such decisions or cannot communicate their decision by any means.

The Assisted Decision-Making (Capacity) Act 2015 was enacted in December 2015. While AHDs have been recognised in Ireland for many years, there was no law governing them and this led to confusion. The 2015 Act sets out the requirement for making a valid AHD.

AHDs mainly concern a person’s right to refuse treatment even if the refusal is considered by others to be unwise, made for non-medical reasons or may result in death provided that the person making the directive had the decision-making capacity at the time of making the AHD.

The 2015 Act provides that a request for specific treatment set out in an AHD is not legally binding (a person cannot demand treatment that is unnecessary) but it must be taken into consideration if it relates to treatment that is relevant to the medical condition of the maker of the advance healthcare directive.

If the AHD is valid and applicable to the specific treatment then doctors are legally bound to follow them. An AHD can be revoked or altered in writing provided the person has the capacity to do so. Any alteration of an AHD must be signed and witnessed in the same manner as the original AHD.

An AHD also allows you to nominate a Designated Healthcare Representative. This is someone who you will authorise to interpret your AHD or to make healthcare decisions on your behalf. They can have as much authority as you decide to give them, up to and including the power to consent to/refuse life-sustaining treatment on your behalf.

There is no obligation to make an Advance Healthcare Directive. It is completely your decision. This section simply provides you with a space to record any preferences you may have in a way which will meet the requirements for a valid Advance Healthcare Directive.

Importantly, an Advance Healthcare Directive will come into effect only if you lose **capacity*** and are unable to communicate your healthcare decisions.

Some people may like to either speak to their GP or primary medical professional before completing this section or tell them afterwards that they have completed this section and what their wishes are.

Designated Healthcare Representative

This section allows you to appoint a Designated Healthcare Representative if you wish. This person may be a trusted family member or a close friend, and will be able to speak for you if you lack the capacity to communicate your wishes. Therefore, it is important to speak to him or her regarding the care you would like or not wish to have. **You do not have to appoint a representative and can merely set out your wishes in an Advance Healthcare Directive provided the formalities are followed, signed and witnessed by two persons.**

If you decide to nominate a representative, they must be over 18 years of age, not someone who is caring for you in return for payment, and not someone who owns or works in a residential or healthcare facility where you are living. It is necessary for this person to sign the directive and confirm their willingness to carry out your wishes.


* See Glossary

Care preferences excerpt from “Think Ahead”



Your Designated Healthcare Representative

Name: _____

Relationship: _____

Address: _____

Phone: _____

Email: _____

I am willing to carry out the will and preferences of the directive-maker

Signature of designated healthcare representative

Alternative Designated Healthcare Representative

(Optional - In the event that the person above is unavailable)

Name: _____

Relationship: _____

Address: _____

Phone: _____

Email: _____

I am willing to carry out the will and preferences of the directive-maker

Signature of designated healthcare representative

Note: Currently, if you specify who you want to act on your behalf, this will be respected.

I have given my Designated Healthcare Representative the following authority:

- Power to advise and interpret what my wishes are regarding treatment which I have set out in this AHD.
- Power to ensure that the wishes I have expressed in this Advance Healthcare Directive are carried out based on my will and preferences according to my directive.
- Power to consent to or refuse medical treatment on my behalf, up to and including life-sustaining treatment based on my will and preferences according to my directive.

Care preferences excerpt from “Think Ahead”



Care Preferences 13

Please state your directives with respect to life-sustaining treatment and cardiopulmonary resuscitation (CPR) here. These wishes will have an impact if you become unable to take part effectively in decisions regarding your medical treatment.

Life-Sustaining Treatments

Life-sustaining treatment* is treatment which replaces, or supports, a bodily function which is not operating properly or failing. Where someone has a treatable condition, life sustaining treatments can be used temporarily until the body can resume its normal function again. However, sometimes the body will never regain that function.

If there is no prospect for my recovery:

I wish to have whatever life-sustaining treatments that my healthcare professionals may consider necessary and appropriate.

OR

I wish to have whatever life-sustaining treatments that my healthcare professionals may consider necessary unless this will require the following treatments, which I do not wish to receive, even if this refusal will result in my death:

- Being placed on a mechanical ventilator/breathing machine
- Dialysis
- Artificial feeding intravenously
- Artificial feeding through a tube in the nose (nasogastric tube)
- Artificial feeding through a tube in the abdomen (PEG tube)

There may be some life-sustaining treatments which you would not want to receive in any situation. These may include dialysis, being placed on a ventilator, artificial feeding. If you develop an infection, you may decide not to have **intravenous antibiotics*** and also, you may decide not to have oral antibiotics. If there are particular life-sustaining treatments which you do not want to receive, please mention these below. If you wish to refuse life-sustaining treatment you need to specifically state this and also state that the directive is to take effect even if your life is at risk. **Specific circumstances in which you wish to refuse treatment need to be clearly outlined, e.g. If I have cancer, I do not wish to receive chemotherapy; If I am in a very serious accident, I do wish to be placed on a ventilator.**

Cardiopulmonary Resuscitation* (CPR)

In order to make decisions regarding resuscitation preferences, it is important to discuss your health with your doctor as some conditions will not benefit from CPR.

Please tick your preference:

It has been explained to me by Dr _____
that I would not benefit from attempted CPR and I understand this.

Therefore:

- I do NOT want CPR. **OR**
- I would only like CPR attempted if my doctor believes it may be medically beneficial.

 *** See Glossary**

Care preferences excerpt from “Think Ahead”



Other Preferences

There may be other situations you would find unacceptable in relation to your health. You can give details here. It is important to specify specific treatments you do not want and the circumstances in which your refusal of treatment is to apply. E.g. If I am diagnosed with terminal cancer, I do not wish to receive chemotherapy.

This form must be signed by you and by 2 witnesses. Both of these people **must be over 18**, and **at least one of them must not be a member of your family** and preferably should not be your attorney or patient-designated healthcare representative.

Your Signature	Date
Witness 1 Signature	Date
Witness 2 Signature	Date

Your wishes may change over time. For this reason we strongly encourage you to review this part of the form annually or as often as is appropriate for you. Please also remember that if you do make any changes to your Advance Healthcare Directive, these must be witnessed in the same way as the original.



Reviews

Signature: _____ Date Reviewed: _____

...
* See Glossary

✓
Remember

Irrespective of any decisions about CPR and life-sustaining treatment, you will receive **basic care***, which will include normal nutrition and hydration as well as care to relieve pain and relieve any suffering.

Taken from: (80)

2. Irish Hospice Foundation Briefing Paper on Advance Healthcare Directives (81).
3. Let Me Decide is an advance healthcare directive designed for use within healthcare settings that can be used to plan future health and personal care (82).
4. Keep Control is a project of the National Centre for the Protection of Older People about keeping control over financial affairs. It aims to assist older people to keep control over decisions, wishes and intentions with particular regard to financial affairs. Chapter 5 of the Keep Control Information booklet addresses “Decision- Making at Critical Life Events” and sets out some useful guidelines for decision making in the event of serious or critical illness to include the following:
 - Make a Will by contacting a solicitor.
 - Decide who will benefit from any assets, money and possessions you have and what they will get.
 - Create an enduring power of attorney.
 - Notify your financial institution about your illness and discuss what action it will take when it is notified of your death.
 - Request the financial institution to continue to make payments from any account held jointly by you and your spouse or partner until new arrangements are in place (83).
5. MABS Thinking Ahead Money Matters and Serious Illness is an information booklet about managing finances in critical illness (84).
6. Assisted Decision-Making – What does it mean? Is a factsheet explaining the Assisted Decision Making (Capacity) Act (2015) developed by Inclusion Ireland (85).
7. “New Times” is a guide to the Assisted Decision Making (Capacity) Act 2015 by SAGE (86).

5.3 Develop understanding of decision making supports

The Assisted Decision Making (Capacity) Act 2015 supports the functional approach to decision making capacity (see section 4.2.1) and recognises that decision making is complex and that cognitive deficits are only relevant if they actually impact on decision making (55). This legislation supports that all people should be assisted and supported to take part in decision making processes that affect them. This indicates that regardless of what stage a person's dementia is at, steps should be taken and supports put in place to assist a person to communicate their will and preferences with regard to a decision that needs to be made at the time the decision needs to be made. These supports should be available at all times.

Throughout the journey with dementia many people may require different levels of support with making decisions, depending on what the decision is and at what time the decision is being made. The Assisted Decision Making (Capacity) Act (2015) outlines the supports that will be made available when the Office of Decision Support Service is established and code of practice is developed and approved by the Director of Decision Support Service.⁸ It is important that health and social care professionals have an understanding of the supports that will be available to people with dementia and the roles and functions of the people acting to support those with dementia. Therefore the guidance offered is:

1. Become familiar with the various decision making supports

Information on the decision making supports which will come into effect when The Assisted Decision Making (Capacity) Act 2015 is commenced is outlined in the following subsections.

5.3.1 Decision making assistant:

This is a person that assists with making decisions. He/she may be a partner, family member, friend or another trusted person. The Assisted Decision Making (Capacity) Act (2015) allows a person to appoint one or more decision making assistants to assist with decisions being made in relation to personal welfare, which includes health, property and affairs. For example, the son of a person with dementia might know about their medical history and as a result they might seek his assistance when making decisions with regard to their healthcare. With regard to their finances the person with dementia might ask a trusted friend to assist with those decisions. It is important to remember that decision making authority remains with the person with dementia. The role of the decision making assistant is to:

- Obtain relevant information about the decision in question
- Explain that information along with the necessary considerations about the decision
- Ascertain the person with dementia's will and preferences in relation to the decision
- Assist the person with dementia to communicate their will and preferences
- Ensure that the person with dementia's decision is implemented

A decision making assistant **cannot** make a decision on a person's behalf (2). This role will be fully realised upon commencement of The Assisted Decision Making (Capacity) Act 2015.

⁸ Commencement of The Assisted Decision Making (Capacity) act 2015 is pending



5.3.2 Co-decision maker:

The role of a co-decision maker is to make decisions jointly with a person in relation to their personal welfare, which includes health, and/or property and financial affairs. He/she may be a partner, family member, friend or other trusted person. This person or persons will be appointed by the person with dementia. The role of a co-decision maker is to:

- Advise the person with dementia by obtaining, explaining and discussing relevant information and considerations relating to the decision
- Ascertain a person with dementia's will and preferences about the decision
- Assist the person with dementia with communicating their will and preferences
- Make a decision jointly with the person with dementia
- Make reasonable efforts to ensure that the decision is implemented as far as practicable

A co-decision maker is entitled to be reimbursed costs and expenses linked with their duties but is not entitled to remuneration (2). For example a co-decision maker may need to travel to the bank or hospital. This role will take effect upon commencement of The Assisted Decision Making (Capacity) Act 2015.

5.3.3 Decision making representative:

A decision making representative is a person (partner, family member, friend or other person) appointed by the court who is given authority by the court to make one or more than one decision on a person's behalf in relation to their personal welfare, which includes health, property and affairs or both. If a person with dementia has an advance healthcare directive or an enduring power of attorney prepared (see below for information on both), regard for these must be shown. The role of the decision making representative is to:

- Ascertain the person with dementia's will and preferences about the relevant decision
- Assist the person with dementia with communicating their wishes and preferences
- Make a relevant decision on the person's behalf
- Act as the person with dementia's agent in relation to the decision

A decision making representative is entitled to be reimbursed reasonable costs and expenses linked with their duties. This role will apply upon commencement of The Assisted Decision Making (Capacity) Act 2015.

5.3.4 Enduring power of attorney:

An enduring power of attorney is a document, drawn up with a person who has legal capacity, which gives another person(s) the power to make general and/or specific decisions. This comes into effect when a person lacks decision making capacity and their enduring power is registered with the Wards of Court Office⁹ (Adapted from (2,5). An enduring power of attorney can be changed at any time before it is registered (2). When The Assisted Decision Making (Capacity) Act 2015 is commenced, at the time a person is making an enduring power of attorney, the nominated attorney will be obliged to sign the document of the enduring power stating that he/she will undertake to carry out the obligations set out in the document when the enduring power comes into effect. An enduring power of attorney will only come into effect when a person lacks decision making capacity and the enduring power of attorney is registered. The person appointed as attorney by the person with dementia can claim out of pocket expenses incurred in carrying out their duties (2). It is important to acknowledge that there is a cost associated with putting an enduring power of attorney in place.

5.3.5 Designated healthcare representative:

A designated healthcare representative is a person appointed by another in an advance healthcare directive (if one has been prepared) to act on another's behalf in relation to healthcare treatment decisions (2). (See section 5.2 for information on advance healthcare directives). A person can make an advance healthcare directive setting out treatment choices without appointing a designated healthcare representative¹⁰. The role of designated healthcare representative will come into effect upon commencement of The Assisted Decision Making Capacity Act 2015.

⁹ When the Assisted Decision Making (Capacity) Act is commenced the enduring power of attorney will be registerable with the Office of Decision Support Services

¹⁰ Under the Assisted Decision Making (Capacity) Act 2015 an Office of Decision Support Services will be established. The Director of this office will be responsible for providing information in relation to the Assisted Decision Making (Capacity) Act (2015), as well as being responsible for maintaining registers of advance healthcare directives, enduring powers of attorney, decision-making representatives and co-decision makers.

5.3.6 Case Studies

The following case studies have been developed and outlined as a guide to illustrate the advance care planning process and the role of advance healthcare directives in practice. They are merely a guide. Each person should be cared for on an individual basis.



CASE STUDY 1 | Helen

Helen completed an advance healthcare directive five years ago stating that if she ever progressed to late stage dementia she would refuse all active treatments including transferring to hospital for intravenous antibiotics. The advance healthcare directive was reviewed regularly over the last five years. Helen nominated her daughter Patricia as her designated healthcare representative in her advance healthcare directive giving Patricia authority to represent her with regard to healthcare decisions. Helen has now progressed to late stage dementia and requires help with daily activities such as washing, dressing, eating and drinking.

Helen currently has a respiratory tract infection that has been treated unsuccessfully with oral antibiotics. After a period of capacity maximising and assessment where medications were reviewed, Patricia was consulted about what time of the day Helen is at her best (the morning time).

Various communication techniques were used (creating a quiet space, monitoring her behaviours and using Helen's life story book and a picture book to promote opportunities for communication), and issues persist with Helen's decision making capacity to indicate her preferences for treating the infection. There is confusion about sending her to hospital to receive intravenous antibiotics.

Does this process need to happen now?

Yes, a decision is required about Helen attending hospital for intravenous antibiotics.

Can Helen:

1. Understand information relative to the decision?
2. Retain the information long enough to make a voluntary choice?
3. Use or weigh the information as part of the process of making the decision?
4. Communicate her decision?

Continued Overleaf ►

CASE STUDY 1

During the process of decision making, capacity maximising with a picture board was used to communicate with Helen in the morning time when she was usually most interactive. It became clear that Helen understood the information but was unable to retain it long enough to make a voluntary choice or subsequently use or weigh it up to communicate a decision.

Consider all practicable supports:

Patricia, along with members of the healthcare team including a doctor, carer and nurse, used various techniques to communicate with Helen in the morning. The assessments consistently found that Helen's decision making capacity was still at issue as she remained unable to retain the information long enough to use or weigh it up to communicate a decision.

Seek evidence of previously expressed will and preferences:

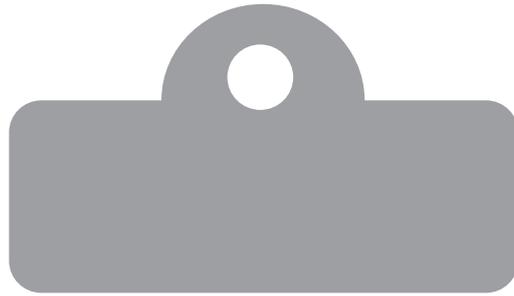
Helen has a legal advance healthcare directive that indicates that she does not wish to be transferred to hospital for intravenous antibiotics if she progresses to late stage dementia. Her advance healthcare directive is valid as she had decision making capacity at the time she made the advance healthcare directive, the advance healthcare directive was made voluntarily, it was not altered or revoked and Helen did not do anything inconsistent with the terms of the advance healthcare directive while she had capacity. Her advance healthcare directive indicates that Helen's daughter, Patricia, is her designated healthcare representative and is consulted.

Consider the least restrictive option to the person:

Helen is not responsive to oral antibiotics and moving her would likely heighten her symptoms of dementia. Providing supportive care in Helen's preferred place of care where she is familiar with people and surroundings would prioritise Helen's comfort and would be in keeping with her previously stated wishes. All decisions with regard to treatment and place of care are discussed with Patricia as her designated healthcare representative. Education and support are provided to care staff to help provide end-of-life care to Helen if her condition deteriorates. Referral is also made to the palliative care team to maximise comfort.

Consider the views of those indicated by Helen:

Helen's daughter and designated healthcare representative, Patricia, confirms Helen's advance healthcare directive and informs the healthcare team that Helen would not like to be transferred to hospital for intravenous antibiotics.



CASE STUDY 2 | Ted

Adapted from (87)

Ted is eighty-three years old. Nine years ago he was diagnosed with Alzheimer's disease and for the last four months he has been attending a day care centre for people with dementia. Initially, he came to the Centre twice a week, but now he spends five days out of seven there. He is well integrated and, according to his family, this has had positive effects on the situation at home. In the last few months, Ted has changed a lot and he is now at late stage of dementia. He is not able to express himself verbally and because of his growing memory loss he can no longer take any decisions on his own. He is therefore dependent on extensive help to complete daily activities such as eating, drinking and washing.

Ted has been living with his wife Mary for forty-five years and the rooms on the ground floor of their house have been converted. Ted's bedroom is now on the ground floor, so that Mary can take care of him. During the day she is helped by caregivers. Furthermore, their son and their daughter, Brian and Carol are present and help with administrative and financial matters. They also accompany their parents to doctors' appointments and give moral support. Besides dementia, Ted has also been living with heart failure for two years now. Two weeks ago they found a lung carcinoma and, according to his doctor, his life expectancy is six months. Undergoing chemotherapy would extend it up to two years. Together with her children, Mary decides that her husband should neither have chemotherapy nor any other life-lengthening treatments.

Ted's daughter Carol informs the staff of the day care centre about her father's state of health and the family's decision to refuse any life prolonging treatments. She also insists that should her father need help, in case of a heart attack for example, that no first aid measures should be taken and no emergency doctor should be called. The person responsible for the day care centre tells Carol that she would find it difficult to follow these instructions and to pass them on to the staff, particularly because there is no advance healthcare directive specifying Ted's wishes. The family explains that prior to his disease Ted made clear statements about not wanting any unnecessary or life prolonging treatments. Carol insists that the family's decision ought to be respected. She then leaves the meeting room.

The day care centre manager discusses the matter with staff members during the following meeting. Feeling insecure about how to react in case of emergency, they express their thoughts:

Continued Overleaf ►

CASE STUDY 2

“Should I just watch him die before my eyes?”

“I would definitely give him first aid and call an ambulance.”

“If it is Ted’s will not to be given first aid, shouldn’t his will be respected?”

“I will surely help him!”

“How am I supposed to do it right?”

“What does the centre’s policies tell us?”

Does this process need to happen now?

An advance care plan needs to be put in place for Ted, although his situation is stable and permanent it is likely to deteriorate due to his new diagnosis of malignancy.

Can Ted:

1. **Understand information relative to the decision?**
2. **Retain the information long enough to make a voluntary choice?**
3. **Use or weigh the information as part of the process of making the decision?**
4. **Communicate his decision?**

Ted appears to understand information but during conversations uses different words and appears to wander indicating that he cannot communicate a decision.

Consider all practicable supports:

Assistance with the use of picture boards and the involvement of a speech and language therapist finds that Ted can communicate a decision and he repeatedly indicates the same decision of not wanting unnecessary treatment. Discussions took part in the evenings as that is when Ted appeared to be at his best. The reassessment indicates that Ted can understand, retain and use information and communicate a decision with help.

Does Ted want to engage in the process of advance care planning?

Yes Ted has, on each occasion engaged in conversations willingly.

Engage in sensitive discussion:

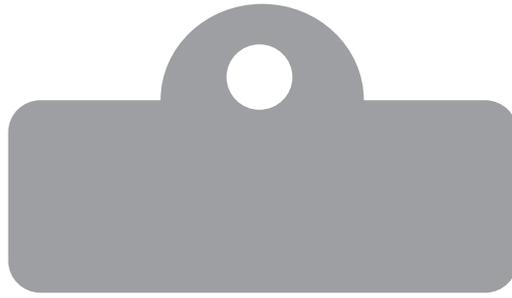
Conversation takes place with Ted where he is asked if he would like any other people involved in the conversation. In addition to this a family meeting was arranged to explore family and staff concerns. (See guidance document 1 “Facilitating discussions on future and end of life care with a person with dementia” (41) for guidance on conducting formal family meetings).

Record will and preferences:

Ted’s will and preferences of not wanting unnecessary treatment are recorded in his medical record so that the staff in the day centre are aware of how to proceed should he become unwell.

Plan review:

It is agreed that the plan will be reviewed in three months’ time.



CASE STUDY 3 | **Chen**

Adapted from (88)

Chen a 70 year old Chinese man who lives with his wife Ning was diagnosed with dementia 3 years ago, but is now failing rapidly. He is very weak and no longer eats due to increased difficulty swallowing and breathing. He does not complain of pain, but Ning says that his back hurts. His two sons live nearby.

Chen says the doctor must talk with his sons Lok and Jin first. After a telephone conversation with Chen's son Lok, hospice services are agreed to. However, Lok does not want his father to know he is dying and does not want the word "death" to be used when talking with Chen. Lok tells the doctor, "We do not tell our father that he is dying. Telling him is harmful, causing undue emotional burden for him. We are responsible for protecting him from harm." Chen does not take part in the conversation nor does he make his wishes known. Chen does not have an advance healthcare directive.

A week later, Chen is admitted to the hospital with aspiration pneumonia. He is barely conscious, febrile, and his breathing is slow and irregular. The family continues to encourage Chen to eat. Lok is considering aggressive treatment and the use of a feeding tube and antibiotics.

Does this process need to happen now?

Yes, it is unclear what the plan of care is and his condition is deteriorating rapidly

Can Chen:

1. **Understand information relative to the decision?**
2. **Retain the information long enough to make a voluntary choice?**
3. **Use or weigh the information as part of the process of making the decision?**
4. **Communicate his decision?**

As Chen is barely conscious he cannot perform these 4 tasks.

Consider all practicable support:

Alternative communication techniques are tried with Chen, who is still unable to communicate a decision.

Continued Overleaf ►

CASE STUDY 3

Seek evidence of previously expressed will and preferences:

Chen has indicated with a previous decision that he would like his sons Lok and Jin involved in the decision making process. However in relation to his current situation there is no record of previously expressed will and preferences.

Consider the least restrictive option:

Chen's condition has markedly deteriorated and there appears to be very little chance of reversibility. The least restrictive option would be to prioritise his comfort through the provision of palliative care. Sensitive discussion with his family members to explore concerns and agree a management plan is essential. He may not be well enough to be transferred home but this should be explored with his family members.

Consider the views of those indicated by Chen:

Chen has previously indicated that he would like his sons involved in the decision making process.

Engage in sensitive conversation:

It is worth arranging a formal family meeting (see guidance document 1 "Facilitating discussions on future and end of life care with a person with dementia" (40) for guidance on conducting formal family meetings) to hear and consider the views of Chen and his family, and give them the opportunity to voice their hopes and expectations. Exploring their understanding of his stage of dementia and the potential benefits or burden from feeding or antibiotics would be helpful as a starting point in helping them to acknowledge Chen's rapidly deteriorating condition and the likelihood of his death.

5.3.7 Resources

Listed below are resources that may be useful to health and social care staff when providing dementia and palliative care. Some of the Irish resources were developed before enactment of The Assisted Decision Making (Capacity) Act 2015 and should therefore be used with caution, with cognisance of other relevant legislation and with consideration for personal scope of practice.

Irish resources

1. Irish Hospice Foundation Perspectives Series 4: A perspective on advance planning for end of life An exploration of contemporary developments concerning the concept and practice of Advance Planning, Advance Care Planning and Advance Healthcare Directives (2016) (89).
2. Irish Hospice Foundation Dementia video clips outline Kathy Ryan's journey with dementia (2016) (90).
3. The Guide to Professional Conduct and Ethics for Registered Practitioners 8th Edition 2016 (3).
4. The Nursing and Midwifery Board of Ireland Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives (2014) (91).
5. National Standards for Residential Care Settings for Older People in Ireland (2016) (65).
6. Supporting people's autonomy: a guidance document (2016) (92).
7. All Ireland Institute of Hospice and Palliative Care Learning Platform has programmes for professionals on palliative care, formal family meetings, palliative dementia care and advance care planning among others (2016) (93).

International resources

8. Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia (BPSD) A Handbook for NSW Health Clinicians (94) (Australia).
9. Supporting me to make choices and decisions is a booklet designed for use within the intellectual disability sector that assists with helping a person in the decision making process (95).
10. Jenny's Diary is a resource for use within intellectual disability services and assists with having conversations about dementia (96).
11. Living well: Using person centred thinking tools with people who have a life limiting illness is a tool that supports having conversations (97).
12. Advance care planning toolkit is an online eLearning course developed by Macmillan Cancer Support in the UK. The course was designed for generalists caring for people with progressive illnesses and those reaching the end stage of their lives (98).
13. End of life care in extra care housing is a learning resource pack for housing, care and support staff based in the United Kingdom (99).
14. Consent what you have a right to expect is an information leaflet available from St Christopher's Hospice UK (100).

ADDITIONAL RESOURCES

6.1 Understanding the progression of dementia

It is important that health and social care staff have a good understanding of how dementia can affect a person as the condition progresses. This section aims to provide some general information on the typical progression of dementia. It is important to remember that each person with dementia is unique and their experience and journey through their condition will reflect that.

Typical Stages and Symptoms:

To understand dementia, it can be useful to consider the condition in four stages; early, moderate, late and final stage. There are typical traits and symptoms associated with each stage but equally these symptoms and stages can fluctuate and overlap. The chart below describes the changes that may present for the person with dementia in the different stages, and has been copied from a publication from the Alzheimer Association in Illinois, USA (101).

Changes in Memory, Thinking, Language and Mood			
Early Stage	Middle Stage	Late Stage	Final Stage
Memory and Thinking Skills			
<ul style="list-style-type: none"> • Difficulty with short-term memory • Loses things • Poor attention • Difficulty with calculations and organizational skills 	<ul style="list-style-type: none"> • Difficulty with short-term and long-term memory • Forget parts of ones history • Has trouble solving simple problems • Becomes disorientated easily 	<ul style="list-style-type: none"> • Mixes up recent and past events • Forgets friends and relatives • Cannot follow a two-step command 	<ul style="list-style-type: none"> • No apparent awareness of past or future
Language			
<ul style="list-style-type: none"> • Trouble finding words or names • Repeats statements or questions 	<ul style="list-style-type: none"> • Has trouble tracking conversations • Has difficulty forming complete sentences 	<ul style="list-style-type: none"> • Unable to carry on a meaningful conversation • Words and sentences often disconnected 	<ul style="list-style-type: none"> • Cannot speak or uses only a few words
Behaviour/Mood			
<ul style="list-style-type: none"> • May become distressed, withdrawn or irritable 	<ul style="list-style-type: none"> • More easily upset or withdrawn 	<ul style="list-style-type: none"> • May express urgent need by yelling/calling out • Difficult to engage 	<ul style="list-style-type: none"> • Severe decline in ability to show emotion
Changes in Ability to Care for Oneself			
Early Stage	Middle Stage	Late Stage	Final Stage
<ul style="list-style-type: none"> • Needs help with household affairs such as cooking and paying bills • Trouble managing money and medications • May get lost or confused when driving 	<ul style="list-style-type: none"> • Needs reminders or practical help with personal care • Slowed walking and reaction time • No longer safe to drive • Fatigues easily 	<ul style="list-style-type: none"> • Loss of control of bowel and bladder • Trouble with balance and coordination • Sleeps often 	<ul style="list-style-type: none"> • Needs total assistance with personal care • Unable to walk and shows little movement • Poor appetite and has swallowing problems • Sleeps most of the time

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 (102,103). The Functional Assessment Staging Test (FAST) is a validated measure of the course of dementia (104).

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 health and social care staff can provide on the probable life expectancy of the person:

- 4.5 years is the average survival time for a person living with dementia (103). However, some people can live for 20 years post diagnosis.
- Half of the people with late stage dementia will die within 1.3 years (102).



6.2 Factsheet to accompany this guidance document

FACT SHEET 2

Advance care planning and advance healthcare directives with a person with dementia



What is an advance care plan?

An advance care plan is written when a person with dementia and their doctor or nurse wish to record the outcome of the advance care planning discussion. Although an advance care plan often emphasises treatment decisions such as Cardio Pulmonary Resuscitation (CPR), antibiotics, and tube feeding; holistic care planning can also involve wider issues such as appointing an attorney under an enduring power of attorney, wills, environmental comforts, spiritual issues and anything else important to the person.

Plan for the probable, work for the possible, hope for the future.
(Ronan Smith, member of Irish dementia working group, Alzheimer Society of Ireland)

What is an advance healthcare directive?

An advance healthcare directive is an expression made by a person who has capacity (in writing, to include voice, video recording and speech recognition technologies) of their will and preferences concerning specific treatment decisions in the context of an anticipated deterioration in their condition with loss of decision making capacity to make these decisions, to give consent to or refuse treatment and communicate them to others. An advance healthcare directive is legally binding (therefore certain formalities must be followed) when a person writes down what treatments they would refuse in the future and the circumstances in which the refusal is intended to apply. The Assisted Decision Making (Capacity) Act 2015 provides that a request for a specific treatment is not legally binding but should be followed if relevant to the medical condition for which treatment is required.

How does an advance healthcare directive differ from an advance care plan?

An advance healthcare directive may indicate refusal of treatment - this is legally binding. An advance care plan is not. (Please see guidance document for more information on both).

Key points about advance care planning with a person with dementia:

1. Advance care planning is a process of discussion and recording. It may take place over more than one conversation
2. People with dementia can participate in the advance care planning process and development of an advance healthcare directive
3. People can choose to or not to take part in the advance care planning process
4. Decisions recorded should be reviewed

Guidance on advance care planning with a person with dementia:

1. Always presume decision making capacity
2. Help the person to maximise their decision making capacity
3. Remember that the person with dementia can choose to not take part in the advance care planning process
4. Be aware of how to assess a person's decision making capacity if required to do so
5. Gain knowledge on what steps to take if decision making capacity is an issue
6. Check existing advance care plans with the person regularly for validity and applicability

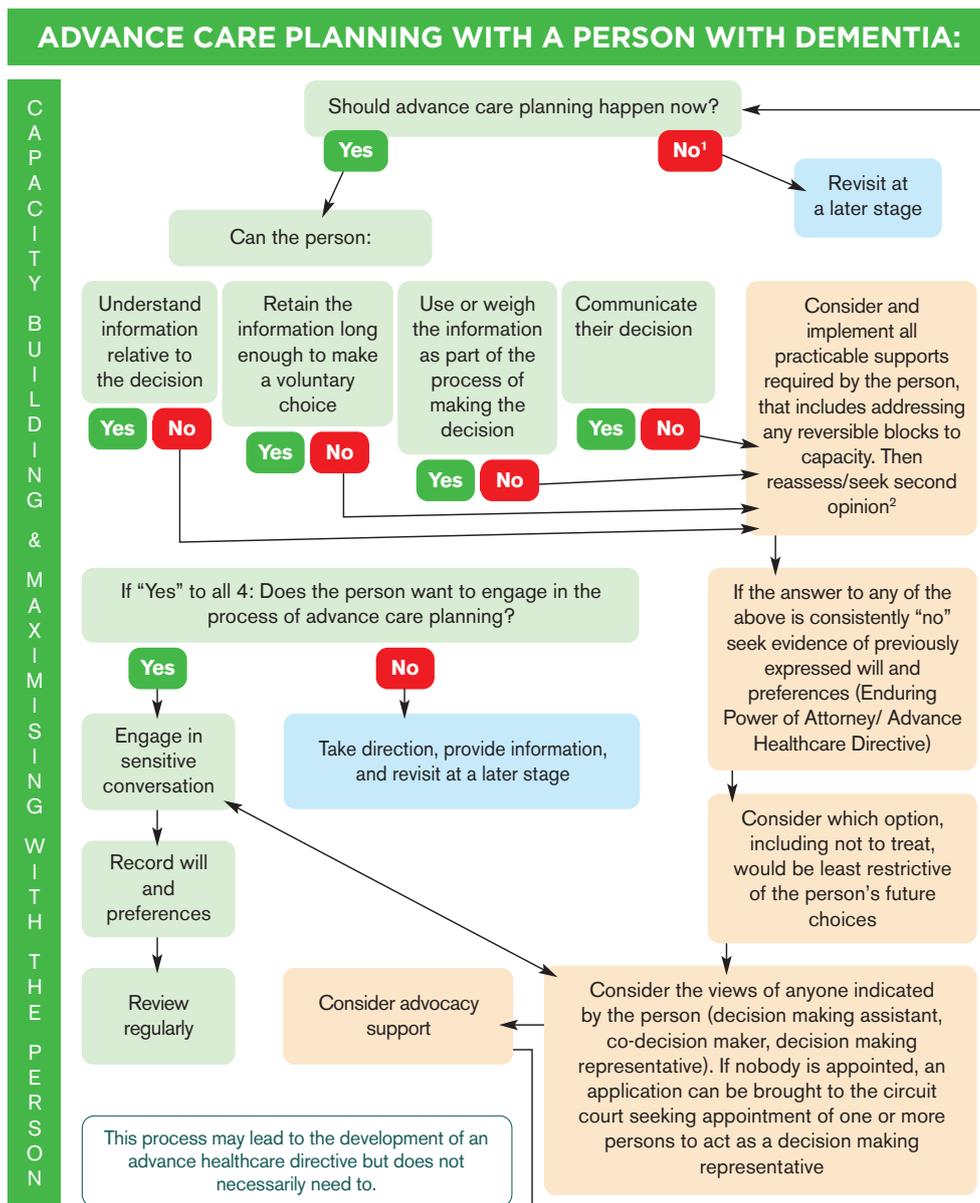
(see over for how to engage in advance care planning with a person with dementia)

Guidance on advance healthcare directives with a person with dementia:

1. Become familiar with what an advance healthcare directive can include
2. Become familiar with what makes an advance healthcare directive legal
3. Check existing advance healthcare directives regularly for validity and applicability

FACT SHEET 2

The following advance care planning algorithm has been prepared in an attempt to illustrate engaging in the advance care planning process with a person with dementia. It is based on the Assisted Decision Making (Capacity) Act 2015 and the HSE National Consent Policy (2014) (Ireland). It is merely a guide. Each person should be cared for on an individual basis with due regard taken for applicable legislation in that jurisdiction.



1. It may be inappropriate to engage in advance care planning if there is a temporary issue with a person's decision making capacity, for example an acute delirium

2. The person/persons that may be called upon to provide a second opinion have not yet been outlined. It is the responsibility of the Director of Decision Support Service to provide guidance and information with regard to this

This fact sheet is a visual aid to accompany IHF guidance document 2: Advance care planning and advance healthcare directives with a person with dementia. It is available to download on www.hospicefoundation.ie



6.3 Irish Hospice Foundation leaflet on advance care discussions

ADVANCE CARE DISCUSSIONS

This handout is based on the NATIONAL CONSENT POLICY (HSE, 2013) and on the Irish Hospice Foundation's End of Life Care Map: <http://hospicefoundation.ie/what-we-do/hospice-friendly-hospitals/resources-publications/>

LEGAL PERSPECTIVE ON ADVANCE CARE PLANS

The freedom to decide one's own destiny is the right of every competent person. this includes the right to accept or refuse medical treatments.

But, if we become critically ill, we may not be able to make these decisions. Many people are taking the opportunity to prepare advance care directives.

Although these directives are not yet underpinned by Irish legislation, the Law Reform Commission has recommended that ACPs should be followed as long as "the treatment is specified, all circumstances outlined are present and there is no evidence that author has changed his/her mind."

30% of Irish adults claim that they are comfortable discussing death.

67% believe that it is important to record their preferences for end-of-life care.

70% acknowledge the importance of discussing end-of-life care with those close to them.

... Yet, less than 1-in-10 have actually written down or recorded their preferences for care, treatment or their funeral wishes.

Source: Nationally Representative Survey of Irish people

WE ALL HAVE AN IDEA OF HOW WE WANT OUR END OF LIFE CARE TO BE... BUT DO WE ASK PEOPLE ABOUT THIS WHEN THEY ARE IN OUR CARE?

ADVANCE CARE PLANNING AND DISCUSSION

An advance care planning discussion with a person includes:

- The persons and/or family's concerns or worries about any aspect of end-of-life
- their values and personal goals for care at this time
- their understanding about their illness and prognosis
- Their preferences for types of care/treatment that may be beneficial in the future. True person-centered care means taking the time to find out what the person (patient) wants to know and what are their preferences are regarding their end of life care.

These discussions should, ideally, be happening even before the person is admitted to hospital but, all too often, they are not. So, hospital and nursing home staff often have an important role to play too, especially as broaching the subject may fall to them and it can be a really important part of person-centered care. The discussion is probably even more important in the following circumstances:

- ◆ When it is clear the patient has a life-limiting advanced progressive illness
- ◆ When you can answer 'yes' to the following question - *"would you be at all surprised if this patient was alive in 12 months' time?"*
- ◆ If the patient/family have expectations which are inconsistent with clinical judgment (for example, the person thinks that they will be able to live independently again)
- ◆ When there is a significant deterioration in the patient's condition
- ◆ When a treatment decision needs to be made
- ◆ If disease-specific treatment is not working
- ◆ At the time of referring the patient to specialist palliative care services.

ASK ME WHAT I WANT

It's really important to us that you are happy here. We want to get to know you and want you to feel comfortable talking to us about your wishes or any worries you might have...

Do you have any worries or wishes about your future care?

We always want to know that we're doing what you want in relation to your care... We want you to be able to tell us what matters to you.

Have you ever thought about what you might want if you became very unwell...?

Is there anything that you'd like to tell us about looking after you in the future?

Respecting patient preferences and choices

discussing our end-of-life wishes and preferences in good time

DNAR

(Do Not Attempt
(Cardio-Pulmonary)
Resuscitation)

A DNAR decision is often a significant aspect of advance care, where a person may decide that they do not want resuscitation attempted in the event of, for example, sudden cardiac arrest. This can be a difficult area and there is evidence of some inconsistency in approach to DNAR decisions. Please see the IHF Prompt for Practice leaflet on communicating with patients and families about CPR and DNAR decisions, or the very comprehensive guidance contained in the HSE's National Consent Policy (May 2013, Part 4).

THE DIGNITY QUESTION

A 2012 study by Canadian palliative experts shows that asking a terminally ill patient one simple question may help health professionals develop more empathy toward their patients.

Termed the "patient dignity question" (PDQ), the question is "What do I need to know about you as a person to give you the best care possible?"

RECOMMENDED PRACTICE & SAMPLE PHRASES

The following are some prompts to help you to have conversations with people to help to clarify and capture what they would like for themselves in terms of their future care. (See also the separate IHF Prompt for Practice leaflet on DEALING WITH BAD NEWS for more communication guidance.)

- Start the conversation by finding out from the patient what their level of understanding is of their current condition and prognosis – this helps to establish a common ground. If the patient doesn't seem to know, it may be worth summarising for him/her what has happened in the patient's illness to date and then beginning to talk about the current situation.
- Always give the patient the option **not** to discuss these topics or to defer the discussion to another time. **Sample Phrase:** *"I am very happy to talk to you about any concerns or questions you have about this now or later... Is there anything you would like to ask me about now?"*
- Do not make assumptions about the information needs of the patient or of his/her family. Clarify what the patient wants to know and the level of detail they'd like before giving new information. **Sample Phrase:** *"Often people with conditions like yours have a lot of questions that are sometimes frightening or sometimes they're not certain if they want to know the answer. So if there's anything you'd like to know, feel free to ask me and I'll answer as best I can."*
- Explore the patient's concerns, expectations and fears about the future. **Sample Phrase:** *"What is your biggest concern at the moment?"*
- Encourage the patient to ask questions and express their wishes. **Sample Phrases:** *"Is there anything else you'd like to discuss?" "Have you ever thought about where you would like to be cared for in the future?"*
- Offer to support the family (as long as the patient has given consent). **Sample Phrase:** *"Would you like me to tell...what we've discussed?"*
- Consider joint as well as separate discussions with the patient and family (once the patient has given consent) so as to explore and address different people's information needs.
- Once a terminal diagnosis is made, patients can often feel abandoned. It is important to reassure the patient that you/the team will be there for them throughout their illness. If this is not possible, it is vital that alternative arrangements are spelled out and are reliable. **Sample Phrases:** *"We will do what we can to manage your symptoms and link you in with the services that will support you and your family. You will not be alone in this."*
- Emphasise the available support, such as the palliative care team. **Sample Phrase:** *"We have different ways to relieve (pain/nausea/ breathlessness) and other symptoms."*
- It is important to enable the patient to feel control over their illness. Help the patient to identify where control can be fostered, e.g. tidying up unfinished business, arranging to attend a particular event. Encourage patients to share in decision making according to their desired level of involvement. **Sample Phrase:** *"People vary in how they want to make medical decisions. Some people want to make decisions themselves, some want to share decision making with the doctor. What would you like?"*



More help on this topic is available from the Irish Hospice Foundation's Think Ahead website which includes a Conversation Starter kit to help people to think and talk more easily with family and with carers about their end of life care wishes.

See web page <http://www.think-ahead.ie/wp-content/uploads/2013/01/TA-Starter-Kit-edits-3-OM-16.1.13.pdf>

6.4 Planning for the Future project, St Vincent’s Hospital, Athy, Co. Kildare

Planning for the Future Project St. Vincent’s Hospital, Athy, Co. Kildare.

‘Planning for the Future Project’ St. Vincent’s Hospital, Athy, Co. Kildare (64) commenced in 2010 and aimed to develop a framework to support staff with initiating discussions around end-of-life care issues with residents and families in Le Cheile (dementia specific unit). The project was funded by the Irish Hospice Foundation. The interim report on this project was published in Sept. 2013. One aspect of the project was the development of an end-of-life care form with accompanying guidance, which is available on the IHF website. See below for adapted content.

End-of-life care form (Adapted from St. Vincent’s, Athy)

Planning for End-of-life Care Form

Before completing this form, please refer to page 2.

It is really important to us that we care for you in the way that you want to be cared for. We want to make sure that any decisions about your end-of-life care and treatment both now and in the future are based on your values, wishes and preferences.

1) We want you to remain as well as possible for as long as possible but have you ever thought about what would be most important to you if you became seriously ill while you are in St Vincent’s?

If the doctor and staff felt that acute treatment in a general hospital would not be of benefit to you at that particular time, what would you prefer to do?

2) Remain in St Vincent’s hospital for treatment and symptom management
 Yes No

3) Transfer for more advanced acute medical treatment to Accident and Emergency department.
 Yes No

ALL DECISIONS ABOUT YOUR ONGOING MEDICAL CARE WILL BE MADE IN CONSULTATION WITH YOU AND YOUR DOCTOR, AND IN YOUR BEST INTEREST.

4) You might find discussing end of life care difficult, in which case could I ask you to think about your wishes and preferences around future end of life care and I will back to you again on
 Nurse’s Signature _____
 Date _____

5) Are there any documents we should be aware of in relation to your end of life care e.g. Enduring Power of Attorney (EPA)/Ward of court?
Ensure relevant information is documented and updated in residents medical notes

6) Can you tell me what you understand about your illness and this particular stage of it?

7) What do you think would be most important to you when you are nearing end of life? E.g; Have you ever thought of where you would like to be? Who would you like to have with you?

8) Would you like to talk about worries or fears that you may have about death and/or dying?

9) Any preferences/wishes for after death?

10) Wish to be Cremated: Yes No

11) Have you shared any of this information with your family, friend or any other person?
 Yes No
 With _____
 Relationship _____

12) Would you like to share this information with your other relatives or friends?
 Yes No

We will give you the opportunity every three months (or sooner if there is any change in your condition), to revisit these discussions. This will allow you to add to, or change any preferences and wishes already discussed.
 Information obtained from _____

 Relationship: _____
 Care Plan Commenced: Yes No Date _____
 Palliative care Plan: Yes No Date _____
 Nurse’s Signature _____ Date _____

Page 1 of 2

End-of-life care form continued (Adapted from St. Vincent's Athy)

Identifying what is most important to the person when they become unwell can be a very broad topic. The person might want to talk about and focus on what is meaningful to them in their daily life before they can specifically focus on what would be most important to them if they became seriously ill. People may want time to consider this question and revisit the conversation in order to allow the healthcare team develop a deeper understanding of what is most important to the person.

"How do you see things going from here?", "What are you hoping for?" "How do you see the future?" "Let me reassure you that we speak to all residents about their future care and this conversation has not been triggered by any bad news about your health" "you said you don't want to be a hero, what do you mean by that". "Could you explain what you meant you said you don't mind if you slip away and die alone"

Explore if they would prefer to remain at home or be transferred to hospital for more aggressive/ burdensome treatment. It is important that the person understands that their care needs will continue to be met and their comfort will be prioritised at all times, regardless of whether they wish to have active treatment or not. In discussing these questions, it can be helpful to ask the person if they ever cared for someone who was sick and what their feelings were about this experience. This may help the person identify what was 'good' or 'bad' about that situation and what they would want for themselves. The issue of capacity should be considered when discussing future care. This should be done by the team and guided by upcoming legislation (Assisted Decision Making (2013) Bill) and the HSE Consent Policy (2013).

"Even when we are not providing aggressive treatment, we will always take a very active approach to making sure you're very comfortable and that any pain or other symptoms are well managed."

When enquiring about what is most important to the person when nearing the end of their life, it can be helpful to think about their final days and hours, as they may wish for different things at different stages of the journey.

Environment "where would you like to be, and if home is not possible, how could we create a comfortable place. e.g. separate room, items from home, bedside altar, candles, music, smells, devotional pictures?"

People "Who would you like to be with you if you were at the end of life/dying. Are there other family and friends you would like to come when you could still tolerate short visit? Are there people you don't want around?"

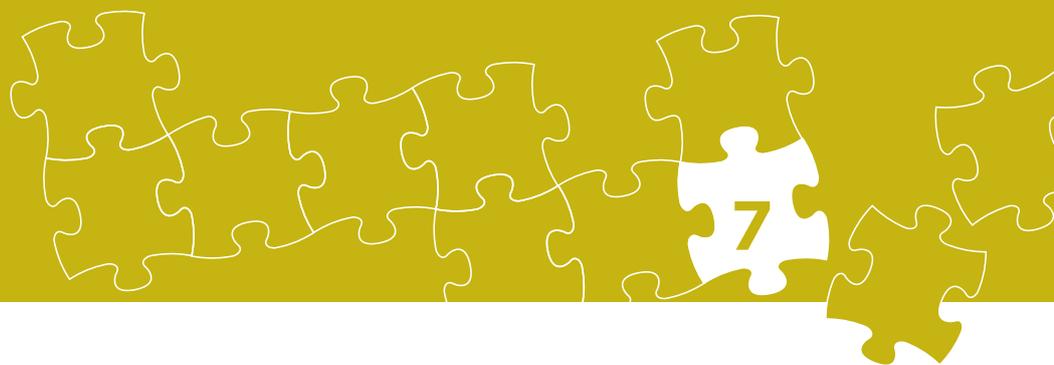
Actions "Are there any spiritual or religious practices that you would like to be carried out before or at the time of death i.e religious leader visits, spiritual rituals, meditation?"

Exploring the person's worries and fears about death provides an opportunity to discuss any concerns they may have about the person's last few days or final minutes. There may also be specific disagreements or regrets that they may wish to resolve to allow a sense of closure to their life (via. Letter, telephone or person).

"Is there anything you are concerned about when you think about dying...big or small worries?"

Asking someone about what their wishes are in relation to after their death can help the person feel in control right to the end of their journey. Some people may have very clear preferences about their burial and related rituals.

"What arrangements would you like to be made...appearance and clothes... location of removal...type of burial...type of spiritual service...readings, poems and songs?"



APPENDIX 1

Membership of the Project Advisory Group

Name:	Organisation:	Profession/Role:
Mary Manning	National Dementia Office, Services For Older People, Social Care Division, HSE	General Manager, Former Director NMPD Office of Nursing and Midwifery Directorate, HSE
Dr. Emer Begley	Alzheimer Society of Ireland	Policy and Research Manager
Anne Quinn	5 Steps to Living Well with Dementia Project, South Tipperary	Advanced Nurse Practitioner for Dementia
Caroline Clifford	Carlow/Kilkenny Psychiatry of Later Life Team	Clinical Nurse Specialist in Psychiatry of Later Life. Dementia Champion
Jacinta Kelly	North West Hospice, Sligo	Clinical Nurse Specialist in Palliative Care
Jean Barber	St. Michael's Hospital, Dublin	Clinical Nurse Specialist in Palliative Care
Carmel Hoey	National Clinical Programme for Older People (NCPOP) HSE	Nursing and Midwifery Practice Development Officer
Prof Willie Molloy	University College Cork	Geriatrician and Head of the Centre for Gerontology and Rehabilitation in UCC
Dr. Suzanne Timmons	University College Cork	Geriatrician and Senior Lecturer in the Centre for Gerontology and Rehabilitation in UCC
Cecelia Hayden	St. Vincent's Hospital, Athy	Clinical Nurse Specialist in Dementia Care
Aideen Lawlor	St. Mary's Hospital, Dublin	Speech and Language Therapy Manager
Lasarina Maguire	Stewart's Care, Palmerstown	Nurse Practice Development Coordinator
Marie Lynch	Irish Hospice Foundation	Head of Healthcare Programmes
Sarah Cronin	Irish Hospice Foundation	Dementia Development Officer
Deirdre Shanagher	Irish Hospice Foundation	Development Officer

Membership of the Expert Advisory Group for this guidance document:

Name:	Organisation:	Profession/Role:
Esther Beck	Ulster University	Nurse and PhD student
Patricia Rickard-Clarke		Solicitor and Former Commissioner of the Law Reform Commission
Dr. Emer Begley	Alzheimer Society of Ireland	Policy and Research Manager
Prof Willie Molloy	University College Cork	Geriatrician and Head of the Centre for Gerontology and Rehabilitation in UCC
Dr Sharon Beatty	University College Hospital, Galway	Palliative Care Consultant
Dr Geraldine McCarthy	Sligo/Leitrim Mental Health Services	Consultant in Psychiatry of old age
Sarah Murphy	Irish Hospice Foundation	Manager, Think Ahead
Dr. John Weafer	Irish Hospice Foundation	Policy and Research Advisor
Marie Lynch	Irish Hospice Foundation	Head of Healthcare Programmes
Deirdre Shanagher (Project lead)	Irish Hospice Foundation	Development Officer

Expert reviewers:

Kathy Ryan Member of the Irish Dementia Working Group (Alzheimer Society of Ireland).	Ronan Smith Member of the Irish Dementia Working Group (Alzheimer Society of Ireland).
Dr Karen Harrison Denning Head of Research and Evaluation Dementia UK Honorary Research Fellow, University of Liverpool Honorary Senior Lecturer, University of Nottingham	Olga Price CNS Palliative Care St Vincent's University Hospital Dublin
Dr Morgan Crowe Consultant Physician in Geriatric Medicine St Vincent's University Hospital Dublin	Dr Graham Hughes Consultant Physician in Geriatric Medicine St Vincent's University Hospital Dublin
Dr Suzanne Timmons Senior Lecturer, Centre for Gerontology and Rehabilitation, School of Medicine UCC @ St. Finbarr's Hospital Cork	Dr Joan McCarthy Lecturer, Healthcare Ethics Coordinator, MSc End-of-Life Healthcare Ethics School of Nursing and Midwifery Brookfield Health Sciences Complex University College Cork Cork

APPENDIX 2

Methodology:

Development of the guidance document:

This guidance document was developed using the following steps:

1. An expert advisory group was established. The role of the expert advisory group was to advise the project lead and ensure relevance, coherence and applicability throughout this document's development. (See appendix 1 for membership of the group. Note that this group is not representative in nature but made up of individuals with experience and expertise in the area of advance care planning and/or Irish legislation).
2. A narrative literature review was undertaken by the project lead (Deirdre Shanagher) using English language articles selected through a systematic search strategy (see below). This literature review was informed by four other literature reviews (see below). A hand search of international and national policy and best practice guidelines which was ongoing throughout the process in order to inform and populate the resources also occurred.
3. Although literature was not graded, consensus within the expert advisory group was achieved through a process of reflection based on literature review findings and on the experience of the group members in the field.
4. Key themes were collated by the expert advisory group to inform the key considerations and guidance.
5. Draft 1 of the guidance document prepared for comment by the expert advisory group.
6. Draft 2 of the guidance document prepared for comment by the expert advisory group and external reviewers Dr. Karen Harrison Denning and Olga Price, Kathy Ryan, Ronan Smith, Dr. Morgan Crowe, Dr. Graham Hughes, Dr Suzanne Timmons and Dr. Joan McCarthy.
7. Draft 3 of the guidance document prepared for external consultation (see Appendix 4 for list of submissions received).
8. Feedback from external consultation to develop final draft. A consultation report was prepared and is available on request.
9. Final version published

Literature Review: Four other literature reviews informed this document. They were carried out by Dr. John Weafer and Sarah Murphy; Carmel Collins, Niamh O'Sullivan and Joanna Leneillon and Deirdre Shanagher. These literature reviews relate to advance care planning, advance care planning, communication and dementia, the palliative care needs of people with intellectual disabilities and dementia and the palliative care needs of people with young onset dementia. Members of the Expert Advisory Group (Appendix 1) also provided additional literature to inform this review.

Search strategy for literature review:

Databases: CINAHL & PubMed

Search terms:	Number of Articles Generated
Advance Care Planning	
Advance Healthcare Planning	
Advance Planning	5557
Advance Directives	10908
Advance Healthcare Directives	
Advance Planning OR Advance Care Planning	10928
Advance Planning OR Advance Care Planning Or Advance Healthcare Planning	10928
Advance Directives OR Advance Healthcare Directives	10911
Advance Planning OR Advance Care Planning Or Advance Healthcare Planning AND Advance Directives OR Advance Healthcare Directives	7107
Dementia	187761
Alzheimer's Disease	8113
Alzheimer's Disease OR Dementia	194729
End of life care	69187
Palliative care	77774
End of life care OR palliative care	128759
End of life care OR palliative care AND Alzheimer's Disease OR Dementia	159259
End of life care OR palliative care AND Alzheimer's Disease OR Dementia AND Advance Planning OR Advance Care Planning Or Advance Healthcare Planning AND Advance Directives OR Advance Healthcare Directives	65

INCLUSION CRITERIA:

- English language
- Published in the last 15 years
- Related to adult population
- Books and book chapters
- Thought pieces and reflections

EXCLUSION CRITERIA:

- Language other than English
- Populations under 18 years of age
- Animal/lab based studies
- Papers more than 15 years old

Articles were screened for relevance and 288 articles were deemed appropriate. These were cross referenced with the existing literature reviews (see above). No further articles were retrieved at this point. Post review with Expert Advisory Group the scope of the guidance document was extended to reach the person with dementia and family carers as well as health and social care staff across all settings. Subsequently the literature search was extended to include these groups and to ensure rigorous development. The literature retrieved was re-evaluated and a further 11 articles relating to people with dementia and family carers were added to relevant literature.

Themes: Articles were reviewed in detail and analysed for common themes by Deirdre Shanagher (IHF) with oversight from the expert advisory group.

The themes that emerged from the literature are as follows:

- Advance Care Planning & Advance Healthcare Directives with People with Dementia
- Supported Decision Making
- Professional Uncertainty
- Advance Care Planning Tools

Collation of Themes/Consensus Building: These key themes were presented to the expert advisory group who considered them in relation to their practice and experience. Based on the literature review, the expert advisory group agreed that guidance was required for people with dementia, their family members and health and social care staff. Post public consultation the scope of the document was narrowed to health and social care staff.

Hand searches of additional information: In order to enrich and further inform the guidance document, direction from the expert advisory group was taken to access other relevant literature in addition to carrying out further searches of; bibliographies, key Irish and international reports and hand searching healthcare policies and best practice guidelines.

Limitations: The approach used to develop this guidance document was based on methods outlined in the National Clinical Effectiveness Committee (NCEC) Standards for Clinical Practice Guidance (106). Literature was examined for relevance. However, it was not explicitly graded due to the nature of the subject matter being discussed. Therefore, it was difficult to explicitly link recommendations or guidance to the supporting evidence at all times, as recommended in NCEC Standards for Clinical Practice Guidance (106). Evidence on effectiveness and cost effectiveness was not explored due to time and resource constraints. When the 7 guidance documents are completed, the plan for their implementation will commence. This will include involvement of key stakeholders, realistic timelines and integration of key guidance areas from each document into clinical practice.

APPENDIX 3

Legislative context

1. The Constitution of Ireland outlines the fundamental rights of people to include that of bodily integrity and the right of a person to decide for themselves (48).
2. The Hague Convention on the international protection of adults (2000) outlines the need to provide for the protection in international situations of adults who, by reason of an impairment or insufficiency of their personal faculties, are not in a position to protect their interest (107).
3. The Universal Declaration on Bioethics and Human Rights (2005) addresses the right of a person to consent to and to refuse medical treatment. Article III of this declaration sets out the requirement for professionalism, honesty, integrity and transparency in the decision making process subsequently upholding human dignity, human rights and fundamental freedoms (108).
4. The United Nations Convention on the Rights of Persons with Disabilities (2006) was signed by countries, to include Ireland, and called for states to facilitate people with disabilities to exercise their right to make choices and express preferences in relation to their care on a similar basis equal to those who do not have any disability (46). With the enactment of the Assisted Decision-Making (Capacity) Act 2015, Ireland proposes to ratify the Convention.
5. In December 2009 the Council of Europe issued a recommendation on principles concerning continuing powers of attorney and advance directives for incapacity to Member States to promote self-determination for adults in the event of their future incapacity (47). The Council of Europe also issued recommendations on the promotion of Human Rights of Older People that seeks to promote, protect and ensure the full and equal enjoyment of human rights and fundamental freedoms of all older people and to promote respect for their inherent dignity (54). This recommendation outlines that older people are entitled to lead their lives independently, in a self-determined and autonomous manner (54). This encompasses making independent decisions with regard to issues that concern them, including those regarding their health, medical treatment or care (54).

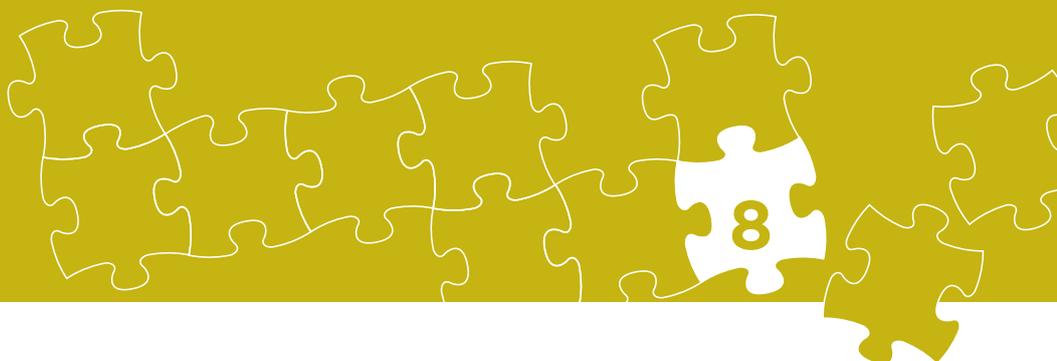
Although the Council of Europe recommendations are incorporated into Irish law by virtue of the European Convention on Human Rights Act 2003, for the purposes of legal certainty as to their status, there was a need for a legislative framework. Subsequently the Assisted Decision Making (Capacity) Act was enacted in December 2015 and includes a legislative scheme for Advance Healthcare Directives.

APPENDIX 4

List of submissions received during consultation process

Organisation:
National Clinical Programme for Older People (NCPOP), HSE
The Progressive Supranuclear Palsy Association (PSPA)
The Nursing and Midwifery Planning and Development Unit West/ Mid-west, HSE
Mayo University Hospital
The Irish Nurses and Midwives Association (INMO) Care of the Older Person Section
Northern Ireland Hospice
SAGE support and Advocacy Service for Older People
Letterkenny University Hospital
Co. Donegal Public Health Nursing and Specialist Palliative Care Nursing Services.
The National Clinical Effectiveness Unit, CMO, Dept. of Health.
St Michaels House
Carew House
Care Alliance Ireland
Association of Occupational Therapists of Ireland (AOTI)
Irish Association for Palliative Care (IAPC)
Dungarvan Community Hospital
St Patricks Hospital, Cashel
District Hospital Gorey

In addition to these submissions, individuals with dementia from the Irish Dementia Working Group and family carers with whom we work were consulted with as to what was practical for them to commit to with regard to being involved in the development of this document. A preference for seeing a designed document was stated by both groups rather than attending meetings from the outset. Two people with dementia who are members of the Irish Dementia Working Group provided feedback prior to public consultation (Appendix 1) and two family carers gave feedback at the public consultation phase of development.



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Striving for the
best care at end
of life for all

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ISBN 978-0-9931534-3-3

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