Policy Document

For Now and For The Future

An Advance Care Planning Policy For Adults In Northern Ireland

Department of Health
An Roinn Sláinte
Männystrie O Poustie

Contents

Introduction **5**

Ambition **6**

What is Advance Care Planning? **7**

Components of Advance Care Planning **8**

Advance Care Planning and Mental Capacity **9**

Values and Principles of Advance Care Planning **9**

- Values: 9
- Principles of Practice: 10

Why is it important to have Advance Care Planning conversations? **11**

When should Advance Care Planning happen? **12**

Having Meaningful Advance Care Planning Conversations **14**

- The 'Six Ts' of Good Communication in Advance Care Planning Conversations 14

Recording and Sharing Advance Care Planning Conversations, Recommendations and Decisions **16**

Reviewing Advance Care Planning Conversations, Recommendations and Decisions **16**

How Advance Care Planning Conversations Are Used **17**

Personal Component of Advance Care Planning **19**

- "What Matters To Me" - Wishes, Feelings, Beliefs and Values 20
- Spirituality 20
- Care and Support for Dependents 21
- Funeral Wishes 21
- Online Accounts 21

Legal Component of Advance Care Planning **23**

- Advance Care Planning and Mental Capacity 24
  - Principles of Mental Capacity Act (NI) 2016 25
  - Mental Capacity Act (NI) 2016 26
  - Aspects To Consider Regarding Mental Capacity 27
- Types of Power of Attorney 28
  - Power of Attorney 28
  - Enduring Power of Attorney 28
  - Lasting Power of Attorney 28
  - Advance Decisions to Refuse Treatment (ADRT) 30

Contents

Clinical Component of Advance Care Planning **33**

Declining Health and Unexpected Emergencies 34

Best Interests Decisions 35

Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) 36

What is ReSPECT? 36

What is recorded on a ReSPECT form? 37

Who is ReSPECT for? 37

Clinical Recommendations for Cardiopulmonary Resuscitation (CPR) 38

Organ Donation 39

Body Donation to Medical Science 39

Financial Component of Advance Care Planning **41**

Making a Will 42

Why it's important to make a will 42

Preparing a will 43

Updating a will 43

Cohabitation 44

Planning for Retirement 44

Planning for Care 45

Conclusion **46**

Appendices **48**

Appendix 1 Glossary of Terms 48

Abbreviations 49

Appendix 2 Mental Capacity Act (Northern Ireland) 2016 50

Appendix 3 Bibliography 51

Introduction

Advance Care Planning is an umbrella term covering personal, legal, clinical, and financial planning. It enables a person to think about what is important to them and plan for their future. It is a voluntary process and helps a person to make known what their wishes, feelings, beliefs and values are, and to make choices that reflect these. Advance Care Planning is an on-going process of conversations between a person, those important to them[1] and those providing care, support or treatment. Advance Care Planning should be an important part of life for all adults.

This Advance Care Planning policy has been written for members of the public, those important to them and those providing care, support or treatment[2].

This Advance Care Planning policy has been developed to support a person to have greater choice and control over decisions for their future. This is very important if the person becomes unable to make the relevant decisions for themselves at any point.

Advance Care Planning provides the opportunity for adults who wish to do so to:

- Think about what matters to them;
- Then tell people who are important to them;
- Discuss it with those who provide care, support or treatment;
- Write it down and share it;
- Revisit the conversations and decisions, make any changes, and then share again.

Advance Care Planning is important for all adults, at whatever stage of life. "The reality that one day each of us will die, is something few of us consider and fewer still plan for or discuss.[3]" Although Advance Care Planning has traditionally been associated with end of life care, it is more far reaching than this. As well as supporting decisions in declining health and unexpected emergencies, Advance Care Planning also provides opportunities to reflect and consider what is important to the person, which can enhance their quality of life now and in the future. It may also provide comfort and reassurance to those important to the person.

This policy provides a framework for Advance Care Planning for adults (aged 18 years and over) in Northern Ireland, including the health and social care aspects. The policy provides an overview of Advance Care Planning, and the values and principles that underpin it. It sets out why Advance Care Planning is important and how it can help people make timely, realistic and practical plans for their future.

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[1] *Those important to the person: This may be family, carers or someone who knows, cares and has affection for the person. They may be connected through their personal, legal, cultural or emotional relationship.*

[2] *Those who provide care, support or treatment. This term is used throughout the policy and includes people working within the community and voluntary sector, independent sector and other health and social care staff working in statutory services.*

[3] *McKenna, D., O'Shea, J. and Tanner, L., (2020). The Heart of Living and Dying: Upstreaming Advance Care Planning into Community Conversations in the Public Domain in Northern Ireland*

It encourages these plans to be made in conversation with those who are important to the person and/or those providing care, support or treatment.

For those important to the person, Advance Care Planning can provide a clearer understanding of the person's wishes, feelings, beliefs and values, including any relevant preferences and decisions the person may have made.

The policy sets out an Advance Care Planning approach that is based on four components. These are personal, legal, clinical and financial. In terms of the clinical component, the policy outlines that although a person or those important to them cannot insist that any specific treatments be provided, understanding what matters to a person informs the recommendations and/or decisions made by those providing care, support or treatment.

For people providing care, support or treatment to someone, the policy provides clarity and support for their role in having these important conversations as part of the holistic care or services they provide. If the person becomes unable to make the relevant decisions for themselves, then these decisions have to be made based on what is in the person's best interests. In determining what is in the person's best interests, special regard should be given to the person's wishes, feelings, beliefs and values. Decisions must not be made on the basis of assumptions based solely on factors such as the person's age, disability[4], or on a professional's subjective view of a person's quality of life.[5]

Even when a person's ability to make a specific decision is impaired, all practicable steps should still be taken to support them to make other decisions and to be as involved in the decision-making process as possible.

The policy provides an ethical and rights-based approach[6] to Advance Care Planning for adults, in line with legislation, best practice and professional guidance and standards. The policy is supported by operational frameworks, training and education and public information to ensure a consistent approach to Advance Care Planning that is inclusive and accessible.

Ambition

The ambition of this policy and how it is put into practice is that:

- Advance Care Planning becomes normalised;
- All adults in Northern Ireland (NI) have regular opportunities to express their wishes, feelings, beliefs and values in relation to Advance Care Planning; and that
- These are reflected in the care, support or treatment they receive.

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[4] *Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Russ L. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Bristol: Norah Fry Research Centre; 2013.*

[5] *'Decisions relating to cardiopulmonary resuscitation Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (previously known as the 'Joint Statement') 3rd edition (1st revision) 2016'*

[6] *Ethical and Human Rights based approach references for example United Nations Convention on the Rights of People with Disabilities Articles 9, 12, 16, 17 & 25*
Ethical Advice & Support Framework Health-ni.gov.uk

What is Advance Care Planning?

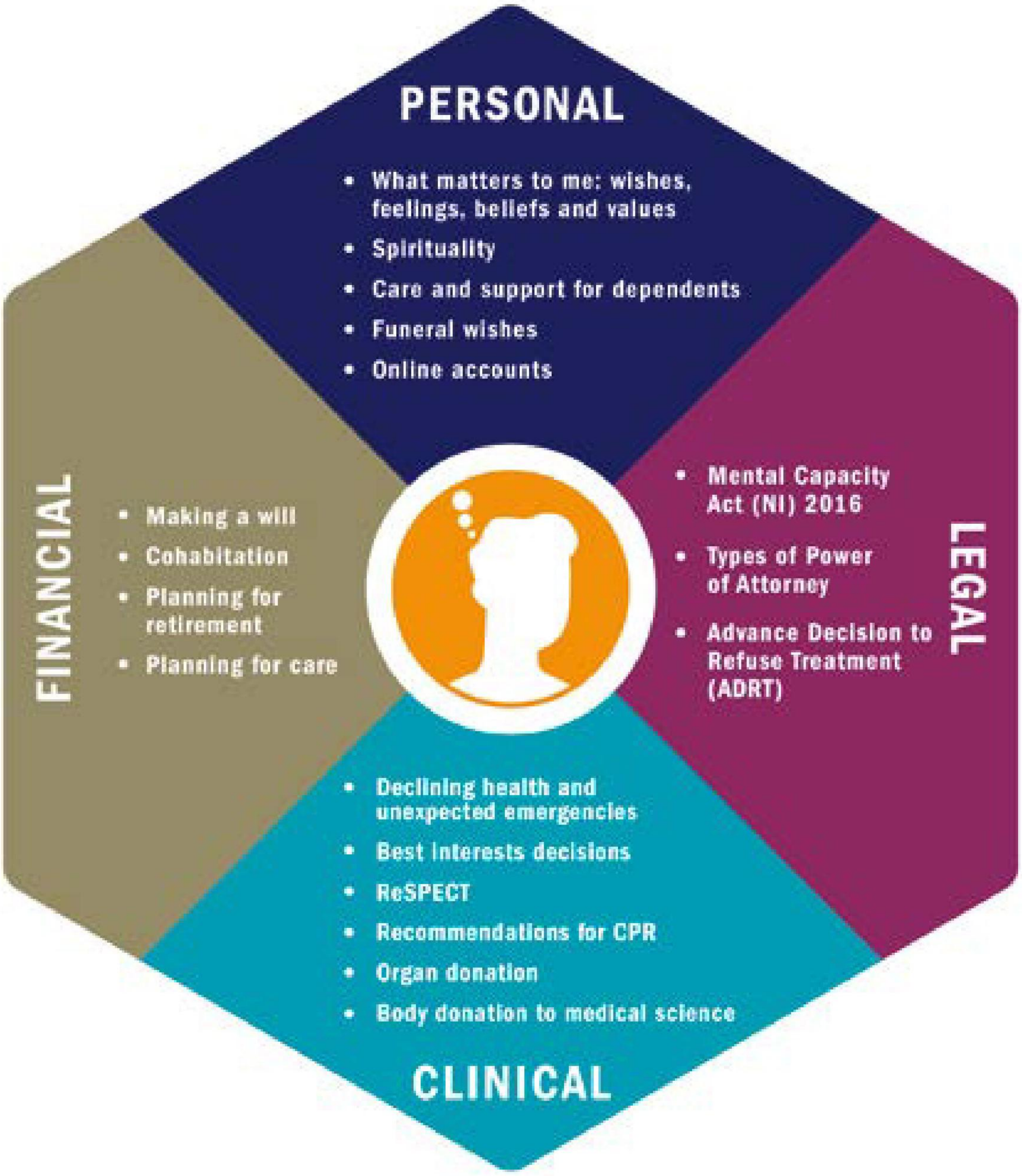
Advance Care Planning is an umbrella term covering personal, legal, clinical, and financial planning. It enables a person to think about what is important to them and plan for their future. It is a voluntary process and helps a person to make known what their wishes, feelings, beliefs and values are, and to make choices that reflect these. Advance Care Planning is an on-going process of conversations between a person, those important to them and those providing care, support or treatment.

Advance Care Planning should be an important part of life for all adults. It needs to be encouraged by those providing care, support or treatment, to ensure that people have the opportunity to have timely, realistic and practical conversations. Some adults may require support for Advance Care Planning. These conversations focus on what matters to the person and what would be important for them to prioritise in the future should they become unable to make decisions for themselves. If the person wants to make a record of these conversations and share them they should be supported to do so.

Components of Advance Care Planning

There are four components of Advance Care Planning. They are Personal, Legal, Clinical and Financial. Each component contains a number of elements. Some elements may fit into more than one component.

A person's Advance Care Planning can start with any component and/or element – whichever is most relevant to them at that particular time of their life. It is important to note that some elements are legally binding, others are not but will inform recommendations and decisions including about a person's future care and treatment.



Advance Care Planning and Mental Capacity

Advance Care Planning includes references to a person having mental capacity so it is important to understand what this means. The Mental Capacity Act (Northern Ireland) 2016 is an Act which makes provision relating to persons who lack capacity.

The first principle of the Mental Capacity Act (NI) 2016 is a person is not to be treated as lacking capacity unless it is established that the person lacks capacity in relation to the matter in question[7]. Mental capacity is both decision and time specific. People may be able to make some decisions at one time but not another. Even if the person lacks the mental capacity for a specific decision at that time, their wishes, feelings, beliefs and values are central and the person still needs to be supported to be involved as much as possible. More detail is provided on page 24.

Values and Principles of Advance Care Planning

Values:

Advance Care Planning:

- Respects and upholds the rights, dignity and culture of the person and is inclusive of all adults;
- Provides an ethical approach to discussing these important and sensitive issues;[8]
- Is accessible to the person in a way that enables them to have meaningful conversations;
- Is a person's individual choice. Some people may not want to think about or engage in Advance Care Planning conversations - their choice should be respected, with the opportunity given to revisit the conversation at another time;
- Is a personal experience. Each person's wishes, feelings, beliefs and values will be individual to the person and their own circumstances;
- Is a voluntary process. Pressure must not be put on the person having the Advance Care Planning conversation by anyone; those providing care, support or treatment, the family or those important to the person, or by any organisation[9].

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[7] *Mental Capacity Act (NI) 2016*

[8] *Ethical Advice & Support Framework Health-ni.gov.uk*

[9] *For further information on safeguarding adults to make informed choices free from duress, pressure or undue influence please refer to Adult Safeguarding Prevention and Protection in Partnership*

Principles of Practice:

- Advance Care Planning needs to be meaningful, conducted with sensitivity and compassion. It requires time and should happen at the person's pace and with the support they need;
- Consent is more than a form or formality. Consent needs to be addressed at each stage of the Advance Care Planning process i.e. having the conversation, sharing the information with others, making a record, sharing the record;[10]
- Where there is a record of Advance Care Planning conversations, this should be accessible across all settings to ensure a person's wishes, feelings, beliefs and values, and any recommendations and/or decisions made, are known;
- A person's confidentiality should be respected;
- Advance Care Planning conversations, any recommendations and/or decisions need to be revisited, reviewed and if needed re-shared to ensure they remain up to date, as a person may change their mind about some things;
- Advance Care Planning incorporates the principles of the Mental Capacity Act (NI) 2016.

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[10] *There is a distinction between consent under UK GDPR and clinical consent*

Why is it important to have Advance Care Planning conversations?

When a person's wishes, feelings, beliefs and values are known, it can help to promote their autonomy and rights, and reduce any potential distress for the person and for those important to them. It also helps guide and inform those providing care, support or treatment.

Numerous research studies (Appendix 3), including 'family or caregivers'[11] experience of Advance Care Planning, indicate that meaningful Advance Care Planning conversations are beneficial for a number of reasons:

Benefits of Advance Care Planning	
An Enhanced Quality of Life	When a person has the opportunity to reflect on and talk about "what matters to them" it can help them make choices now that are in keeping with their wishes, feelings, beliefs and values.
Peace of Mind	When a person has the opportunity to talk about any hopes or fears they may have, it can help them feel more content.
Clarifying Decisions	When a person has the information they need to make decisions, and/or has the opportunity to say what matters to them, then those important to the person can know what the person wants or doesn't want. This can reduce the potential for confusion or conflict.
Easing Caregiver Concerns	When those important to the person are clear about what matters to the person, they can feel more confident in making known what the person would want if they became unable to communicate or make decisions for themselves.

Local research studies in Northern Ireland also reinforce the need for a greater awareness and understanding of Advance Care Planning and for more open, timely and meaningful conversations on this (Appendix 3).

Advance Care Planning is relevant for all adults. Ideally, it is a series of conversations, which evolve over time. If the person wants, those important to them should also be involved or be made aware of the conversations.

Advance Care Planning is an important part of providing care, support or treatment, by ensuring people have the opportunity to have realistic and practical conversations about what matters to them, and to consider and record their wishes, feelings, beliefs and values, if they choose to do so.

Anyone providing care, support or treatment and who regularly interacts with people has a role to play. They should understand the values and principles of Advance Care Planning and the operational processes which enable the appropriate conversations to take place and if the person consents, to have them recorded and shared. Education and training will be provided to those providing care, support or treatment.

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[11] *"Family or caregivers" is the phrase used within research studies. This policy uses the term "those important to the person"*

When should Advance Care Planning happen?

Advance Care Planning is important for every adult at any stage of life and is relevant to people who are in good health as well as for those who are very unwell. Ideally, Advance Care Planning should happen long before any crisis or serious illness, such as a mental health crisis or the diagnosis of a serious physical illness.

By beginning the conversation early on in their life, the person may feel more emotionally able for it, and can take their time to think and talk about what matters to them. This can involve several stages which may range from not knowing anything about Advance Care Planning, to knowing but not wanting to have the conversation, through to feeling able to think about their personal wishes, feelings, beliefs and values and then having Advance Care Planning conversations.

Everyone will approach this differently, and what one person needs may differ from the next person. People's own experience of how they change their behaviour can be different. It may take time as behaviour change is an ongoing process. The diagram below shows how a person's behaviour can move from not knowing about, to doing Advance Care Planning.

Not Knowing	Knowing	Thinking	Understanding	Doing	Reviewing
I have never heard about Advance Care Planning.	I have heard about Advance Care Planning but I am not doing anything about it.	I think Advance Care Planning is a good idea for me.	I want to find more information about this & who might support me. + I have enough information and I understand what I need to do.	I am having Advance Care Planning conversations and I may choose to write them down.	I will review my Advance Care Plan and keep it up to date.

It can take time for some people to feel ready to have these conversations and/or make a record of them. This is normal, and there can be many reasons for this; for example, some people can be afraid to express their wishes or may believe that if they do, people important to them might become upset. People may also be reluctant to consider a time when they may become unable to make the necessary decisions about their care.

It is important to increase awareness and understanding of Advance Care Planning to normalise it. Some life events that may be helpful prompts for Advance Care Planning may include when a person;

- Starts work;
- Gets married;
- Moves into their first home;
- Starts a family;
- Experiences a bereavement;
- Is planning for retirement;
- Faces a change in health.

It is important therefore to emphasise the benefits and support people to move from thinking about having an Advance Care Planning conversation to actually having one.

For those people with serious or progressive conditions, or approaching the end of their life, if Advance Care Planning hasn't already happened, it should offered as soon as possible, and when the person is medically stable. This may be prompted when:

- A person indicates they are ready to have these conversations;
- It is part of a holistic assessment between the person and those providing care, support or treatment;
- The person has had time to adjust following a diagnosis of a progressive condition and feels ready to have these conversations;
- A person has had a significant deterioration in physical health or a number of unplanned hospital admissions;
- A person may have experienced a mental health crisis during which their ability to make some decisions was impaired;
- The person's cognitive state is likely to deteriorate;
- The person's ability to communicate is likely to deteriorate.

People may express their wishes, feelings, beliefs and values over a period of time, to those important to them or to those providing care, support or treatment. Advance Care Planning conversations can take place in any setting but should, where possible, be done when and where the person feels most comfortable. Wherever the conversation takes place, every effort should be made to ensure it is suitable to having meaningful Advance Care Planning conversations[12].

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[12] *Such as having adequate time, using a quiet place that allows for confidentiality and lessens possibility of inappropriate interruptions or distractions; provision of appropriate and accessible material, appropriate people involved, and specific communication preferences or needs the person may have.*

Having Meaningful Advance Care Planning Conversations

When people are ready to have Advance Care Planning conversations, those providing care, support or treatment have an important role. It is vital that they have the knowledge, confidence and communication skills needed to support this.

The importance of good, effective communication has been consistently highlighted across research studies as well as through reported personal experiences (Appendix 3). This reinforces the need to improve capabilities[13] including knowledge, skills and understanding of Advance Care Planning and in particular, communication skills[14].

The 'Six Ts' of Good Communication in Advance Care Planning Conversations

The diagram and table below offer a guide on how to communicate during Advance Care Planning conversations whether the conversation is being prompted by the person or by those providing care and support or treatment. It should be remembered that there are two sides to these conversations: the person who is thinking about and wants to have an Advance Care Planning conversation and the person who is listening to and/or facilitating the conversation. This may be someone important to the person and/or someone who is providing care, support or treatment. For everyone involved, keeping the following in mind supports meaningful Advance Care Planning conversations.

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[13] *Refer to Advance Care Planning Capabilities Framework.*

[14] *If levels of health literacy are under-developed, this can lead to a communication gap between the person and those providing care support or treatment when having Advance Care Planning conversations.[Towards an action plan for health literacy in Northern Ireland: A Patient and Client Council scoping paper January 2021. Further information on Health Literacy - PCC Health Literacy Scoping Paper FINAL Jan 21 v2 - Patient and Client Council Northern Ireland (hscni.net)]*

Trust	Trust is central to these conversations. A person who is thinking about Advance Care Planning, will want to have a conversation with someone who respects their values and opinions, and is seen as reliable and dependable – someone they trust. The person who is listening to and/or facilitating these conversations should respect the wishes, feelings, beliefs and values of the person as they plan for their care, and they should support the person throughout the conversation.
Timing	Should be when the person feels ready to begin the Advance Care Planning conversation and be for as long as the person wishes to continue the conversation(s). When the person providing care, support or treatment wants to begin the Advance Care Planning conversation, they should check if this is a good time for the person to have the conversation.
Task	If some of the person's wishes, feelings, beliefs and values are already known; build on this. It's important to be clear on what it is you want to say. Check that the other person has heard and understands what it was you wanted to say.
Tone	How we say something is as important as the words we use. These are important conversations and can be emotional. Therefore, be gentle, sensitive and compassionate when having an Advance Care Planning conversation.
Tailored	Use clear, accessible language, without jargon and make sure that if a person needs help to communicate, e.g. Interpreter, sign language or a device that helps them to communicate, that this is available.
Tuned In	To how the person might be feeling about and during the conversation. To the other person's pace. To the other person's understanding.

Recording and Sharing Advance Care Planning Conversations, Recommendations and Decisions

A person should be encouraged to record[15] their wishes, feelings, beliefs and values as part of their Advance Care Planning. This record may be shared if they consent to do so. For example, within the clinical component this record could include recommendations recorded on the ReSPECT form.[16]

Reviewing Advance Care Planning Conversations, Recommendations and Decisions

Advance Care Planning is not 'set in stone'. It can be revisited and reviewed at any time to ensure that any wishes, recommendations and/or decisions made are still relevant to the person's circumstances. Reviewing Advance Care Planning conversations, any recommendations and/or decisions, is an integral part of the Advance Care Planning process and any review should be done in line with the values and principles that underpin Advance Care Planning.

A review may be initiated by the person themselves or by someone providing care, support or treatment. The timing or frequency of any review will vary for each person. Reviewing Advance Care Planning conversations, any recommendations and/or decisions, is especially important if there are any changes in the person's circumstances or in their health condition. It is important that any changes to Advance Care Planning conversations, any recommendations and/or decisions are communicated and re-shared with those important to the person and/or those providing care, support or treatment as the person consents.

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[15] *The Amber Book will be available as a standardised way for people to record their Advance Care Planning.*

[16] *See section "Recommended Summary Plan for Emergency Care & Treatment (ReSPECT)" page 36.*

How Advance Care Planning Conversations Are Used

A person's Advance Care Planning conversations, any recommendations and/or decisions will be used in the future should a person be unable to make a specific decision for themselves. This may be because they do not have mental capacity or are unable to communicate what their wishes are. At this time, no one in Northern Ireland has the legal authority to consent to any care or treatment on behalf of another adult. In situations where a person lacks the mental capacity to make a specific decision about their treatment at that time, and does not have a valid and applicable Advance Decision to Refuse Treatment, the clinician who is treating the person will make a 'best interests' decision(s). In such circumstances, previous Advance Care Planning conversations, any recommendations and/or decisions will be used to guide and inform the 'best interests'[17] decision(s).

Advance Care Planning can also help a person consider what is important to them in a situation where, whilst they have mental capacity, they may need to consider their care, support or treatment.

These key components are considered in the following sections.

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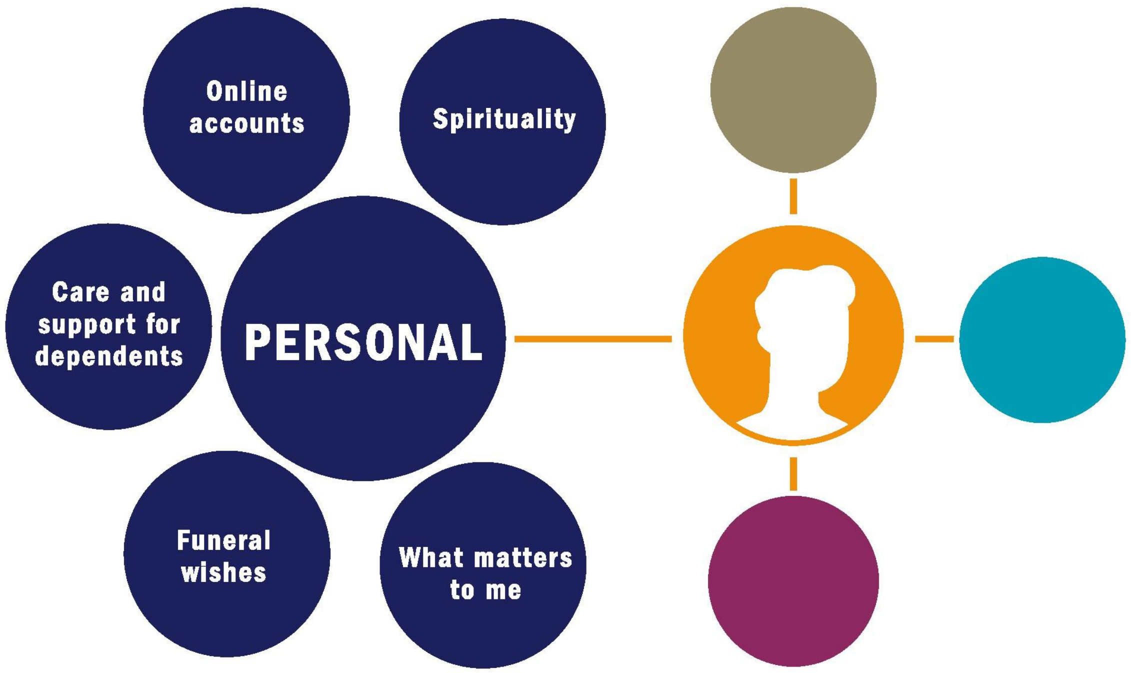
[17] See "Best Interests" section page 35.

Personal Advance Care Planning



Personal Component of Advance Care Planning

"What Matters To Me" - Wishes, Feelings, Beliefs and Values

This part of Advance Care Planning is about those very personal things that give meaning and purpose to a person's life. It can include people, places, spirituality or other things that matter to the person.

A person can tell others about what matters to them, or write it down. These can be specific wishes about what is important to them now and what is important to them if they became unable to make the relevant decisions about their lives.

Wishes, feelings, beliefs and values will differ according to each person. For example, for some, managing pain is an absolute priority, while for others, tolerating some pain in order to be with people important to them, is their priority.

It is important for anyone involved in the person's care, to know what matters to them, whether or not it is written down. Knowing what matters to the person helps to guide and inform those providing care, support or treatment to make decisions when the person is unable to make the relevant decisions and/or communicate what their wishes are.

Spirituality

Advance Care Planning conversations focus on what is important to a person and may include the person speaking about the spiritual aspect of their lives. Spirituality is about what gives meaning and purpose to life and it is based on a person's core beliefs and values. Spirituality can be expressed in many different ways. For some people, they may express their spirituality through their faith and within a formal religion. For others, it may be expressed through music, arts, or nature. Spirituality informs and guides a person in how they behave and in how they relate to others and it can provide comfort, support and strength through a person's life. Spirituality can become even more important to a person as they grow older or if they are faced with very serious illness.

Care and Support for Dependents

For some, a key priority for their Advance Care Planning will be to have the reassurance that care and support will be in place for their dependents. For many carers for example, having conversations about and making arrangements for the future care and support of those they care for will be an important part of their own Advance Care Planning and may even be a prompt for this.

It is important to recognise the peace of mind that such conversations and plans can bring. This is not only for those with dependents. For some people, Advance Care Planning will include making arrangements for the care of their pets if they were unable to look after them themselves.

Funeral Wishes

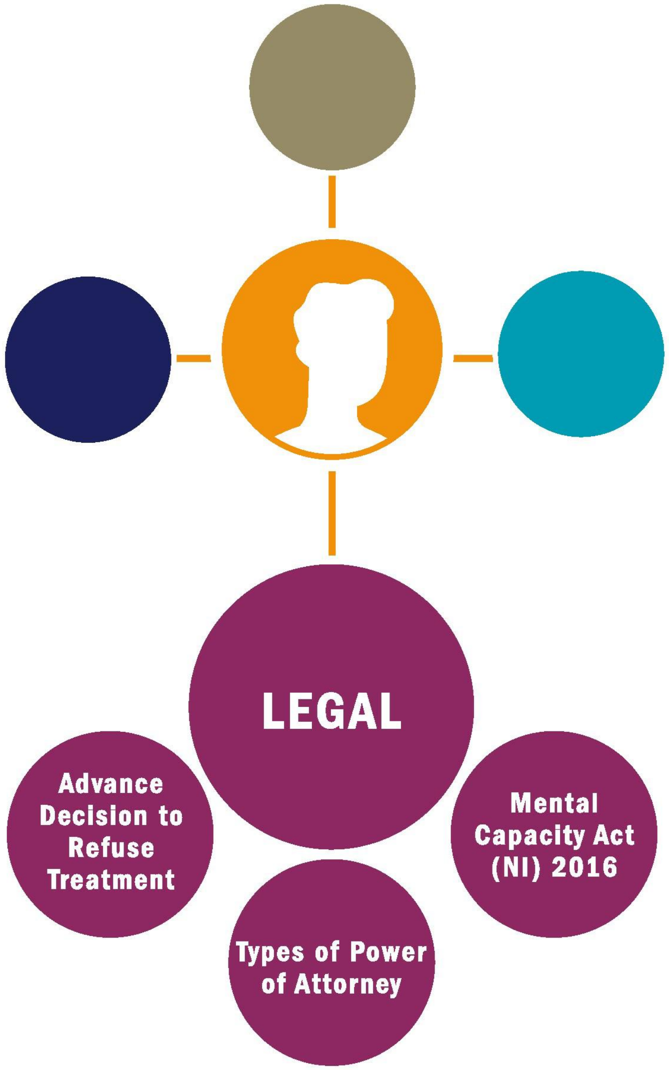
For some, thinking about their own funeral or having conversations about it with those important to them can be emotional. Having these conversations however can ensure that the person's wishes and preferences are known and reflected. This can also help reduce any concerns that those important to the person may have, as they are involved in the conversations and know what type of funeral the person would want.

Online Accounts

It is important for a person to consider and plan for what will happen to any online accounts they have if they lose capacity or after they die. This is sometimes known as a digital legacy. This can be made up of banking, email and social media accounts, and include photos, videos, any websites owned and/or any blogs a person may have written and published.

People may decide to share their personal wishes regarding their digital legacy and plan in advance to ensure those important to them have relevant information to manage the person's digital legacy e.g. delete or keep open email or social media accounts.

Legal Advance Care Planning



LEGAL

Advance Decision to Refuse Treatment

Mental Capacity Act (NI) 2016

Types of Power of Attorney

Legal Component of Advance Care Planning

Advance Care Planning and Mental Capacity

Advance Care Planning includes references to a person having mental capacity so it is important to understand what this means. The first principle of the Mental Capacity Act (NI) 2016 is a person is not to be treated as lacking capacity unless it is established that the person lacks capacity in relation to the matter in question.[18] A person may be able to make some decisions at one time but not another. Mental capacity is both decision and time specific. This means:

- A person should have the relevant mental capacity for a specific decision at that time;
- A person may lack the mental capacity for some specific decisions at that time but retain the mental capacity for many others;
- Even if a person lacks the relevant mental capacity for a specific decision at that time, their wishes, feelings, beliefs and values are central and the person still needs to be supported to be involved as much as possible.

Advance Care Planning conversations, any recommendations and/or decisions will be used when the person cannot make decisions for themselves. This may be because even with support, they lack the mental capacity to make the specific decision at that time.

In order to have the capacity to make the specific decision, a person must be able to: understand; retain; appreciate, use and weigh the relevant information; and communicate their decision. When a person lacks capacity for a specific decision, prior Advance Care Planning conversations, any recommendations and/or decisions can help guide those providing care, support or treatment so that, as far as is possible, this is provided in line with the person's wishes, feelings, beliefs and values for their future care.

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[18] *Mental Capacity Act (Northern Ireland) 2016 (legislation.gov.uk)*

Principles of Mental Capacity Act (NI) 2016

There are a number of very important principles in the Mental Capacity Act (NI) 2016 which safeguard the individual and help prevent it being wrongly assumed a person has lack of mental capacity. Section 1 of the Mental Capacity Act (NI) 2016[19] sets out the principles which relate to "capacity" (see Appendix 2). The principles of that section are paraphrased below;

Principle 1 – The first principle of the Mental Capacity Act (NI) 2016 is a person is not to be treated as lacking capacity unless it is established that the person lacks capacity in relation to the matter in question.

Principle 2 – The question if a person is able to make a decision for himself or herself can only be determined by considering the requirements of the Act and no assumptions can be made merely on the basis of any condition that the person has or any other characteristics of the person.

Principle 3 – A person is not to be treated as unable to make a decision for himself or herself unless all practicable help and support to enable the person to make the decision has been given without success.

Principle 4 – A person is not to be treated as unable to make a decision merely because the person makes an unwise decision.

Principle 5 – Any act done, or decision made, must be made in the person's best interests.

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[19] Mental Capacity Act (NI) 2016

Mental Capacity Act (NI) 2016

The Mental Capacity Act (NI) 2016 is an Act of the Northern Ireland Assembly. The Act received Royal Assent on the 9th May 2016.[20]

Section 3 of the Mental Capacity Act (NI) 2016 assigns the following meaning to the term “lack of capacity”;

Part 1 Section 3 of the Mental Capacity Act (NI) 2016

“1. For the purposes of this Act, a person who is 16 or over lacks capacity in relation to a matter if, at the material time, the person is unable to make a decision for himself or herself about the matter (within the meaning given by section 4) because of an impairment of, or a disturbance in the functioning of, the mind or brain.
2. It does not matter;
   a. whether the impairment or disturbance is permanent or temporary;
   b. what the cause of the impairment or disturbance is.
3. In particular, it does not matter whether the impairment or disturbance is caused by a disorder or disability or otherwise than by a disorder or disability.”

The Act specifies that a ‘lack of capacity’ is about a person not being able to make a decision for themselves in relation to a specific matter.

It also recognises that mental capacity can fluctuate and can be temporary or permanent.

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[20] *The Mental Capacity Act (NI) 2016 refers to anyone over the age of 16 but the scope of this policy is for those aged 18 and over.*

Aspects To Consider Regarding Mental Capacity

These are important aspects to consider regarding mental capacity.

Why is a person unable to make the decision?	Section 4 of the Mental Capacity (NI) Act 2016 defines the meaning of being "unable to make a decision". The provisions of that section are paraphrased below; **A person is not able to make a decision if they are not able to:** • understand the information they need which would help them to make a decision. • retain that information for the time needed to make the decision. • appreciate the relevance of that information for use to weigh up the pros and cons as part of the process of making the decision. • communicate their decision (whether by talking, using sign language or by any other means).
Supporting a person to make a decision	Section 5 of the Mental Capacity (NI) Act 2016 sets out the steps to be taken in "supporting a person to make a decision". The provisions of that section are paraphrased below; A person must be given all practicable help and support to enable them to make a decision. **The steps required are:** • provide the person with all the relevant information in a way which best suits them and their needs. (e.g. written, spoken, using sign language, etc.). • ensure that the conversation with the person is at a time or times which suit the person best (e.g. some people feel more able or alert early in the morning). • ensure the setting (environment) to have the conversation suits the person best (e.g. not noisy, no interruptions nor with too many distractions). • ensure that those important to the person or those who may support their communication are involved.
Establishing if someone lacks capacity	**To establish if a person lacks capacity to make a decision on a specific matter, those assessing the person must:** • ensure compliance with the principles in the Mental Capacity Act (NI) 2016 • reasonably believe that the person lacks capacity to make that specific decision. • have provided the relevant information in a way that is accessible to the person. • have provided the support the person needs to enable them to make the decision.
Who can determine if someone lacks Mental Capacity?	Determining capacity is a core function of any health and social care worker, and it is expected that all health and social care professionals should be able to carry out routine mental capacity assessments. For serious interventions and treatment decisions, a person completing a statement of incapacity must be suitably qualified, as detailed within the Mental Capacity Act (NI) 2016.[21] Only "suitably qualified" persons are permitted to carry out a "formal capacity assessment" Regulations made under section 14(4) of the Mental Capacity (NI) Act 2016 prescribe the description of persons who are "suitably qualified" to carry out the aforementioned "formal capacity assessments"

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[21] *"Determining a lack of capacity is a core function of the Mental Capacity Act (Northern Ireland) 2016 (section 14(4)) (legislation.gov.uk)-. Currently, a statement of incapacity can only be carried out by a medical practitioner, nurse, midwife, social worker, dentist, occupational therapist, speech and language therapist or a practitioner psychologist who has received specific training in the 36 months prior to making a statement; and has 2 years' experience in the last 10, in working with people who lack capacity. Further detail about current arrangements may be found at Part 2 of The Mental Capacity (Deprivation of Liberty) (No. 2) Regulations (Northern Ireland) 2019 (legislation.gov.uk)*

Types of Power of Attorney

There are three different types of 'Power of Attorney' and each are described here. It is important to note though, that only the first two are currently in place in Northern Ireland. It is advisable to seek legal advice, as careful consideration should be given to the range of powers a person wishes to give an attorney[22].

Power of Attorney

Power of Attorney is a legal document which the person can use to give someone else the authority to take actions or make decisions on their behalf. It enables the person, while they still have mental capacity, to have someone else (called an attorney) to deal with their property and finance. For example, if they aren't physically able to carry out tasks for themselves, such as visiting the bank.

A Power of Attorney ceases when the person loses mental capacity for managing their own affairs.

Enduring Power of Attorney

An Enduring Power of Attorney (EPA) is a legal document which allows a person to appoint others to make decisions on their behalf about their property and financial affairs.

Having an EPA allows a person to plan ahead in case they lose the mental capacity to make their own decisions about their finances or property[23].

Lasting Power of Attorney

Part 5 of the Mental Capacity Act (NI) 2016 makes provision in respect of Lasting Power of Attorney (LPA). This Part of the Act has not yet been commenced, therefore, the provisions of Part 5 of the Act which relate to Lasting Power of Attorney are not yet in force in Northern Ireland.

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[22] *Managing your affairs and enduring power of attorney*
NI Courts & Tribunal Service: Enduring Power Of Attorney – An explanatory note

[23] *Making an Enduring Power of Attorney*

An LPA is a legal document, which allows a person to appoint others to make decisions on their behalf. It can be made for property and financial affairs, and can also be made for health and social care decisions, including decisions around treatment and end of life care. Section 97 defines Lasting Power of Attorney as follows:

Part 5 of the Mental Capacity Act (NI) 2016: Section 97

97.

1. A lasting power of attorney is a power of attorney by which the donor confers on the attorney (or attorneys) authority to make decisions about (or about specified matters concerning) all or any of the following;
    a. the donor's care, treatment and personal welfare;
    b. the donor's property and affairs;

and which includes authority to make such decisions in circumstances where the donor no longer has capacity.

2. A lasting power of attorney is created only if;
    a. an instrument conferring authority of the kind mentioned in subsection (1) is made and registered in accordance with Schedule 4;
    b. at the time when the donor executes the instrument, the donor is 16 or over and has capacity to execute it; and;
    c. section 101 (requirements as respects attorneys) is complied with.
3. An instrument which;
    a. purports to create a lasting power of attorney, but;
    b. does not comply with this section, section 101 or Schedule 4,confers no authority.

An LPA is made when the person has capacity and gives the attorney full decision making power to come into effect only at the time when the person lacks mental capacity. A decision by an LPA attorney is the same as that of the person themselves if they had mental capacity.

An LPA will be a very powerful tool in Advance Care Planning when the relevant provisions of the Mental Capacity Act (NI) 2016 are brought into force. It will ensure that a person can choose who will make decisions on their behalf should they ever lack mental capacity.

At this time[24] no one can consent to treatment on behalf of another adult in Northern Ireland. In situations where a person has not the mental capacity to make a specific decision for themselves, a 'best interests' decision is made.[25]

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[24] *The Mental Capacity Act (NI) 2016 introduces the role of a Lasting Power of Attorney (LPA) to Northern Ireland. The Mental Capacity Act (NI) 2016 has come into effect here in phases of implementation. LPA was not included in Phase 1. Implementation is ongoing, but there is currently no timeline for the start of that phase which will include LPA coming into use.*

[25] *See 'Best Interests' section page 35.*

Advance Decisions to Refuse Treatment (ADRT)

An ADRT is a set of instructions from a person to those providing clinical treatment. It sets out specific circumstances in which the person would not want certain treatments or would want a particular treatment to be stopped.

An ADRT cannot be used to refuse any basic care a person might need to keep them comfortable. This includes warmth, shelter, food and fluids by mouth.

An ADRT cannot be used to:

- ask for specific medical treatment;
- request something that is illegal, e.g. assisted suicide;
- nominate someone else to make decisions;
- refuse treatment for a mental health condition if the treatment is in accordance with the Mental Health (NI) Order 1986.[26]

In Northern Ireland, an ADRT is legally binding if it is valid and applicable to the particular situation. This means those providing care, support or treatment must follow an ADRT provided that they know about it.

An ADRT is recorded while a person is able to make their own decisions and communicate these. It will only be followed when a person loses the mental capacity to make specific decisions or is unable to communicate what their wishes are.

Those providing care, support or treatment should follow the Advance Care Planning Regional Operational Frameworks.[27]

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26 *When the Mental Capacity Act (Northern Ireland) 2016 is fully commenced it will replace the Mental Health (NI) Order 1986, for everyone aged 16 and over, and will include mental health treatment. The Mental Capacity Act NI 2016 will provide a statutory foundation for an ADRT. It will note that if there is a valid and applicable ADRT, this cannot be overruled by a decision under the Act.*

27 *Advance Care Planning Regional Operational Frameworks have been developed to support this policy.*

Clinical Advance Care Planning

Clinical Component of Advance Care Planning

Declining Health and Unexpected Emergencies

This clinical component of Advance Care Planning recognises that across the course of a person's life, their health can begin a gradual decline over a period of time. At other times, a person's health can be suddenly affected by an unexpected emergency situation, such as an accident, a heart attack or a mental health crisis. It is really important therefore, for everyone to think about and plan for the fact that such situations can happen.

Advance Care Planning can include conversations, recommendations and/or decisions regarding a person's wishes for future care in the event of declining health and/or unexpected emergencies. These conversations help to provide a shared understanding[28] of what matters to the person and inform the clinical recommendations and/or decisions about what is realistic in terms of their future care and treatment.

Although a person or those important to them cannot insist that any specific treatments be provided[29], understanding what matters to a person informs the recommendations and/or decisions made by those providing care, support or treatment.

When making such clinical recommendations and/or decisions, these must not be based on the clinical decision-maker's view of the person's quality of life, but an objective assessment of that which is acceptable to the person. This must take account of all relevant factors, particularly the person's wishes, feelings, beliefs and values.

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[28] National Institute for Health & Care Excellence: Decision-making and mental Capacity

[29] General Medical Council- Treatment and Care towards the end of life: Good practice in decision making

Best Interests Decisions

When a person lacks the mental capacity to make a specific decision about their treatment at that time, and does not have a valid and applicable ADRT, the clinician who is treating the person will make a 'best interests' decision(s). Advance Care Planning ensures that a person can make their wishes, feelings, beliefs and values known and, in doing so, this will help guide and inform those making 'best interests' decision(s).

At this time, no one[30] has the legal authority to consent to treatment on behalf of another adult, but those important to the person should be included in these 'best interests' discussions regarding what the person may have wanted. Even when the person lacks the relevant mental capacity for a specific decision at that time, their wishes, feelings, beliefs and values are central. The person must be placed at the heart of the decision-making process and supported to be involved in the decision-making process as far as possible.[31]

The clinician who is treating the person should base their best interests decision(s)[32] on the principles provided for under section 7 of the Mental Capacity Act (NI) 2016 and on their experience and understanding of the person's circumstances and be informed by the person's prior Advance Care Planning conversations. Decisions must not be made on the basis of assumptions based solely on factors such as the person's age, disability[33], or on a professional's subjective view of a person's quality of life[34].

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[30] *The Mental Capacity Act (NI) 2016 introduces the role of a Lasting Power of Attorney (LPA) to Northern Ireland. The Mental Capacity Act (NI) 2016 has come into effect here in phases of implementation. LPA was not included in Phase 1. Implementation is ongoing, but there is currently no timeline for the start of that phase which will include LPA coming into use*

[31] *Quality statement 4: Best interests decision making | Decision making and mental capacity | Quality standards | NICE*

[32] *When fully implemented Section 7 of the Mental Capacity Act (NI) 2016*

[33] *Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Russ L. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Bristol: Norah Fry Research Centre; 2013*

[34] *Decisions relating to cardiopulmonary resuscitation 2016*

Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

Ideally, Advance Care Planning should happen long before any decline in a person's health or any crisis or emergency. There may however be instances where Advance Care Planning conversations have not taken place and those providing care, support or treatment will have to introduce these conversations in circumstances such as a sudden decline in health or an unexpected emergency. No matter when these conversations happen, they should include talking about and recording what matters to a person.

Where appropriate, conversations and clinical recommendations about what is realistic and appropriate treatment and care for the person should be recorded on a ReSPECT form.[35]

What is ReSPECT?

ReSPECT stands for "Recommended Summary Plan for Emergency Care and Treatment." The ReSPECT process includes recommendations and/or decisions about specific interventions that may or may not be wanted or be clinically appropriate.

The ReSPECT process and form provides information and recommendations for those providing care, support or treatment at a time when the person is unable to communicate what their wishes are or does not have mental capacity to make that specific decision, such as in a future unexpected emergency. These recommendations can also help a person consider what is important to them in a situation where, whilst they have mental capacity, they may need to consider their care, support or treatment.

The ReSPECT form should be signed by the clinician providing clinical recommendations but is kept by the person[36].

The ReSPECT form is not a legally binding document.

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[35] *Advance Care Planning Regional Operational Frameworks.*

[36] *Advance Care Planning Regional Operational Frameworks.*

What is recorded on a ReSPECT form?

The ReSPECT form includes:

- What matters to the person regarding their care and treatment e.g. wishes, feelings, beliefs and values;
- Existing care planning documents;
- Clinical recommendations for emergency care and treatment e.g. resuscitation recommendations;
- Recording mental capacity for the person's involvement in the recommendations made.

As with any other aspect of Advance Care Planning, information recorded on a ReSPECT form should be kept under review and updated as appropriate.

The ReSPECT form is the regional form for recording all recommendations about emergency care and treatment.

The ReSPECT form is transferable across all care settings. As the ReSPECT form includes cardiopulmonary resuscitation recommendations, do not attempt cardiopulmonary resuscitation (DNACPR) forms will no longer be used.[37]

Who is ReSPECT for?

The ReSPECT process is appropriate for any adult aged 18 years or over, however it may have more relevance for those;

- With particular health needs that may involve a sudden physical or mental deterioration in a person's health;
- With a life limiting condition, such as advanced organ failure or cancer;
- At risk of sudden acute health events;
- At foreseeable risk of death or sudden cardiorespiratory arrest;
- Whose beliefs mean they would not want to have a particular intervention and/or treatment;
- Who want to make known that they have an ADRT.

Those providing care, support or treatment should follow the Advance Care Planning Regional Operational Frameworks that have been developed to support this policy.

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[37] *Arrangements to be detailed in an HSS (MD) CIRCULAR*

Clinical Recommendations for Cardiopulmonary Resuscitation (CPR)

Advance Care Planning can involve conversations, recommendations and/or decisions about cardiopulmonary resuscitation (CPR). This is important, as an unexpected emergency situation may include a cardiac arrest. A cardiac arrest is when the heart has stopped pumping blood around the body and the person becomes unresponsive and stops breathing.

An intervention such as cardiopulmonary resuscitation seeks to restart the heart. It requires hard pressure to be applied to the person's chest. Such interventions often mean that those important to the person may not be able to be present or, if they are present, they may find this very distressing to watch.

There comes a time for everyone however, when attempting to restart the heart would either not be successful or where the risks of CPR outweigh the benefit. In this instance, there are clear medical indications that the person's health or condition has declined, or is expected to decline, to the point where CPR is not an appropriate intervention as it interferes with the normal dying process, whereby the heart is the last organ to stop.

Where there is no evidence of Advance Care Planning conversations, ADRT or clinical recommendations for care and treatment in the event of a sudden decline in health or an unexpected emergency, including cardiac arrest, the clinician who is treating the person will make a 'best interests' decision.

Organ Donation

A person can choose to donate their organs and tissues for transplant. There are two different types of organ donation. One is where the person donates an organ as a 'live donor', for example someone may wish to be a kidney donor. The second is where someone has died and their organs and tissues are donated.

From spring 2023, the law on organ donation in Northern Ireland[38] will change to a system of 'deemed consent[39]'. At such time as the amendments effected under the Organ and Tissue Donation (Deemed Consent) Act (NI) 2022 are commenced, if a person does not want to become an organ donor after they die, it will be necessary to 'opt out' on the NHS Organ Donor Register.[40] Many people do not realise that the support of those important to them is necessary for organ donation to go ahead. Knowing a person's wishes in relation to organ donation helps those important to them at this difficult time.

Body Donation to Medical Science

A person may wish to donate their body to medical science.

It is important for the person to discuss this with those important to them, and those providing care, support or treatment. There is a correct process[41] which must be followed; this will include keeping a copy of the fully completed consent form.

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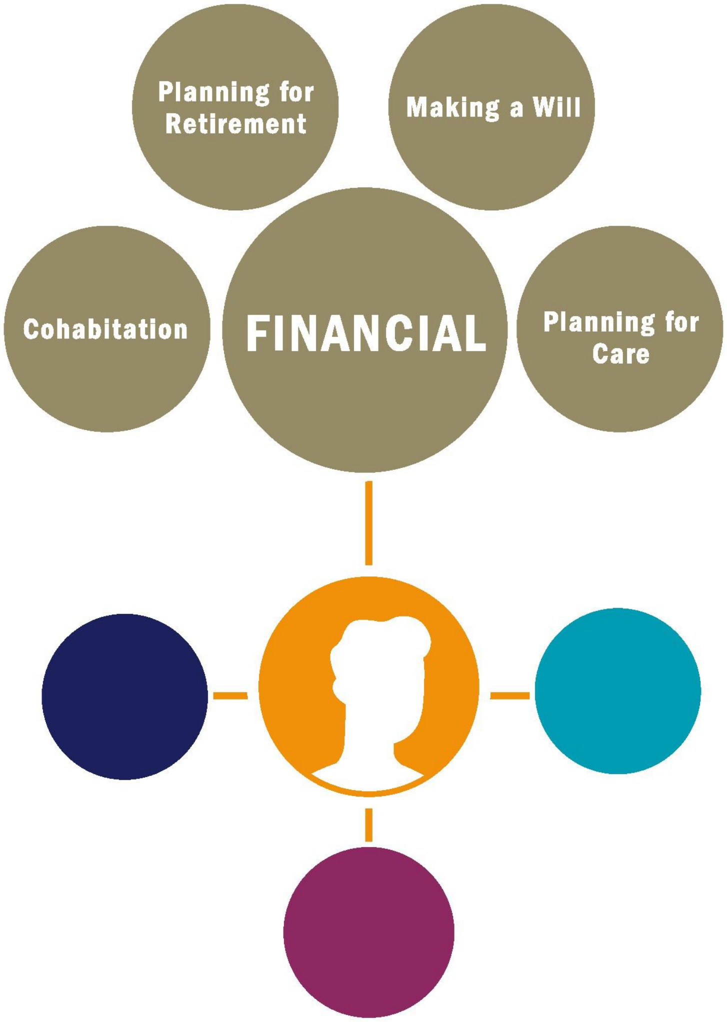
[38] *Organ Donation Northern Ireland*

[39] *Section 1 of the Organ and Tissue Donation (Deemed Consent) Act (Northern Ireland) 2022 (c. 10) amends section 3 of the Human Tissue Act 2004, to provide that deemed consent of the person concerned amounts to appropriate consent for the purposes of certain transplantation activities, unless the person concerned is an "excepted adult" (see section 3(9A) of the Human Tissue Act 2004, as amended by section 1(4) of the Organ and Tissue Donation (Deemed Consent) Act (NI) 2022). This is achieved by virtue of the amendment to section 3(6) (ba) of the Human Tissue Act 2003. The effect of these amendments is to change the default position in relation to consent away from an opt-in system to an opt-out one*

[40] *Organ Donor Register*

[41] *Information booklets including Consent Form are available from the Queen's University Anatomy Office.*
If you would like to receive an Information Booklet including a Consent Form, please email the Anatomy Office at anatomy@qub.ac.uk or telephone 028 90 972131. Staff will be very happy to discuss any queries that you may have.

Financial Advance Care Planning



Financial Component of Advance Care Planning

Making a Will

Making a will provides a person with the opportunity to ensure their wishes are followed after they die. It helps to ensure a person can leave any belongings or instructions they wish to those important to them.

A will is a legal document that gives clear instructions which can include:

- Care of children or dependents;
- Financial affairs - money, property and belongings.

Why it's important to make a will

Having a will simplifies the process of managing a person's affairs after they die:

- A person can decide how their assets are shared;
- An unmarried couple can make sure their partner is provided for;
- If a person is divorced, they can decide whether to leave anything to their former partner;
- A person can get more information on Inheritance Tax.

Preparing a will

Although it is possible for a person to write a will themselves, it is advisable to use a solicitor as there are various legal formalities. If a person does not have a will and dies intestate[42], the laws of intestacy will apply.

An Executor is the person who is responsible for ensuring that a person's will is executed and administered according to their wishes. A person can appoint an Executor by naming them in their will. The courts can also appoint the Executor(s).

Once a person has made their will, it is important they keep it in a safe place and tell their Executor, close friend or relative where and how to locate their will. If a solicitor makes the will, they will normally keep the original and send the person a copy. A person can ask for the original if they wish to hold it.

Updating a will

A person should review their will, particularly after any major change in their life, such as getting separated, married or divorced, having a child or moving house.

A person can make changes by adding a note to their existing will or by revoking their original will and making a new will[43].

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[42] *A person who dies without leaving a will is called an intestate person.*

[43] *NI Direct – Making a Will*

Cohabitation

In any financial planning, it is important to be aware that if a person is living with a partner but is not married or in a civil partnership, they do not have the same rights as married couples or civil partners. Legal and financial problems can arise in the event of separation or death. As part of Advance Care Planning, a person may wish to consider and take legal advice on what steps are appropriate to protect them and their partner in such circumstances, including the importance of making a will.

Planning for Retirement

Considering options and taking steps to ensure that appropriate financial plans, including pension arrangements, are put in place for retirement can help a person have more reassurance about their financial future and how they can best ensure that they have enough money to live comfortably[44]. When planning for retirement a person should consider their State Pension; personal or workplace pensions and other savings and investments and should seek appropriate financial planning advice as required.[45]

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[44] *Planning for retirement | nidirect*

[45] *Getting information and help with pensions | nidirect*

Planning for Care

A person may also wish to think about what their preferences would be should they need care and support in the future. In the event of a person moving to a supported living, residential or care home, Health and Social Care professionals will assess the person's needs and help them find a suitable home. This will also involve an assessment of a person's finances to establish what they can afford to pay for residential or nursing home care.[46]

Financial planning can be complicated. For more personal and specific advice about financial arrangements, it is recommended that a person speaks to an authorised financial and/or legal adviser.

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[46] *Introduction to residential care and nursing homes | nidirect*
Choosing a residential care or nursing home | nidirect

Conclusion

This Advance Care Planning policy has been developed for members of the public, those important to them and those providing care, support or treatment. This policy emphasises the relevance of Advance Care Planning for all adults, at any stage of life, with an ambition that Advance Care Planning becomes normalised, that people have the opportunities to have these conversations and that these are reflected in the care, support or treatment they receive.

This policy provides a framework to support all adults (aged 18 and over) to consider, record and share what matters to them and to make timely, realistic and practical plans for the future. It encourages them to have those important conversations about their wishes, feelings, beliefs and values that will help inform the future care, support or treatment they receive.

This policy sets out an Advance Care Planning approach that is based on four components, each of which includes a number of elements. A person may choose to think about and plan for some of the components or elements, but not others, and to do so at different times of their life. This reflects the personal and voluntary principles of Advance Care Planning and the importance of reviewing Advance Care Planning over time.

Advance Care Planning is not only to inform care, support or treatment in the future where a person is unable to make the relevant decisions for themselves. In addition, it can also enhance quality of life in the present and can help a person to think about what is important to them in a situation where, whilst they have mental capacity, they may need to consider their care, support or treatment.

Implementation of this policy will be enabled and supported through four pillars:

Public Messaging – to increase understanding and confidence about what Advance Care Planning is, its benefits and how to do it.

Operational Frameworks – providing practical advice and information to support people to do Advance Care Planning. Regional Operational Frameworks will also provide guidance to those providing care, support or treatment.

Training and Education– a Capabilities Framework underpins all training and education and provides a structure for the development of the knowledge and skills to support Advance Care Planning.

Evaluation and Outcomes – that will help measure progress towards achieving the policy's ambition.

Advance Care Planning

Where are you starting?

- FINANCIAL
  - Planning for Retirement
  - Making a Will
  - Cohabitation
  - Planning for Care
- PERSONAL
  - Online accounts
  - Spirituality
  - Care and support for dependents
  - Funeral wishes
  - What matters to me
- CLINICAL
  - Recommendations for CPR
  - ReSPECT
  - Organ donation
  - Declining health & unexpected emergencies
  - Body donation to medical science
  - Best interests decisions
- LEGAL
  - Advance Decision to Refuse Treatment
  - Mental Capacity Act (NI) 2016
  - Types of Power of Attorney

For more information visit:

https://www.health-ni.gov.uk/what-advance-care-planning

Appendices

Appendix 1 Glossary of Terms

- **Advance Care Planning:** Advance Care Planning is an umbrella term covering personal, legal, clinical, and financial planning. It enables a person to think about what is important to them and plan for their future. It is a voluntary process and helps a person to make known what their wishes, feelings, beliefs and values are, and to make choices that reflect these. Advance Care Planning is an on-going process of conversations between a person, those important to them and those providing care, support or treatment. Advance Care Planning should be an important part of life for all adults.
- **Advance Decisions to Refuse Treatment (ADRT):** In Northern Ireland, an ADRT is legally binding if it is valid and applicable to the particular situation.
- **Advance Statement:** This term is sometimes used when a person writes down their non-legally binding wishes, feelings, beliefs and values.
- **Behaviour Change:** Behaviour change can refer to any transformation or modification of human behaviour.
- **Best interests:** When a person lacks the mental capacity to make a specific decision about their treatment at that time, and does not have a valid and applicable Advance Decision to Refuse Treatment, the clinician who is treating the person will make a "best interests' decision regarding care and treatment. See section 7 of the Mental Capacity Act (NI) 2016.
- **Cardiac Arrest:** A cardiac arrest is when the heart has stopped pumping blood around the body and the person becomes unresponsive and stops breathing normally.
- **Cardiopulmonary resuscitation:** a medical intervention involving compression of the chest and artificial respiration, performed to maintain blood circulation and oxygenation in a person who has suffered a cardiac arrest.
- **Care, Support or Treatment:** The term 'those who provide care, support or treatment', term is used throughout the policy and includes people working within the community and voluntary sector, independent sector and other health and social care staff working in statutory services.
- **Consent:** Consent is more than a form or formality. For consent to be valid, it must be voluntary and informed, and the person consenting must have the capacity to make the decision. There is a distinction between consent under UK GDPR and clinical consent, or consenting to all components of Advance Care Planning.
- **End of Life:** A period of time during which a person's condition is actively deteriorating to the point where death is expected.
- **End of Life Care:** Is an approach that improves the quality of life of patients and their families living with a life-threatening illness. Care includes assessment and treatment of pain and other needs, physical, psychosocial and spiritual.
- **Enduring Power of Attorney:** A legal document which allows a person to appoint others to make decisions on their behalf about their property and financial affairs.[47]
- **Guidance (Clinical):** Evidence-based clinical recommendations on the most effective and cost-effective treatment and care of people with specific diseases and conditions, and recommendations for populations and individuals on interventions that can help prevent disease or improve health.
- **Guidance (Professional):** The professional regulators include General Medical Council (GMC), Nursing Midwifery Council (NMC), Health & Care Professions Council (HSPC), General Pharmaceutical Council (GPhc) and Northern Ireland Social Care Council (NISCC). Professional regulators produce regulatory 'guidelines'/ 'guidance' on how professional standards should be achieved.
- **Holistic assessment:** Comprehensive assessment that addresses the social, psychological, emotional, physical and spiritual needs of the person.
- **Holistic care:** Provision of care to a person based on an understanding of their social, psychological, emotional, physical and spiritual needs.

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[47] *Managing your affairs and enduring power of attorney*

- **Intestate:** A person who dies without leaving a will is called an intestate person.
- **Lasting Power of Attorney (LPA):** Is a legal document, which allows a person to appoint others to make decisions on their behalf[48].
- **Mental Capacity Act (Northern Ireland) 2016:** Legislation that when fully commenced, will fuse together mental capacity and mental health law.
- **National Institute for Health and Care Excellence (NICE):** An organisation that provides a robust and independent appraisal of the best available evidence to make recommendations for the health and social care system.
- **Organ Donation:** Organ donation is when one person chooses to give an organ or tissue to save or improve the life of someone else.
- **Palliative Care:** The active, holistic care of people with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is to achieve the best quality of life for people and those important to the person. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.
- **Progressive condition:** A disease or health condition that gets worse over time, resulting in a general decline in health or function.
- **Power of Attorney:** Is a legal document which the person can use to give someone else the authority to take actions or make decisions on their behalf.
- **ReSPECT:** Is an element of the clinical component of Advance Care Planning enabling personalised recommendations for care and treatment to be documented.
- **Serious Illness:** A health condition that carries a high risk of mortality and may impact a person's daily function or quality of life.
- **Spirituality:** Spirituality is about what gives meaning and purpose to life and is based on a person's core beliefs and values.
- **Those important to the person:** This may be family, carers or someone who knows, cares and has affection for the person. They may be connected through their personal, legal, cultural or emotional relationship.

Abbreviations

- **ADRT -** Advance Decision to Refuse Treatment
- **CPR -** Cardiopulmonary resuscitation
- **DNACPR -** Do not attempt cardiopulmonary resuscitation
- **EPA -** Enduring Power of Attorney
- **LPA -** Lasting Power of Attorney
- **MCA -** Mental Capacity Act (Northern Ireland) 2016
- **NI -** Northern Ireland
- **NICE -** National Institute for Health and Care Excellence
- **ReSPECT -** Recommended Summary Plan for Emergency Care and Treatment

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[48] *The Mental Capacity Act (NI) 2016 introduces the role of a Lasting Power of Attorney (LPA) to Northern Ireland. The Mental Capacity Act (NI) 2016 has come into effect here in phases of implementation. LPA was not included in Phase 1. Implementation is ongoing, but there is currently no timeline for the start of that phase which will include LPA coming into use.*

Appendix 2 Mental Capacity Act (Northern Ireland) 2016 – Part 1 Principles

Principles: capacity

1—*(1) The principles in subsections (2) to (5) must be complied with where for any purpose of this Act a determination falls to be made of whether a person who is 16 or over lacks capacity in relation to a matter.*

(2) The person is not to be treated as lacking that capacity unless it is established that the person lacks capacity in relation to the matter within the meaning given by section 3.

(3) Whether the person is, or is not, able to make a decision for himself or herself about the matter—
(a) is to be determined solely by reference to whether the person is or is not able to do the things mentioned in section 4(1)(a) to (d); and

(b) accordingly, is not to be determined merely on the basis of any condition that the person has, or any other characteristic of the person, which might lead others to make unjustified assumptions about his or her ability to make a decision.

(4) The person is not to be treated as unable to make a decision for himself or herself about the matter unless all practicable help and support to enable the person to make a decision about the matter have been given without success (see section 5).

(5) The person is not to be treated as unable to make a decision for himself or herself about the matter merely because the person makes an unwise decision.

(6) Nothing in subsections (1) to (5) removes any obligation that a person may be under in a particular situation to take steps to establish whether another person has capacity in relation to a matter."

"Principle: best interests

2—*(1) The principle in subsection (2) applies where, under this Act—*

(a) an act is done for or on behalf of a person who is 16 or over and lacks capacity in relation to whether the act should be done; or

(b) a decision is made for or on behalf of a person who is 16 or over and lacks capacity to make the decision.

(2) The act must be done, or the decision must be made, in the person's best interests (see section 7)."

Appendix 3 Bibliography

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Online Videos

July 2016, “Advance Care Planning in Dementia”, webinar by Dr Karen Harrison Dening, Dementia UK: https://youtu.be/7TAkLBaABlY

April 2020 – Project ECHO AIIHPC: Intellectual Disability Services, “Advance Care Planning & Anticipatory Prescribing during a Crisis”, webinar: https://youtu.be/YbPt_D5sLxE [speakers include: Professor Mary McCarron, Dr. Regina McQuillan, Dr. Jean Lane, Dr. John O Brien, Professor Sean Kennelly, Dr. Cathy Payne].

June 2020, “Advance Care Planning – Issues Raised by the Covid19 Pandemic”, webinar by John Lombard, University of Limerick, PCRN member https://youtu.be/TyadgPsPITI

Sept 2020, “Advance care planning. An awareness raising session for district nursing”, webinar by Niall Gallagher, Specialist Social Work: https://youtu.be/DbfsdftNmrg

Notes

Produced by:

Department of Health, Castle Buildings Belfast, BT4 3SQ

Published: *October 2022*

This document will be reviewed by the Department of Health as policy and legislation develops and/or in the light of evolving changes in practice. The most up-to-date version of this policy document will be available on **https://www.health-ni.gov.uk/what-advance-care-planning**

Advance Care Planning

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