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1 Introduction

2

3 Advance Care Planning is an umbrella term covering personal, legal, clinical, and
4 financial planning. It enables a person to think about what is important to them and
5 plan for their future. It is a voluntary process and helps a person to make known
6 what their wishes, feelings, beliefs and values are, and to make choices that reflect
7 these. Advance Care Planning is an on-going process of conversations between a
8 person, those important to them¹ and those providing care, support or treatment.
9 Advance Care Planning should be an important part of life for all adults.

10 The Advance Care Planning policy has been written for members of the public, those
11 important to them and those providing care, support or treatment².

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

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

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

23 Advance Care Planning is important for all adults, at whatever stage of life. “The
24 reality that one day each of us will die, is something few of us consider and fewer
25 still, plan for or discuss” (McKenna et al, 2020). Although Advance Care Planning
26 has traditionally been associated with end of life care, it goes beyond this. As well as
27 supporting decisions in declining health and unexpected emergencies, the
28 opportunity it provides to reflect and consider what is important to the person can
29 enhance their quality of life. It may also provide comfort and reassurance to those
30 important to the person.

31 This policy provides a framework for Advance Care Planning for adults (aged 18
32 years and over) in Northern Ireland, focusing on the health and social care aspects.
33 The policy provides an overview of Advance Care Planning, and the values and
34 principles that underpin it. It sets out why Advance Care Planning is important and

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.

1 how it can help people make timely, realistic and practical plans for their future.
2 It encourages these plans to be made in conversation with those who are important
3 to them and/or someone providing care, support or treatment.

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

7 For people providing care, support or treatment to someone, the policy provides
8 clarity and support for their role in having these important conversations as part of
9 the holistic care or services they provide. If the person becomes unable to make the
10 relevant decisions for themselves, then these decisions have to be made based on
11 what is in the person's best interests. In determining what is in the person's best
12 interests, special regard should be given to the person's wishes, feelings, beliefs and
13 values. Decisions must not be made on the basis of assumptions based solely on
14 factors such as the person's age, disability³, or on a professional's subjective view of
15 a person's quality of life.⁴

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

20 The policy provides an ethical and rights based approach⁵ to Advance Care Planning
21 for adults, in line with legislation, best practice and professional guidance and
22 standards. The policy is supported by guidance, training and education and public
23 information to ensure a consistent approach to Advance Care Planning that is
24 inclusive and accessible. (Guidance and information documents pending post Public
25 Consultation).

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³ 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.

⁴ [20160123 Decisions Relating to CPR - 2016.pdf \(resus.org.uk\)](https://www.resus.org.uk/20160123-Decisions-Relating-to-CPR-2016.pdf)

⁵ 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 <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> COVID-19 Guidance Ethical Advice and Support Framework COVID-19 HSC Clinical Ethics Forum <https://www.health-ni.gov.uk/sites/default/files/publications/health/COVID-19-Guidance-Ethical-Advice-and-Support%20Framework.pdf>

1 **Ambition**

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

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

8 **What is Advance Care Planning?**

9

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

16 Advance Care Planning should be an important part of life for all adults. It needs to
17 be encouraged by those providing care, support or treatment, to ensure that people
18 have the opportunity to have timely, realistic and practical conversations. These
19 conversations focus on what matters to the person and what would be important for
20 them to prioritise in the future should they become unable to make decisions for
21 themselves.

22 If the person wants to make a record of these conversations and share them they
23 should be supported to do so. The conversations may include for example, mental
24 health crisis planning, Advance Decisions to Refuse Treatment (ADRT) and the
25 person's view on cardiopulmonary resuscitation (CPR).

26

27 **Advance Care Planning and Mental Capacity**

28

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

32 The first principle of the Mental Capacity Act (NI) 2016 is a person is not to be
33 treated as lacking capacity unless it is established that the person lacks capacity in

1 relation to the matter in question⁶. Mental capacity is both decision and time specific.
2 People may be able to make some decisions at one time but not another. Even if the
3 person lacks the mental capacity for a specific decision at that time, their wishes,
4 feelings, beliefs and values are central and the person still needs to be supported to
5 be involved as much as possible. More detail is provided on page 19.

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

7 **Values:**

8 Advance Care Planning:

- 9 • Respects and upholds the rights, dignity and culture of the person and is
10 inclusive of all adults;
- 11 • Provides an ethical approach to discussing these important and sensitive
12 issues;
- 13 • Is accessible to the person in a way that enables them to have meaningful
14 conversations;
- 15 • Is a person's individual choice. Some people may not want to think about or
16 engage in Advance Care Planning conversations - their choice should be
17 respected, with the opportunity given to revisit the conversation at another
18 time;
- 19 • Is a personal experience. Each person's wishes, feelings, beliefs and values
20 will be individual to the person and their own circumstances;
- 21 • Is a voluntary process. Pressure must not be put on the person having the
22 Advance Care Planning conversation by anyone; those providing care,
23 support or treatment, the family or someone important to the person, or by
24 any organisation⁷.

25 **Principles of Practice:**

- 26 • Advance Care Planning conversations need to be meaningful, conducted with
27 sensitivity and compassion. They require time and should happen at the
28 person's pace;

⁶ <https://www.legislation.gov.uk/nia/2016/18/section/1/enacted>

⁷ Further information on safeguarding adults to make informed choices free from duress, pressure or undue influence please refer to <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/adult-safeguarding-policy.pdf>

- 1 • Consent is more than a form or formality. Consent needs to be addressed at
2 each stage of the Advance Care Planning process i.e. having the
3 conversation, sharing the information with others, making a record, sharing
4 the record;
- 5 • Where there is a record of Advance Care Planning conversations, these
6 should be accessible across all settings to ensure a person’s wishes, feelings,
7 beliefs and values, and any recommendations and/or decisions made, are
8 known;
- 9 • A person’s confidentiality should be respected;
- 10 • Advance Care Planning conversations, any recommendations and/or
11 decisions need to be revisited, reviewed and if needed re-shared to ensure
12 they remain up to date as a person may change their mind about some things;
- 13 • Advance Care Planning incorporates the principles of the Mental Capacity Act
14 (NI) 2016.

15

16 **Why is it important to have Advance Care Planning** 17 **conversations?**

18

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

23 Numerous national and international research studies [Appendix 2] on ‘family or
24 caregivers’⁸ experience of Advance Care Planning indicate that meaningful Advance
25 Care Planning conversations are beneficial for a number of reasons:

26

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⁸ “Family or caregivers” is the phrase used within research studies. This policy uses the term “those important to the person”

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 “put their affairs in order” or 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.
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.

1

2 Local research studies in Northern Ireland also reinforce the need for a greater
3 awareness and understanding of Advance Care Planning and for more open, timely
4 and meaningful conversations on this [Appendix 2].

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

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

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

17

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

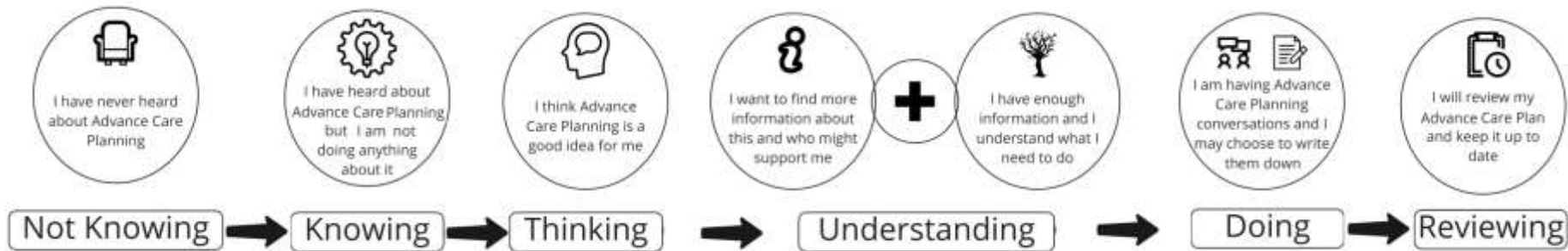
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3 Advance Care Planning is important for every adult at any stage of life and is
4 relevant to people who are in good health as well as for those who are very unwell.
5 Ideally Advance Care Planning should happen long before any crisis or serious
6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

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

13 It can take time for some people to feel ready to have these conversations and/or
14 make a record of it. This is normal, and there can be many reasons for this; for
15 example, some people can be afraid to express their wishes or may believe if they
16 do, people important to them might become upset. People may also be reluctant to
17 consider a time when they may become unable to make the necessary decisions
18 about their care. It is important to increase awareness and understanding of
19 Advance Care Planning conversations, to normalise them. It is important therefore to
20 emphasise the benefits and support people to move from thinking about having an
21 Advance Care Planning conversation to actually having one.

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



1

2 For those people with serious or progressive conditions, and those who may be approaching the end of their life, these conversations
3 should happen as early as possible and when the person is medically stable.

4 Where these conversations haven't already happened, they may be prompted when:

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

1 People may express their wishes, feelings, beliefs and values over a period of time,
2 to those important to them or to those providing care, support or treatment. Advance
3 Care Planning conversations can take place in any setting but should, where
4 possible, be done when and where the person feels most comfortable. Wherever
5 the conversation takes place, every effort should be made to ensure it is suitable⁹ to
6 having meaningful Advance Care Planning conversations.

7 **Having Meaningful Advance Care Planning Conversations**

8

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

12 The importance of good, effective communication has been consistently highlighted
13 across research studies as well as through reported personal experiences [Appendix
14 2]. This reinforces the need to improve capabilities¹⁰ including knowledge, skills and
15 understanding of Advance Care Planning and in particular, communication skills¹¹.

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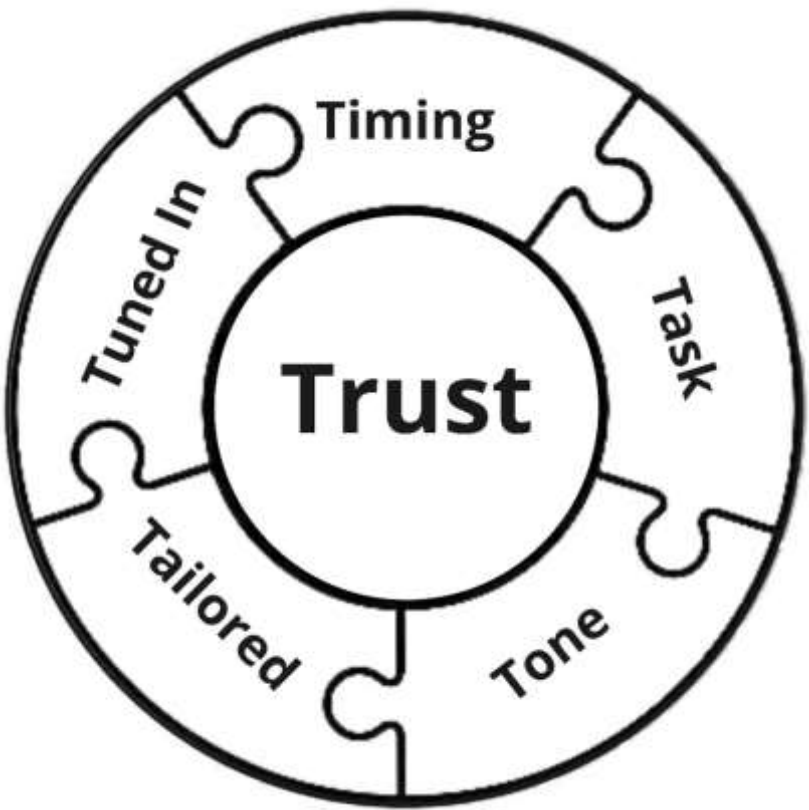
⁹ Such as having adequate time, using a quiet place that allows for confidentiality and lessens possibility of inappropriate interruptions or distractions; provision of appropriate and accessible material, appropriate people involved, and specific communication preferences or needs the person may have.

¹⁰ Refer to Advance Care Planning Capabilities Framework (Pending)

¹¹ 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 conversation. [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 \(hscni.net\)](#)]

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

3
4 The diagram and table below offer a guide on how to communicate during Advance
5 Care Planning conversations whether the conversation is being prompted by the
6 person or by those providing care and support or treatment. It should be
7 remembered that there are two sides to these conversations: either the person who
8 is thinking about and wants to have an Advance Care Planning conversation, or the
9 person who is listening to and/or facilitating the conversation. This may be someone
10 important to the person, and/ or someone who is providing care, support or
11 treatment. Keeping the following in mind supports meaningful Advance Care
12 Planning conversations.



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Trust	<p>Trust is central to these conversations.</p> <p>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.</p> <p>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.</p>
Timing	<p>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).</p> <p>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.</p>
Task	<p>If some of the person’s wishes, feelings, beliefs and values are already known; build on this.</p> <p>It’s important to be clear on what it is you want to say.</p> <p>Check that the other person has heard and understands what it was you wanted to say.</p>
Tone	<p>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.</p>
Tailored	<p>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.</p>
Tuned In	<p>To how the person might be feeling about and during the conversation.</p> <p>To the other person’s pace.</p> <p>To the other person’s understanding.</p>

1 **Sharing Advance Care Planning Conversations,** 2 **Recommendations and Decisions**

3

4 During Advance Care Planning conversations, the person's wishes, feelings, beliefs
5 and values (including ADRT¹² decisions & ReSPECT recommendations¹³) may be
6 recorded and shared, if they consent to do so.

7 **Reviewing Advance Care Planning Conversations,** 8 **Recommendations and Decisions**

9

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

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

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

25

26 A person's Advance Care Planning conversations, any recommendations and/or
27 decisions will be used in the future should a person be unable to make a specific
28 decision for themselves. This may be because they do not have mental capacity or
29 are unable to communicate what their wishes are.

30 No-one in Northern Ireland has the legal authority to consent to any care or
31 treatment on behalf of another adult. In situations where a person lacks the mental
32 capacity to make a specific decision about their treatment at that time, and does not
33 have a valid and applicable Advance Decision to Refuse Treatment, the clinician

¹² See section "Advance Decisions to Refuse Treatment" page 25.

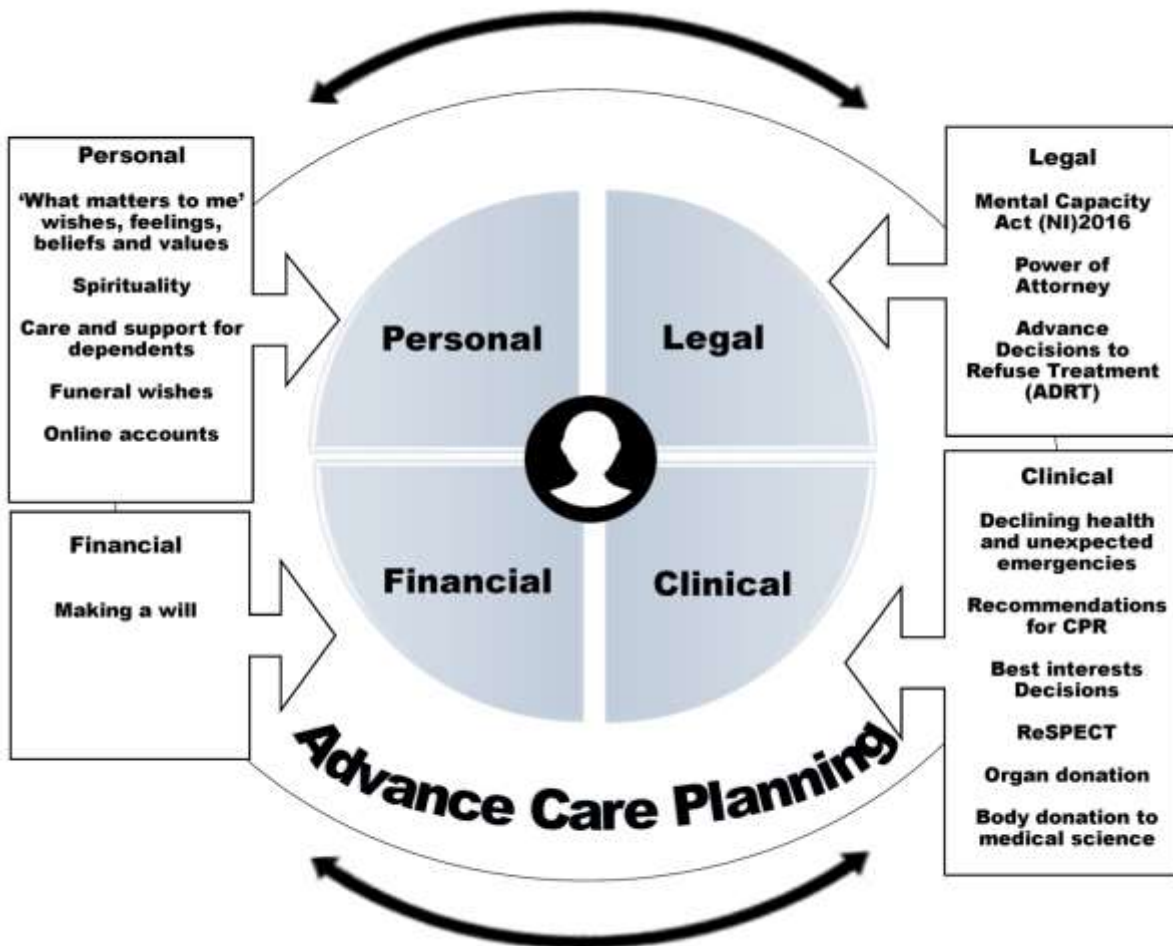
¹³ See section "Recommended Summary Plan for Emergency Care & Treatment (ReSPECT)" page 28.

1 who is treating the person will make a 'best interests' decision(s). Therefore previous
2 Advance Care Planning conversations, any recommendations and/or decisions will
3 be used to guide and inform the 'best interests'¹⁴ decision.

4 **Components of Advance Care Planning**

5

6 This section covers the four components of Advance Care Planning. They are
7 Personal, Legal, Clinical and Financial. Each component contains one or more
8 elements and each is described in detail below. Some elements may fit into more
9 than one component. (Public information on these elements will be available
10 following public consultation).



11

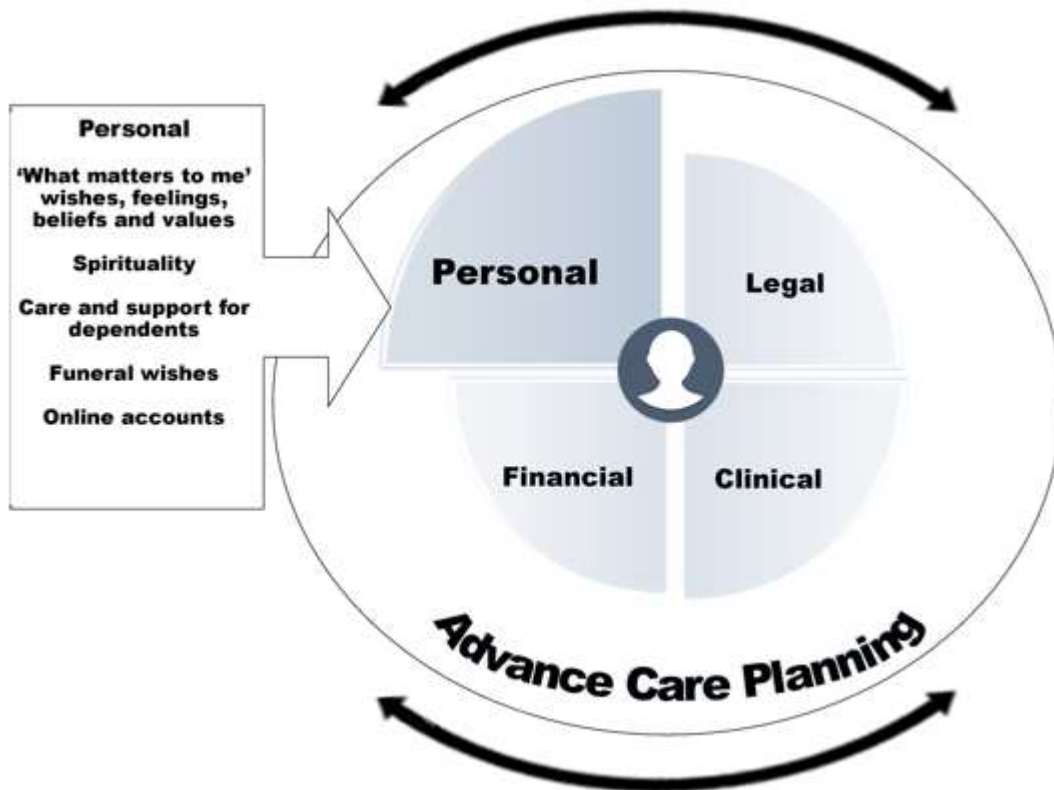
12 These key components are considered in the following sections.

13

¹⁴ See "Best Interests" section page 27.

1 **Personal Component of Advance Care Planning**

2



3

4 **“What Matters To Me” - Wishes, Feelings, Beliefs and Values**

5

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

9 A person can tell people about what matters to them, or write it down. These can be
10 specific wishes about what is important to them when they are well and what is
11 important to them if they became unable to make the relevant decisions about their
12 lives.

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

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

1 **Spirituality**

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

12

13 **Care and Support for Dependents**

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

19 It is important to recognise the peace of mind that such conversations and plans can
20 bring.

21 This is not only for those with dependents. For some people, Advance Care
22 Planning will include making arrangements for the care of their pets if they were
23 unable to look after them themselves.

24

25 **Funeral Wishes**

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

32

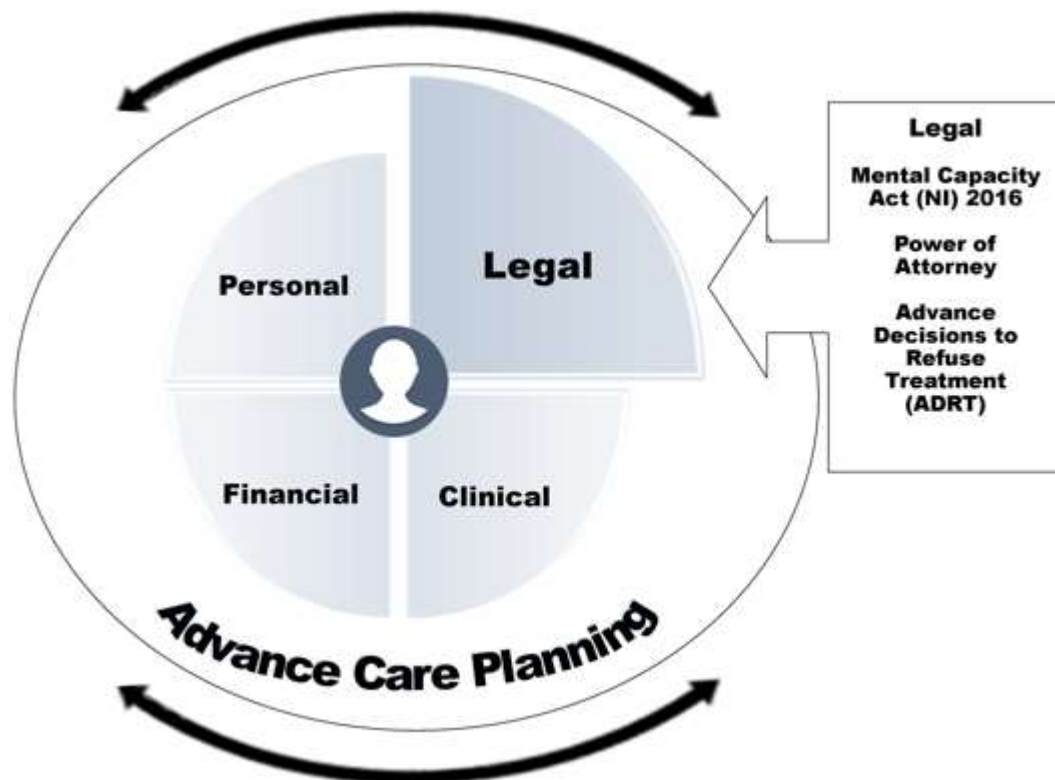
33 **Online Accounts**

34 It is important to consider what will happen to any online accounts after a person
35 dies. This may include a person deciding what they would want to happen to photos,
36 videos, emails, banking or other information stored online, sometimes known as a
37 person's digital legacy.

1 For some people, they may decide to share their personal wishes regarding social
2 media or online accounts. (e.g. delete or keep open email, or social media
3 accounts).

4

5 **Legal Component of Advance Care Planning**



6

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

8 Advance Care Planning includes references to a person having mental capacity so it
9 is important to understand what this means. The first principle of the Mental Capacity
10 Act (NI) 2016 is a person is not to be treated as lacking capacity unless it is
11 established that the person lacks capacity in relation to the matter in question.¹⁵ A
12 person may be able to make some decisions at one time but not another. Mental
13 capacity is both decision and time specific, this means:

- 14
- 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;
- 17

¹⁵ [Mental Capacity Act \(Northern Ireland\) 2016 \(legislation.gov.uk\)](http://legislation.gov.uk)

- 1 • Even if a person lacks the relevant mental capacity for a specific decision at
2 that time, their wishes, feelings, beliefs and values are central and the person
3 still needs to be supported to be involved as much as possible.

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

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

15 The Mental Capacity Act (NI) 2016 is an Act of the Northern Ireland Assembly. The
16 Act received Royal Assent on the 9th May 2016.¹⁶ Section 3 of the Mental Capacity
17 Act (NI) 2016 assigns the following meaning to the term "lack of capacity";

18

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."

19

20 The Act specifies that a 'lack of capacity' is about a person not being able to make a
21 decision for themselves on a specific matter.

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

¹⁶ 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.

1 There are a number of very important principles in the Mental Capacity Act (NI) 2016
2 about capacity which help prevent it being wrongly assumed a person has lack of
3 mental capacity. The statutory principles of the Mental Capacity Act (NI) 2016 are¹⁷:

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

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

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

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

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

18 **Aspects To Consider Regarding Mental Capacity**

19 These are important aspects to consider regarding mental capacity.

<p>Why is a person unable to make the decision?</p>	<p>A person is not able to make a decision if they are not able to:</p> <ul style="list-style-type: none">• understand the information they need which would help them to make a decision.• remember that information for the time needed to make the decision.• use that information 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).
---	--

¹⁷ Mental Capacity Act (NI) 2016 <https://www.legislation.gov.uk/nia/2016/18/section/1/enacted>

<p>Supporting a person to make a decision</p>	<p>A person must be given all practicable help and support to enable them to make a decision. The steps required are:</p> <ul style="list-style-type: none"> • 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.
<p>Establishing if someone lacks capacity</p>	<p>To establish if a person lacks capacity to make a decision on a specific matter, those assessing the person must:</p> <ul style="list-style-type: none"> • 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.
<p>Who can determine if someone has Mental Capacity?</p>	<p>Determining capacity is a core function of any health and social care worker, and it is expected all health and social care professionals should be able to carry out routine mental capacity assessments.</p> <p>For serious interventions and treatment decisions, a person determining mental capacity must be suitably qualified, as detailed within the Mental Capacity Act (NI) 2016¹⁸.</p>

1

2 Types of Power of Attorney

3 There are three different types of 'Power of Attorney' and each are described here. It
 4 is important to note though, that only the first two are currently in place in Northern

¹⁸ [Mental Capacity Act \(Northern Ireland\) 2016 \(legislation.gov.uk\)](http://legislation.gov.uk)

1 Ireland. It is advisable to seek legal advice as careful consideration should be given
2 to the range of powers a person wishes to give an attorney¹⁹.

3

4 **Power of Attorney**

5

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

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

13

14 **Enduring Power of Attorney**

15

16 An Enduring Power of Attorney (EPA) is a legal document which allows a person to
17 appoint others to make decisions on their behalf about their property and financial
18 affairs if they were to lose mental capacity.

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

21

22 **Lasting Power of Attorney**

23

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

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

¹⁹ <https://www.nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney>
<https://www.justice-ni.gov.uk/sites/default/files/publications/justice/epa-notes-for-guidance-Aug-2018-updated-Nov-2019.pdf>

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.

2

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

7 An LPA will be a very powerful tool in Advance Care Planning, when the relevant
8 provisions of the Mental Capacity Act (NI) 2016²⁰ are brought into force. It will
9 ensure that a person can choose who will make decisions on their behalf should they
10 ever lack mental capacity.

11 Currently no one can consent to treatment on behalf of another adult in Northern
12 Ireland. In situations where a person has not the mental capacity to make a specific
13 decision for themselves, a 'best interests' decision is made²¹.

14

²⁰ 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.

²¹ See 'Best Interests' section page 27.

1 **Advance Decisions to Refuse Treatment (ADRT)**

2

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

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

- 9 • ask for specific medical treatment;
- 10 • request something that is illegal, e.g. assisted suicide;
- 11 • nominate someone else to make decisions;
- 12 • refuse treatment for a mental health condition if the treatment is in accordance
13 with the Mental Health (NI) Order 1986.²²

14

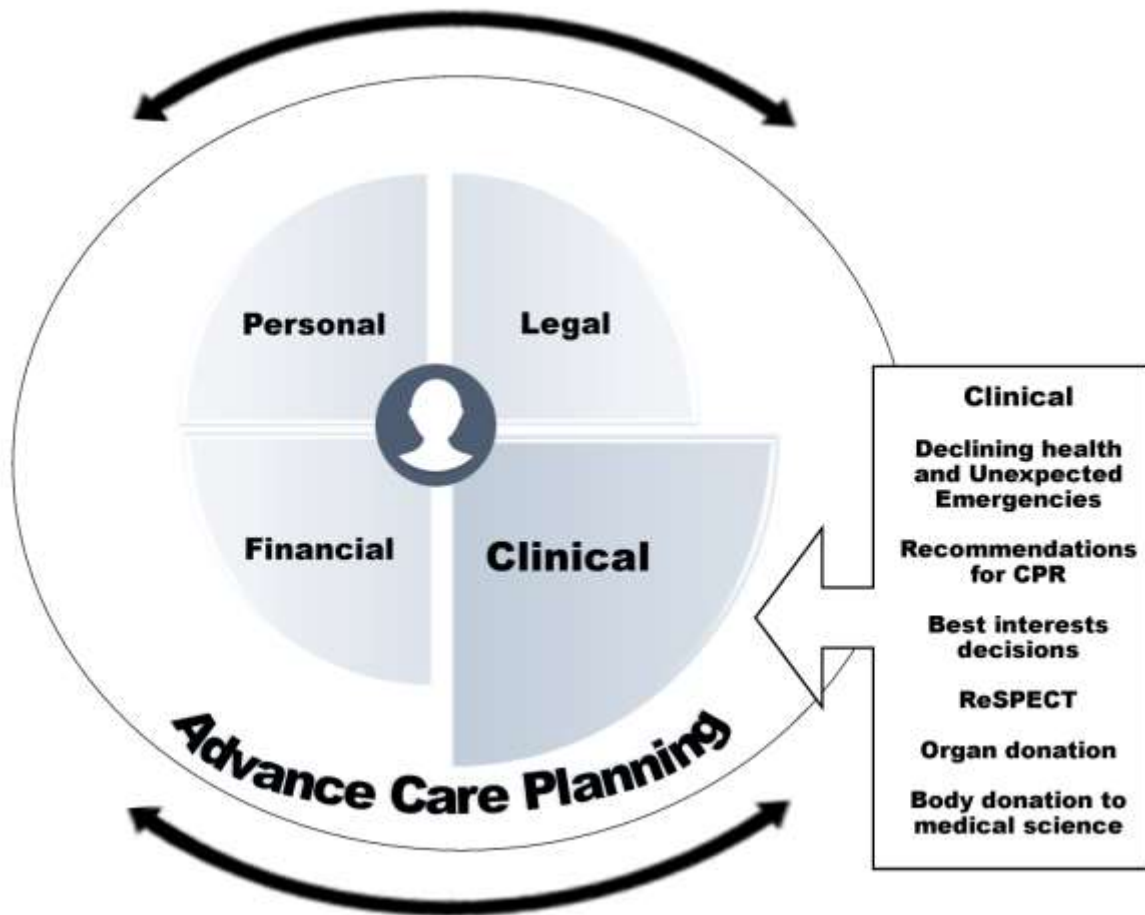
15 In Northern Ireland, an ADRT is legally binding (governed by common law instead of
16 an Act) if it is valid and applicable to the particular situation. This means those
17 providing care, support or treatment must follow an ADRT provided that they know
18 about it.

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

22 Those providing care, support or treatment should follow the Advance Care Planning
23 Regional Operational Framework (will be developed in line with Policy development).

²² When the Mental Capacity Act (Northern Ireland) 2016 is fully commenced it will provide a statutory foundation for an ADRT. It will note that if there is a valid ADRT it cannot be overruled by a decision under the Act. This will include mental health treatment.

1 Clinical Component of Advance Care Planning



2

3 Declining Health & Unexpected Emergencies

4

5 Across the course of a person's life, their health can begin a gradual decline over a
6 period of time. At other times, a person's health can be suddenly affected by an
7 unexpected emergency situation, such as an accident, a heart attack or a mental
8 health crisis. It is really important therefore, for everyone to think about and plan for
9 the fact that such situations can happen.

10 Advance Care Planning can include conversations, recommendations and/or
11 decisions regarding a person's wishes for future care in the event of declining health
12 and/or unexpected emergencies. These conversations help to provide a shared
13 understanding of what matters to the person and inform the clinical
14 recommendations and/or decisions about what is realistic in terms of their future care
15 and treatment as their health declines, and/or specific treatments such as
16 resuscitation, ventilation or artificial nutrition/hydration.

17

18

1 **Clinical Recommendations for Cardiopulmonary Resuscitation (CPR)**

2

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

8 An intervention such as cardiopulmonary resuscitation (CPR) seeks to restart the
9 heart. It requires hard pressure to be applied to the person's chest, which often
10 means those important to the person cannot be present or if they are present, can
11 find this very distressing to watch.

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

18 A person or those important to the person cannot insist on any specific treatments to
19 be in provided if deemed inappropriate by the treating clinician, this includes CPR.
20 Knowing what matters to a person helps inform those providing clinical treatment to
21 make and record specific clinical recommendations, including whether CPR would
22 be an appropriate intervention in the event of a cardiac arrest. The key issue is not
23 the decision-maker's view of the quality of life following CPR, but an objective
24 assessment of what is in the best interests of the patient. This must take account of
25 all relevant factors, particularly the persons wishes, feelings, beliefs and values
26 about what would be an acceptable level of recovery for them.

27

28 **Best Interests Decisions**

29

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

36 No one has the legal authority to consent to treatment on behalf of another adult but
37 those important to the person should be included in these 'best interests' discussions
38 regarding what the person may have wanted. Even when the person lacks the

1 relevant mental capacity for a specific decision at that time, their wishes, feelings,
2 beliefs and values are central. The person must be placed at the heart of the
3 decision-making process and supported to be involved in the decision-making
4 process as far as possible.²³

5 The clinician who is treating the person should base their best interests decision²⁴ on
6 their experience and understanding of the person's circumstances and be informed
7 by the person's prior Advance Care Planning conversations. Decisions must not be
8 made on the basis of assumptions based solely on factors such as the person's age,
9 disability²⁵, or on a professional's subjective view of a person's quality of life²⁶.

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

14

15 **Recommended Summary Plan for Emergency Care & Treatment (ReSPECT)**

16

17 Ideally Advance Care Planning should happen long before any decline in a person's
18 health or any crisis or emergency. There may however be instances where Advance
19 Care Planning conversations have not taken place and those providing care, support
20 or treatment will have to introduce these conversations in circumstances such as a
21 sudden decline in health or unexpected emergency.

22 No matter when these conversations happen, they should include talking about and
23 recording what matters to a person and specific clinical recommendations about
24 what is realistic and appropriate treatment and care for the person.

25 Conversations and recommendations for future care and treatment will be recorded
26 on a ReSPECT form.

27 ReSPECT stands for "Recommended Summary Plan for Emergency Care and
28 Treatment." The ReSPECT form sets out information that will help guide and inform
29 those providing care, support or treatment at a time when the person is unable to

²³ [Quality statement 4: Best interests decision making | Decision making and mental capacity | Quality standards | NICE](#)

²⁴ When fully implemented Section 7 of the Mental Capacity Act (NI) 2016
<https://www.legislation.gov.uk/nia/2016/18/section/7/enacted>

²⁵ 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

²⁶ Decisions relating to cardiopulmonary resuscitation 2016 <https://www.resus.org.uk/sites/default/files/2020-05/20160123%20Decisions%20Relating%20to%20CPR%20-%202016.pdf>

1 communicate what their wishes are or does not have mental capacity to make that
2 specific decision, such as in a future unexpected emergency.

3 The ReSPECT form includes recommendations and/or decisions about specific
4 interventions that may, or may not be wanted or be clinically appropriate.

5 The ReSPECT form will be signed by the clinician providing clinical
6 recommendations but will be held by the person. The ReSPECT form is not a legally
7 binding document. The ReSPECT form includes:

- 8 • What matters to the person regarding their care and treatment e.g. wishes
9 feelings, beliefs and values;
- 10 • Existing care planning documents e.g. if the person has made an Advance
11 Decisions to Refuse Treatment (ADRT);
- 12 • Clinical recommendations for emergency care and treatment e.g.
13 Resuscitation recommendations;
- 14 • Recording mental capacity for involvement in the recommendations made;

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

17 The ReSPECT form will be the regional form for recording all recommendations
18 about emergency care and treatment. The ReSPECT form will be transferable
19 across all care settings. As the ReSPECT form includes CPR recommendations, do
20 not attempt cardiopulmonary resuscitation (DNACPR) forms will no longer be used.

21 Those providing care, support or treatment should follow the relevant regional
22 operational documents that have been developed to support this policy.

23

24 **Organ Donation**

25

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

30 A person can record whether they do or do not want to donate their organs and
31 tissues after death on the NHS Organ Donor Register.²⁷ Many people do not realise
32 that the support of those important to them is necessary for organ donation to go

²⁷ Organ Donor Register <https://www.organdonation.nhs.uk/register-your-decision/>

1 ahead. Knowing a person's wishes in relation to organ donation helps those
2 important to them at this difficult time.

3

4 **Body Donation to Medical Science**

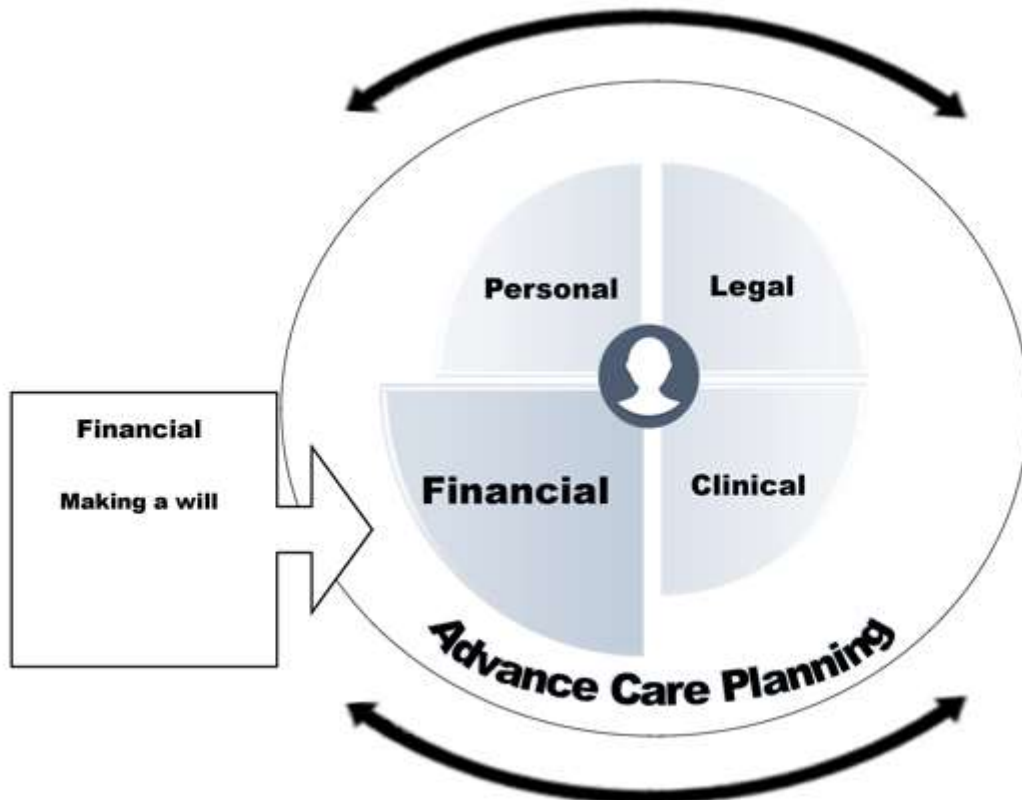
5

6 A person may wish to donate their body to medical science. It is important for the
7 person to discuss this with those important to them, and those providing care,
8 support or treatment. There is a correct process²⁸ which must be followed; this will
9 include keeping a copy of the fully completed consent form.

10

11 **Financial Component of Advance Care Planning**

12



13

14

15

16

²⁸ Information booklets including Consent Form are available from the Queens 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.

1 **Making a Will**

2

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

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

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

9

10 **Why it's important to make a will**

11

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

- 13 • A person can decide how their assets are shared.
- 14 • An unmarried couple can make sure their partner is provided for.
- 15 • If a person is divorced, they can decide whether to leave anything to their
16 former partner.
- 17 • A person can get more information on Inheritance tax.

18

19 **Preparing your will**

20

21 Although it is possible to write a will by yourself, it is advisable to use a solicitor as
22 there are various legal formalities. If a person doesn't have a will, the law says who
23 gets what.

24 An executor is the person who would carry out the wishes in a person's will. A
25 person can appoint an executor by naming them in their will. The courts can also
26 appoint other people to be responsible for doing this job.

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

31

32

1 **Updating your will**

2

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

5 A person can make changes by adding a note to their existing will or by making a
6 new will²⁹.

7

8 **Conclusion**

9

10 Advance Care Planning contains a number of components, within which there are a
11 number of elements. A person may choose to think about and plan for some of the
12 elements, but not others, and at different times within their life. This reflects the
13 personal and voluntary principles of Advance Care Planning and the need to provide
14 opportunities for a person to have Advance Care Planning conversations and to
15 review these conversations and/or any record that may be documented.

16 Advance Care Planning enables a person to think about what matters to them. This
17 can enhance their quality of life and enable their wishes, feelings, beliefs and values
18 to inform the care, support or treatment they receive if they become unable to make
19 decisions for themselves.

20 “Advance Care Planning, probably the most important conversation you will ever
21 have in your life” (Stakeholder quote from engagement, February 2021).

22

23

24

25

26

27

28

²⁹ <https://www.nidirect.gov.uk/articles/making-will>

1 Appendices

2 Appendix 1 Glossary of Terms

3

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

12 • **Advance Decisions to Refuse Treatment (ADRT):** In Northern Ireland, an ADRT
13 is legally binding (governed by common law instead of an Act) if it is valid and
14 applicable to the particular situation

15 • **Behaviour Change:** Behaviour change can refer to any transformation or
16 modification of human behaviour.

17 • **Best interests:** When a person lacks the mental capacity to make a specific
18 decision about their treatment at that time, and does not have a valid and applicable
19 Advance Decision to Refuse Treatment, the clinician who is treating the person will
20 make a “best interests’ decision regarding care and treatment.

21 • **Cardiac Arrest:** A cardiac arrest is when the heart has stopped pumping blood
22 around the body and the person becomes unresponsive and stops breathing
23 normally.

24 • **Cardiopulmonary resuscitation:** a medical procedure involving compression of
25 the chest and artificial respiration, performed to maintain blood circulation and
26 oxygenation in a person who has suffered a cardiac arrest.

27 • **Care, Support or Treatment:** Those who provide care, support or treatment, this
28 term is used throughout the policy and includes people working within the
29 community and voluntary sector, independent sector and other health and social
30 care staff working in statutory services.

- 1 • **Consent:** Consent is more than a form or formality. For consent to be valid, it must
2 be voluntary and informed, and the person consenting must have the capacity to
3 make the decision.
- 4 • **End of Life:** A period of time during which a person's condition is actively
5 deteriorating to the point where death is expected.
- 6 • **End of Life Care:** Is an approach that improves the quality of life of patients and
7 their families living with a life-threatening illness. Care includes assessment and
8 treatment of pain and other needs, physical, psychosocial and spiritual.
- 9 • **Enduring Power of Attorney:** A legal document which allows a person to appoint
10 others to make decisions on their behalf about their property and financial affairs if
11 they were to lose mental capacity.
- 12 • **Guidance:** Evidence-based recommendations on the most effective and cost-
13 effective treatment and care of people with specific diseases and conditions, and
14 recommendations for populations and individuals on interventions that can help
15 prevent disease or improve health. The professional regulators include (General
16 Medical Council (GMC), Nursing Midwifery Council (NMC), Health & Care
17 Professions Council (HSPC) and General Pharmaceutical Council (GPhc), Northern
18 Ireland Social Care Council (NISCC) produce regulatory 'guidelines'/ 'guidance' on
19 how professional standards should be achieved.
- 20 • **Holistic assessment:** Comprehensive assessment that addresses the social,
21 psychological, emotional, physical and spiritual needs of the person.
- 22 • **Holistic care:** Provision of care provided to a person based on an understanding of
23 their social, psychological, emotional, physical and spiritual needs.
- 24 • **Lasting Power of Attorney (LPA):** see section 97 of the Mental Capacity Act (NI)
25 2016, Is a legal document, which allows a person to appoint others to make
26 decisions on their behalf³⁰.
- 27 • **Mental Capacity Act (Northern Ireland) 2016:** Legislation that when fully
28 commenced, will fuse together mental capacity and mental health law.

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.

- 1 • **National Institute for Health and Care Excellence (NICE):** An organisation that
2 provides a robust and independent appraisal of the best available evidence to make
3 recommendations for the health and social care system.
- 4 • **Organ Donation:** Organ donation is the entire practice of retrieving a human organ
5 from a living or deceased person.
- 6 • **Palliative Care:** The active, holistic care of people with advanced progressive
7 illness. Management of pain and other symptoms and provision of psychological,
8 social and spiritual support is paramount. The goal of palliative care is to achieve the
9 best quality of life for people and those important to the person. Many aspects of
10 palliative care are also applicable earlier in the course of the illness in conjunction
11 with other treatments.
- 12 • **Progressive condition:** A disease or health condition that gets worse over time,
13 resulting in a general decline in health or function.
- 14 • **Power of Attorney:** Is a legal document which the person can use to give
15 someone else the authority to take actions or make decisions on their behalf.
- 16 • **ReSPECT:** Is an element of the clinical component of Advance Care Planning
17 enabling personalised recommendations for emergency care and treatment to be
18 documented.
- 19 • **Serious Illness:** A health condition that carries a high risk of mortality and impacts
20 a person's daily function or quality of life.
- 21 • **Spirituality:** Spirituality is about what gives meaning and purpose to life and is
22 based on a person's core beliefs and values.
- 23 • **Those important to the person:** This may be family, carers or someone who
24 knows, cares and has affection for the person. They may be connected through their
25 personal, legal, cultural or emotional relationship.

26
27
28
29

1 **Abbreviations**

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

12

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