

1 Contents

2

3	Innin	4
4	Ambeetion	6
5	Whit is Advance Care Plannin?	6
6	Advance Care Plannin an Mental Capacity	6
7	Vailyies an Preenciples o Advance Care Plannin	7
8	Vailyies	7
9	Preenciples o Prattick	7
10	Whit for is it important tae hae Advance Care Plannin collogues?	8
11	Benefits o Advance Care Plannin	9
12	Whan Shoud Advance Care Plannin Happen?	10
13	Haein Meaninfu Advance Care Plannin Collogues	12
14	The 'Sax Ts' o Guid Traffeck in Advance Care Plannin Collogues	13
15	Skarin Advance Care Plannin Collogues, Recommends an Deceesions	15
16	Reviewin Advance Care Plannin Collogues, Recommends an Deceesions	15
17	Whit wey Advance Care Plannin Collogues Is Used	15
18	Components o Advance Care Plannin	16
19	Personal Component o Advance Care Plannin	17
20	"Whit Maiters Tae Me" – Wisses, Feelins, Beliefs an Vailyies	17
21	Speerituality	18
22	Care an Uphaud for Dependants	18
23	Funeral Wisses	18
24	Online Accoonts	18
25	Legal Component o Advance Care Plannin	19
26	Mental Capacity Act (NI) 2016	19
27	Types o Pouer o Attorney	22
28	Pouer o Attorney	22
29	Endurin Pouer o Attorney	23
30	Lestin Pouer o Attorney	23
31	Advance Deceesions tae Refuse Treatment (ADRT)	24
32	Cleenical Component o Advance Care Plannin	25
33	Dwynin Halth & Unforeseen Emergencies	25

1	Clinical Recommendations for Cardiopulmonary Resuscitation (CPR)	26
2	Best Interests Decisions	26
3	Recommending Short Plan for Emergency Care & Treatment (ReSPECT)	27
4	Organ donation	28
5	Organ Donation for Medical Science.....	29
6	Financial Component of Advance Care Planning.....	29
7	Making a Will.....	30
8	Conclusion	31
9	Appendices	32
10	Appendix 1 Glossary of Terms.....	32
11	Abbreviations	35
12	Appendix 2 Bibliography	35

13

14

15

16

17

18

19

20

21

22

23

1 Innin

2

3 Advance Care Plannin is an umbrella term kiverin personal, legal, cleenical, an
4 financial plannin. It allous a body tae think about whit is important tae thaim an plan
5 for thair futur. It is a voluntar process an helps a body tae mak knawn whit thair
6 wisses, feelins, beliefs an vailyies is, an tae mak chyces that reflects thir. Advance
7 Care Plannin is an ongaun process o colloques atween a body, thaim that's
8 important tae thaim,¹ an thaim giein care, uphaud or treatment. Advance Care
9 Plannin shoud be an important pairt o life for aw adults.

10 The Advance Care Plannin policy haes been written for members o the public, thaim
11 that's important tae thaim, an thaim giein care, uphaud or treatment.²

12 This Advance Care Plannin policy haes been developed for tae gie a body a haund
13 tae hae mair chyce an control ower deceesions, comprehendin plans for thair futur
14 care an treatment. This is gey an important gin the body staps bein able tae mak the
15 relevant deceesions for thairsels at ony pynt.

16 Advance Care Plannin provides the inlat for adults that wisses tae dae thon tae:

- 17 • Think about whit maiters tae thaim;
- 18 • Syne tell fowk that's important tae thaim;
- 19 • Discuss it wi thaim that gies care, uphaud or treatment;
- 20 • Write it doun an skare it;
- 21 • Gang back tae the colloques an deceesions, mak ony cheenges, an syne
22 skare again.

23 Advance Care Plannin is important for aw adults, at whitiver stage o life. "The reality
24 that ae day ilkane o us will dee is something few o us conseeders an fewer still plans
25 for or discusses" (McKenna et al., 2020). Tho Advance Care Plannin haes
26 tradeetionally been associate wi end-o-life care, it gangs ayont this. As weel as
27 supportin deceesions in dwynin halth an unforeseen emergencies, the inlat that it
28 provides tae reflect an conseeder whit is important tae the body can meliorate thair
29 quality o life. It could be a soorce o comfort an reassurance tae thaim that's important
30 tae the body an aw.

31 This policy provides a framework for Advance Care Plannin for adults (aged 18 year
32 an abuin) in Northren Ireland, focussin on the halth an social care aspects. The
33 policy gies an owerview o Advance Care Plannin, an the vailyies an preinciples that
34 unnerpins it. It sets oot whit for Advance Care Plannin is important an whit wey it can
35 help fowk mak timeous, realistic an prattickal plans for thair futur. It encourages thir

¹ Thaim that's important tae the body: This could be family, carers or a body that knaws, cares an is fain o the body. Thay could be claucht throu thair personal, legal, cultural or emotional relationship.

² Thaim that gies care, uphaud or treatment: This term is used athort the policy an taks in fowk wirkin in the community an voluntar sector, independent sector an ither halth an social care staff wirkin in statutor services.

1 plans tae be made in collogue wi thaim that's important tae thaim an/or a body giein
2 care, uphaud or treatment.

3 For thaim that's important tae the body, Advance Care Plannin coud provide a
4 clearer unnerstaundin o the body's wisses, feelins, beliefs an vailyies, comprehendin
5 ony relevant preferences an deceesions the body micht coud hae made.

6 For fowk giein care, uphaud or treatment tae a body, the policy provides clarity an
7 uphaud for thair role in haein thir important collogues as pairt o the end-tae-end care
8 or services that thay provide. Gin the body staps bein able tae mak the relevant
9 deceesions for thairsels, than thir deceesions haes tae be made grundit on whit is in
10 the body's best interests. In wirkin oot whit is in the body's best interests, special
11 regaird shoud be giein tae the body's wisses, feelins, beliefs an vailyies. Deceesions
12 maunna be made on the foonds o assumptions anent factors the like o the body's
13 age or disabeelity thair lane,³ or on a professional's subjective view o a body's quality
14 o life.⁴

15 E'en whan a body's abeelity tae mak a speceefic deceesion is impaired, aw
16 prattickable staps shoud still be taen tae uphaud thaim tae mak ither deceesions.
17 Whan a body isna able tae mak the speceefic deceesion, the body shoud be
18 supportit tae be as involved in the deceesion-makkin process as possible.

19 The policy provides an ethical an richts-grundit oncome⁵ tae Advance Care Plannin
20 for adults, conform tae legislation, best prattick an professional guidal an staundarts.
21 The policy is supportit by guidal, trainin an lear an public wittins for tae mak shuir o a
22 conseestent oncome tae Advance Care Plannin that's inclusive an accessible.
23 (Guidal an wittins documents pendin post Public Consultation).

24

25

26

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 An ethical an Human Richts grundit oncome references, for example, the Unitit Naitions Convention on the Richts o Fowk wi Disabeelities Airticles 9, 12, 16, 17 & 25.

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

1 **Ambeetion**

2 The ambeetion o this policy an whit wey it is pitten intae prattick is that:

- 3 • Advance Care Plannin collogues comes tae be normaleesed;
- 4 • Aw adults in Northren Ireland (NI) haes raiglar inlats tae express thair wisses,
5 feelins, beliefs an vailyies anent Advance Care Plannin; an that
- 6 • Thir is reflectit in the care, uphaud or treatment that thay get.

7 **Whit is Advance Care Plannin?**

8

9 Advance Care Plannin is an umbrellae term kiverin personal, legal, cleenical, an
10 financial plannin. It allous a body tae think aboot whit is important tae thaim an plan
11 for thair futur. It is a voluntar process an helps a body tae mak knawn whit thair
12 wisses, feelins, beliefs an vailyies is, an tae mak chyces that reflects thir. Advance
13 Care Plannin is an ongaun process o collogues atween a body, thaim that's
14 important tae thaim, an thaim giein care, uphaud or treatment.

15 Advance Care Plannin shoud be an important pairt o life for aw adults. It needs tae
16 be fordert by thaim giein care, uphaud or treatment for tae mak shuir that fowk haes
17 the inlat tae hae timeous, realistic an prattickal collogues. Thir collogues focusses on
18 whit maiters tae the body an whit wad be important for thaim tae prioriteese in the
19 futur gin thay stap bein able tae mak deceesions for thairsels.

20 Gin the body wants tae mak a record o thir collogues an skare thaim, thay shoud be
21 supportit tae dae thon. The collogues coud tak in, for example, mental halth crisis
22 plannin, Advance Deceesions tae Refuse Treatment (ADRT), an the body's view on
23 cardiopulmonar resuscitation (CPR).

24

25 **Advance Care Plannin an Mental Capacity**

26

27 Advance Care Plannin taks in references tae a body haein mental capacity, sae it is
28 important tae unnerstaund whit this means. The Mental Capacity Act (Northren
29 Ireland) 2016 is an Act that maks proveesion anent bodies that wants capacity.

30 The first preinciple o the Mental Capacity Act (NI) 2016 is that a body isna tae be
31 treatit as wantin capacity unless it is established that the body wants capacity anent
32 the maiter in quaisten.⁶ Mental capacity is baith deceesion- an time-speceefic. Fowk
33 coud be able tae mak some deceesions at ae time but no anither. E'en gin the body

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

1 wants the mental capacity for a specific decision at that time, their wishes,
2 feelings, beliefs and values is central, and the body aye still needs to be supported to
3 be involved as much as possible. More detail is given on page 19.

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

5 **Values:**

6 Advance Care Planning:

- 7 • Respects and upholds the rights, dignity and culture of the body and is inclusive
- 8 of all adults;
- 9 • Provides an ethical outcome to discuss their important and little questions;
- 10 • Is accessible to the body in a way that lets them have meaningful dialogues;
- 11 • Is a body's individual choice. Some people might not want to think about
- 12 or engage in Advance Care Planning dialogues – their choice should be
- 13 respected, with the option to go back to the dialogue at another time;
- 14 • Is a personal experience. A body's wishes, feelings, beliefs and values will be
- 15 individual to the body and their own circumstances;
- 16 • Is a voluntary process. Pressure must not be put on the body during the Advance
- 17 Care Planning dialogue by anyone: their own care, support or treatment; the
- 18 family; a body important to the body; or by any organisation.⁷

19 **Principles of Practice:**

- 20 • Advance Care Planning dialogues need to be meaningful, conducted with
- 21 sensitivity and compassion. They need time and should happen at the body's
- 22 pace;
- 23 • Consent is more than a form or formality. Consent needs to be thought about at
- 24 each stage of the Advance Care Planning process, i.e. during the dialogue, signing
- 25 the document with others, making a record, signing the record;
- 26 • Where there is a record of Advance Care Planning dialogues, this should be
- 27 accessible at all times to make sure that a body's wishes, feelings, beliefs
- 28 and values, and any recommendations and/or decisions made, are known;
- 29 • A body's confidentiality should be respected;

⁷ For more 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 • Advance Care Plannin collogues, ony recommends an/or deceesions needs
2 tae be reveesitit, reviewed an, gin needit, skared again for tae mak shuir that
3 thay bide up tae date, as a body micht coud cheenge thair mind about a
4 when things;
- 5 • Advance Care Plannin incorporates the preenciples o the Mental Capacity Act
6 (NI) 2016.
7

8 **Whit for is it important tae hae Advance Care Plannin** 9 **collogues?**

10

11 Whan a body's wisses, feelins, beliefs an vailyies is knawn, it can help tae gie a
12 heeze tae thair autonomy an richts, an reduce ony potential distress for the body an
13 thaim that's important tae thaim. It helps guide an inform thaim giein care, uphaud or
14 treatment an aw.

15 A fouth o naitional an internaitional resairch studies [Appendix 2] on 'faimily or
16 caregivers"⁸ experience o Advance Care Plannin shaws that meaninfu Advance Care
17 Plannin collogues is benefeecial for a when raisons:

18

19

20

21

22

23

24

25

26

27

⁸ "Faimily or caregivers" is the phrase uised in resairch studies. This policy uses the term "thaim that's important tae the body".

Benefits o Advance Care Plannin	
A Better Quality o Life	Whan a body haes the inlat tae reflect on an talk about “whit maiters tae thaim”, it can help thaim mak chyces nou that's conform tae thair wisses, feelins, beliefs an vailyies.
Peace o Mind	Whan a body haes the inlat tae “pit thair affairs in order” or talk about ony howps or fears thay micht coud hae, it can help gie thaim a lift.
Clarifeein Deceesions	Whan a body haes the wittins that thay need for tae mak deceesions, an/or haes the inlat tae say whit maiters tae thaim, than thaim that's important tae the body can know whit the body wants or disna want.
Easin Caregier Concerns	Whan thaim that's important tae the body is clear about whit maiters tae the body, thay can feel shuirer in makkin knawn whit the body wad want gin thay cam tae be no able tae communicate or mak deceesions for thairsels.

1

2 Local resairch studies in Northren Ireland reinforces the need for mair awaurness an
 3 unnerstaundin o Advance Care Plannin an aw, an for mair appen, timeous an
 4 meaninful collogues on this [Appendix 2].

5 Advance Care Plannin is relevant tae aw adults. Ideally, it is a series o collogues,
 6 that evolves ower time. Gin the body wants, thaim that's important tae thaim shoud
 7 be involved or be made awaur o the collogues an aw.

8 Advance Care Plannin is an important pairt o giein care, uphaud or treatment, by
 9 makkin shuir that fowk haes the inlat tae hae realistic an prattickal collogues about
 10 whit maiters tae thaim, an tae conseeder an record thair wisses, feelins, beliefs an
 11 vailyies, gin thay chuisse tae dae thon.

12 Onybody giein care uphaud or treatment an that haes raiglar interaction wi fowk
 13 haes a role tae play in unnerstaundin the vailyies an preinciples o Advance Care
 14 Plannin an the operational processes that allous the appropriate collogues tae tak
 15 place, an gin the body consents, tae hae thaim clarkit an skared. Lear an trainin will
 16 be providit tae thaim giein care, uphaud or treatment.

17

18

19

1 **Whan Shoud Advance Care Plannin Happen?**

2

3 Advance Care Plannin is important for ilka adult at ony stage o life an is relevant tae
4 fowk in guid halth as weel as thaim that's sair smitten. Ideally Advance Care Plannin
5 shoud happen lang afore ony crisis or sairious seekness the like o a mental halth
6 crisis or the diagnosis o a sairious pheesical seekness.

7 By beginnin the colloque early on in thair life, the body can feel mair able for it
8 emotionally, an can tak thair time tae think an talk about whit maiters tae thaim. This
9 can involve a wheen stages that coud reenge frae no knawin ocht about Advance
10 Care Plannin, tae knawin but no wantin tae hae the colloque, throu tae feelin able
11 tae think about thair personal wisses, feelins, beliefs an vailyies an than haein
12 Advance Care Plannin colloques.

13 It can tak time for some fowk tae feel ready tae hae thir colloques an/or mak a record
14 o it. This is normal, an thare can be mony raisons for this: for example, some fowk
15 can be feart tae express thair wisses or believe gin thay dae that fowk important tae
16 thaim micht get mismuived. Fowk can be sweir tae conseeder a time whan thay coud
17 stap bein able tae mak the necessar deceesions aboot thair care an aw. It is
18 important tae raise awaurness an unnerstaundin o Advance Care Plannin colloques,
19 for tae normaleese thaim. It is important, therefore, tae emphaseese the benefits an
20 gie fowk a haund tae muive frae juist thinkin aboot haein an Advance Care Plannin
21 colloque tae actually haein ane.

22 Awbody will leuk at this differently, an whit ae body needs can differ frae the neist
23 body. Fowk's ain experience o whit wey thay cheenge thair behaviour can be
24 different. It can tak time, for behaviour cheenge is an ongaun process. The diagram
25 ablo shaws whit wey a body's behaviour can muive frae no knawin aboot tae daein
26 Advance Care Plannin.



1

2 For thae fowk wi sairious or progressive condeetions, an thaim that's mebbe nearin the end o thair life, thir collogues shoud happen
3 as early as possible an when the body is medically stable.

4 Whaur thir collogues haesna awreadies happent, they can be promptit whan:

5 • A body shaws that thay ar ready tae hae thir collogues;

6 • Pairt o an end-tae-end assessment atween the body an thaim giein care, uphaud or treatment;

7 • The body haes haen time tae adjust follaein a diagnosis o a progressive condeetion an feels ready tae hae thir collogues;

8 • A body haes haen a signeeficant deterioration in pheelsical halth or a when unplanned hospital admeessions;

9 • A body micht coud hae experienced a mental halth crisis whan thair abeelity tae mak some deceesions wis impaired;

10 • The body's cognitive state is like tae deteriorate;

11 • The body's abeelity tae communicate is like tae deteriorate.

1 Fowk can express thair wisses, feelins, beliefs an vailyies ower a period o time, tae
2 thaim that's important tae thaim or tae thaim giein care, uphaud or treatment.
3 Advance Care Plannin collogues can tak place in ony settin but shoud, whaur
4 possible, be duin whan an whaur the body feels maist comfortable. Whauriver the
5 collogue taks place, ilka effort shoud be made tae mak shuir that it is suitit⁹ tae haein
6 meaninfu Advance Care Plannin collogues.

7 **Haein Meaninfu Advance Care Plannin Collogues**

8

9 Whan fowk is ready tae hae Advance Care Plannin collogues, thaim giein care,
10 uphaud or treatment haes an important role. It is vital that thay hae the knowledge,
11 confidence an communications skeels needit tae uphaud this.

12 The importance o guid, effective traffeck haes been conseestently hielichtit athort
13 resairch studies as weel as throu reportit personal experiences [Appendix 2]. This
14 reinforces the need tae better capabeelities,¹⁰ comprehendin knowledge, skeels an
15 unnerstaundin o Advance Care Plannin an, in parteecular, traffeck skeels.¹¹

16

17

18

19

20

21

22

23

24

25

⁹ The like o haein eneuch time, uisin a lown place that allous for confidentiality an lessens the possibeelity o inappropriate interruptions or distractions; proveesion o appropriate an accessible material, appropriate fowk involved, an speceefic traffeck preferences or needs the body micht coud hae.

¹⁰ Refer tae Advance Care Plannin Capabeelities Framework (Pendin).

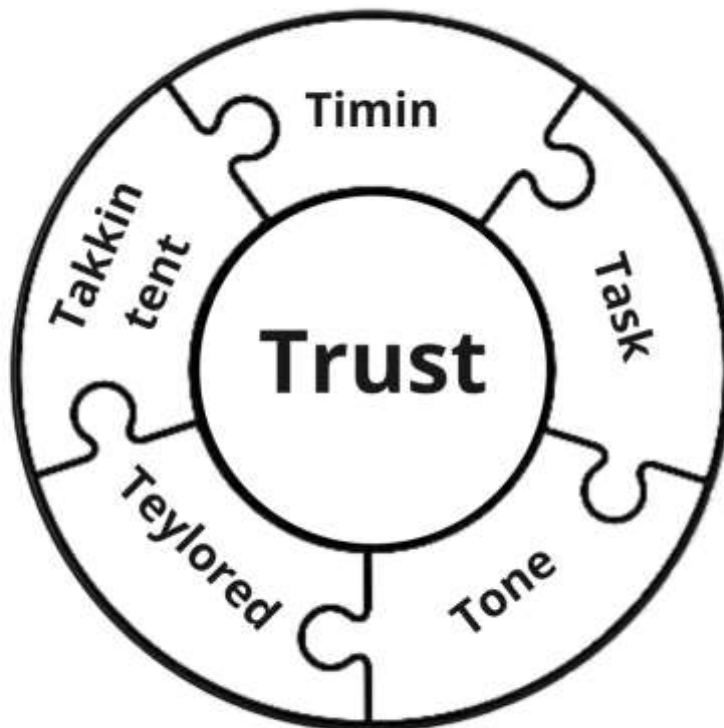
¹¹ Gin levels o halth leeteracy is unnerdeveloped, this can lead tae a traffeck gap atween the body an thaim giein care, uphaud or treatment whan haein an advance care plannin collogue.[Towards an action plan for health literacy in Northern Ireland: A Patient and Client Council scoping paper January 2021. Mair wittins on Health Leeteracy – [PCC Health Literacy Scoping Paper FINAL Jan 21 v2 – Patient and Client Council Northern Ireland \(hscni.net\)](https://www.hscni.net)]

1 **The 'Sax Ts' o Guid Traffeck in Advance Care Plannin Collogues**

2

3 The diagram an table ablo gies guidal on whit wey tae communicate whan haein
4 Advance Care Plannin collogues, whether the collogue is bein promptit by the body
5 or by thaim giein care an uphaid or treatment. It should be mindit that thare is twa
6 sides tae thir collogues: either the body that's thinkin aboot an wants tae hae an
7 Advance Care Plannin collogue, or the body that's listenin tae an/or faceelitatin the
8 collogue. This coud be a body important tae the body, an/or a body giein care,
9 uphaid or treatment. Mindin the follaein uphaid's meaninfu Advance Care Plannin
10 collogues.

11



12

13

14

15

16

17

Trust	<p>Trust is central tae thir colloques.</p> <p>A body that's thinkin about Advance Care Plannin will want tae hae a collogue wi a body that respects thair vailyies an opeenions an is seen as reliable an dependable – a body that thay lippen tae.</p> <p>The body that's listenin tae an/or faceelitatin thir colloques shoud respect the wisses, feelins, beliefs an vailyies o the body as thay plan for thair care, an thay shoud uphaud the body durin the hale collogue.</p>
Timin	<p>Shoud be whan the body feels ready tae begin the Advance Care Plannin collogue an be for as lang as the body wisses tae conteenue the collogue(s).</p> <p>Whan the body giein care, uphaud or treatment wants tae begin the Advance Care Plannin collogue, thay shoud find oot gin this is a guid time for the body tae hae the collogue.</p>
Task	<p>Gin some o the body's wisses, feelins, beliefs an vailyies is awreadies knawn, big on this.</p> <p>It's important tae be clear on whit it is ye want tae say.</p> <p>Mak shuir that the ither body haes heard an unnerstands whit it wis ye wantit tae say.</p>
Tone	<p>Whit wey we say something is as important as the wirts we uise. Thir is important colloques an can be emotional; therefore, be gentle, sensitive an compassionate whan haein an Advance Care Plannin collogue.</p>
Teylored	<p>Uise clear, accessible langage, 'ithoot jargon, an mak shuir, gin a body needs help tae communicate, e.g. interpreter, sign langage or a device that helps thaim tae communicate, that this is available.</p>
Takkin Tent	<p>Tae whit wey the body micht be feelin about an durin the collogue.</p> <p>Tae the ither body's pace.</p> <p>Tae the ither body's unnerstaundin.</p>

1

2

1 **Skarin Advance Care Plannin Collogues, Recommends an** 2 **Deceesions**

3

4 Whan haein Advance Care Plannin collogues, the body's wisses, feelins, beliefs an
5 vailyies (comprehendin ADRT¹² deceesions & ReSPECT recommends¹³) can be
6 clarkit an skared, gin thay consent tae dae thon.

7 **Reviewin Advance Care Plannin Collogues, Recommends** 8 **an Deceesions**

9

10 Advance Care Plannin deceesions isna 'setten in stane'. Thay can be reveesitit an
11 reviewed at any time for tae mak shuir that ony wisses, recommends an/or
12 deceesions made bides relevant tae the body's circumstances. Reviewin Advance
13 Care Plannin collogues, ony recommends an/or deceesions is an integral pairt o the
14 Advance Care Plannin process, an ony review shoud be duin conform tae the
15 vailyies an preenciples that unnerpins Advance Care Plannin.

16 A review can be ineetiate by the body thairsels or by a body giein care, uphaud or
17 treatment. The timin or frequency o ony review will vary for awbody. Reviewin
18 Advance Care Plannin collogues, ony recommends an/or deceesions is especially
19 important gin thare is ony cheenges in the body's circumstances or in thair health
20 condeetion. It is important that ony cheenges tae Advance Care Plannin collogues,
21 ony recommends an/or deceesions is communicatit an skared wi thaim that's
22 important tae the body an/or a body giein care, uphaud or treatment.

23 **Whit wey Advance Care Plannin Collogues Is Used**

24

25 A body's Advance Care Plannin collogues, ony recommends an/or deceesions will
26 be used in the futur gin a body's no able tae mak a speceefic deceesion for
27 thairsels. This coud be acause thay dinna hae mental capacity or arna able tae
28 communicate whit thair wisses is.

29 Naebody in Northren Ireland haes the legal authority tae consent tae ony care or
30 treatment on behauf o anither adult. In seetuations whaur a body wants the mental
31 capacity tae mak a speceefic deceesion about thair treatment at that time, an disna
32 hae a valid an appleeable Advance Deceesion tae Refuse Treatment, the
33 clineecian that's treatin the body will mak (a) 'best interests' deceesion(s). Therefore,

¹² See section "Advance Deceesions tae Refuse Treatment" blad 24.

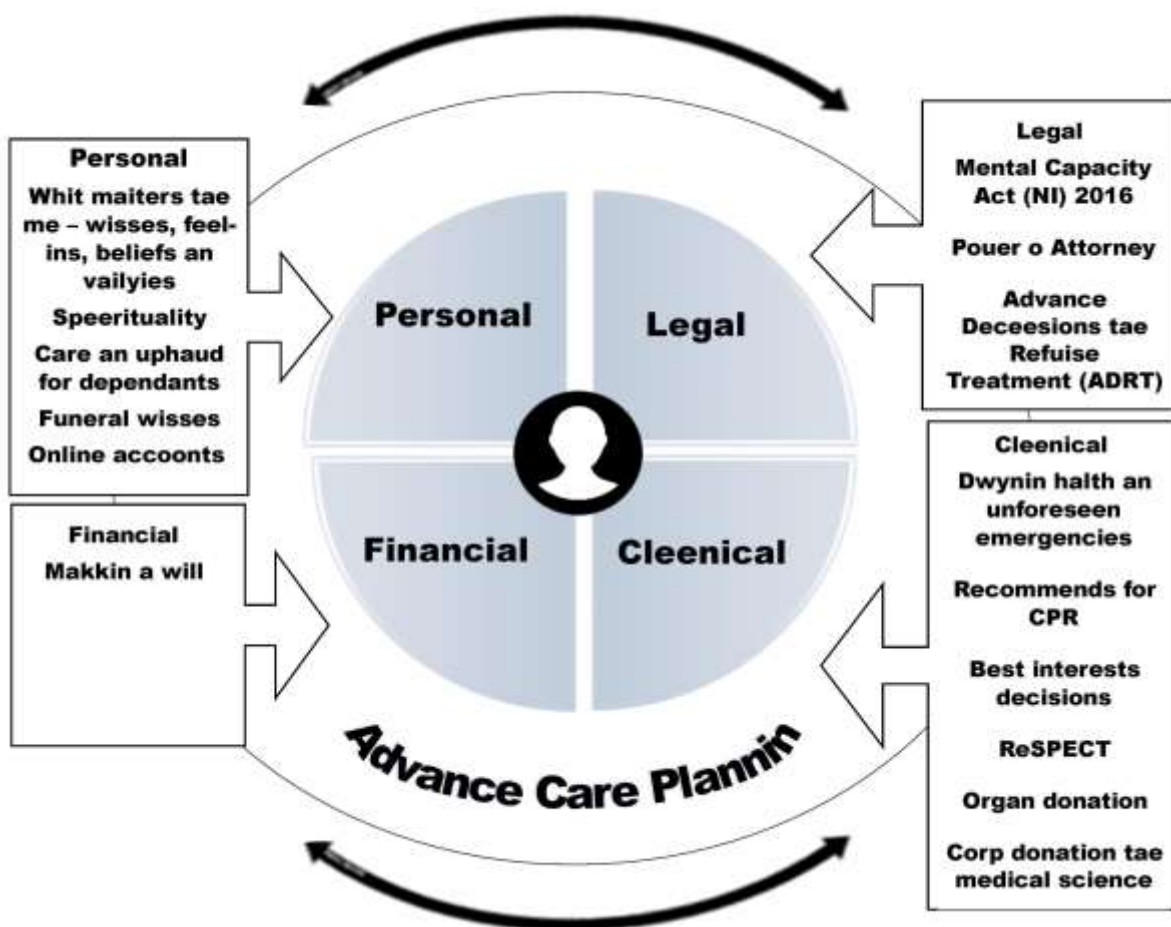
¹³ See section "Recommendit Short Plan for Emergency Care & Treatment (ReSPECT)" blad 27.

1 previous Advance Care Plannin collogues, ony recommends an/or deceesions will
2 be used tae guide an inform the 'best interests'¹⁴ deceesion.

3 **Components o Advance Care Plannin**

4

5 This section kivers the fower components o Advance Care Plannin. Thay ar
6 Personal, Legal, Cleenical an Financial. Ilka component conteens ane or mair
7 elements, an ilkane is descrided in detail ablo. A when elements mebbe fits intae
8 mair nor ae component. (Public wittins on thir elements will be available follaein
9 public consultation).



10

11 Thir preencipal components is conseedert in the follaein sections.

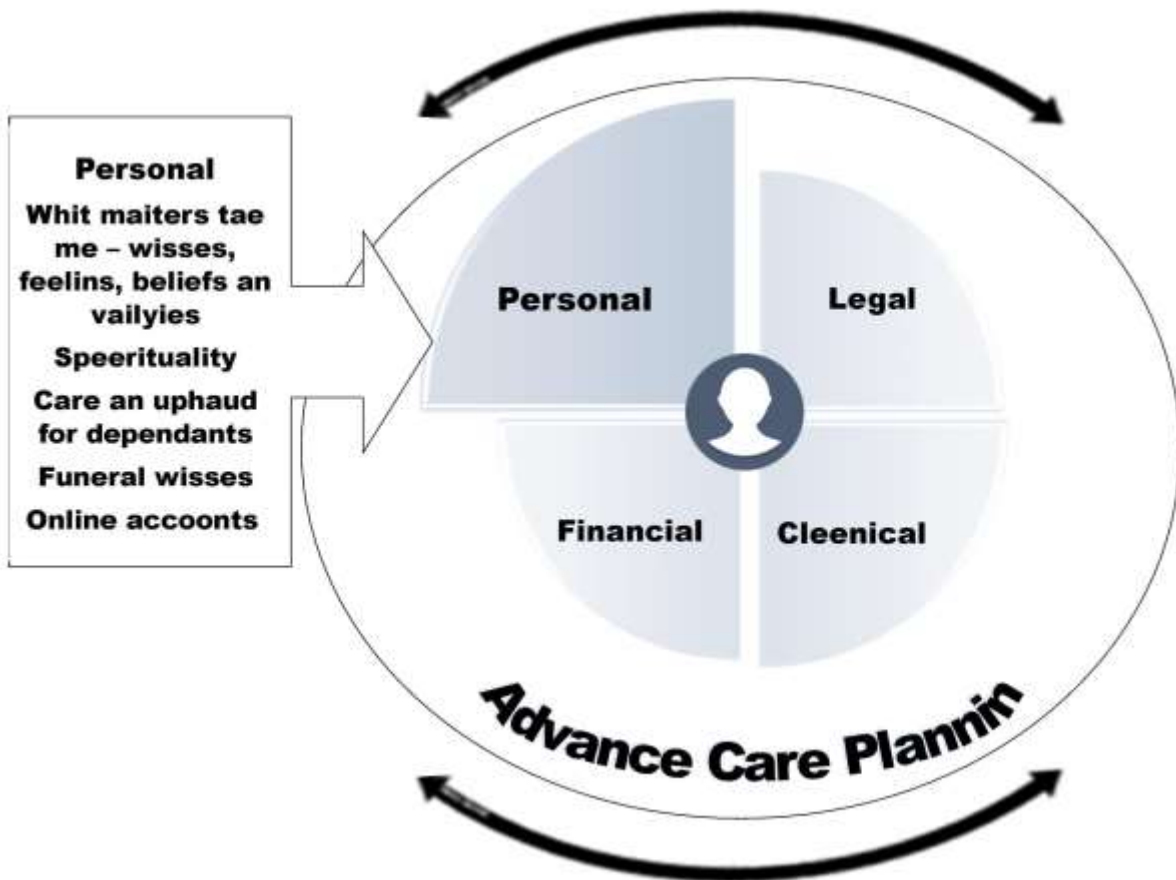
12

13

¹⁴ See "Best Interests" section blad 26.

1 Personal Component o Advance Care Plannin

2



3

4 “Whit Maiters Tae Me” – Wisses, Feelins, Beliefs an Vailyies

5

6 This part o Advance Care Plannin is about thae gey an personal things that gies
7 meanin an purpose tae a body's life. It can tak in fowk, places, speerituality or ither
8 things that maiters tae the body.

9 A body can tell fowk about whit maiters tae thaim, or write it doun. Thir can be
10 speceefic wisses about whit is important tae thaim when thay ar weel an whit is
11 important tae thaim gin thay cam tae be no able tae mak the relevant deceesions
12 about thair lifes.

13 Wisses, feelins, beliefs an vailyies will differ accordin tae awbody. For example, for
14 some fowk, managin pain is an absolute priority, while for ithers, tholin some pain tae
15 be wi fowk important tae thaim is thair priority.

16 It is important for onybody involved in the body's care tae know whit maiters tae
17 thaim, whether or no it is written doun. Knowin whit maiters tae the body helps tae
18 guide an inform thaim giein care, uphaud or treatment tae mak deceesions when the
19 body isna able tae mak the relevant deceesions an/or communicate whit thair wisses
20 is.

1 **Speerituality**

2 Advance Care Plannin collogues focusses on whit is important tae a body an can tak
3 in the body speakin about the speeritual aspect o thair lifes. Speerituality is about
4 whit gies meanin an purpose tae life, an it is grundit in a body's core beliefs an
5 vailyies. Speerituality can be expressed in mony different ways. For some fowk, thay
6 can express thair speerituality throu thair faith an 'ithin a formal releegion. For ithers,
7 it can be expressed throu muisic, airts, or natur. Speerituality informs an guides a
8 body in whit wey thay behave an in whit wey thay relate tae ithers, an it can be a
9 soorce o comfort, uphaud an strenth throu a body's life. Speerituality can come tae
10 be e'en mair important tae a body as thay growe aulder or gin thay ar smitten wi gey
11 an sairious seekness.

12

13 **Care an Uphaud for Dependants**

14 For a wheen fowk, a preencipal priority for thair Advance Care Plannin will be tae
15 hae the reassurance that care an uphaud will be in place for thair dependants. For
16 mony carers, for example, haein collogues aboot an makkin arreengements for the
17 futur care an uphaud o thaim that thay care for will be an important pairt o thair ain
18 Advance Care Plannin an mebbe e'en be a prompt for this.

19 It is important tae recogneese the peace o mind that sic collogues an plans can
20 bring.

21 This isna anely for thaim wi dependants. For some fowk, Advance Care Plannin will
22 tak in makkin arreengements for the care o thair pets gin thay warna able tae leuk
23 efter thaim thairsels.

24

25 **Funeral Wisses**

26 For a wheen fowk, thinkin about thair ain funeral or haein collogues about it wi thaim
27 that's important tae thaim can be emotional. Haein thir collogues, houiver, can mak
28 shuir that the body's wisses an preferences is knawn an reflectit. Forby thon, it can
29 help reduce ony fashes that thaim that's important tae the body micht coud hae, as
30 thay ar involved in the collogues an knaw whit type o funeral the body wad want.

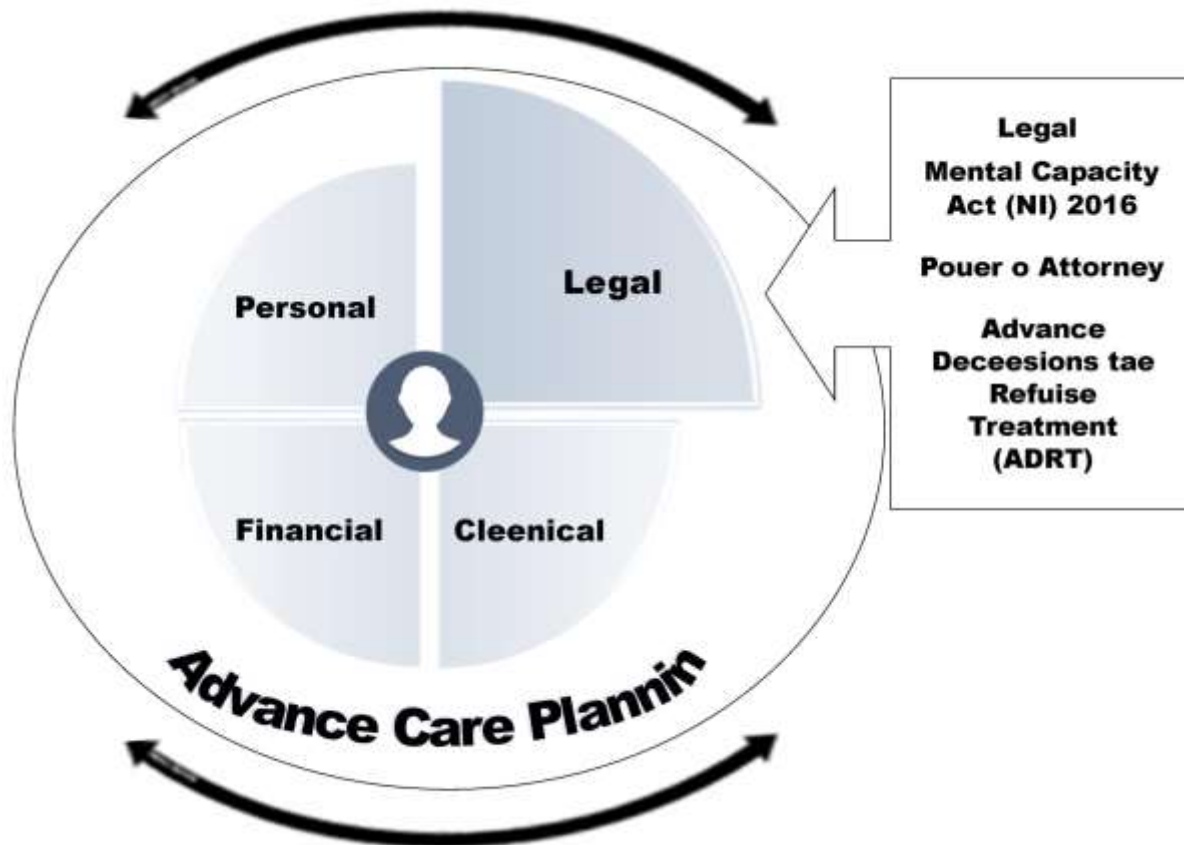
31

32 **Online Accoonts**

33 It is important tae conseeder whit will happen tae ony online accoonts efter a body
34 dees. This can tak in a body decidin whit thay wad want tae happen tae photos,
35 videos, e-mails, bankin or ither wittins hauden online, whiles knawn as a body's
36 deegital heirskip.

37 Some fowk can decide tae skare thair personal wisses about social media or online
38 accoonts. (e.g. delete or keep appen e-mail, or social media accoonts).

1 Legal Component o Advance Care Plannin



2

3 Mental Capacity Act (NI) 2016

4 Advance Care Plannin taks in references tae a body haein mental capacity, sae it is
5 important tae unnerstaund whit this means. The first preinciple o the Mental
6 Capacity Act (NI) 2016 is that a body isna tae be treatit as wantin capacity unless it
7 is established that the body wants capacity anent the maiter in quaisten.¹⁵ A body
8 could be able tae mak some deceesions at ae time but no anither. Mental capacity is
9 baith deceesion- an time-speceefic, whit means:

- 10 • A body shoud hae the relevant mental capacity for a speceefic deceesion at
11 that time;
- 12 • A body can want the mental capacity for some speceefic deceesions at that
13 time but reteen the mental capacity for mony ithers;
- 14 • E'en gin a body wants the relevant mental capacity for a speceefic deceesion
15 at that time, thair wisses, feelins, beliefs an vailyies is central, an the body aye
16 still needs tae be supportit tae be involved as muckle as possible.

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

1 Advance Care Plannin collogues, ony recommends an/or deceesions will be used
 2 whan the body canna mak deceesions for thairsels. This can be acause, e'en wi
 3 uphaud, thay want the mental capacity tae mak the speceefic deceesion at that time.

4 For tae hae the capacity tae mak the speceefic deceesion, a body maun be able tae:
 5 lift; reteen; appreciate, uise an wecht the relevant wittins; an communicate thair
 6 deceesion. Whan a body wants capacity for a speceefic deceesion, prior Advance
 7 Care Plannin collogues, ony recommends an/or deceesions can help guide thaim
 8 giein care, uphaud or treatment sae that, sae faur as possible, this is providit
 9 conform tae the body's wisses, feelins, beliefs an vailyies for thair futur care.

10 The Mental Capacity Act (NI) 2016 is an Act o the Northren Ireland Assemmlly. The
 11 Act received Royal Assent on 9 Mey 2016.¹⁶ Section 3 o the Mental Capacity Act
 12 (NI) 2016 assigns the follaein meanin tae the term “want o capacity”:
 13

Section 3 o the Mental Capacity Act (NI) 2016
<p>“(1) For the purposes o this Act, a body that's 16 or abuin wants capacity anent a maiter gin, at the material time, the body isna able tae mak a deceesion for hissel or hersel about the maiter ('ithin the meanin gien by section 4) acause o an impairment o, or a disturbance in the functionin o, the mind or harn.</p> <p>(2) It disna maiter:</p> <p>(a) whether the impairment or disturbance is permanent or temporar;</p> <p>(b) whit the cause o the impairment or disturbance is.</p> <p>(3) In parteecular, it disna maiter whether the impairment or disturbance is caused by a disorder or disabeelity or itherwise nor by a disorder or disabeelity.”</p>

14

15 The Act specifees that a ‘want o capacity’ is about a body no bein able tae mak a
 16 deceesion for thairsels on a speceefic maiter.

17 It recogneeses an aw that mental capacity can simmer an winter an can be temporar
 18 or permanent.

19 There is a when gey an important preenciples in the Mental Capacity Act (NI) 2016
 20 about capacity that can hinder it bein wrangly assumed that a body haes a want o
 21 mental capacity. The statutor preenciples o the Mental Capacity Act (NI) 2016 is:¹⁷

22 Preenciple 1 – The first preenciple o the Mental Capacity Act (NI) 2016 is that a body
 23 isna tae be treatit as wantin capacity unless it is established that the body wants
 24 capacity anent the maiter in quaisten.

¹⁶ The Mental Capacity Act (NI) 2016 refers tae onybody abuin the age o 16, but the scowth o this policy is for thaim aged 18 an abuin.

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

1 Prenciple 2 – The quaisten gin a body is able tae mak a deceesion for hissel or
 2 hersel can anely be determined by conseederin the obligations o the Act, an nae
 3 assumptions can be made juist on the foonds o ony condeetion that the body haes
 4 or ony ither chairacteristics o the body.

5 Prenciple 3 – A body isna tae be treatit as no able tae mak a deceesion for hissel or
 6 hersel unless aw prattickable help an uphaud tae enable the body tae mak the
 7 deceesion haes been gien 'ithoot success.

8 Prenciple 4 – A body isna tae be treatit as no able tae mak a deceesion juist
 9 acause the body maks an unwicelike deceesion.

10 Prenciple 5 – Ony act duin, or deceesion made, maun be made in the body's best
 11 interests.

12 **Aspects tae Conseeder anent Mental Capacity**

13 Thir is important aspects tae conseeder anent mental capacity.

<p>Whit for is a body no able tae mak the deceesion?</p>	<p>A body isna able tae mak a deceesion gin thay ar no able tae:</p> <ul style="list-style-type: none"> • lift the wittins thay need that wad help thaim mak a deceesion. • mind thae wittins for the time needit tae mak the deceesion. • uise thae wittins tae wecht the pros an cons as pairt o the process o makkin the deceesion. • communicate thair deceesion (whether by talkin, uisin sign langage, or by ony ither means).
<p>Supportin a body tae mak a deceesion</p>	<p>A body maun be gien aw prattickable help an uphaud tae enable thaim tae mak a deceesion. The staps needit is:</p> <ul style="list-style-type: none"> • provide the body wi aw the relevant wittins in a wey that best suits thaim an thair needs. (e.g., written, spoken, uisin sign langage, etc.). • mak shuir that the collogue wi the body is at a time or times that suits the body best (e.g. some fowk feel mair able or alert early in the morn). • mak shuir the settin (environment) tae hae the collogue suits the body best (e.g. no noisy, nae interruptions nor wi ower mony distractions). • mak shuir that thaim that's important tae the body or thaim that can uphaud thair traffeck is involved.

<p>Establishin gin a body wants capacity</p>	<p>Tae establish gin a body wants capacity tae mak a deceesion on a speceefic maiter, thaim assessin the body maun:</p> <ul style="list-style-type: none"> • mak shuir o prestaton wi the preenciples in the Mental Capacity Act (NI) 2016 • reasonably believe that the body wants capacity tae mak that speceefic deceesion. • hae providit the relevant wittins in a wey that's accessible tae the body. • hae providit the uphaud the body needs tae enable thaim tae mak the deceesion.
<p>Wha can determine gin a body haes Mental Capacity?</p>	<p>Pruivin capacity is a core function o ony halth an social care worker, an it is expectit that aw halth an social care professionals shoud be able tae cairy oot routine mental capacity assessments.</p> <p>For sairious interventions an treatment deceesions, a body pruvuin mental capacity maun be suitably qualiffee'd, as laid down in the Mental Capacity Act (NI) 2016¹⁸.</p>

1

2 **Types o Pouer o Attorney**

3 There is three different types o 'Pouer o Attorney', an ilkane is descrived here. It is
4 important tae note, tho, that anely the first twa is in place in Northren Ireland at the
5 meenit. It is wicelike tae seek legal advisement, for tentie conseederation shoud be
6 gien tae the reenge o pouers that a body wisses tae gie an attorney.¹⁹

7

8 **Pouer o Attorney**

9

10 Pouer o Attorney is a legal document that the body can uise tae gie anither body the
11 authority tae tak actions or mak deceesions on thair behauf. It allous the body, while
12 thay still hae mental capacity, tae hae anither body (cried an attorney) tae deal wi
13 thair haudin an finance, for example, gin thay're no pheesically able tae cairy oot
14 tasks for thairsels, the like o veesitin the bank.

15 A Pouer o Attorney ends whan the body tines mental capacity for managin thair ain
16 affairs.

¹⁸ [Mental Capacity Act \(Northern Ireland\) 2016 \(legislation.gov.uk\)](https://www.legislation.gov.uk/ukpga/2016/5/contents/enacted)

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>

1 **Endurin Pouer o Attorney**

2

3 An Endurin Pouer o Attorney (EPA) is a legal document that allous a body tae
4 appynt ithers tae mak deceesions on thair behauf aboot thair haudin an siller gin
5 thay tint mental capacity.

6 Haein an EPA allous a body tae plan ahead in case thay tine the mental capacity tae
7 mak thair ain deceesions aboot thair siller or haudin.

8

9 **Lestin Pouer o Attorney**

10

11 Pairt 5 o the Mental Capacity Act (NI) 2016 maks proveesion anent Lestin Pouer o
12 Attorney (LPA). This Pairt o the Act haesna yet been commenced; therefore, the
13 proveesions o Pairt 5 o the Act that relates tae Lestin Pouer o Attorney isna yet in
14 force in Northren Ireland.

15 An LPA is a legal document that allous a body tae appynt ithers tae mak deceesions
16 on thair behauf. It can be made for haudin an siller, an can be made for halth an
17 social care deceesions an aw, comprehendin deceesions aboot treatment an end-o-
18 life care. Section 97 defines Lestin Pouer o Attorney as follaes:

Pairt 5 o the Mental Capacity Act (NI) 2016: Section 97
<p>97. (1) A lestin pouer o attorney is a pouer o attorney that the donor confers authority on the attorney (or attorneys) by tae mak deceesions aboot (or aboot specifee'd maiters anent) aw or ony o the follaein:</p> <ul style="list-style-type: none"> (a) the donor's care, treatment an personal weel; (b) the donor's haudin an affairs; <p>an that taks in authority tae mak sic deceesions in circumstances whaur the donor nae langer haes capacity.</p> <p>(2) A lestin pouer o attorney is creautit anely gin:</p> <ul style="list-style-type: none"> (a) an instrument conferrin authority o the kind mentioned in subsection (1) is made an registert conform tae Schedule 4; (b) at the time whan the donor executes the instrument, the donor is 16 or ower an haes capacity tae execute it; an (c) section 101 (obligations as respects attorneys) is complee'd wi. <p>(3) An instrument that:</p> <ul style="list-style-type: none"> (a) purports tae creaut a lestin pouer o attorney, but; (b) disna obtemper wi this section, section 101 or Schedule 4 confers nae authority.

19

1 An LPA is made when the body has capacity and gives the attorney full decision-
2 making power to come into effect only at the time when the body wants mental
3 capacity. A decision by an LPA attorney is the same as by the body themselves if
4 they had mental capacity.

5 An LPA will be a very powerful limit in Advance Care Planning, when the relevant
6 provisions of the Mental Capacity Act (NI) 2016²⁰ is brought into force. It will make
7 clear that a body can write what will make decisions on their behalf if they ever
8 want mental capacity.

9 At the moment nobody can consent to treatment on behalf of another adult in
10 Northern Ireland. In situations where a body does not have the mental capacity to make a
11 specific decision for themselves, a 'best interests' decision is made.²¹

12 13 **Advance Decisions to Refuse Treatment (ADRT)**

14

15 An ADRT is a set of instructions from a body to them to refuse clinical treatment. It
16 sets out specific circumstances that the body would not want certain treatments in or
17 where they would want a particular treatment to be stopped.

18 An ADRT cannot be used to refuse any basic care that a body might need to keep
19 them comfortable. This takes in warmth, food, drink and fluids by mouth. An ADRT
20 cannot be used to:

- 21 • ask for specific medical treatment;
- 22 • ask for something that's illegal, e.g. assisted suicide;
- 23 • nominate another body to make decisions;
- 24 • refuse treatment for a mental health condition if the treatment is conform
25 to the Mental Health (NI) Order 1986.²²

26

27 In Northern Ireland, an ADRT is legally binding (governed by common law instead of an
28 Act) if it is valid and applies to the particular situation. This means that them
29 to receive care, support or treatment must follow an ADRT, provided that they know about
30 it.

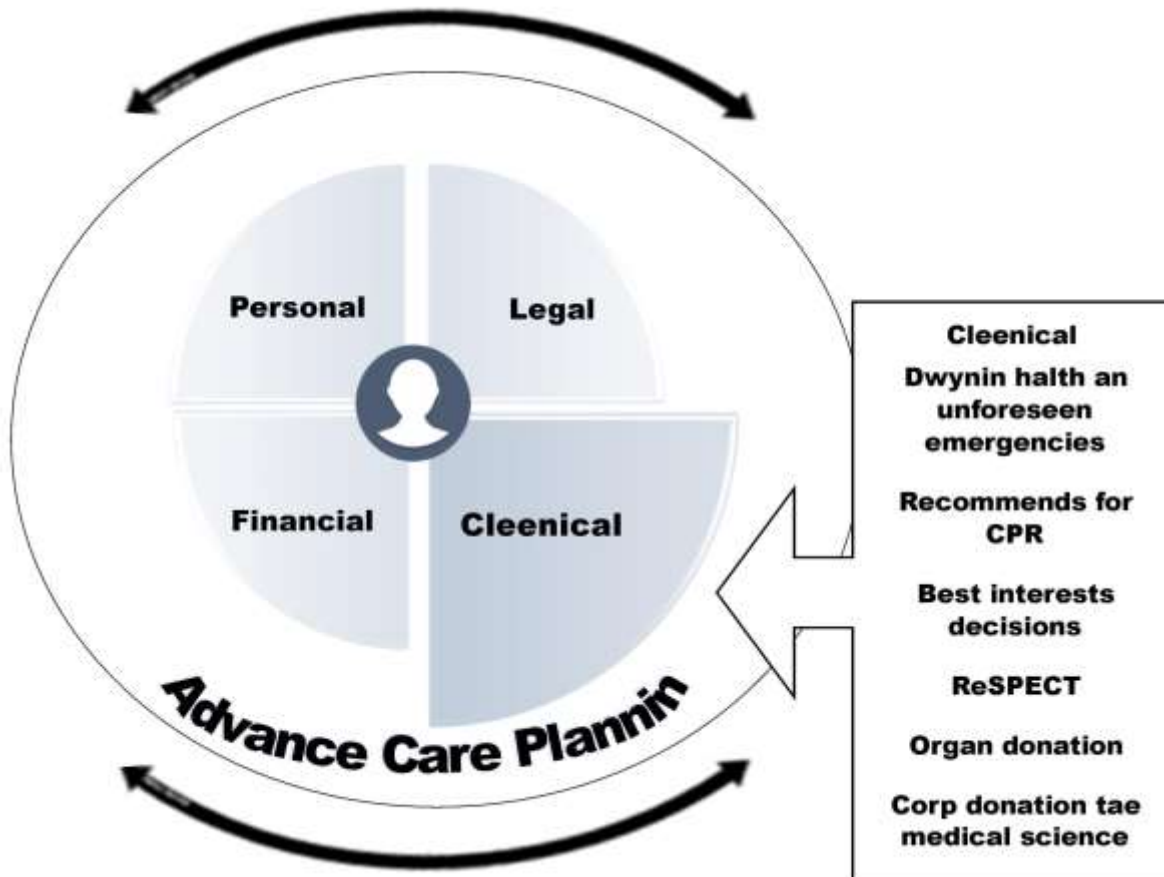
²⁰ The Mental Capacity Act (NI) 2016 introduces the role of a Lasting Power of Attorney (LPA) in Northern Ireland. The Mental Capacity Act (NI) 2016 has come into effect here in phases of implementation. LPA was included in phase 1. Implementation is ongoing, but at the moment there is no timeline for the start of the phase that will take LPA into force.

²¹ See 'Best Interests' section page 26.

²² When the Mental Capacity Act (Northern Ireland) 2016 is fully commenced, it will provide a statutory basis 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 take in mental health treatment.

- 1 An ADRT is recorded while a body is able to make their own decisions and
- 2 communicate their. It will only be followed when a body loses the mental capacity to
- 3 make specific decisions or is not able to communicate what their wishes are.
- 4 Their given care, up and or treatment should follow the Advance Care Planning
- 5 Regional Operational Framework (that will be developed conform to the policy order).

6 **Clinical Component of Advance Care Planning**



7

8 **Dwylin Halth & Unforeseen Emergencies**

9

10 Throughout the course of a body's life, their health can begin a slow decline over a period of

11 time. At other times, a body's health can be suddenly affected by an unforeseen

12 emergency situation, the like of an accident, a heart attack or a mental health crisis. It

13 is very important, therefore, for anybody to think about a plan for the fact that such

14 situations can happen.

15 Advance Care Planning can take in colloquies, recommends and/or decisions about a

16 body's wishes for future care in the event of decline in health and/or unforeseen

17 emergencies. This colloquy helps to provide a shared understanding of what matters

18 to the body and informs the clinical recommendations and/or decisions about what is

19 realistic for their future care and treatment as their health declines, and/or specific

20 treatments the like of resuscitation, ventilation or artificial nutrition/hydration.

1 **Cleeneal Recommends for Cardiopulmonar Resuscitation (CPR)**

2

3 Advance Care Plannin can involve collogues, recommends an/or deceesions about
4 cardiopulmonar resuscitation. This is important, as an unforeseen emergency
5 seetuation can tak in a cardiac arrest. A cardiac arrest is whan the hert haes stappit
6 pumpin bluid throu the bouk, an the bouk comes tae be unresponsive an staps
7 breithin in the ordinar wey.

8 An intervention the like o cardiopulmonar resuscitation (CPR) ettles tae restert the
9 hert. It needs haurd pressur tae be applee'd tae the body's kist, whit aften means
10 that thaim that's important tae the body canna be present or, gin thay ar present, can
11 find this sair mismuivin tae witness.

12 Thare comes a time for awbody, houiver, whan ettlin tae restert the hert wad aither
13 no come aff or whaur the risks o CPR ootweys the benefit. In this instance, there is
14 clear medical indications that the body's halth or condeetion is, or is expectit, tae
15 dwyne tae the pynt whaur CPR isna an appropriate intervention, as it interferes wi
16 the normal deein process, whaur the hert is the last organ tae stap.

17 A body or thaim that's important tae the body canna insist on ony speceefic
18 treatments tae be providit gin thocht inappropriate by the treatin clineecian, an this
19 taks in CPR. Knawin whit maiters tae a body helps inform the fowk gin cleeneal
20 treatment tae mak an record speceefic cleeneal recommends, comprehendin
21 whether CPR wad be an appropriate intervention in the event o a cardiac arrest. The
22 preencipal eessue isna the deceesion-makker's view o the quality o life follaein CPR,
23 but an objective assessment o whit is in the best interests o the patient. This maun
24 tak accoot o aw relevant factors, maist ava the body's wisses, feelins, beliefs an
25 vailyies about whit wad be an acceptable level o rekivery for thaim.

26

27 **Best Interests Deceesions**

28

29 Whan a body wants the mental capacity tae mak a speceefic deceesion about thair
30 treatment at that time, an disna hae a valid an appleecable ADRT, the clineecian
31 that's treatin the body will mak a 'best interests' deceesion(s). Advance Care Plannin
32 maks shuir that a body can mak thair wisses, feelins, beliefs an vailyies knawn, an
33 daein thon will help guide an inform thae makkin 'best interests' deceesions.

34 Naebody haes the legal authority tae consent tae treatment on behauf o anither
35 adult, but thaim that's important tae the body shoud be includit in thir 'best interests'
36 discussions anent whit the body nicht coud hae wantit. E'en whan the body wants
37 the relevant mental capacity for a speceefic deceesion at that time, thair wisses,
38 feelins, beliefs an vailyies is central. The body maun be placed at the hert o the

1 decession-makkin process an supportit tae be involved in the decession-makkin
2 process sae faur as possible.²³

3 The clineecian that's treatin the body shoud grund thair best interests decession²⁴ on
4 thair experience an unnerstaundin o the body's circumstances an be informed by the
5 body's prior Advance Care Plannin collogues. Decessions maunna be made on the
6 foonds o assumptions tae dae wi factors the like o the body's age or disabeelity²⁵
7 thair lane, or on a professional's subjective view o a body's quality o life.²⁶

8 Whaur there is nae evident o Advance Care Plannin, ADRT or cleenical
9 recommends for care an treatment in the event o an unforeseen emergency,
10 comprehendin cardiac arrest, the clineecian that's treatin the body will mak a 'best
11 interests' decession.

12

13 **Recommendit Short Plan for Emergency Care & Treatment (ReSPECT)**

14

15 Ideally, Advance Care Plannin shoud happen lang afore ony dwyne in a body's halth
16 or ony crisis or emergency. Thare can, houiver, be instances whaur Advance Care
17 Plannin collogues haesna taen place an thaim giein care, uphaud or treatment will
18 hae tae introduce thir collogues in circumstances the like o a suddent dwyne in halth
19 or unforeseen emergency.

20 Nae maiter whan thir collogues happens, thay shoud tak in talkin aboot an recordin
21 whit maiters tae a body an speceefic cleenical recommends aboot whit is realistic an
22 appropriate treatment an care for the body.

23 Collogues an recommends for futur care an treatment will be recordit on a ReSPECT
24 form.

25 ReSPECT stands for "Recommendit Short Plan for Emergency Care an Treatment."
26 The ReSPECT form sets oot wittins that will help guide an inform thaim giein care,
27 uphaud or treatment at a time whan the body isna able tae communicate whit thair
28 wisses is or disna hae the mental capacity tae mak that speceefic decession, the like
29 o in a futur unforeseen emergency.

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

²⁴ Whan fully implemented Section 7 o the Mental Capacity Act (NI) 2016.
<https://www.legislation.gov.uk/ni/2016/18/section/7/enact>

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

1 The ReSPECT form takes in recommends an/or decessions about speceefic
2 interventions that coud, or coudna, be wantit or cleenically appropriate.

3 The ReSPECT form will be signed by the clineecian providin cleenical recommends
4 but will be hauden by the body. The ReSPECT form isna a legally bindin document.

5 The ReSPECT form taks in:

6 • Whit maiters tae the body anent thair care an treatment, e.g. wisses, feelins,
7 beliefs an vailyies;

8 • Exeestin care plannin documents, e.g. gin the body haes made an Advance
9 Decession tae Refuise Treatment (ADRT);

10 • Cleenical recommends for emergency care an treatment, e.g. resuscitation
11 recommends;

12 • Recordin mental capacity for involvement in the recommends made.

13 As wi ony ither aspect o Advance Care Plannin, wittins recordit on a ReSPECT form
14 shoud be keepit unner review an updatit as appropriate.

15 The ReSPECT form will be the regional form for recordin aw recommends about
16 emergency care an treatment. The ReSPECT form will be transferable athort aw
17 care settins. As the ReSPECT form taks in CPR recommends, "dinna attempt
18 cardiopulmonar resuscitation" (DNACPR) forms will nae langer be uised.

19 Thaim giein care, uphaud or treatment shoud follae the relevant regional operational
20 documents that haes been developed tae uphaud this policy.

21

22 **Organ donation**

23

24 A body can chuisse tae donate thair organs an tissues for transplant. Thare is twa
25 different types o organ donation. Ane is whaur the body donates an organ as a
26 'leevin donor', for example, a body micht wiss tae be a neer donor. The seicont is
27 whaur a body haes dee'd an thair organs an tissues is donatit.

28 A body can record whether or no thay want tae donate thair organs an tissues efter
29 deith on the NHS Organ Donor Register.²⁷ Mony fowk disna realeese that the
30 uphaud o thaim that's important tae thaim is necessar for organ donation tae gang
31 ahead. Knawin a body's wisses anent organ donation helps thaim that's important tae
32 thaim at this difficult time.

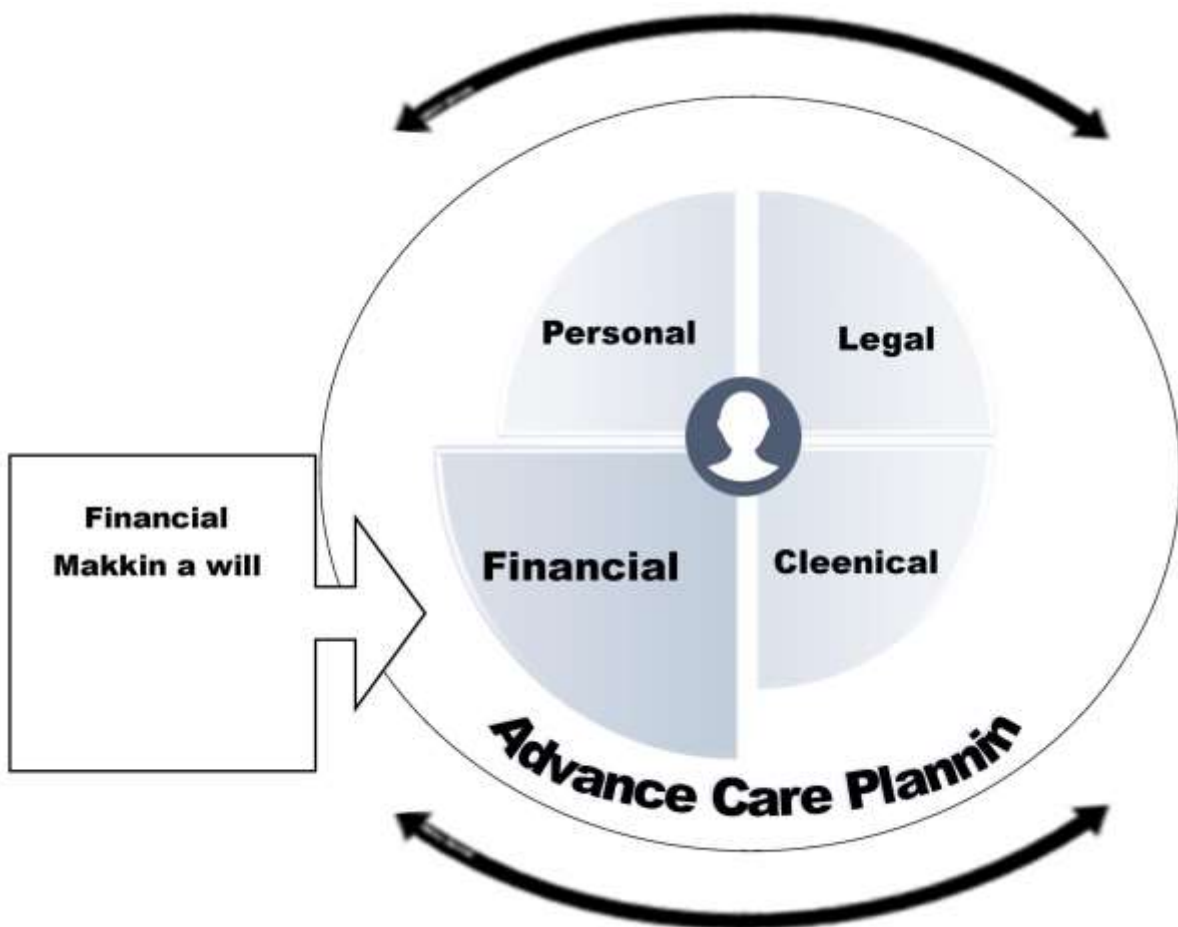
²⁷ Organ Donor Register <https://www.organdonation.nhs.uk/register-your-decision/>

1
2
3
4
5
6
7
8
9
10

Corp Donation tae Medical Science

A body micht wiss tae donate thair corp tae medical science. It is important for the body tae discuss this wi thaim that's important tae thaim, an thaim giein care, uphaud or treatment. There is a correct process²⁸ that maun be follaed; this will tak in keepin a copy o the fully completit consent form.

Financial Component o Advance Care Plannin



11
12
13
14

²⁸ Wittins beukies comprehendin a Consent Form is available frae the Queen's University Anatomy Office. Gin ye wad like tae receive an Information Beukie comprehendin a Consent Form, please e-mail the Anatomy Office at anatomy@qub.ac.uk or telephone 028 90 972131. Staff will be gey an blythe tae discuss any queries that ye micht hae.

1 **Makkin a Will**

2

3 Makkin a will gies a body the inlat tae mak shuir that thair wisses is follaed efter thay
4 dee. It helps tae mak shuir that a body can leave ony gear or instructions that thay
5 wiss tae thaim that's important tae thaim.

6 A will is a legal document that gies clear instructions that can tak in:

- 7 • Care o bairns or dependants;
- 8 • Financial affairs – siller, haudin an gear.

9

10 **Whit for it's important tae mak a will**

11

12 Haein a will semplifees the process o managin a body's affairs efter thay dee:

- 13 • A body can decide whit wey thair assets is skared.
- 14 • Ae hauf o an unmairit twasome can mak shuir that thair pairtner is fendit for.
- 15 • Gin a body is divorced, thay can decide whether tae leave ocht tae thair
16 umwhile pairtner.
- 17 • A body can get mair wittins on heirskip tax.

18

19 **Reddin yer will**

20

21 Tho it is possible tae write a will yer lane, it is wicelike tae uise a solicitor, for thare is
22 sindry legal formalities. Gin a body disna hae a will, the law sets oot wha gets whit.

23 An executor is the body that wad cairy oot the wisses in a body's will. A body can
24 appynt an executor by namin thaim in thair will. The coorts can appynt ither fowk tae
25 be sponsal for daein this jab an aw.

26 Ance a body haes made thair will, it is important that thay keep a haud o it in a sauf
27 place an tell thair executor, close fere or bluid-freend whaur it is. Gin a solicitor maks
28 the will, for ordinar they will haud ontae the oreiginal an send the body a copy. A
29 body can ask for the oreiginal gin thay wiss tae haud it.

30

31

1 **Updatin yer will**

2

3 A body shoud review thair will, maist ava efter ony muckle cheenge in thair life, the
4 like o gettin separatit, mairit or divorced, haein a bairn or flittin.

5 A body can mak cheenges by eikin a note tae thair exeestin will or by makkin a new
6 will.²⁹

7

8 **Conclusion**

9

10 Advance Care Plannin conteens a wheen components, comprehendin sindry
11 elements. A body can chuse tae think about an plan for some o the elements, but no
12 ithers, an at different times in thair life. This reflects the personal an voluntar
13 preinciples o Advance Care Plannin an the need tae provide inlats for a body tae
14 hae Advance Care Plannin collogues an tae review thir collogues an/or ony record
15 that coud be documentit.

16 Advance Care Plannin allous a body tae think about whit maiters tae thaim. This can
17 meliorate thair quality o life an enable thair wisses, feelins, beliefs an vailyies tae
18 inform the care, uphaud or treatment that thay receive gin thay stap bein able tae
19 mak decessions for thairsels.

20 “Advance Care Plannin, likely the maist important collogue ye will iver hae in yer life”
21 (Stakehauder quote frae engagement, Februar 2021).

22

23

24

25

26

27

28

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

1 Appendices

2 Appendix 1 Glossar o Terms

3

4 • **Advance Care Plannin:** Advance Care Plannin is an umbrellae term kiverin
5 personal, legal, cleenical, an financial plannin. It allous a body tae think aboot whit is
6 important tae thaim an plan for thair futur. It is a voluntar process an helps a body
7 tae mak knawn whit thair wisses, feelins, beliefs an vailyies is, an tae mak chyces
8 that reflects thir. Advance Care Plannin is an ongaun process o colloques atween a
9 body, thaim that's important tae thaim, an thaim giein care, uphaud or treatment.
10 Advance Care Plannin shoud be an important pairt o life for aw adults.

11 • **Advance Deceesions tae Refuse Treatment (ADRT):** In Northren Ireland, an
12 ADRT is legally bindin (governed by common law insteid o an Act) gin it is valid an
13 appleees tae the parteeecular seetuation.

14 • **Behaviour Cheenge:** Behaviour cheenge can refer tae ony transformation or
15 modification o human behaviour.

16 • **Best interests:** Whan a body wants the mental capacity tae mak a speceefic
17 deceesion aboot thair treatment at that time, an disna hae a valid an appleecable
18 Advance Deceesion tae Refuse Treatment, the clineecian that's treatin the body will
19 mak a "best interests" deceesion anent care an treatment.

20 • **Cardiac Arrest:** A cardiac arrest is whan the hert haes stappit pumpin bluid around
21 the bouk, an the bouk comes tae be unresponsive an staps breithin in the ordinar
22 wey.

23 • **Cardiopulmonar resuscitation:** a medical procedure involvin compression o the
24 kist an artefeecial respiration, performed tae mainteen bluid circulation an
25 oxygenation in a body that haes dree'd a cardiac arrest.

26 • **Care, Uphaud or Treatment:** thaim that gies care, uphaud or treatment: this term
27 is used athort the policy an taks in fowk wirkin in the community an voluntar sector,
28 independent sector, an ither halth an social care staff wirkin in statutor services.

29 • **Consent:** Consent is mair nor a form or formality. For consent tae be valid, it maun
30 be voluntar an informed, an the body consentin maun hae the capacity tae mak the
31 deceesion.

- 1 • **End o Life:** A period o time whan a body's condeetion is actively gettin waur tae
2 the pynt whaur deith is expectit.
- 3 • **End-o-life Care:** Is an oncome that betteres the quality o life o patients an thair
4 faimlies leevin wi a life-threitenin seekness. Care taks in assessment an treatment o
5 pain an ither needs, pheesical, psychosocial an speeritual.
- 6 • **Endurin Pouer o Attorney:** A legal document that allous a body tae appynt ithers
7 tae mak deceesions on thair behauf about thair haudin an siller gin thay tint mental
8 capacity.
- 9 • **Guidal:** Evidence-grundit recommends on the maist effective an cost-effective
10 treatment an care o fowk wi speceefic diseases an condeetions, an recommends for
11 populations an indiveeduals on interventions that can help tae hinder disease or
12 better halth. The professional regulators taks in (General Medical Cooncil (GMC),
13 Nursin Midwifery Cooncil (NMC), Halth & Care Professions Cooncil (HSPC) an
14 General Pharmaceutical Cooncil (GPhc), Northren Ireland Social Care Cooncil
15 (NISCC) produce regulator 'guidelines'/ 'guidal' on whit wey professional staundarts
16 shoud be won tae.
- 17 • **End-tae-end assessment:** Comprehensive assessment that addresses the social,
18 psychological, emotional, pheesical an speeritual needs o the body.
- 19 • **End-tae-end care:** Proveesion o care providit tae a body grundit in an
20 unnerstaundin o thair social, psychological, emotional, pheesical an speeritual
21 needs.
- 22 • **Lestin Pouer o Attorney (LPA):** see section 97 o the Mental Capacity Act (NI)
23 2016, is a legal document that allous a body tae appynt ithers tae mak deceesions
24 on thair behauf.³⁰
- 25 • **Mental Capacity Act (Northren Ireland) 2016:** Legislation that whan fully
26 commenced will cleek thegither mental capacity an mental halth law.

³⁰ The Mental Capacity Act (NI) 2016 introduces the role o a Lestin Pouer o Attorney (LPA) tae Northren Ireland. The Mental Capacity Act (NI) 2016 haes come intae effect here in phases o implementation. LPA wisna includit in phase 1. Implementation is ongaun, but at the meenit there is nae timeline for the stert o the phase that will tak in LPA comin intae force.

- 1 • **Naitional Institute for Halth an Care Excellence (NICE):** An organisation that
2 provides a strenthie an independent appraisal o the best available evident tae mak
3 recommends for the halth an social care seestem.
- 4 • **Organ donation:** Organ donation is the hale prattick o howkin oot a human organ
5 frae a leevin or deceased body.
- 6 • **Pailiative Care:** The active, end-tae-end care o fowk wi advanced progressive
7 seekness. Management o pain an ither symptoms an proveesion o psychological,
8 social an speeritual uphaud is paramoont. The ettle o pailiative care is tae win tae
9 the best quality o life for fowk an thaim that's important tae thaim. Mony aspects o
10 pailiative care is appelecable earlier in the coorse o the seekness thegither wi ither
11 treatments an aw.
- 12 • **Progressive condeetion:** A disease or halth condeetion that gets waur ower time,
13 resultin in a general dwyne in halth or function.
- 14 • **Pouer o Attorney:** Is a legal document that the body can uise tae gie anither body
15 the authority tae tak actions or mak deceesions on thair behauf.
- 16 • **ReSPECT:** Is an element o the cleenical component o Advance Care Plannin
17 enablin personaleesed recommends for emergency care an treatment tae be
18 documentit.
- 19 • **Sairious Seekness:** A halth condeetion that cairies a hie risk o mortality an affects
20 a body's daily function or quality o life.
- 21 • **Speerituality:** Speerituality is aboot whit gies meanin an purpose tae life an is
22 grundit in a body's core beliefs an vailyies.
- 23 • **Thaim that's important tae the body:** This can be faimily, carers or a body that
24 knaws, cares an is fain o the body. Thay coud be claucht throu thair personal, legal,
25 cultural or emotional relationship.

26
27
28
29

1 **Abbreviations**

- 2 • **ADRT** – Advance Deceesioe tae Refuise Treatment
- 3 • **CPR** – Cardiopulmonar resuscitatioe
- 4 • **DNACPR** – dinna attempt cardiopulmonar resuscitatioe
- 5 • **EPA** – Endurin Pouer o Attorney
- 6 • **LPA** – Lestin Pouer o Attorney
- 7 • **MCA** – Mental Capacity Act (Northren Ireland) 2016
- 8 • **NI** – Northren Ireland
- 9 • **NICE** – Naitional Institute for Halth an Care Excellence
- 10 • **ReSPECT** – Recommendit Short Plan for Emergency Care an Treatment

11

12 **Appendix 2 Bibliography**

13

14 **Journal**

15 Abba, K., Llyod-Williams, M. & Horton, S. (2019). Discussing end of life wishes – the
16 impact of community interventions? *BMC Palliative Care*. **18** pp18-26 DOI:

17 <https://doi.org/10.1186/s12904-019-0407-8>

18 Abel J., Kellehear, A., Millington Sanders, C., Taubert, M., & Kingston, H. (2020).
19 Advance Care Planning re-imagined: a needed shift from COVID times and beyond.
20 *Palliative Care and Social Practice*. **14**

21 Beck E-R, McIlpatrick S, Hasson F, Leavey G. (2017) Health care professionals' per-
22 spectivee of advance care planning for people with dementia living in long-term care
23 settinge: A narrative review of the literature. *Dementia*. 2017;**16**(4):486-512.
24 doi:10.1177/1471301215604997

25 Beck ER, McIlpatrick S, Hasson F, Leavey G. (2017) Nursing home manager's
26 knowledge, attitudee and beliefe about advance care planning for people with de-
27 mentia in long-term care settinge: a cross-sectional survey. *J Clin Nurs*. 2017
28 Sep;**26**(17-18):2633-2645. doi: 10.1111/jocn.13690. Epub 2017 Feb 9. PMID:
29 27995678.

30 Biondo, P.D., King, S., Minhas, B. et al. (2019). How to increase public participation
31 in advance care planning: findinge from a World Café to elicit community group per-
32 spectivee. *BMC Public Health*. **19** 679 DOI: [https://doi.org/10.1186/s12889-019-](https://doi.org/10.1186/s12889-019-7034-4)
33 [7034-4](https://doi.org/10.1186/s12889-019-7034-4)

34 Brazil K, Carter G, Cardwell C, et al. (2017) Effectiveness of advance care planning
35 with family carere in dementia nursing homee: A paired cluster randomized con-

- 1 trolled trial. *Palliative Medicine*. 2018;**32**(3):603-612.
2 doi:[10.1177/0269216317722413](https://doi.org/10.1177/0269216317722413)
- 3 Brazil, K., Carter, G., Galway, K. et al. (2015). General practitioners' perceptions on
4 advance care planning for patients living with dementia. *BMC Palliat Care* **14**, 14
5 (2015). <https://doi.org/10.1186/s12904-015-0019-x>
- 6 Canacott, L. & Moghaddam, N. (2019). Is the Wellness Recovery Action Plan
7 (WRAP) efficacious for improving personal and clinical recovery outcomes? A sys-
8 tematic review and meta-analysis. *Psychiatric Rehabilitation Journal* **42**(4) pp372-
9 381 DOI: <https://psycnet.apa.org/doiLanding?doi=10.1037%2Fprj0000368>
- 10 Carr K, Hasson F, McIlfatrick S, Downing J. Factors associated with health profes-
11 sionals decision to initiate paediatric advance care planning: A systematic integrative
12 review. *Palliat Med*. 2021 Mar;**35**(3):503-528. doi: 10.1177/0269216320983197.
13 Epub 2020 Dec 29. PMID: 33372582; PMCID: PMC7975890.
- 14 Demirkapu, H., Van den Block, L., De Maesschalck, S., De Vleminck, A., Colak, Z. &
15 Devroey, D. (2021). Advance Care Planning Among Older Adults of Turkish Origin in
16 Belgium: Exploratory Interview Study. *Journal of Pain and Symptom Management*.
17 **62**(2) pp252 – 259 doi: <https://doi.org/10.1016/j.jpainsymman.2020.12.017>
- 18 Detering, K. M., Buck, K., Ruseckaite, R., et al. (2019). Prevalence and correlates of
19 advance care directives among older Australians accessing health and residential
20 aged care services: multicentre audit study *BMJ Open*. **9** pp1-9 DOI:
21 <https://bmjopen.bmj.com/content/9/1/e025255.abstract>
- 22 Somal, K., & Foley, T. (2021). A Literature Review of Possible Barriers and
23 Knowledge Gaps of General Practitioners in Implementing Advance Care Planning in
24 Ireland: Experience from Other Countries. *International Journal of Medical Students*,
25 **9**(2), 145–156. <https://doi.org/10.5195/ijms.2021.567>
- 26 Dixon, J. and Knapp, M. (2019). Delivering advance care planning support at scale:
27 a qualitative interview study in twelve international healthcare organisations. *Journal*
28 *of Long-term Care*., pp127-142.
- 29 Dunphy, E., Conlon, S. C., O'Brien, S. A., Loughrey, E., & O'Shea, B. J. (2016). End-
30 of-life planning with frail patients attending general practice: an exploratory prospec-
31 tive cross-sectional study. *British Journal of General Practice*. **66**(650): pp661-666.
32 DOI: <https://doi.org/10.3399/bjgp16X686557>
- 33 Ernecoff, N.C., Keane, C.R. & Albert, S. M. (2016). Health behavior change in ad-
34 vance care planning: an agent-based model. *BMC Public Health*. **16** 193 DOI:
35 <https://doi.org/10.1186/s12889-016-2872-9>
- 36 Gilissen, J., Hunt, L., Van den Block, L., Van Der Steen, J., Tahir, P. and Ritchie, C.
37 (2021). Earlier initiation of palliative care in the disease trajectory of people living
38 with dementia: a scoping review protocol. *BMJ Open*. **11**(6)

- 1 Graham-Wisener, L., Nelson, A., Byrne, A., Islam, I., Harrison, C., Geddis, J., & Ber-
2 ry, E. (2021). Upstreaming advance care planning: application of health behavior
3 change theory to understand barriers and facilitators to talking about death and dying
4 in the community. <https://doi.org/10.31234/osf.io/pm7ny>
- 5 Harding, A., Preston, N., Doherty, J. et al. (2021). Developing and evaluating online
6 COVID-centric advance care planning training and information resources for nursing
7 staff and family members in nursing homes: the necessary discussions study proto-
8 col. *BMC Geriatr* **21**, 456. <https://doi.org/10.1186/s12877-021-02398-1>
- 9 Hill LM, McIlfratrick S, Taylor B, Dixon L, Fitzsimons D. (2019) Implantable cardio-
10 verter defibrillator (ICD) functionality: patient and family information for advanced de-
11 cision-making. *BMJ Support Palliat Care*. 2019 Nov 26;bmjspcare-2019-001835. doi:
12 10.1136/bmjspcare-2019-001835. Epub ahead of print. PMID: 31771959.
- 13 J Stevens, P Pype, K Eecloo, L Deliens, K Pardon, A D Vleminck. (2021). Facilitating
14 advance care planning in the general practice setting for patients with a chronic, life-
15 limiting illness: protocol for a phase-III cluster-randomized controlled trial and pro-
16 cess evaluation of the ACP-GP intervention. *BMC Palliative Care*. **20**(19)
- 17 Kelly, B. D. (2014). An end to psychiatric detention? Implications of the United Na-
18 tions Convention on the Rights of Persons with Disabilities. *The British Journal of*
19 *Psychiatry*. **204** (3) pp174–175 DOI: <https://doi.org/10.1192/bjp.bp.113.135475>
- 20 Kelly, B. D. (2015). Best Interests, mental Capacity legislation and the UN conven-
21 tion on the Rights of Persons with Disabilities. *BJPsych Advances*. **21** pp188-195
22 DOI: <https://doi.org/10.1192/apt.bp.114.012922>
- 23 Litzelman, D. K., Cottingham A. H., Griffin, W. Inui, T. S. & Ivy, S. S. (2016). Enhanc-
24 ing the prospects for palliative care at the end of life: A statewide educational
25 demonstration project to improve advance care planning. *Palliative & Supportive*
26 *Care*. **14**(6) pp641 – 651 DOI: <https://doi.org/10.1017/S1478951516000353>
- 27 Mallon, A., Hasson, F., Casson, K. et al. (2021). Young adults understanding and
28 readiness to engage with palliative care: extending the reach of palliative care
29 through a public health approach: a qualitative study. *BMC Palliative Care*. **20**(1),
30 pp.1-13. DOI: <https://doi.org/10.1186/s12904-021-00808-0>
- 31 Marshall, H. & Sprung, S. (2017). The Mental Capacity Act: ‘Best interests’—a re-
32 view of the literature. *British Journal of Community Nursing*., **22**(8), pp384-390 DOI:
33 <https://doi.org/10.12968/bjcn.2017.22.8.384>
- 34 McIlfratrick S, Slater P, Bamidele O, Muldrew D, Beck E, Hasson F. (2021) ‘It’s al-
35 most superstition: If I don’t think about it, it won’t happen’. Public knowledge and atti-
36 tudes towards advance care planning: A sequential mixed methods study. *Palliative*
37 *Medicine*. 2021;**35**(7):1356-1365. doi:10.1177/02692163211015838

- 1 McIlfratrick, S., Slater, P., Beck, E., Bamidele, O., McCloskey, S., Carr, K., Muldrew,
2 D., Hanna-Trainor, L. & Hasson, F. (2021). Examining public knowledge, attitudes
3 and perceptions towards palliative care: a mixed method sequential study. *BMC Pal-*
4 *liative Care.* **20** (44) DOI:<https://doi.org/10.1186/s12904-021-00730-5>
- 5 McKenna, D., O'Shea, J. and Tanner, L., 2020. The Heart of Living and Dying: Up-
6 streaming Advance Care Planning into Community Conversations in the Public Do-
7 main in Northern Ireland. *Journal of social work in end-of-life & palliative care*, **16**(4),
8 pp.346-363.
- 9 Meehan, E., Foley, T., Kelly, M.C., Kelleher, A.B., Sweeney, C., Hally, R.M., Deter-
10 ing, K. and Cornally, N., (2019). Advance care planning for individuals with chronic
11 obstructive pulmonary disease: a scoping review of the literature. *Journal of Pain*
12 *and Symptom Management.*
- 13 Meehan, E., Sweeney, C., Foley, T., Lehane, E., Kelleher, A.B., Hally, R.M., Sha-
14 nagher, D., Korn, B., Rabbitte, M., Detering, K.M. and Cornally, N., (2019). Advance
15 care planning in COPD: guidance development for healthcare professionals. *BMJ*
16 *supportive & palliative care.*
- 17 Molyneaux, E., Turner, A., Candy, B., Landau, S., Johnson, S & Llyod-Evans B.
18 (2019). Crisis-planning interventions for people with psychotic illness or bipolar dis-
19 order: systematic review and meta-analyse. *BJPsych Open.* **5** pp1-9 DOI:
20 <https://doi.org/10.1192/bjo.2019.28>
- 21 O'Connell, J., Gardner, G. & Coyer, F. (2014) Beyond competencies: using a capa-
22 bility framework in developing practice standards for advanced practice nurs-
23 ing. *Journal of Advanced Nursing* **70**(12), 2728– 2735. doi: [10.1111/jan.12475](https://doi.org/10.1111/jan.12475)
- 24 O'Halloran P, Noble H, Norwood K, Maxwell P, Murtagh F, Shields J, Mullan R, Mat-
25 thews M, Cardwell C, Clarke M, Morton R, Shah K, Forbes T, Brazil K.(2020) Nurse-
26 led advance care planning with older people who have end-stage kidney disease:
27 feasibility of a deferred entry randomised controlled trial incorporating an economic
28 evaluation and mixed methods process evaluation (ACReDiT). *BMC Nephrol.* 2020
29 Nov **13**;21(1):478. doi: 10.1186/s12882-020-02129-5. PMID: 33187506; PMCID:
30 PMC7663906.
- 31 O'Halloran P, Noble H, Norwood K, Maxwell P, Shields J, Fogarty D, Murtagh F,
32 Morton R, Brazil K. (2018) Advance Care Planning With Patients Who Have End-
33 Stage Kidney Disease: A Systematic Realist Review. *J Pain Symptom Manage.*
34 2018 Nov;**56**(5):795-807.e18. doi: 10.1016/j.jpainsymman.2018.07.008. Epub 2018
35 Jul 17. PMID: 30025939; PMCID: PMC6203056
- 36 Oliver, D. (2021). Improving DNACPR discussions, decisions, and documentation.
37 *BMJ.* 372:n722 DOI: <https://doi.org/10.1136/bmj.n772>

- 1 O'Riordan J, Noble H, Kane PM, et al. (2019) Advance care plan barriers in older pa-
2 tients with end-stage renal disease: a qualitative nephrologist interview study. *BMJ*
3 *Supportive & Palliative Care* 2020;**10**:e39.
- 4 Owen, G. S., Gergel, T., Stephenson, L. A., Hussain, O., Rifkin, L., & RuckKeene, A.
5 (2019). Advance decision-making in mental health – Suggestions for legal reform in
6 England and Wales. *International Journal of Law and Psychiatry*. **64** pp162-177
- 7 Piers, R., Braeckel, E. V., Benoit, D & Van Den Norrtgate, N. (2021). Early resuscita-
8 tion orders in hospitalized oldest-old with COVID-19: A multicentre cohort study. *Pal-*
9 *liative Medicine*. **35**(7) pp1288-1294 DOI:
10 <https://doi.org/10.1177/02692163211018342>
- 11 Prince-Paul M, DiFranco E. (2017).Upstreaming and Normalizing Advance Care
12 Planning Conversations—A Public Health Approach. *Behavioral Sciences*. **7**(2):18.
13 <https://doi.org/10.3390/bs7020018>
- 14 Rawlings D, Miller-Lewis L, Collien D, Tieman J, Parker D, Sanderson C. (2017).
15 Lessons Learned from the Dying2Learn MOOC: Pedagogy, Platforms and Partner-
16 ships. *Education Sciences*. **7**(3) 67 DOI: <https://doi.org/10.3390/educsci7030067>
- 17 Ryan, T., McKeown, J. (2020). Couples affected by dementia and their experiences
18 of advance care planning: a grounded theory study. *Ageing & Society*. **40** pp439-
19 460
- 20 Somal, K., & Foley, T. (2021). A Literature Review of Possible Barriers and
21 Knowledge Gaps of General Practitioners in Implementing Advance Care Planning in
22 Ireland: Experience from Other Countries. *International Journal of Medical Students*.
23 **9**(2) pp145-156 DOI: <https://doi.org/10.5195/ijms.2021.567>
- 24 Stein, G. L., Cagle, J. G. & Christ, G. H. (2017). Social Work Involvement in Advance
25 Care Planning: Findings from a Large Survey of Social Workers in Hospice and Pal-
26 liative Care Settings. *Journal of Palliative Medicine*. **20**(3) pp253-259 DOI:
27 <https://doi.org/10.1089/jpm.2016.0352>
- 28 Szmukler, G. (2019). “Capacity”, “best interests”, “will and preferences” and the UN
29 Convention on the Rights of Persons with Disabilities. *World Psychiatry*. **18** pp34-41
30 DOI: <https://doi.org/10.1002/wps.20584>
- 31 Tieman, J., Miller-Lewis, L., Rawlings, D. *et al.* (2018). The contribution of a MOOC
32 to community discussions around death and dying. *BMC Palliative Care*. **17**(31)
33 DOI: <https://doi.org/10.1186/s12904-018-0287-3>
- 34 Webb, P., Davidson, G., Davidson et al. (2020). Key components of supporting and
35 assessing decision making ability. *International Journal of Law and Psychiatry*. **72**
36 pp1-9 DOI: <https://doi.org/10.1016/j.ijlp.2020.101613>.

1 Webb, P, Davidson, G, Edge, R, et al. (2020). Service users' experiences and views
2 of support for decision making. *Health Soc Care Community*. **28** pp1282– 1291 DOI:
3 <https://doi.org/10.1111/hsc.12961>

4 Wendrich-van Dael, A., Gilissen, J., Van Humbeeck, L., Deliëns, L., Vander Stichele,
5 R., Gastmans, C., Pivodic, L. and Van Den Block, L. (2021). Advance care planning
6 in nursing homes: new conversation and documentation tools. *BMJ Supportive &*
7 *Palliative Care*. **1** pp312-317.

8

9 **Book**

10 Gregson P, Nolte L, Todd J, Detering KM. 2020. *Advance care planning education*
11 *capability framework: implementation guide*. Advance Care Planning Australia, Aus-
12 tin Health, Melbourne.

13 Leonard, R., Noonan, K., Horfall, D., Psychogios, H., Kelly, M., Rosenberg, J., Rum-
14 bold, B., Grindrod A., Read, N. & Rahn, A. (2020). *Death Literacy Index: A Report on*
15 *its Development and Implementation*. Sydney: Western Sydney University. DOI:
16 <https://doi.org/10.26183/5eb8d3adb20b0>

17 Macmillan Cancer Support & The Public Health Agency Northern Ireland (2016) Your
18 Life, Your Choices: Plan Ahead. Northern Ireland.

19 **Report**

20 Byrne, O & Baker, S. Ireach & All Ireland Institute of Hospice and Palliative Care
21 (2020) Palliative Care Research Study All Island (ROI & NI Combined).

22 Byrne, O & Baker, S. Ireach & All Ireland Institute of Hospice and Palliative Care
23 (2020) Palliative Care Research Study NI.

24 Canadian Hospice Palliative Care Association (2020) Advance Care Planning in
25 Canada: A Pan-Canadian Framework. Available at:
26 <https://www.advancecareplanning.ca/resource/advance-care-planning-framework/>

27 Compassion in Dying (2018) Starting the conversation: Planning ahead for your
28 treatment and care.

29 Department of Health (2020) Advance Care Planning Policy for Northern Ireland (for
30 adults): Thematic Review of DNACPR Issues.

31 Department of Health (2016) A Strategy for Children's Palliative and End-of-Life
32 Care 2016-26.

33 Department of Health COVID-19 HSC Clinical Ethics Forum (2020) COVID-19 Guid-
34 ance: Ethical Advice and Support Framework.

- 1 Department of Health (2019) Mental Capacity Act (NI) 2016: Deprivation of Liberty
2 Safeguard Code of Practice. Available at: [https://www.health-](https://www.health-ni.gov.uk/sites/default/files/publications/health/mca-dols-cop-november-2019.pdf)
3 [ni.gov.uk/sites/default/files/publications/health/mca-dols-cop-november-2019.pdf](https://www.health-ni.gov.uk/sites/default/files/publications/health/mca-dols-cop-november-2019.pdf)
4 [accessed December 2020]
- 5 Department of Health (2019) Review of the law relating to Advance Decisions to Re-
6 fuse Treatment: Mental Capacity Act (NI) 2016 section 284.
- 7 Genentech. (2020). A guide for initiating advance care planning conversations with
8 your patients. Available at:
9 [https://www.mycareforward.com/content/dam/gene/mycareforward/pdfs/A_guide_for](https://www.mycareforward.com/content/dam/gene/mycareforward/pdfs/A_guide_for_initiating_advance_care_planning_conversations_with_your_patients.pdf)
10 [_initiating_advance_care_planning_conversations_with_your_patients.pdf](https://www.mycareforward.com/content/dam/gene/mycareforward/pdfs/A_guide_for_initiating_advance_care_planning_conversations_with_your_patients.pdf)
- 11 Healthwatch Norfolk (2016) 'Thinking ahead' Advance Care Planning.
- 12 Healthwatch Staffordshire (2017) Think Different, Think end of Life Care.
- 13 Marie Curie (2021) Terminal Illness and bereavement during the Covid-19 pandemic
14 in Northern Ireland: Perspectives of those left behind and lessons for the future.
- 15 McIlpatrick, S., Slater, P., Beck, E., Muldrew, D., Hanna-Trainor, L. & Hasson, F.
16 (2021). Where Are We Now? - Examining public knowledge and attitudes towards
17 palliative care and advance care planning in Northern Ireland. Ulster University
18 [https://www.ulster.ac.uk/_data/assets/pdf_file/0012/819678/Where-are-we-now-](https://www.ulster.ac.uk/_data/assets/pdf_file/0012/819678/Where-are-we-now-Examining-public-knowledge-and-attitudes-towards-palliative-care-and-advance-care-planning-in-NI.pdf)
19 [Examining-public-knowledge-and-attitudes-towards-palliative-care-and-advance-](https://www.ulster.ac.uk/_data/assets/pdf_file/0012/819678/Where-are-we-now-Examining-public-knowledge-and-attitudes-towards-palliative-care-and-advance-care-planning-in-NI.pdf)
20 [care-planning-in-NI.pdf](https://www.ulster.ac.uk/_data/assets/pdf_file/0012/819678/Where-are-we-now-Examining-public-knowledge-and-attitudes-towards-palliative-care-and-advance-care-planning-in-NI.pdf)
- 21 National Institute for Health and Care Excellence. (2019) Advance Care Planning: A
22 quick guide for registered managers of care homes and home care services.
- 23 National Institute for Health and Care Excellence. (2007) Behaviour Change: general
24 approaches.
- 25 National Institute for Health and Care Excellence. (2016) Community engagement:
26 improving health and wellbeing and reducing health inequalities.
- 27 NHS Benchmarking Network. National Audit of Care at the End of Life: Second
28 round of audit report. Northern Ireland (2020).
- 29 Patient Client Council (2020) Exploring the experiences and perspectives of clinically
30 extremely vulnerable people during COVID-19 shielding. Final Report.
- 31 Patient Client Council (2021) Towards an action plan for health literacy in Northern
32 Ireland.
- 33 **Online**

- 1 Acts of the Northern Ireland Assembly, Mental Capacity Act (Northern Ireland) 2016
2 available at: <https://www.legislation.gov.uk/nia/2016/18/contents> [accessed Decem-
3 ber 2020].
- 4 All Ireland Institute of Hospice and Palliative Care: Palliative Care Research Study NI
5 (July 2020) Version 1.2. [https://thepalliativehub.com/wp-
6 content/uploads/2020/10/Palliative-Care-Study-NI-July-2020-V1.2.pdf](https://thepalliativehub.com/wp-content/uploads/2020/10/Palliative-Care-Study-NI-July-2020-V1.2.pdf) [accessed De-
7 cember 2020].
- 8 An evidence-based blog article by Dr Nicola Cornally, University College Cork,
9 PCRN member: [Advance Care Planning as a Medium for Providing Care Aligned to
10 Peoples Wishes](#) [accessed November 2021]
- 11 Arkless, C., Goodwin, J. & Muir, S. (2016). Advance Care Planning Training Manual:
12 Understanding Advance Care Planning
13 https://www.hqsc.govt.nz/assets/ACP/PR/ACP_Training_Manual_V1.2.pdf [ac-
14 cessed December 2020].
- 15 Booth, R. 'Do not resuscitate' orders caused potentially avoidable deaths, regulator
16 finds. The Guardian. 3 December 2020.
17 [https://www.theguardian.com/society/2020/dec/03/do-not-resuscitate-orders-caused-
18 potentially-avoidable-deaths-regulator-finds](https://www.theguardian.com/society/2020/dec/03/do-not-resuscitate-orders-caused-
18 potentially-avoidable-deaths-regulator-finds) [accessed December 2020].
- 19 Decision making and mental capacity. National Institute for Health and Care Excel-
20 lence. 11 August 2020. [https://www.nice.org.uk/guidance/qs194/chapter/Quality-
21 statement-4-Best-interests-decision-making](https://www.nice.org.uk/guidance/qs194/chapter/Quality-
21 statement-4-Best-interests-decision-making) [accessed December 2020].
- 22 Enduring Power of Attorney – an explanatory note. Northern Ireland Courts and Tri-
23 bunals Service July 2018. [epa-notes-for-guidance-Aug-2018-updated-Nov-2019.pdf
24 \(justice-ni.gov.uk\)](https://www.justice-ni.gov.uk/epa-notes-for-guidance-Aug-2018-updated-Nov-2019.pdf) [accessed December 2020].
- 25 Gregson P, Nolte L, Todd J, Detering KM. 2020. Education Capability Framework:
26 2020 Implementation Guide. Advance Care Planning Australia. Austin Health, Mel-
27 bourne. [https://www.advancecareplanning.org.au/docs/default-source/acpa-
28 resource-library/acpa-learning/education-framework/acpa-education-capability-
29 framework-guide.pdf](https://www.advancecareplanning.org.au/docs/default-source/acpa-
28 resource-library/acpa-learning/education-framework/acpa-education-capability-
29 framework-guide.pdf) [accessed December 2020].
- 30 Health Quality & Safety Commission New Zealand Advance Care Planning Compe-
31 ten-
32 cies. [https://www.hqsc.govt.nz/assets/ACP/PR/ACP_self_assessment_competency_f
33 ramework.pdf](https://www.hqsc.govt.nz/assets/ACP/PR/ACP_self_assessment_competency_f
33 ramework.pdf) [accessed December 2020].
- 34 Health Quality & Safety Commission New Zealand (2019) The Five Year Advance
35 Care Planning Strategy [https://www.hqsc.govt.nz/assets/ACP/PR/acp-5year-
36 strategy-2019-web-final.pdf](https://www.hqsc.govt.nz/assets/ACP/PR/acp-5year-
36 strategy-2019-web-final.pdf) [accessed December 2020].
- 37 Health Quality & Safety Commission New Zealand. (2020) Serious illness conversa-
38 tions: Reference guide for health care professionals

- 1 <https://www.hqsc.govt.nz/assets/ACP/PR/SICG-reference-guide-July-2020.pdf> [ac-
2 cessed December 2020].
- 3 Managing your affairs and enduring power of attorney. NI Direct Government Ser-
4 vices (2021). [https://www.nidirect.gov.uk/articles/managing-your-affairs-and-
5 enduring-power-attorney](https://www.nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney) [accessed January 2021].
- 6 Ministry of Health. (2011). Advance Care Planning: A guide for the New Zealand
7 health care workforce. Wellington: Ministry of Health
8 [https://www.health.govt.nz/publication/advance-care-planning-guide-new-zealand-
9 health-care-workforce](https://www.health.govt.nz/publication/advance-care-planning-guide-new-zealand-health-care-workforce) [accessed December 2020].
- 10 National Ethics Advisory Committee. (2014). Ethical Challenges in Advance Care
11 Planning. Wellington: Ministry of Health New Zealand.
12 [https://neac.health.govt.nz/assets/Uploads/NEAC/publications/ethical-challenges-in-
13 advance-care-planning.pdf](https://neac.health.govt.nz/assets/Uploads/NEAC/publications/ethical-challenges-in-advance-care-planning.pdf) [accessed December 2020].
- 14 Northern Ireland Life & Times Survey. (2021). Economic and Social research Coun-
15 cil. <https://www.ark.ac.uk/nilt/> [accessed March 2021].
- 16 Rao. J. K. Engaging Public Health in End-of-Life Issues: It Is Time to Step Up to the
17 Plate. *Ann Intern Med* 2015 **162** pp230-231. [Epub ahead of print 7 March 2020].
18 <https://www.acpjournals.org/doi/10.7326/M14-2479> [accessed December 2020].
- 19 United Nations Convention on the Rights of People with Disabilities (2008) available
20 at: [https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-
21 persons-with-disabilities.html](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html) [accessed December 2020].
- 22 United Nations General Assembly, Universal Declaration of Human Rights, 10 De-
23 cember 1948, 217 A (III), available at:
24 <https://www.refworld.org/docid/3ae6b3712c.html> [accessed December 2020].
- 25 **Online Videos**
- 26 June 2020, “Advance Care Planning – Issues Raised by the Covid19 Pandemic”,
27 webinar by John Lombard, University of Limerick, PCRN member
28 <https://youtu.be/TyadgPsPITI>
- 29 Sept 2020, “Advance care planning. An awareness raising session for district nurs-
30 ing”, webinar by Niall Gallagher, Specialist Social Work:
31 <https://youtu.be/DbfsdftNmrq>
- 32 April 2020 – Project ECHO AIIHPC: Intellectual Disability Services, “Advance Care
33 Planning & Anticipatory Prescribing during a Crisis”, webinar:
34 https://youtu.be/YbPt_D5sLxE [speakers include: Professor Mary McCarron, Dr. Re-
35 gina McQuillan, Dr. Jean Lane, Dr. John O'Brien, Professor Sean Kennelly, Dr.
36 Cathy Payne].

1 July 2016, "Advance Care Planning in Dementia", webinar by Dr Karen Harrison
2 Denning, Dementia UK: <https://youtu.be/7TAKLBaABIY>

3

4

5

6

7