Northern Ireland Assembly

Research and Information Service Briefing Paper

Paper 000/00 21st October 2015 NIAR 286-15

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Advance Decisions

Mental Capacity Bill

Table of Contents

Key Points

Across the UK and Ireland the law, albeit in differing ways, provides for people to make advanced decisions regarding future treatment in anticipation of a time when they lose capacity to make or communicate these decisions themselves.

The law, in general, treats advanced decisions to refuse treatment differently from preferences regarding which treatment a person would wish to receive.

Currently under the common law in Northern Ireland, advance decisions to refuse treatment (ADRTs) are, given that certain criteria are met, legally recognised under the common law. Clause 11 of the Bill, which relates to protection from liability when an advance decision exists, recognises this position, but does not further provide for/prescribe how advanced decisions should operate.

In essence, the Bill does not include *statutory provision* for ADRTs but it does provide *statutory recognition* for them.

The Department of Health, Social Services and Public Safety has expressed its view that to codify the law would not be desirable, given that it considers the law in this area is continuing to evolve. In addition, the Department has indicated that, from its analysis, there is a 'lack of consensus' on the way forward.

There was significant support among consultees (particularly amongst those working with and representing the elderly) for codification of the law in relation to advanced decisions.

It is, therefore, worth noting that in England and Wales, the Mental Capacity Act 2005 (the MCA) does include statutory provision for those aged 18 and over who have capacity to plan for their future through the use of ADRTs.

It is also worth noting that the Law Commission in England & Wales, has highlighted that, whilst ADRTs were placed on a statutory footing in 2005 by the MCA, they had been recognised 17 years earlier under common law.

During the passage of the MCA, the concern that ADRT's might lead to 'euthansia by the back door' was raised. Section 62 was inserted into the MCA to remove any doubt regarding this issue:

> *62 Scope of the Act*
>
> *For the avoidance of doubt, it is hereby declared that nothing in this Act is to be taken to affect the law relating to murder or manslaughter or the operation of section 2 of the Suicide Act 1961 (c. 60) (assisting suicide).*

Mirroring this provision, Clause 275 of the Bill clarifies that the provisions contained within it do not affect the existing laws on murder, manslaughter, or assisted suicide

Whilst the Department has expressed the desire not to codify the law regarding advanced decisions, research for this paper has identified a range of policy questions relating to advanced decisions that could require consideration for either potential inclusion in statute or a code of practice for NI. These questions include, for example:

- Should an advance decision be limited to refusal of specific treatment(s) or should it also allow for positive statements requesting a specific treatment?
- Should people of all ages, including children, be able to make advanced decisions?
- Should an advance decision be confined to an already diagnosed condition or extend to a future condition or future circumstances (such as pregnancy)?; and
- Should an advance decision be able to include both treatments for physical illness and mental illness?

In the context of the last question, it is important to note that, as the Bill will revoke the Mental Health Order as it currently applies to those aged 16 and over, a doctor will no longer have the authority to override an effective ADRT for a mental disorder. This is one of the key impacts of the 'fusion' of mental health and mental capacity legislation and places NI in a unique position compared with other parts of the UK or Ireland.

1 Introduction

Mental capacity legislation has been introduced in other parts of the UK - Mental Capacity Act 2005 in England and Wales and the Adults with Incapacity (Scotland) Act 2000. In Northern Ireland (NI), however, mental capacity issues in relation to health and welfare interventions continue to be governed by the common law. This broadly provides for a presumption of capacity in persons aged 16 and over, a test of incapacity, and protection from liability when intervening in someone's life, provided it is reasonably believed that the person lacks capacity to consent to the intervention and it is in his or her best interests (common law "doctrine of necessity").[1]

This does not apply to decisions governed by the Mental Health (Northern Ireland) Order 1986, under which there are statutory powers to remove and detain people for the assessment and treatment of a mental disorder provided certain criteria are met, regardless of whether or not the person has capacity.

The development of a single, capacity-based, legislative framework for the reform of mental health legislation and for the introduction of mental capacity legislation in NI was recommended by the Bamford Review in its report published in 2007, 'A Comprehensive Legislative Framework'.[2]

The proposals have been described as 'ground breaking', as there is the potential for the first single statutory framework governing all decision making in relation to the care, treatment (physical or mental illness) or personal welfare of a person aged 16 or over, who lacks capacity to make a specific decision. If the legislation is passed, this means that the current Mental Health (NI) Order 1986 will no longer apply to a person aged 16 or over.[3]

The range of factors that have driven the need for legislative change in this area of the law in NI and the key principles of the Mental Capacity Bill (the Bill) for NI have already been described in the published RaISe paper NIAR 292-15, *Draft Mental Capacity Bill – Principles Framework* (May 2015).[4]

This paper focuses on advance decisions to refuse treatment (ADRTs), and their legal status across the UK and ADRTs and their interaction with and impact on a number of clauses of the Mental Capacity (NI) Bill. The Bill does not propose any changes with regard to the legal status of ADRTs as there is no statutory provision for them but it

[1] Mental Capacity Bill (as introduced to the NI Assembly on 8th June 2015, Bill 49/11-16), Explanatory and Financial Memorandum, Background and Policy Objectives http://www.niassembly.gov.uk/globalassets/documents/legislation/bills/executive-bills/session-2014-2015/mental-capacity/mental-capacity-bill---efm---as-introduced.pdf

[2] The Bamford Review, DHSSPS (2007), Published Reports, http://www.dhsspsni.gov.uk/index/bamford/published-reports.htm

[3] Draft Mental Capacity Bill (NI), Consultation Document, May 2014, DHSSPS, page 2, http://www.dhsspsni.gov.uk/mental_capacity_bill_consultation_paper.pdf

[4] http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2015/hssps/6315.pdf

does provide *statutory recognition* for them. They are currently legally binding in common law in NI, provided certain criteria are met.

ADRTs are a part of wider advance care planning, which is a generic term to describe an individual's process of planning for the future to prepare for a time when they may lack capacity to make these decisions for themselves[5]. In regard to health care it is generally understood to be an ongoing process in which patients, their families/friends and their healthcare providers reflect on the patient's values, beliefs and discuss how these could inform current and future care.[6]

ADRTs are understood as a form of substitute decision making, providing:

> *a mechanism to communicate the prior capable wishes of the person at a time in the future when they may lack capacity…they are increasingly being seen….as a vehicle that enables clinicians to respect the human rights of their patients while providing optimal care.*[7]

With regard to the Bill, many of the provisions to be put on statute underpin good practice in advance care planning. These include Lasting Powers of Attorney (LPAs), nominated persons, advocacy and second opinions. These are all supported by the Bill's stated fundamental belief in respect for personal autonomy.

2 Advance Decisions in the UK and Republic of Ireland - Overview of the Law

Table 1: Advance Decisions in the UK and Republic of Ireland – Overview of the Law

(see next page)

[5] Guardianship: Final Report, Victoria Law Reform Commission (tabled in Parliament 18 April 2012, Chapter 11 Documenting wishes about the future, http://www.lawreform.vic.gov.au/projects/guardianship-final-report

[6] Detering, K and Silveira M J (2015) Advance care planning and advance directives, UpToDate website, topic last updated 6/04/15, www.uptodate.com/contents/advance-care-planning-and-advance-directives

[7] Weller, P (2013) New Law and Ethics in Mental Health Advance Directives, The Convention on the Rights of Persons with Disabilities and the Right to Choose, Routledge, Chapter 1, The right to choose, page 10

Jursidication	Type of Advance Decision	Legal Status of Advance Decision	Relevant Legislation	Scope – Key Points
England/Wales	Advance Decision to Refuse Treatment (ADRT) --- Advance Statement	Legally binding --- Not legally binding	Mental Capacity Act 2005	MCA 2005 applies to those age 16+ (ADRTs can be made by those with capacity, age 18+) Refusal of specific treatment(s) in specified circumstances Can extend to life-sustaining treatment (must be in writing) --- Preferences for any future aspect of health and social care No age restriction (must have capacity to make the AS)
Scotland	Advance Directive/Decision --- Advance Statement (AS)	Legally binding --- Not legally binding (but duty to have regard to AS)	No statute, but Adults with Incapacity Act 2000 – *account must be taken of present and past wishes of the adult as far as they can be ascertained by any means of communication* (Section 1(4a)) --- Mental Health (Care and Treatment) (Scotland) Act 2003 (Sections 275 and 276)	Refusal of specific treatment(s) in specific circumstances (can be made by those with capacity, age 16+) Can extend to life-sustaining treatment --- Future treatment refusals and requests specific to a patient's mental disorder (no age restriction but must have capacity to make the AS)
Northern Ireland	Advance Decision (current law) --- Advance Decision (proposed law)	Legally binding --- Legally binding	No statutory provision (case law applies) --- No statutory provision, but statutory recognition in Mental Capacity (NI) Bill	Refusal of specific treatment(s) in specified circumstances (can be made by those with capacity, age 18+) Can extend to life-sustaining treatment --- As above

Jursidication	Type of Advance Decision	Legal Status of Advance Decision	Relevant Legislation	Scope – Key Points
Republic of Ireland	Advance Decision (current law) --- Advance Health Care Directives (proposed law)	Potential to be legally binding[8] --- Legally binding (except for treatment requests)	Common Law (limited case law) --- Assisted Decision-Making (Capacity) Bill 2013	Refusal of specific treatment(s) in specific circumstances (can be made by those with capacity, age 18+) Can extend to life-sustaining treatment --- Refusal of specific treatment(s) in specific circumstances (can be made by those with capacity, age 18+) Can extend to life-sustaining treatment Can include treatment requests – these are not proposed to be legally binding

Table 1 Continued

[8] Is it time for advance healthcare directives? Opinion, Irish Council for Bioethics (2007), page 6

3 The Mental Capacity (NI) Bill

A number of the provisions of the Mental Capacity Bill, such as Lasting Powers of Attorney (LPAs); nominated persons; advocacy and second opinions support good practice in advance care planning as does the Bill's stated fundamental belief in respect for personal autonomy.

Advance Decisions are a part of wider advance care planning and are a generic term to describe an individual's process of planning/decision-making for the future, when they have the capacity to do so, to prepare for a time when they may lack capacity to make these decisions for themselves[9].

However, with regard to Advance Decisions to Refuse Treatment (ADRTs), the Bill does not codify the common law 'rules' in relation to advance decisions. It does provide statutory recognition for ADRTs in that the Bill requires an 'effective' advance decision to be complied with, if it is valid and applicable under the common law.

The legislative framework proposed by the Bamford Review, commented that the key provisions of the MCA 2005 should be adopted in NI, with minimal amendment, including[10]:

> *The recognition of advance decisions to refuse treatment and, in addition, advance statements about preferred treatment.*

The original intention of the DHSSPS appears to have been to include provision for advance decisions in the legislation, as the 2009 'Policy Consultation Document' states that[11]:

> *The proposed Bill will also include provision for:*
>
> *Advance decision-making – this allows people with capacity to make a valid advance decision concerning their future treatment, including refusal, with appropriate safeguards in place.*

A key point highlighted by the Department during development of the Bill was that it would revoke the Mental Health Order as it currently applies to those aged 16 and over, meaning that[12]:

> *A doctor will no longer have the authority to override an effective advance decision to refuse medical treatment for a mental disorder (which can happen at present).*

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[9] Guardianship: Final Report, Victoria Law Reform Commission (tabled in Parliament 18 April 2012, Chapter 11 Documenting wishes about the future, http://www.lawreform.vic.gov.au/projects/guardianship-final-report

[10] A Comprehensive Legislative Framework, The Bamford Review of Mental Health and Learning Disability (NI), August 2007, pages 53-54, paragraph 6.5, http://www.dhsspsni.gov.uk/index/bamford/published-reports/cl-framework.htm

[11] Legislative Framework for Mental Capacity and Mental Health Legislation in Northern Ireland, A Policy Consultation Document, January 2009, DHSSPS, paragraph 5.1, page 9

[12] Draft Mental Capacity Bill (NI), Consultation Document, May 2014, paragraph 2.17

At present, under the Mental Health (NI) Order 1986, Section 12 (1)(a), a patient can be detained for medical treatment for - a mental illness or severe mental impairment of a nature or degree which warrants his detention in hospital for medical treatment. Section 12 (1)(b) further adds that this detention is warranted when a failure to detain and treat would "create a substantial likelihood of serious physical harm to himself or to other persons".[13]

A range of consultees to the Bill expressed a strong desire to see the common law in this area codified (See Section 3.3). The DHSSPS explaining its decision not to include statutory provision for ADRTs in the Bill, on a number of occasions, made reference to the evolution of law in this area and, in what it perceived as a lack of consensus on the way forward[14]:

> *Our view is that the Bill goes as far as we possibly can go at the moment in giving statutory recognition to advance decisions. We fully appreciate the strength of view on this and gave careful consideration to all the arguments that were put forward, of which not all were in favour of codifying the rules for advance decisions. There was not a great deal of consensus. Others raised issues about the effect on the protection of other rights. We took the view that it would be better to let the debate continue than to fix the rules in statute at this time.*
>
> *There was a lack of consensus on whether it should be codified in the Bill. In particular, there was a lack of clarity on what those rules should be across the board. We are talking here about advance decisions to refuse treatment. Where a best interests decision is being made, there must be special regard for decisions that are made in advance, or for the views and wishes that people have. This is a specific category of advance decisions to refuse treatment. Our view was that it was better to let society debate the issue, let the common law develop, reflect as much as possible of that in the code of practice and then allow the code of practice to be updated as common law evolves. That can inform future legislation should there be clarity and consensus on what the rules should be.*

In contrast, in England and Wales, the Law Commission, believe the law in this area to be well established has recently stated[15]:

> *As a matter of law, advance decision-making is well-established. For example, advance decisions to refuse medical treatment were placed on a*

[13] Mental Health (NI) Order 1986, Section 12, http://www.legislation.gov.uk/nisi/1986/595/pdfs/uksi_19860595_en.pdf
[14] Mental Capacity Bill: Part 2 – Lack of Capacity: Protection from Liability; and Safeguards, Ad Hoc Joint Committee on the Mental Capacity Bill, Hansard, 21 September 2015, http://data.niassembly.gov.uk/HansardXml/committee-14963.pdf
[15] Mental Capacity and Deprivation of Liberty, A Consultation Paper, Consultation Paper No. 22, para. 13.22. The Law Commission (2015),

> *statutory footing recently by the Mental Capacity Act, but were recognised 17 years earlier by Lord Goff in F v West Berkshire Health Authority*.

3.1 ADRTs and the Bill

The Bill does provide *statutory recognition* for ADRTs in that they impact on the operation of a number of clauses of the Bill:

Clause 7 – "Best Interests" – The 'best interests' section applies where, for any purpose of the Act it falls to a person to determine what would be in the best interests of a person who is 16 or over. Clause 7(6) states that "that person must have special regard to (so far as they are reasonably ascertainable - (a) P's past and present wishes and feelings (and in particular, any relevant written statement made by P when P had capacity)".[16] This 'written statement' is "sometimes referred to as an 'advance statement'".[17]

Clause 9 - A key clause in the Bill because it puts into statute the common law doctrine or defence of 'necessity'.[18] The defence in Clause 9 can be used by a person 'D' who does an act in connection with the care, treatment or personal welfare of a person 'P', who is 16 or over and lacks capacity in relation to making decision themselves regarding the act.[19]

Clause 11 - The impact of ADRTs on Clause 9 is provided for in Clause 11 – "Advance decisions – effect on clause 9". Clause 11(1) provides that any act to treat 'P' (carry out treatment or continuation of treatment) that conflicts with an effective AD to *refuse* the treatment under the common law will also not attract the defence in Clause 9.[20] The Bill defines an "effective advance decision to refuse treatment" in Clause 11(2) as meaning a:

> *Decision, which under the common law relating to advance decisions has the same effect as if at the material time P - (a) refused consent to the treatment's being carried out or continued; and (b) had capacity to refuse that consent.*

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[16] Mental Capacity Bill (as introduced to the NI Assembly on 8th June 2015, Bill 49/11-16), Clause 7, page 4, http://www.niassembly.gov.uk/globalassets/documents/legislation/bills/executive-bills/session-2014-2015/mental-capacity/mental-capacity---as-introduced.pdf

[17] Mental Capacity Bill, Explanatory and Financial Memorandum, page 10, http://www.niassembly.gov.uk/globalassets/documents/ad-hoc-mental-capacity-bill/legislation/mental-capacity-bill-efm-as-introduced.pdf

[18] As above - Clause 9, page 6

[19] Mental Capacity Bill (as introduced to the NI Assembly on 8th June 2015, Bill 49/11-16), Explanatory and Financial, page 11, Clauses 9-12, http://www.niassembly.gov.uk/globalassets/documents/legislation/bills/executive-bills/session-2014-2015/mental-capacity/mental-capacity-bill---efm---as-introduced.pdf

[20] Mental Capacity Bill (as introduced to the NI Assembly on 8th June 2015, Bill 49/11-16), Clause 11, page 7, http://www.niassembly.gov.uk/globalassets/documents/legislation/bills/executive-bills/session-2014-2015/mental-capacity/mental-capacity---as-introduced.pdf

NB: Nothing in Clause 11 prevents a person from providing life sustaining treatment or doing an act that the person "reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court" (Clause 11(4)).[21]

Clause 96 - provides the link between the scope of a Lasting Power of Attorney (LPA) and an ADRT. Clause 96(1) states that where an LPA authorises an attorney to make decisions about the donor's care, treatment and personal welfare, the authority is subject (as stated in 96 (1)(b)) to Clause 97(2). 97(2) means that the person given LPA for health and welfare must act within the confines of any directions in a valid and applicable ADRT made after or at the same time as the registration of the LPA.[22]

3.2 Advance Decisions to Refuse Treatment – Consultation Opinions

With regard to ADRTs the Bill, as introduced, has not altered from the Departmental proposals consulted on from 27th May 2014 to 2nd September 2014.

The information in this section summarises the key issues and range of opinion regarding advance decisions from over 60 consultees from that consultation process[23] and from the NI Assembly Ad Hoc Joint Committee call for evidence, which welcomed "views/comments on the contents of the Bill" by 7th July 2015[24].

There was a general welcome that ADRTs have been given statutory recognition in the Bill. However, many felt that the Bill does not go far enough and have called for codification of ADRTs, rather than continuing to rely on courts and case law.[25]

A number of consultees[26] understood the Department's expressed position that the law in this area is still evolving and that it would be premature to fix it in statute at this point.[27] However, it was commented that:

> *it would be helpful if the Code of Practice set out expressly the conditions under which advance decisions may be complied with or challenged. This element of practice continues to be enshrined in an area of law which many practitioners find confusing and ambiguous.*[28]

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[21] Mental Capacity Bill (as introduced to the NI Assembly on 8th June 2015, Bill 49/11-16), Clause 11, page 7, http://www.niassembly.gov.uk/globalassets/documents/legislation/bills/executive-bills/session-2014-2015/mental-capacity/mental-capacity---as-introduced.pdf

[22] As above - Clause 96, page 51,

[23] Mental Capacity Bill Consultation (27th May 2014 to 2nd September 2014), DHSSPS, http://www.dhsspsni.gov.uk/index/consultations/mental-capacity-bill-responses-2014.htm

[24] Ad Hoc Joint Committee on the Mental Capacity Bill, http://www.niassembly.gov.uk/assembly-business/committees/ad-hoc-committee-to-consider-the-mental-capacity-bill/call-for-evidence/

[25] Advocacy (NI), British Geriatric Society, Lead Nurse – Learning Disability (Western HSC Trust), Marie Curie, Volunteer Now

[26] NI Association of Social Workers, the NI Approved Social Worker Training Programme and NI Practice and Education Council for Nursing and Midwifery

[27] Mental Capacity Bill Consultation (27th May 2014 to 2nd September 2014), NIAMH, http://www.dhsspsni.gov.uk/index/consultations/mental-capacity-bill-responses-2014.htm

[28] As above - NIPEC

Somewhat contrary to the main body of consultee opinion, the Royal College of Psychiatrists expressed some concern about ADs[29]:

> *We recognize their value in allowing a person to make a capacitous decision about how they wish to be treated when ill. This can be a useful basis for mental health professionals and patients to work together. Some clinical situations may prove difficult however. The case of a person refusing lifesaving treatment on the basis of an advance decision is a concern. We welcome that the Bill appears to allow that an advance decision does not prevent provision of treatment to save life or prevent serious deterioration (Clause 11 (4) (a and b)). This gives some reassurance to those working in emergency situations.*

In connection with this quote, it should be noted that Clause 11 (4) applies only "while a decision as respects any relevant issue is sought from the court".[30]

Key issues/questions which were highlighted in the consultation responses are now considered in turn:

- Statutory provision for ADRTs;
- Mitigating factors to support wider recognition of ADRTs (if they remain under 'common law');Defining and prescribing an 'effective' ADRT;
- ADRTs for 16 and 17 year-olds; and
- Implications of an ADRT to refuse treatment for a mental disorder.

3.2.1 Statutory Provision for ADRTs

A wide range of consultees[31] recommended that the Bill is used to provide statutory provision for ADRTs, rather than leaving this for the courts to determine. This was of particular importance to those groups working with the elderly.

The Bill keeps ADRTs on a common law footing whilst setting out that they can outweigh elements of the statute, (section 3.1 above). It has been suggested by a range of consultees that the effect of this would be clearer if there was statutory provision for ADRTs in the Bill.[32]

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[29] Ad Hoc Joint Committee on the Mental Capacity Bill, written evidence from the Royal College of Psychiatrists, http://www.niassembly.gov.uk/assembly-business/committees/ad-hoc-committee-to-consider-the-mental-capacity-bill/call-for-evidence/

[30] Mental Capacity Bill (as introduced to the NI Assembly on 8th June 2015, Bill 49/11-16), Clause 11, page 7, http://www.niassembly.gov.uk/globalassets/documents/legislation/bills/executive-bills/session-2014-2015/mental-capacity/mental-capacity---as-introduced.pdf

[31] Including Age NI, Alzheimer's Society, Belfast HSC Trust, BMA, Cause, Children's Law Centre, Clinical Education Centre, Commissioner for Older People, Compassion in Dying, Dignity in Dying, FEBE, Law Centre MNI, Medical Protection Society, Mencap, Mind Yourself, Niamh, and nine responses from individuals

[32] Compassion in Dying, Mental Capacity Bill Consultation (27th May 2014 to 2nd September 2014), DHSSPS, http://www.dhsspsni.gov.uk/index/consultations/mental-capacity-bill-responses-2014.htm

There were concerns expressed that the current common law legal status does not provide the clarity about what is needed for an ADRT to be deemed 'effective' (the term used in the Bill). A selection of relevant statements includes;

Compassion in Dying:

> *Given the commitment to introduce mental capacity legislation in Northern Ireland, it seems to make sense to make the legal status of Advance Decisions as clear as possible – so that people have the best chance possible of making use of and benefiting from the new law, and so that healthcare professionals will understand the law and their responsibilities in relation to Advance Decisions.*[33]

In responding to the Ad Hoc Committee call for evidence, Compassion in Dying added:

> *The detail within the MCA*[34] *which defines valid and applicable Advance Decisions also gives people greater confidence and peace of mind that their Advance Decisions will be respected in the future. This is especially true in the context of Advance Decisions that refuse life sustaining treatment. The additional criteria not only gives people greater confidence that their wishes will be respected but also makes healthcare professionals more confident in following Advance Decisions...*

The Medical Protection Society:

> *Healthcare professionals are sometimes required to deal with difficult ethical issues surrounding advance decisions and it is far from ideal to expect them to apply principles enunciated in court judgements, in circumstances where the common law is readily codifiable into the Bill. The Bill should include provisions similar to those contained within sections 24-26 of the Mental Capacity Act 2005.*[35]

NI Association for Mental Health (NIAMH) believes that:

> *Without codified Advanced Decisions, there is a high risk that the recorded will and preference of individuals will be (i) unavailable in crises or emergencies (because it is not centrally lodged) or (ii) partially or completely disregarded. We consider codified Advanced Decisions to be a fundamental safeguard.*[36]

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[33] Compassion in Dying, Mental Capacity Bill Consultation (27th May 2014 to 2nd September 2014), DHSSPS, http://www.dhsspsni.gov.uk/index/consultations/mental-capacity-bill-responses-2014.htm

[34] MCA – Mental Capacity Act 2005, http://www.legislation.gov.uk/ukpga/2005/9/contents

[35] Mental Capacity Bill Consultation (27th May 2014 to 2nd September 2014), DHSSPS, Medical Protection Society, http://www.dhsspsni.gov.uk/index/consultations/mental-capacity-bill-responses-2014.htm

[36] As above - NIAMH

The Alzheimer's Society, responding to the Ad Hoc Committee, stated[37]:

> *The fact that advance decisions remain in common law presents a high risk that they will be ill-defined in contrast to the detail attached to other provisions; misunderstood and as a consequence subject to a 'chill effect' which will inhibit widespread understanding and use.*
>
> *Alzheimer's Society takes the view that advance decisions should be included in the Bill, as they play a pivotal role in advance care planning for a person with dementia. A person with dementia may live for many years with a good quality of life but will lose their capacity to make decisions as their condition advances and towards the end of their life. It is neither a possibility nor a probability- loss of capacity is a certainty. For this reason advance decisions to refuse treatment have a key part to play in advance care planning.*

The Commissioner for Older People, responding to the Ad Hoc Committee call for evidence expressed a desire for clarity:

> *In an attempt to avoid confusion and to clearly set out the mechanisms and parameters for an Advance Decision there should be appropriate clauses placed on the face of the draft Bill. At present, the draft legislation does not include sufficient detail on the face of the Bill.*

The Centre for Disability and Law, responding to the Ad Hoc Committee, proposed the concept of legally-binding support agreements (in addition to ADRTs) to support people with disabilities to exercise their legal capacity[38]:

> *…the Bill should explicitly recognise different forms of support which people with disabilities might use in the exercise of their legal capacity. This should include the option of making formal, legally-binding support agreements and advance directives, where individuals set out the support they intend to use in exercising their legal capacity in various areas of their lives.*

3.2.2 Mitigating factors to support wider recognition of ADRTs

A number of consultees focused on potential mitigating factors to support wider use and recognition of ADRTs (particularly if they remain in 'common law'). These came under two main areas:

(i) raising public and professional awareness and

[37] Ad Hoc Joint Committee on the Mental Capacity Bill, written evidence from the Alzheimer's Society, http://www.niassembly.gov.uk/assembly-business/committees/ad-hoc-committee-to-consider-the-mental-capacity-bill/call-for-evidence/

[38] Ad Hoc Joint Committee on the Mental Capacity Bill, written evidence from the Centre for Disability and Law http://www.niassembly.gov.uk/assembly-business/committees/ad-hoc-committee-to-consider-the-mental-capacity-bill/call-for-evidence/

(ii) including a **duty** on health and social care trusts to promote advance care planning, including ADRTs.

The Alzheimer's Society believe that if ADRTs remain in common law, this is a "far reaching omission":

> *significant measures must to put in place to ensure people are made aware, are supported to document advance decisions and that advocates are engaged to ensure these directives are followed at the material time of a person's care and treatment… these should include raising public and professional awareness of what the common law is around advance decisions/directives, and ensuring that people know that they have rights to make an advance decision...*[39]

CAUSE highlighted that more widespread use of ADs would need to be:

> *supported by a public promotion / education initiative accompanied by training for organisations who could be involved in giving advice and guidance on advance directives (e.g. from statutory services through to community advice centres).*[40]

NIAMH requested that,

> *if the Department continues with its decision not to codify Advance Decisions, clarification of what systems will be put in place in order to ensure that professionals and services are up-to-date with common law [and that there is a] commitment to a public awareness raising programme regarding the common law on Advance Decisions.*[41]

The Children's Law Centre[42] highlighted the recommendations made in relation to ADs from the House of Lords review of the MCA 2005 (see Section 4.2):

- That the Government must urgently address the low level of awareness among the general public of ADs to refuse treatment;
- That there is a need to promote better understanding among health care staff of ADs;
- To promote early engagement between health care staff and patients to ensure that ADs can meet the test of being valid and applicable; and
- To promote the inclusion of ADs in electronic medical records.

[39] Mental Capacity Bill Consultation (27th May 2014 to 2nd September 2014), DHSSPS, Alzheimer's Society, http://www.dhsspsni.gov.uk/index/consultations/mental-capacity-bill-responses-2014.htm
[40] As above - CAUSE
[41] As above - NIAMH
[42] As above - Children's Law Centre

The Bamford Monitoring Group requested that the DHSSPS commits to including a **duty** upon Health and Social Care Trusts to promote the uptake of future planning mechanisms and to put in place funded measures to allow individuals to make a Lasting Power of Attorney or 'advance statement'.[43]

This was also reflected by the Patient and Client Council[44]:

> *We recommend that the Bill includes a legal duty upon Health and Social Care Trusts to promote uptake of future planning tools. We are concerned that the lack of codification in this Bill of advance directives creates legal uncertainty which may mean that unless a person creates a formal Lasting Power of Attorney; their advance directive will not be recognised.*

3.2.3 Defining and prescribing an 'effective' ADRT

A number of consultees[45] noted that the Bill does not define or is not clear on what constitutes an 'effective' or valid ADRT. The Children's law Centre concluded[46]:

> *It is essential that both the DHSSPS and DoJ take the opportunity available through the Mental Capacity Bill to define what is meant by a valid advance decision, to clarify who can make such a decision and the degree to which such a decision must be followed and respected by all professionals in relation to both the physical and mental health treatment of an individual aged 16 and over.*

A number of other questions and practicalities were raised regarding an 'effective' ADRT, including:

- How will it be ensured that P was not under undue influence or duress when making the AD[47] - the Commissioner for Older People, highlighted[48]:

> *Alongside the right to make an advance decision stringent safeguards to ensure that the 'advanced decision' making process is free from third party interference should be implemented….Any concern of undue influence being placed on an older person should be raised with an appropriate*

[43] Mental Capacity Bill Consultation (27th May 2014 to 2nd September 2014), DHSSPS, Bamford Monitoring Group, http://www.dhsspsni.gov.uk/index/consultations/mental-capacity-bill-responses-2014.htm

[44] Ad Hoc Joint Committee on the Mental Capacity Bill, written evidence from Patient and Client Council, http://www.niassembly.gov.uk/assembly-business/committees/ad-hoc-committee-to-consider-the-mental-capacity-bill/call-for-evidence/

[45] Action Mental Health, Age NI, Belfast HSC Trust, BMA, Carers NI, Children's law Centre, Compassion in Dying, GMC, Law Centre (NI), law Society (NI), NI Approved Social Worker Training Programme, Regional Approved Social Worker Forum, South Eastern Health and Social Care Trust

[46] Ad Hoc Joint Committee on the Mental Capacity Bill, written evidence from Children's Law Centre, http://www.niassembly.gov.uk/assembly-business/committees/ad-hoc-committee-to-consider-the-mental-capacity-bill/call-for-evidence/

[47] AMH, Aware Defeat Depression and CAUSE

[48] Ad Hoc Joint Committee on the Mental Capacity Bill, written evidence from the Commissioner for Older People, http://www.niassembly.gov.uk/assembly-business/committees/ad-hoc-committee-to-consider-the-mental-capacity-bill/call-for-evidence/

> *review body. A legislative duty placed on appropriate health practitioners could help to alleviate any concerns about older people being pressurised into making certain 'advance decisions'.*

- How will it be ensured that P had mental capacity at the time of making the ADRT?[49];
- Will P be formally reminded to review the ADRT regularly[50]?
- For those tasked to take account of an ADRT when considering an intervention - will a database be available on a 24 hours basis?[51]
- The BMA(NI) expressed concern around the scenario where a patient with serious mental illness recovers, regains capacity and then makes an ADRT not to be treated with medication in the future but, according to practitioners, continues to lack insight into the need for treatment - will the 'appreciation' aspect of the capacity assessment be sufficient to address this?[52] and
- Clarification is needed on how ADRTs will work in connection with health and well-being Lasting Power of Attorneys (in particular is the last document to be signed, the operative document?)[53].

3.2.4 ADRTs for 16 and 17 year-olds

The Children's Law Centre believe that the Bill appears to deviate from the Bamford position on ADRTs for capacitous 16 and 17 year olds, as

> *Whilst not listed in the 16 and 17 year old section of the consultation document as an exclusion from the draft Bill it would appear that it is the intention of the Department that advance decisions may not be executed by a capacitous 16 or 17 year old in line with the common law position. The Bamford Review of Mental Health and Learning Disability recommended that a person from the age of 16 should be able to make a valid advance statement.*[54]

The Bamford recommendation on this point states that "Advance Statements and Refusals should only apply to persons over 16 years".[55]

[49] AMH, Aware Defeat Depression and CAUSE
[50] As above
[51] Mental Capacity Bill Consultation (27th May 2014 to 2nd September 2014), DHSSPS, The Belfast HSC Trust, http://www.dhsspsni.gov.uk/index/consultations/mental-capacity-bill-responses-2014.htm
[52] As above - BMA (NI)
[53] As above - Law Society (NI)
[54] As above - Children's Law Centre
[55] A Comprehensive Legislative Framework, The Bamford Review of Mental Health and Learning Disability, page 47, http://www.dhsspsni.gov.uk/index/bamford/published-reports/cl-framework.htm

3.2.5 Implications of an AD to refuse treatment for a mental disorder

The Medical Protection Society highlighted concerns about the potential implications of an ADRT for a mental disorder, as this may prevent doctors from treating serious psychiatric conditions such as psychosis,

> *We appreciate the purpose of this approach is to afford parity between physical and mental illnesses, and to respect the right of people with capacity to be able to decide, in advance, which treatments they will and will not consent to. However, it could result in a situation whereby effective treatment cannot be provided to a patient, in circumstances where the patient has been deprived of their liberty (because of the risk of self-harm or harm to others).*[56]

4 England and Wales - Mental Capacity Act 2005

The Mental Capacity Act 2005 (MCA 2005) applies to everyone involved in the care, treatment and support of people aged 16 and over living in England and Wales who are unable to make all or some decisions for themselves.

England and Wales are, at present, the only jurisdictions of the UK where an ADRT has statutory provision, which is contained in the Mental Capacity Act (2005).[57] The ADRT is legally binding providing it meets the criteria laid out in the Act and the patient's healthcare team must follow the ADRT provided they know about it.[58]

4.1 Mental Capacity Act – Advance Decisions to Refuse Treatment

Unlike the NI Bill, the MCA 2005 includes provision for those aged 18 and over who have capacity and choose to plan for their future through the use of ADRT to refuse treatment.[59]

A 'valid' and 'applicable' ADRT has the same force as a 'contemporaneous decision' by the individual and this has been a fundamental principle of the common law for many years. This is essentially what is provided for in Sections 24-26 of the MCA 2005.[60]

In addition, in England and Wales, patients can also make an Advance Statement (AS) (not legally binding) in which an individual can set out their preferences for any aspect of future health and social care, including practical personal issues.[61]

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[56] Mental Capacity Bill Consultation (27th May 2014 to 2nd September 2014), DHSSPS, Medical Protection Society http://www.dhsspsni.gov.uk/index/consultations/mental-capacity-bill-responses-2014.htm

[57] Mental Capacity Act (2005), http://www.legislation.gov.uk/ukpga/2005/9/contents

[58] Advance Decision to Refuse Treatment, Macmillan Cancer Support, webpage accessed 29/07/15, http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Advancedcancer/AdvanceDecision.aspx

[59] At a Glance 5: Mental Capacity Act 2005, Social Care Institute for Excellence, June 2009, http://www.scie.org.uk/publications/ataglance/ataglance05.asp

[60] MCA 2005, Code of Practice, Dept. of Constitutional Affairs (2007), Chapter 9, paragraph 9.1, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf

The Code of Practice gives an overview of what the Act says about ADRTs[62]:

> *Healthcare professionals must follow an advance decision if it is valid and applies to the particular circumstances. If they do not, they could face criminal prosecution (they could be charged for committing a crime) or civil liability (somebody could sue them).*
>
> *Advance decisions can have serious consequences for the people who make them. They can also have an important impact on family and friends, and professionals involved in their care. Before healthcare professionals can apply an advance decision, there must be proof that the decision:*
>
> *•exists*
>
> *• is valid, and*
>
> *• is applicable in the current circumstances.*

It has been commented that the provisions relating to the existence, validity and applicability of ADRTs (especially those relating to life-sustaining treatment) are,

> *some of the most important in the Mental Capacity Act 2005. The penalties for failing to comply with the procedural requirements can result in the overriding by the Court of what may appear to be clear and strongly-held views expressed by P before the onset of incapacity[63]*;
>
> *One can detect even in this jurisdiction an understandable queasiness on the part of the judiciary as to the implications of an 'absolutist' approach to advance decisions. This underpins, in particular, the concern expressed to ensure that at the time the decision was made the patient knowingly and freely intended that it would apply to the situation that would confront them in the future.*[64]

Chapter 9, Part 1, Sections 24 to 26 of the MCA cover ADRTs.[65] Broadly, the sections codified the common law rules, integrating them into the broader scheme of the Act. An "advance decision" as defined in these sections represents an actual decision to *refuse* treatment.

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[61] What is the Mental Capacity Act? NHS Choices, Mental Capacity Act – Care and Support, www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mental -capacity.aspx

[62] MCA 2005, Code of Practice, Dept. of Constitutional Affairs (2007), Chapter 9, paragraphs 9.2 and 9.3 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf

[63] Rucke Keene, A., Advance Decisions: getting it right? 39 Essex Street Chambers, http://www.39essex.com/docs/articles/advance_decisions_paper_ark_december_2012.pdf

[64] As above

[65] Mental Capacity Act 2005, Sections 25-26, http://www.legislation.gov.uk/ukpga/2005/9/section/24, http://www.legislation.gov.uk/ukpga/2005/9/section/25, http://www.legislation.gov.uk/ukpga/2005/9/section/26

The key characteristics of an ADRT for the purposes of the Act are set out in subsection (1) of Section 24[66]:

- It must be made by a person who is *18 or over* and at a time when the person has capacity to make it.
- A qualifying ADRT must specify the treatment that is being refused, although this can be in lay terms. It may specify particular circumstances, again in lay terms, in which the refusal will apply.
- A person can change or completely withdraw the ADRT if he has capacity to do so (subsection (3)). Subsection (4) confirms that the withdrawal, including a partial withdrawal, does not need to be in writing and can be by any means. Subsection (5) confirms that an alteration of an ADRT does not need to be in writing, *unless* it applies to refusing life-sustaining treatment, in which case formalities will need to be satisfied in order for it to apply.

Section 25 introduces the two safeguards of 'validity' and 'applicability' in relation to ADRTs[67]:

- To be 'valid', the ADRT must not have been withdrawn or overridden by a subsequent Lasting Power of Attorney giving a 'donee' the authority to consent or refuse consent to the treatment. If the person has acted in a way that is clearly inconsistent with the ADRT remaining his decision, then it is invalid.
- An ADRT will not be applicable if the person actually has capacity to make the decision when the treatment concerned is proposed. It is also not applicable if there are reasonable grounds for believing that the current circumstances were not anticipated by the person and, if they had been anticipated by him, would have affected his decision. For example, there may be new medications available.

Section 25, subsection (5) introduced further rules about the applicability of ADRTs to refuse life-sustaining treatment:

- The ADRT will not apply to life-sustaining treatment unless it is verified by a written, signed, witnessed statement confirming that the decision is to apply to that treatment even if life is at risk;
- A person does not physically need to write his ADRT himself. This means that ADRTs recorded in medical notes by healthcare staff are considered to be in writing as are electronic records; and
- If the maker of the AD cannot sign then another person can sign for him at his direction and in his presence (section 25(6)(b)). The witness must be present when the third party signs.[68]

[66] Mental Capacity Act, Explanatory Notes, Paragraphs 84-85, http://www.legislation.gov.uk/ukpga/2005/9/notes/division/6/1/6?view=plain
[67] As above - Paragraphs 87-88
[68] As above - Paragraphs 89-90

Section 26 deals with the legal effect of a qualifying ADRT:

- If it is both 'valid' and 'applicable' it has the same effect as a current refusal of treatment by a person with capacity. That is, the treatment *cannot* lawfully be given;
- A treatment-provider may safely treat unless satisfied that there is a valid and applicable qualifying ADRT; and
- A treatment-provider may safely withhold or withdraw treatment as long as he has reasonable grounds for believing that there is a valid and applicable qualifying ADRT.

If there is doubt or a dispute about the existence, validity or applicability of an ADRT then the Court of Protection can determine the issue. There is an important proviso in that action may be taken to prevent the death of the person concerned, or a serious deterioration in his condition, whilst any such doubt or dispute is referred to the court.[69]

With regard to the history of the MCA, the issue of ADRTs caused considerable concern during debates with "some concerns that their adoption might lead to euthansia by the back door". In the end the MCA was passed when the Westminster Government introduced a specific clause (Section 62) to remove any doubt about the issue:[70]

> *62 Scope of the Act*
>
> *For the avoidance of doubt, it is hereby declared that nothing in this Act is to be taken to affect the law relating to murder or manslaughter or the operation of section 2 of the Suicide Act 1961 (c. 60) (assisting suicide).*

The NI Bill also contains a similar provision in Clause 275[71]:

> *Relationship of Act with law relating to murder etc*
>
> *275.For the avoidance of doubt, it is hereby declared that nothing in this Act is to be taken to affect the law relating to murder or manslaughter or the operation of section 13 of the Criminal Justice Act (Northern Ireland) 1966 (encouraging or assisting suicide).*

Appendix 1 outlines what should be included in an ADRT according the Code of Practice of the MCA 2005.[72]

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[69] Mental Capacity Act, Explanatory Notes, Paragraphs 91-92, http://www.legislation.gov.uk/ukpga/2005/9/notes/division/6/1/6?view=plain

[70] History of the Mental Capacity Act and the Court of Protection, Welfare cases and thew Court of Protection, Resources, Cardiff University, http://sites.cardiff.ac.uk/wccop/resources/8-where-can-i-find-out-more-about-the-history-of-the-mental-capacity-act-2005-and-the-court-of-protection/

[71] Mental Capacity Bill (as introduced), Clause 275, http://www.niassembly.gov.uk/globalassets/documents/legislation/bills/executive-bills/session-2014-2015/mental-capacity/mental-capacity---as-introduced.pdf

[72] MCA 2005, Code of Practice, Dept. of Constitutional Affairs (2007), Chapter 9, paragraphs 9.10 – 9.28 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf

It is important to note the continued existence of separate mental health law (Mental Health Act 1983, substantially amended by the Mental Health Act 2007 (MHA)) and capacity law in England and Wales.

This means that the interaction between the MCA 2005 and the Mental Health Act must be taken into account in considering ADRTs[73]:

> *An advance decision will cease to have effect if the person is detained under the Mental Health Act and the treatment comes within the scope of Part 4 of that Act.*

It has been concluded that the provisions of the MCA with regard to ADRTs *do not apply* if the treatment is authorised under the Part IV of the MHA (*Consent to Treatment*) (except with respect to electroconvulsive therapy[74])[75]:

This does allow for the operation of ADRTs in conjunction with other parts of the MHA.

> *Advance refusals may be made by*
>
> - *People with a mental disorder that is not of a nature or severity that warrants detention under Part IV;*
> - *People who are detained under the MHA for short periods;*
> - *People (whether or not they are detained) who refuse electroconvulsive therapy (ECT) or other regulated treatment;*
> - *Adult community patients who have not been recalled to hospital; and*
> - *Those people who wish to refuse general medical treatment.*
>
> *Furthermore, any expression of a person's views or wishes, including those wishes that are expressed in a written statement, remains relevant to the treatment decision, including when treatment is provided pursuant to the authority provided in Part IV[76].*

4.2 Post-Legislative Scrutiny of the MCA 2005 by the House of Lords Select Committee

The House of Lords Select Committee was established in May 2013 to conduct post-legislative scrutiny of the MCA 2005. Overall, the Committee endorsed the aspiration of the Act:

[73] Mental Capacity and Deprivation of Liberty, A Consultation Paper, Consultation Paper No 222, Law Commission, paragraph 13.8, http://www.lawcom.gov.uk/wp-content/uploads/2015/07/cp222_mental_capacity.pdf
[74] Mental Health Act 2007, Section 27(5)(c), Section 27(9), http://www.legislation.gov.uk/ukpga/2007/12/contents
[75] Weller, P (2013) New Law and Ethics in Mental Health Advance Directives, The Convention on the Rights of Persons with Disabilities and the Right to Choose, Routledge, Chapter 1, The right to choose, page 86
[76] As above

> *Our findings suggest that the Act, in the main, continues to be held in high regard. However, its implementation has not met the expectations that it rightly raised. The Act has suffered from a lack of awareness and a lack of understanding. For many who are expected to comply with the Act it appears to be an optional add-on, far from being central to their working lives. The evidence presented to us concerns the health and social care sectors principally. In those sectors the prevailing cultures of paternalism (in health) and risk-aversion (in social care) have prevented the Act from becoming widely known or embedded.*[77]

The Select Committee concluded that one reason for the Act's 'patchy' implementation is that there is no central ownership it. The key recommendation was that responsibility for oversight of its implementation should be given to a single independent body.[78]

4.2.1 Findings Concerning ADRTs

Evidence to the Select Committee[79] suggested that public awareness of ADRTs is low. Compassion in Dying cited research showing that only 3% of the public have made an Advance Decision, even though 82% have "clear views about their end-of-life care preferences".

It was also suggested by a number of witnesses that the introduction of welfare LPAs had led to a corresponding decrease in ADRTs, since having an attorney provided the prospect of advocacy and meaningful engagement with local authorities and other public bodies on behalf of the person concerned.

Evidence from the North East London NHS Trust showed that although it had a policy on ADRTs (including a standard format and guidance for staff) use of ADRTs was still low.

Other evidence expressed concern about the low levels of awareness among professionals of the role and status of ADRTs with no widely available and approved standard format.

The Select Committee highlighted that nevertheless it had,

[77] HOUSE OF LORDS Select Committee on the Mental Capacity Act 2005 , Report of Session 2013–14, Mental Capacity Act 2005: post-legislative scrutiny, Marc h 2014, Summary, http://www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf

[78] As above

[79] As above - pages 75-76

> *received evidence from a number of hospital trusts who had made significant local efforts to raise awareness, encourage take-up and ensure respect for advance decisions.*[80]
>
> *Despite a few examples of local good practice the evidence suggested that there was no "systematic process for the recording, storage and retrieval of this information at the time when the person who made the [advance decision] lost capacity.*[81]

The Select Committee recommended that the Government, working with the independent oversight body[82]:

- Urgently address the low level of awareness among the general public of ADRTs;
- Promote better understanding among health care staff, in order to ensure ADRTs are followed when 'valid' and 'applicable';
- Promote early engagement between health care staff and patients about ADRTs to ensure that such decisions can meet the test of being valid and applicable when the need arises; and
- Promote the inclusion of ADRTs in electronic medical records to meet the need for better recording, storage and communication of such decisions.

4.2.2 The Government's Response to the Select Committee

The Government did not agree with the recommendation from the Select Committee to set up an independent body, however, it did agree that there was no mechanism for maintaining oversight across the key sectors where the Mental Capacity Act has a critical role to play,

> *we will therefore consider the case for establishing, at the national level, a new Mental Capacity Advisory Board. Any such Board would contain representation from all national bodies responsible for the Act and a representative range of stakeholders with an interest in the MCA including service users. The Board would be led by an independent Chair who would be accountable to Ministers at the Ministry of Justice and Department of Health.*[83]

The written response to a recent Parliamentary Question (July 2015) reveals that the Government is responding to the Committee's recommendation by establishing what is

[80] HOUSE OF LORDS Select Committee on the Mental Capacity Act 2005 , Report of Session 2013–14, Mental Capacity Act 2005: post-legislative scrutiny, March 2014, page 76 http://www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf

[81] As above

[82] As above - page 77

[83] Valuing every voice, respecting every right: making the case for the Mental Capacity Act. The Government's response to the House of Lords Select Committee Report on the Mental Capacity Act 2005,HM Government, June 2014, pages 9-10, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/318730/cm8884-valuing-every-voice.pdf

being referred to as a "National Mental Capacity Forum" and was in the final stages of appointing a chair.[84]

Specifically with regard to ADRTs, the Government response to the Select Committee report was[85]:

> *Advance decisions to refuse treatment (ADRTs) form an important part of the care and treatment planning process as do health and welfare Lasting Powers of Attorney (LPAs). We support the House of Lords recommendation that further work be done to raise awareness and understanding of ADRTs.*
>
> *The report of the Select Committee quite rightly draws attention to current best practice in some hospital trusts. For example, the standard operating procedure introduced in Warrington and Halton Hospitals NHS Foundation Trust. This is exactly the type of best practice that the national level needs to capture and help disseminate across the wider NHS.*
>
> *We would ask the new Mental Capacity Advisory Board to include advance decision-making in its programme of work and we urge our system partners to use their networks to increase information on ADRTs so that more individuals may realise the right to assert their wishes in this manner.*

5 Scotland – Adults with Incapacity (Scotland) Act 2000 and Mental Health (Care and Treatment) (Scotland) Act 2003

The law of Scotland generally presumes that those aged 16 or over are legally capable of making personal decisions for themselves and managing their own affairs. That presumption can only be overturned on evidence of impaired capacity. The Adults with Incapacity (Scotland) Act 2000 sets out a framework for regulating interventions in the affairs of adults who have impaired capacity:[86]

> *The common law doctrine of necessity allows medical practitioners to give life saving treatment to patients who cannot consent and in these circumstances there is no need to invoke the mechanisms in Part 5 of the 2000 Act. Part 5 covers non-emergency medical treatment and includes 'any procedure or treatment designed to safeguard or*

[84] Parliamentary Question, House of Lords, HL 1469, http://www.parliament.uk/written-questions-answers-statements/written-question/lords/2015-07-15/HL1469

[85] Valuing every voice, respecting every right: making the case for the Mental Capacity Act. The Government's response to the House of Lords Select Committee Report on the Mental Capacity Act 2005,HM Government, June 2014, page 23, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/318730/cm8884-valuing-every-voice.pdf

[86] Guidance for Obtaining Informed Consent, NHS Scotland, NHS Fife, October 2012, Section 2, http://publications.1fife.org.uk/weborgs/nhs/uploadfiles/publications/c64_Guidanceforobtaininginformedconsent_2_%5bfinal%5d.pdf

> *promote physical or mental health', including treatment for mental disorder.*

With regard to ADRTs two pieces of legislation are most relevant:

- The Adults with Incapacity (Scotland) Act 2000 - ADRTs are not legally enforceable under this Act, however, one of the general principles of the Act states that the wishes of the adult should be taken into consideration when acting or making a decision on their behalf;[87]
- The Mental Health (Care and Treatment) (Scotland) Act 2003 - gives the patient the right to make a non-legally binding Advance Statement (AS) about the treatment they would prefer to receive or not receive for the mental disorder if at some point in the future the patient is too unwell to make decisions about their treatment.[88]

5.1 Adults with Incapacity (Scotland) Act 2000

ADRTs do not have any statutory legal authority in Scotland[89]:

> *Their common law authority has never been tested in Scotland as there is no Scottish case law on advance directives or living wills, but English case law may be persuasive.*

The BMA have also noted that there is no reason to assume that the courts in Scotland would take a different approach to the English courts[90]:

> *The relevant code of practice states that valid advance refusals of treatment 'are potentially binding', and, in the BMA's view, doctors should comply with an unambiguous and informed advance refusal when the refusal specifically addresses the situation that has arisen.*

However, the third general principle of the Adults with Incapacity (Scotland) Act 2000 states that in deciding if an action or decision is to be made, and what that should be, account must be taken of the present and past wishes and feelings of the person, as far as this may be ascertained. The rationale behind this is that some adults will be able to express their wishes and feelings clearly, even although they would not be

[87] Adults with Incapacity (Scotland) Act 2000, Part 1, Section 1, http://www.legislation.gov.uk/asp/2000/4/section/1

[88] The New Mental Health Act, A Guide to Advance Statements, Scottish Executive, July 2005, http://www.gov.scot/Publications/2004/10/20017/44081

[89] Guidance for Obtaining Informed Consent, NHS Scotland, NHS Fife, October 2012, Section 2, http://publications.1fife.org.uk/weborgs/nhs/uploadfiles/publications/c64_Guidanceforobtaininginformedconsent_2_%5bfinal%5d.pdf

[90] Medical treatment for adults with incapacity - guidance on ethical and medico-legal issues in Scotland, April 2009, BMA Ethics, Paragraph 9.2.1, http://bma.org.uk//media/files/pdfs/practical%20advice%20at%20work/ethics/adultswithincapacityscotlandapril2009.pdf?la=en

capable of taking the action or decision being considered[91]. The relevant extract from the Act is[92]:

> *1 General principles and fundamental definitions……*
>
> *(4) In determining if an intervention is to be made and, if so, what intervention is to be made, account shall be taken of—*
>
> *(a) the present and past wishes and feelings of the adult so far as they can be ascertained by any means of communication, whether human or by mechanical aid (whether of an interpretative nature or otherwise) appropriate to the adult;*

As a result, some legal authorities think it is arguable that a medical practitioner who ignores the wishes of a patient, properly expressed in an AD, could be guilty of assault in the same way as if he or she had continued treatment immediately following refusal of that treatment by a fully competent, fully informed adult.[93]

5.2 Advance Statements - Mental Health (Care and Treatment) (Scotland) Act 2003

In Scotland, Sections 275 and 276 of the Mental Health (Care and Treatment) (Scotland) Act 2003 enable a patient to make an advance statement (AS). This is a written statement setting out how they would wish to be treated, or wish not to be treated, for their mental disorder should their ability to make decisions about treatment become significantly impaired as a result of their mental disorder.[94]

The provision to make an advance statement applies to everyone[95],

> *If you can understand what you are putting in the statement and the effect it might have on your future treatment, you can make an advance statement. This includes young people under 16 years of age so long as you can understand the nature and possible consequences of the procedure or treatment.*

There is no provision for parents to make an advance statement on behalf of their child or for welfare guardians, named persons or others to do so for adults who do not have capacity.[96]

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[91] The Adults with Incapacity (Scotland) Act 2000: A Short Guide to the Act, About the Adults with Incapacity Act, The Scottish Government, http://www.gov.scot/Publications/2008/03/25120154/1

[92] Adults with Incapacity (Scotland) Act 2000, Part 1, Section 1, http://www.legislation.gov.uk/asp/2000/4/section/1

[93] MND Scotland, MND Factsheet 44 Advance Directives, 27/10/11, http://www.mndscotland.org.uk/wp-content/uploads/2011/save/44%20Advance%20Directives%202009.pdf

[94] Mental Health (Care and Treatment) (Scotland) Act 2003, Code of Practice, Volume 1, Chapter 6, Para. 44, http://www.gov.scot/Resource/Doc/57346/0017038.pdf

[95] The New Mental Health Act, A Guide to Advance Statements, October 2004, The Scottish Government, http://www.gov.scot/Publications/2004/10/20017/44081#5

An AS is not legally binding but there is a *duty to have regard* to it:

> *The duty to have regard to an advance statement is one aspect of the duty on doctors and other persons discharging functions under the Act as set out in section 1. These functions include having regard to the past and present wishes and feelings of the patient which are relevant to the discharge of the function. The advance statement is not the only means of ascertaining the patient's past and present wishes and feelings, and other relevant sources of information should be taken into account when decisions are being made about care and treatment (whether an advance statement exists or not).*[97]

To be valid, the Act requires that an AS must be signed by the patient and witnessed by a prescribed person. The witness must sign the statement and certify in writing at the time that in their opinion the patient making the statement has the capacity to properly intend the wishes specified in it.[98]

When a decision is made conflicting with the AS, either by a person giving medical treatment under the Act, the Tribunal or a designated medical practitioner, Section 276(8) of the Act requires that this is recorded in writing. The record must state how the treatment conflicted with the patient's requests, and the reasons why this treatment decision was made. A copy must be sent to the patient, the named person, any guardian or welfare attorney and to the Mental Welfare Commission and a record must also be placed in the patient's medical records.

The Mental Health (Scotland) Act 2015 (received Royal Assent on August 4, 2015) amended the 2003 Act in relation to ASs. It is now required that Health Boards place ASs with a patient's medical records, inform the Mental Welfare Commission (Section 26). The Commission must register the AS and Health Boards must publicise their support for making ASs (Section 27).[99]

It has been highlighted that the legislative model for mental health advance statements adopted in Scotland is viewed internationally as a best practice model for mental health laws in common law jurisdictions[100]:

> *The attraction of the Scottish model is its promise of accommodating the strongly expressed preferences of consumer groups for the recognition of advance instructions, and the expectation that people with mental health*

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[96] Advance Statement Guidance, Good Practice Guide, Mental Welfare Commission for Scotland, page 9, http://www.mwcscot.org.uk/media/128044/advance_statement_final_version_jan_2014.pdf

[97] Mental Health (Care and Treatment) (Scotland) Act 2003, Code of Practice, Volume 1, Chapter 6, Para. 44, http://www.gov.scot/Resource/Doc/57346/0017038.pdf

[98] As above - Para. 69

[99] Mental Health (Scotland) Act 2015, Sections 26 and 27, http://www.legislation.gov.uk/asp/2015/9/pdfs/asp_20150009_en.pdf

[100] Weller, P (2013) New Law and Ethics in Mental Health Advance Directives, The Convention on the Rights of Persons with Disabilities and the Right to Choose, Routledge, Chapter 1, The right to choose, page 102

conditions are equally entitled to control their health and mental health care.

6 Republic of Ireland – Assisted Decision Making Bill

In the Republic of Ireland, at present there is no specific legislation regarding advance decisions:[101]

Given the fact there is no legislation addressing directives in Ireland, this doesn't necessarily mean that they are not valid in Ireland but their status is unclear.

However, the situation is on course to change in the near future as the Assisted Decision-Making (Capacity) Bill (introduced to the Houses of the Oireachtas on 15th July 2013) now includes provision for 'Advance Healthcare Directives'.

The Assisted Decision-Making (Capacity) Bill 2013 as introduced, was to provide for the reform of the law relating to persons who require (or may require) assistance in exercising their decision-making capacity, whether immediately or in the future, including to provide for the[102]:

- Appointment by such persons of other persons to assist them in decision-making or (subject to the approval of the Circuit Court) to make decisions jointly with such persons;
- Appointment and functions of the Public Guardian in respect of persons who require or may shortly require assistance in exercising their decision-making capacity; and
- Amendment of the law relating to enduring powers of attorney

However, in March 2013, the Irish Government agreed that legislation was to be drafted to draw up 'Advance Healthcare Directives' and that these provisions would be integrated into the Assisted Decision-Making (Capacity) Bill at Committee stage.[103] A draft General Scheme of Legislative Provisions to provide for the Making of healthcare directives, was consulted on and subsequently the necessary amendments (253 to 264) agreed at Committee stage of the Bill on 17th June 2015.[104]

[101] Advance Care Directives, Citizens Information Board, website accessed 7th October 2015, http://www.citizensinformation.ie/en/health/legal_matters_and_health/advance_care_directives.html

[102] Assisted Decision-Making (Capacity) Bill 2013, Houses of the Oireachtas, http://www.oireachtas.ie/viewdoc.asp?fn=/documents/bills28/bills/2013/8313/document1.htm

[103] Speech by Minister for Justice, Equality & Defence at the Assisted Decision-Making (Capacity) Bill 2013: Consultation Symposium, Printworks Conference Centre, Dublin Castle, 25 September 2013.

[104] Assisted Decision-Making Capacity Bill 2013: Committee Stage, Houses of the Oireachtas, 17th June 2015, http://www.oireachtas.ie/viewdoc.asp?fn=/documents/bills28/bills/2013/8313/document1.htm

The Bill has recently completed Committee Stage and was amended by the Select Committee on Justice, Defence and Equality on 17th June 2015 to include a new Part 9, which provides a legislative framework for 'advance health care directives.[105]

Subsequent to the introduction of the Bill but prior to the Committee Stage, the Department of Health consulted on[106] a draft General Scheme of legislative provisions for 'advance health care directives', with the aim of these being incorporated into the Bill. The consultation document noted that[107]:

- These instruments predominantly relate to refusals of treatment up to and including life sustaining treatments but do not pertain to euthanasia or assisted suicide;
- A treatment refusal in an advance health care directive is intended to be legally-binding, so the directive must state clearly the specific treatments and situations to which the refusal(s) relates;
- An individual's will and preferences can encompass treatment refusals and treatment requests. Requests for treatment should be taken into consideration during the decision-making process but cannot be legally-binding, due to the balance to be struck between the wishes of the individual and health care resources; and
- The instruments enable an individual to appoint another person (patient designated healthcare representative) to make treatment decisions on his/her behalf or to interpret the terms of the advance health care directive.

Following the Departmental Consultation, amendments to the Bill were agreed at the Committee Stage (amendments 1, 2 and 253-264) to incorporate the provisions for advanced health care directives.[108] Amendments 1 and 2 provided for the Minister for Health to commence the provisions on advance health care directives, in consultation with the Minister for Justice and Equality, with amendments 253-264 providing the detail[109]:

> *The Assisted Decision-Making (Capacity) Bill was considered the most appropriate vehicle for providing a legislative framework for advance health care directives…Officials in the Department of Health published the draft general scheme of the advance health care directive provisions in February 2014 and conducted an extensive public consultation process on those provisions.*

[105] Assisted Decision-Making (Capacity) Bill 2013: Committee Stage, Houses of the Oireachtas, 17th June 2015, http://oireachtasdebates.oireachtas.ie/Debates%20Authoring/DebatesWebPack.nsf/committeetakes/JUS2015061700001?opendocument

[106] The consultation ran from 6th February 2014 to 7th March 2014

[107] Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, Department of Health, 2014, http://health.gov.ie/wp-content/uploads/2014/04/Discussion_Paper_AHDs.pdf

[108] Assisted Decision-Making (Capacity) Bill 2013: Committee Stage, Houses of the Oireachtas, 17th June 2015, http://oireachtasdebates.oireachtas.ie/Debates%20Authoring/DebatesWebPack.nsf/committeetakes/JUS2015061700001?opendocument

[109] As above

Clause 7 of the Assisted Decision-Making (Capacity) Bill 2013 (as amended in the Select Committee on Justice, Defence and Equality) permits these 'advance health care directives' to be over-ridden by the Mental Health Act 2001 as the following extract shows:

> *(7) (a) Subject to subsections (1) to (6) and paragraph (b), an advance healthcare directive shall be complied with unless, at the time when it is proposed to treat the directive-maker, his or her treatment is regulated by Part 4 of the Mental Health Act 2001 or he or she is the subject of a conditional discharge order under section 13A (inserted by section 8 of the Criminal Law (Insanity) Act 2010) of the Criminal Law (Insanity) Act 2006.*
>
> *(b) Notwithstanding paragraph (a), where a refusal of treatment set out in an advance healthcare directive by a directive-maker relates to the treatment of a physical illness not related to the amelioration of a mental disorder of the directive-maker, the refusal shall be complied with.*

The full text of the Bill as amended at the Committee Stage can be found on the Houses of the Oireachtas website[110].

7 Key Policy Issues

A review of the legislation surrounding advance decisions has identified the approaches taken between our neighbouring jurisdictions to the legal recognition of these instruments.

The Mental Capacity Bill for NI does not propose any changes with regard to the legal status of ADRTs. The Bill provides statutory recognition for ADRTs but not statutory provision. The Bill does require an 'effective' advance decision to be complied with, if it is valid and applicable under the common law.

The Departmental position regarding the proposal not to include statutory provision for ADRTs has been stated on a number of occasions, including[111]:

> *Our view is that the Bill goes as far as we possibly can go at the moment in giving statutory recognition to advance decisions. We fully appreciate the strength of view on this ….We took the view that it would be better to let the debate continue than to fix the rules in statute at this time.*

[110] Assisted Decision-Making (Capacity) Bill 2013 As amended in the Select Committee on Justice, Defence and Equality, http://www.oireachtas.ie/viewdoc.asp?fn=/documents/bills28/bills/2013/8313/b83a13d.pdf

[111] Mental Capacity Bill: Part 2 – Lack of Capacity: Protection from Liability; and Safeguards, Ad Hoc Joint Committee on the Mental Capacity Bill, Hansard, 21 September 2015, http://data.niassembly.gov.uk/HansardXml/committee-14963.pdf

> *There was a lack of consensus on whether it should be codified in the Bill. In particular, there was a lack of clarity on what those rules should be across the board…..Our view was that it was better to let society debate the issue, let the common law develop, reflect as much as possible of that in the code of practice and then allow the code of practice to be updated as common law evolves….*

Research for this paper has identified a *range* of policy variables/questions that require consideration around the scope of an advance decision for either potential inclusion in statute or, if relevant, for inclusion in a code of practice for NI:

1. Should an advance decision be limited to refusal of specific treatment(s) or should it allow for positive statements requesting a specific treatment? For example:
    a. An advance decision is defined in the MCA 2005 as an Advance Decision to Refuse Treatment (ADRT) (see section 4.1 of this paper); and
    b. The Assisted Decision Making (Capacity) Bill for the Republic of Ireland provides for a request for a specific treatment to be set out in an 'advance healthcare directive' but requests will not be legally binding (due to potential resource issues) but shall be taken into consideration.[112]
2. Should an advance decision be permitted to extend beyond healthcare treatments to encompass social care (even if these are positive requests to be taken into account, rather than legally binding), for example, how a person wants any religious or spiritual beliefs they hold to be reflected in their care or where they would like to be cared for – for example, at home or in a hospital, a nursing home, or a hospice.
3. Should an advance decision be able to include both treatments for physical illness and mental illness? For example, in Scotland, a patient diagnosed with a mental disorder has the right to make an Advance Statement (AS) (not legally-binding) about the treatment they would prefer to receive or not receive for the mental disorder if at some point in the future they become to unwell to make decisions about their treatment. The relevant legislation is the Mental Health (Care and Treatment) (Scotland) Act 2003.
4. The key legal safeguards of the MCA 2005 are that an ADRT to refuse treatment must be deemed both 'valid' and 'applicable' – what factors should be included in statute to ensure these or similar criteria are met (see section 4.1 of this paper)?
5. Should an advance decision be confined to an already diagnosed condition or extend to a future condition or future circumstances (such as pregnancy) that may require the treatment specified. For example, Section 25 of the MCA 2005 provides that an ADRT will not be 'applicable' if there are reasonable grounds for believing that the

[112] Assisted Decision-Making (Capacity) Bill 2013, Houses of the Oireachtas, Clause 65(3) http://www.oireachtas.ie/viewdoc.asp?fn=/documents/bills28/bills/2013/8313/document1.htm

current circumstances were not anticipated by the by the person at the timing of making the ADRT. The code of practice of the MCA 2005 advises that including possible future circumstances in the ADRT is good practice.

6. Should an advance decision be able to state refusal of life-sustaining treatment; for example:
    a. Section 25 of the MCA 2005 states that an ADRT will not apply to life-sustaining treatment unless it is verified by a written, signed, witnessed statement to that effect (see section 4.1 of this paper);
    b. Similarly, the Assisted Decision Making (Capacity) Bill for the Republic of Ireland states that an advance healthcare directive is not applicable to life-sustaining treatment unless this is substantiated by a statement in the directive by the directive-maker to that effect[113];
7. Palliative care – neither the MCA 2005 nor the Assisted Decision Making (Capacity) Bill allows advance decisions to be applicable to administration of basic or palliative care such as offers of oral fluids and foods, warmth and hygiene measures;
8. Are there circumstances in which an advance decision may cease to have effect due to being over-ridden? For example:
    a. In emergency situations while awaiting court decisions (in the MCA 2005 if there is doubt or dispute about an ADRT then the Court of Protection can determine the issue, however, action may be taken in the interim to prevent death or serious deterioration of the patient;
    b. Implications of separate mental health law. For example:
        i. In England and Wales an ADRT will cease to have effect if the person is detained under the Mental Health Act and the treatment comes within the scope of Part 4 of that Act (except with respect to electroconvulsive therapy); and
        ii. The Bill for NI will revoke the Mental Health Order as it currently applies to those aged 16 and over, meaning that a doctor will no longer have the authority to override an effective advance decision to refuse medical treatment for a mental disorder (which can happen at present).
    c. If the advance decision has not been recently reviewed?
9. Should written and oral advance decisions be equally valid in law? For example:
    a. The MCA 2005 provides for both written and oral ADRTs being legally binding, however, to refuse life-sustaining treatment, the ADRT must be written and be witnessed (see section 4.1 and Appendix 1 of this paper); and

[113] Assisted Decision-Making (Capacity) Bill 2013, Houses of the Oireachtas, Clause 66(3) http://www.oireachtas.ie/viewdoc.asp?fn=/documents/bills28/bills/2013/8313/document1.htm

   b. The Assisted Decision Making (Capacity) Bill for the Republic of Ireland, provides only for written advance health care directives (see section 6 of this paper);

10. At what age can an advance decision be made? For example:
    a. There appears to be a lack of clarity around the NI Bill whether or not capacitous 16 and 17 year olds can make advance decisons in line with the common law position (see section 3.2.4);
    b. The Section 24 of the MCA 2005 provides for those age 18 and over to make ADRTs (see section 4.1of this paper); and
    c. In Scotland, Advance Statements (not legally binding but must be taken into account) made under the Mental Health (Care and Treatment) Act can be made by anyone of any age as long as they can understand the nature and consequences of the treatment (see section 5.2 of this paper).
11. What level of public and professional awareness is required – should there be a duty on HSC Trusts and/or DHSSPS to promote advance decisions and provide the necessary templates and procedures? (see section 3.2.2 of this paper);
12. Is the process for withdrawing or re-making the advance decision clear in law?
13. Should there be 'offences' in legislation if an individual has found to have been coerced into making an advance decision, for example:
    a. The Assisted Decision Making (Capacity) Bill for the Republic of Ireland includes offences to be used if a person uses *fraud, coercion or undue influence to force another person to make, alter or revoke an advance healthcare directive* (see section 6 of this paper*).*

Appendix 1 – MCA 2005 – Structure and Composition of an ADRT

This section now outlines what should be included in an ADRT according the Code of Practice of the MCA 2005.[114]

An ADRT can be written or verbal, unless it deals with life-sustaining treatment, in which case it must be written and specific rules apply. An ADRT can include medical language or everyday language, it:

- Must state precisely what treatment is to be refused;
- May set out the circumstances when the refusal should apply;
- Will only apply at a time when the person lacks capacity to consent to or refuse the specific treatment;
- An AD refusing all treatment in any situation (for example, where a person explains that their decision is based on their religion or personal beliefs) *may* be valid and applicable;
- Including possible future circumstances in the AD is good practice. For example, a woman may want to state whether or not it should still apply if she later becomes pregnant;
- A written document can be evidence of an AD. It is good practice to tell others that the document exists and where it is.

Written ADRTs - according to the MCA Code of Practice, it is helpful to include the following information:

- Full details of the person making the ADRT, including date of birth, home address and any distinguishing features;
- The name and address of the person's GP and whether they have a copy of the document;
- A statement that the document should be used if the person ever lacks capacity to make treatment decisions;
- A clear statement of the decision, the treatment to be refused and the circumstances in which the decision will apply;
- The date the document was written (or reviewed);
- The person's signature (or the signature of someone the person has asked to sign on their behalf and in their presence);
- The signature of the person witnessing the signature.

[114] MCA 2005, Code of Practice, Dept. of Constitutional Affairs (2007), Chapter 9, paragraphs 9.10 – 9.28 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf

For verbal ADRTs - healthcare professionals will need to consider whether a verbal AD exists and whether it is valid and applicable. Where possible, healthcare professionals are advised to record a verbal ADRT in a person's healthcare record to include:

- A note that the decision should apply if the person lacks capacity to make treatment decisions in the future;
- A clear note of the decision, the treatment to be refused and the circumstances in which the decision will apply;
- Details of someone who was present when the verbal AD was recorded and the role in which they were present; and
- Whether they heard the decision, took part in it or are just aware that it exists.

With regard to ADs to refuse life-sustaining treatment - the MCA imposes particular legal requirements and safeguards:

- They must be put in writing. If the person is unable to write, someone else should write it down for them, e.g. a family member or a healthcare professional can record it in the person's healthcare notes;
- The ADRT must include a clear, specific written statement from the person making it that the ADRT is to apply to the specific treatment *even if life is at risk.*
- The person must sign the ADRT. If they are unable to sign, they can direct someone to sign on their behalf in their presence;
- The person making the decision must sign in the presence of a witness. The witness must then sign the document in the presence of the person making the ADRT;
- If the person making the ADRT is unable to sign, the witness can witness them directing someone else to sign on their behalf. The witness must then sign to indicate that they have witnessed the nominated person signing the document in front of the person making the ADRT;
- If this statement is made at a different time or in a separate document to the ADRT, the person making it (or someone they have directed to sign) must sign it in the presence of a witness, who must also sign it.

In this regard life-sustaining treatment is treatment which a healthcare professional who is providing care to the person regards as necessary to sustain life, for example, in some situations antibiotics may be life-sustaining, but in others they can be used to treat conditions that do not threaten life. Artificial nutrition and hydration (ANH) has been recognised as a form of medical treatment. Refusing ANH in an ADRT is likely to result in the person's death, if it is followed.

An ADRT cannot refuse actions that are needed to keep a person comfortable, for example, warmth, shelter, actions to keep a person clean and the offer of food and water by mouth.