

PUBLIC CONSULTATION RESPONSE: ADVANCE HEALTHCARE DIRECTIVES

An Ageing Perspective: Older Adults may wish to make Advance Healthcare Directives regarding the type of care they wish to receive should they become ill and are unable to make to make their wishes known at the time.

*Draft Scheme for
Advance Healthcare
Directives for
Incorporation into
the Assisted
Decision-Making
(Capacity) Bill 2013*



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This submission¹ is endorsed by the following organisations, which aim to ensure the wishes and rights of ageing individuals inform the integration of advance healthcare directives into the capacity legislation.

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Advance Healthcare Directives

1. Introduction

In 2009 the Law Reform Commission published a report which included a draft Bill concerning advance care directives: Bioethics: Advance Care Directives LRC 94-2009. This year draft amendments to the Assisted Decision Making (Capacity) Bill 2013 (ADM Bill) have been produced, some of which are similar to those produced by the LRC. The amendments will integrate legislation regarding advance care directives into the ADM Bill. We are broadly in agreement with the proposed amendments, but have a number of comments to make.

Advance healthcare directives may be made by adults who wish to control the kind of healthcare they receive should they become seriously ill and be unable either to decide on the treatment they want, or to communicate their wishes. Such a directive honours the will and preferences of the person, supports autonomy and facilitates healthcare planning by the individual. The focus on will and preferences is welcome given the language of the Convention on the Rights of Persons with Disabilities.

It is a well-established principle that adults are entitled to refuse consent to medical treatment even if it leads to their death, unless it can be shown that they lack the capacity to consent/refuse.² The proposed amendments to the Assisted Decision Making (Capacity) Bill 2013 would put this common law principle on a statutory basis. Most advance healthcare directives contain a refusal of certain treatments, but may express a preference for other treatments such as palliative care. In some jurisdictions they are very detailed and contain instructions concerning a wide variety of matters. In Ireland the draft amendments provide for a limited range of issues: the person may make an advance care directive and may also appoint a healthcare proxy to deal with healthcare professionals on his or her behalf should s/he ever lack capacity.

Anyone may experience severe illness or injury at any time and be unable to make their wishes regarding their care and treatment known. People living with progressive neurological disorders such as dementia, or those with a family history of neurological disease such as Huntington's or Alzheimer's may be particularly interested in making an advance healthcare directive because they believe it very likely that they will lose capacity in the future and be unable to make their wishes known. An advance healthcare directive is of interest to all adults and could be made at the same time as a will, or when donating an enduring power of attorney, or at any other time, for example upon receiving a diagnosis of severe illness. About 10% of people visiting a solicitor to make a will also want to make an

² *In Re A Ward of Court (withholding medical treatment) No 2* [1996] 2 IR 79

advance healthcare directive.³ In European studies 13-14% of people dying in hospital had made AHDs.⁴

An advance healthcare directive cannot be used to request treatment that is unlawful or unethical (such as euthanasia), or treatment that is unavailable.

This submission is specific to the interests of older people. It is particularly relevant for those experiencing the onset of dementia and other illnesses which may affect the person's capacity to make decisions.

2. Advance Healthcare Directives and the ADM Bill

If amended the Assisted Decision Making (Capacity) Bill would allow the relevant person to make an advance healthcare directive refusing various kinds of care, including life sustaining treatment. The relevant person would be able to appoint a healthcare proxy, described as a patient designated healthcare representative, to consent to or refuse treatment, or ensure compliance with the directive. The proxy is only able to refuse life sustaining treatment if empowered to do so by the relevant person. An attorney appointed by the person to make decisions relating to healthcare should also be able to refuse life sustaining treatment if empowered by the person to do so. This would involve amending section 41(2)(b) of the ADM Bill.

We discuss the following matters in relation to the amendments:

- (A) Interpretation/ definitions
- (B) Purpose and guiding principles
- (C) Advance healthcare directives: general and refusing treatment.
- (D) Validity and applicability of an advance care directive
- (E) Scope of AHD
- (F) Patient designated healthcare representatives (also known as healthcare proxies)
- (G) Revoking an AHD
- (H) Monitoring and administering AHD
- (I) Liability

(A) Interpretation/definitions

A number of terms need to be defined, including advance healthcare directive itself. Some types of care should not be refused in advance and these would be called 'basic care'. The term 'treatment' is used instead of healthcare which is used in the title of the proposed

³ Legal Issues Affecting the Older Person. John Costello. Presentation at Medicine Law and the Vulnerable Adult Conference. Dublin Jan 25th 2014

⁴ Hartog et al. Are written advance directives helpful to guide end of life therapy in the intensive care unit? J Crit Care 2014 Feb; 29(1): 128-133. Klinkenberg M et al. Preferences in end of life care of older persons: after death interviews with proxy residents. Soc Sci Med 2004 Dec;59(12):2467-77

amendments. We prefer the term ‘healthcare’. We suggest some definitions below. There should not be an artificial division between healthcare delivered by psychiatrists and other healthcare professionals. The term “healthcare professional” is defined in the Bill.

Advance healthcare directive

Recommendation: The directive is called an advance healthcare directive, yet it refers to ‘treatment’ which is a restrictive definition and is not the same as healthcare. Integrate this definition of healthcare into section 2 of the ADM Bill:

An advance healthcare directive is a valid and applicable advance expression of will and preferences, made by a person with capacity in accordance with the scope, conditions and requirements for advance healthcare directives concerning future health and social care issues which may arise in the event that the person loses capacity.

Basic Care

Basic care includes, but is not limited to, warmth, shelter, offering oral nutrition and hydration, and hygiene measures. These types of care may be regarded as the necessities of a comfortable and dignified life. It would be inhumane to deprive a person of warmth, shelter, food and drink. We do not think that many people would make an advance directive refusing shelter and warmth, but hygiene and nutrition may be contentious.

Hygiene is not a necessity of life and does not in itself sustain life, but it is part of a dignified and comfortable life, and may prevent the onset of infection or facilitate the healing of wounds. Basic hygiene measures would be necessary in a nursing home or hospital or hospice in order to prevent the spread of infection and/or infestations such as fleas, lice and scabies. The rights of a person refusing basic hygiene must be tempered by the rights of other patients’ to bodily integrity which would involve NOT being exposed to avoidable infections and infestations.

At some stage during the dying process it might be intrusive and unpleasant to provide anything except very limited washing and changing, but this would be for a very short period of time and would be dictated by the person’s condition.

Oral Nutrition and hydration: There is a difference between providing food and drink for voluntary consumption by the person, and providing artificial hydration and nutrition via intravenous line, PEG tube or nasogastric tube: one allows the person to accept food and drink if offered; the other can only be initiated after an invasive procedure such as cannulation of a vein, passing a nasogastric tube or inserting a PEG tube. Offering food and

drink for consumption, including prompting if necessary, is basic care; using an invasive procedure or any form of compulsion is not.

On some occasions, such as a stroke or other brain injury, the person may require supportive measures such as intravenous fluids while their injuries are evaluated. There may be a waiting period before the true extent and effect of a brain injury is clear. The role of a proxy would be very important in deciding how long this period would be and whether or when to withdraw measure such as intravenous fluids or mechanical ventilation. If the matter is to be decided by the courts, clinicians would be permitted to continue these measures pending a decision.

Most healthcare staff would regard it as unethical not to provide shelter, warmth, hygiene and the offer of oral nutrition and hydration. An advance healthcare directive cannot be used to refuse basic care.

Recommendation: integrate this definition into section 2 of the ADM Bill:

Basic care includes, but is not limited to, warmth, shelter, offering oral nutrition and hydration, and hygiene measures.

Healthcare

We prefer the use of the term ‘healthcare’ rather than treatment: it closer to the spirit of the ADM Bill which goes on define the term ‘healthcare professional’. We believe the use of the term ‘healthcare’ is more appropriate, particularly since the proposed amendments are designed to facilitate healthcare planning. It seems anomalous to introduce amendments regarding advance healthcare directives and restrict the range of things that can be refused to ‘treatment’ which we think would exclude issues of social care such as nursing home admission.

If the scope of an advance healthcare directive is limited to treatment rather than wider health and social care issues, the principle of autonomy is undermined. Many older people want to delay nursing home admission, a social care matter, for as long as possible. They may choose to donate an Enduring Power of Attorney to this effect, but an advance healthcare directive is a cheaper and easier alternative. A homecare package is often more desirable than nursing home admission. Sometimes the person is so ill that if basic care needs are to be fulfilled admission to a nursing home, hospice or hospital is the only viable option. On many occasions, however, the option of home care is not fully explored: and an advance healthcare directive could ensure that this option is explored. We think a more appropriate interpretation of ‘advance healthcare directive’ should refer to healthcare, not just treatment.

There should not be an artificial division between services provided under the Mental Health Act 2001 and other services: both are healthcare. A person who is admitted under the Mental Health Act still has physical and social care needs and preferences which may precede their current episode of mental illness.

Recommendation: *Health Care is acknowledged as care provided by a health or social care professional.*

Healthcare professional

Healthcare professional is defined in section 2 of the ADM Bill as:

A member of any health or social care profession whether or not the profession is a designated profession within the meaning of section 3 of the Health and Social Care Professionals Act 2005.

Section 4 of the 2005 Act goes on to list designated health and social care professionals.

Recommendation: Define healthcare as care provided by a health or social care professional and integrate this definition into section 2 of the ADM Bill.

Palliative care

Some people may make a specific directive asking for palliative care rather than more active treatment such as radical surgery or chemotherapy should they suffer from terminal cancer. This includes things like analgesia and anti-emetics, but may also include some forms of chemotherapy and radiotherapy which are designed to relieve symptoms rather than affect the course of the disease. Palliative care should not be confined to cancer treatment, and could be offered to anyone experiencing distress at the end of life, for example from advanced cardiac failure. We suggest that palliative care include treatment to relieve pain and distress. There may well be considerable overlap between basic care and palliative care.

Palliative care is care that is designed to relieve pain and distress in situations where it is not possible to effect a cure.

Patient designated healthcare representative

We find the term '**healthcare proxy**' perfectly acceptable and considerably easier to say than 'patient designated healthcare representative' and suggest the term 'healthcare proxy' be used instead. An AHD could be used to designate a representative/proxy to clarify the terms of a directive, or the proxy could be given either general or specific powers to refuse or accept treatment offered. The proxy's power to refuse life sustaining treatment could be

given in an AHD. Only the courts could make decisions regarding organ donation while the person is alive, but decisions regarding organ donation after death could be recorded in an advance care directive either directly by the relevant person, or by bestowing the power to make this decision on the healthcare representative or proxy.

(B) Purpose and guiding principles

An advance healthcare directive honours the will and preferences of the person making it, and provides clarity about their wishes to both family members and healthcare professionals. It facilitates healthcare planning by an individual. The presumption of capacity and the other guiding principles in section 8 of the ADM Bill operate in relation to advance healthcare directives as it does for any other form of decision making. The ADM Bill allows that a person may make an unwise decision without necessarily being regarded as lacking the capacity to make that decision.

The person should be provided with information in a form understandable to them in order to make a decision: it is important that decision making is informed. The way in which information is imparted is very important. This information should include the consequences of refusal of the proposed treatment as well as the length of time the treatment takes and the probability of success. No one should be regarded as being unable to make an AHD unless every effort has been made to assist them to do so.

Refusal of treatment may be based on perfectly rational grounds, namely that it has little chance of success, or that the person's quality of life is so poor as to render their continued existence intolerable to them. Refusal may be based on non-rational grounds such as religious belief.

Raising awareness of AHD

There should be a mechanism to make older people aware of the option of making an advance healthcare directive. We suggest notices in GP surgeries, hospital outpatient departments and solicitors' offices informing people about AHD. Information could also be made available by Citizen's Information Offices. Sample directives developed by the Public Guardian's Office (PGO) could be made available. We think that most people would want to discuss their healthcare directives with their GP or hospital consultant, but it is not mandatory for them to do so. Some people, mostly younger people in good health would not have a GP as they are not ill, but may well recognise the need to make a directive.

(C) Making an advance healthcare directive: general and refusing treatment

We suggest that the word 'healthcare' be substituted for 'treatment' in Head 4(2). Otherwise we agree with Head 4.

It is appropriate that the person making an advance care directive be an adult. The person must have the capacity to make the decision and this should be in accordance with section 3 of the ADM Bill. To allow *any* adult to make an advance care directive would mean that older adults with severe dementia, and others, could be coerced or unduly influenced into signing a directive they did not understand or did not intend to make, which could result in their not receiving healthcare they would otherwise receive, possibly with fatal consequences. For example: an advance directive refusing antibiotics could result in the person dying of an otherwise survivable infection.

The assessment of capacity is problematic. We suggest that the directive contain a statement from the person or persons who witness it that they believe that the person has the capacity to execute an advance healthcare directive. If they have deliberately witnessed a directive by a person who lacks capacity, they will become liable to penalties under section 113 of the ADM Bill. If there is doubt about the capacity to make a directive expert opinion should be sought and attached to the directive. Generally, though, the presumption of capacity would operate.

There may be some circumstances, such as the sudden onset of illness or injury, where there is no time to make a written advance directive, and a verbal directive could be made. A person who has suffered injuries in a road traffic accident may arrive in the Emergency Room fully conscious and able to give instructions regarding the care they want to receive, but later lapse into unconsciousness. Their wishes should be valid as a verbal advance directive. It is preferable that any kind of advance directive is in writing or another permanent form such as video because it provides clarity about the wishes of the person. It is not unusual to have several different family members who all have different understanding of the wishes of the person providing conflicting advice about those wishes. Advance healthcare directives would normally involve the refusal of treatment, but a person may prefer one form of treatment over another, for example medical treatment rather than an operation; conservative procedures over more radical ones. They may want palliative care rather than chemotherapy. Many older people would like to refuse admission to nursing homes and prefer to receive care in their own homes. Some would like to refuse the administration of antipsychotic drugs, which are an inappropriate response to dementia, especially over long periods of time.

Anyone with capacity can change their mind at any time. The person should be able to revoke an advance care directive verbally even if the directive was made in writing.

(D) Conditions and requirements for advance care directives

A valid advance care directive should be made when the person had the requisite decision making capacity. It should come into force at a point specified by the person, for instance when they have developed a neurological condition such as stroke or brain tumour or dementia which means they are unable to make their wishes regarding their care known. The healthcare specified should be contained in the advance care directive and the person should not have revoked it. It should be registered with the Public Guardian's office (PGO) and available to healthcare professionals treating the person. The PGO should be responsible for monitoring and overseeing the operation of ACDs

Registering, displaying and reviewing an AHD

We suggest that when an advance care directive is registered with the PGO the person is issued with a card stating that they have made and registered an advance care directive, together with a website address where the person's directive can be viewed. Perhaps something similar to the Cervical Check website could be set up, where the person or healthcare professional can enter the name, date of birth and PPS number to gain access. The information on the card should include the name and contact details of a healthcare proxy and GP or any other person such a hospital consultant.

The AHD does not have to be registered to be valid, so long as it is available to the treating healthcare professionals: we recognise that there may be a gap in time between sending copies to the PGO's office and the person's AHD appearing on the website.

The PGO could develop a standard form, or the person may prefer to write their own directive. The directive should be witnessed by two people. Some people might have very specific requirements which could not easily be accommodated on a standard form, but there would be minimum requirements (see below).

The AHD should be in a prominent place, and in a standardised manner. Many hospital and GP records are computerised, so consideration should be given to where and how an ACD is recorded, for example flagged on referral letters to the hospital as "past medical history: has made an AHD, please file the attached copy in the patient's notes."

People making an AHD should be encouraged to review its terms on an annual basis, perhaps with their GP or healthcare proxy. A previously fatal illness may become treatable over the years: for example AIDS is no longer fatal if appropriate treatment is started: it now has the status of a chronic illness. Some cancers, previously fatal, are now treatable, a few are regarded as curable, for example some forms of lymphoma and leukaemia.

(E) Scope of advance care directives

An advance care directive should be applicable to all kinds of healthcare, so long as it is lawful, ethical and available. Since the requirements of a psychiatric advance care directive

may be very different to one relating to ordinary medical care it should be possible to develop separate sections of an AHD form which apply to mental health care. Advance directives relating to psychiatric care may not be applicable if the person is involuntarily detained under the Mental Health Act, or the Criminal Law (Insanity) Act 2006.

An advance care directive relating to medical care may well involve the withholding or withdrawal of lifesaving or life prolonging treatment ranging from CPR to chemotherapy. The person has a right to refuse such treatments.

Where a person makes a specific positive request for a particular drug or a particular doctor or hospital, the same standard should apply whether considering medical or psychiatric treatment. We suggest that if the treatment is lawful, ethical and available the person could request it.

No one can request treatment which is unlawful, unethical or unavailable. Euthanasia cannot be requested, but withdrawal of futile treatment which merely prolongs the dying process, can. If a healthcare professional feels it is unethical to comply with an advance healthcare directive, perhaps because they have had a long relationship with a patient, and feel unable to withdraw treatment, they should refer the patient to another professional.⁵

Some treatments are unavailable. Home care packages may be very limited or unavailable in some areas of Ireland. The ability to comply with advance directives in relation to preferred care is greatly hampered by the inability to pay for it. This may be because different kinds of care are ring-fenced: there may be funding for nursing homes, but not for home care: the money does not necessarily follow the patient.

(F) Healthcare proxies/Patient designated healthcare representatives

We are broadly in agreement with the provisions relating to healthcare proxies. Their role in relation to consent to admission to a nursing home should be clarified.

(G) Revoking an advance care directive

The person should be able to revoke the advance healthcare directive at any time either verbally or in writing, whether they are for mental healthcare or physical care.

(H) Monitoring and administering an advance care directive

⁵ In *B v an NHS Trust* [2002] EWHC 429 (Fam) a woman who was dependent on mechanical ventilation after a stroke had made an advance directive asking for withdrawal of treatment in these circumstances. She was conscious and able to communicate and reiterated her request. Staff on the ward who had cared for her over a long period of time felt unable to comply. Her treating clinician felt that her decision making capacity was impaired by depression. The court ordered that she be transferred to the care of another clinician who would comply with her request for withdrawal of treatment.

The Office of the Public Guardian should produce a code of practice on advance healthcare directives. This should include guidance on basic care, palliative care, artificial hydration and nutrition, and other life sustaining treatments.

A mediation service should be available for when there are disagreements between proxies and healthcare professionals.

(l) Liability

Failure to seek informed consent for a procedure or treatment may give rise to civil liability, and in theory a failure to comply with an AHD is an assault on the person because they are being given treatment they have refused. In reality there seem to be very few cases where the person or their estate sought damages from hospitals or individuals who have failed to comply with AHDs. This does not mean that there is never any failure to comply.

There is an underlying presumption in favour of the preservation of life which would influence judicial decision making. Would judges be reluctant to award damages to a person who would be dead but for the intervention? In Canada in 1990 a Jehovah's Witness who had received a life saving transfusion despite carrying a card refusing transfusion was awarded \$20,000 damages by the Ontario Court of Appeal. The damages were said to be nominal, however such a sum would represent about 2-3 months pay for the doctor involved.⁶

The amount of damages, however, is not the issue: it is the ability to obtain recognition of the individual's autonomy and bodily integrity. The presumption in favour of life is not absolute. A person who made an AHD refusing CPR and who was resuscitated against his or her wishes, and who experienced severe neurological damage as a result may well seek and obtain damages.

The threat of professional disciplinary action may offer some incentive to comply with ACDs but it remains to be seen whether any professional sanctions would be imposed. In cases where non compliance with an advance care directive amounts to an assault it may be possible to seek penalties under section 113 of the ADM legislation. A failure of the proxy to act should also attract sanctions unless there is good reason for it.

We do not think that not knowing of the existence of an ACD should operate as a full defence: It may do so in some circumstances, for example in the case of a patient brought to the Emergency Room with no ID, unconscious, and suffering from life threatening illness or injury. It is entirely different if a person is already in hospital and is given treatment that he or she refused in a valid directive which is contained in the notes. It is an invitation to

⁶ Malette v Schulman [1990] 72 OR (2d) 417

dispose of the directive and then plead ignorance of its existence. Under such circumstances the hospital could not evade liability.

Recommendation:

Failure to comply with an advance care directive may lead to civil, criminal or professional sanctions for the healthcare professionals and institutions involved. In some cases it may be construed as an offence under section 113 of the ADM legislation.

3. What should an Advance Care Directive contain?

1. Name and contact details of the person making the directive
2. Name and contact details of the healthcare proxy
3. Signed agreement to act as healthcare proxy. Date
4. Witnesses to healthcare proxy. Date
5. Statement that the person makes an advance directive that would be activated in the following circumstances: - When the person is unable to express their wishes regarding healthcare:
 - Brain injury
 - Dementia
 - Progressive neurological disorder
 - Terminal illness
 - Other
6. Treatment refused:
 - CPR
 - Artificial Hydration or Nutrition. Include permission to withdraw once started
 - Futile treatment. Include permission to withdraw once started
 - Antibiotics
 - Mechanical ventilation
 - Blood Transfusion
 - Antipsychotics
 - Other: include treatment preferences such as palliative care, analgesia, wishes regarding nursing home care.
7. Signature of the person and date
8. Signature of witnesses and date
9. List of persons who have a copy

10. The contact details of the person's GP or hospital consultant, if known. Many young people do not have a regular GP and hardly ever receive medical care. This should not preclude them from making an AHD.