



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

March 2014

The Irish Heart Foundation (IHF) is the national charity supporting people with heart, stroke and blood vessel disease. The Foundation promotes policy changes that reduce premature death and disability from cardiovascular disease and advocates for better patient treatment and services.

Introduction

The IHF welcomes the publication of the General Scheme for Advance Healthcare Directives to provide legal certainty for people who wish to plan for their continuing care and end-of-life care. Our submission will focus on Advanced Healthcare Directives (AHDs) as they relate to the cardiovascular patients we represent, with a particular focus on patients with heart failure and stroke. Many heart failure and stroke patients may require end-of-life care in the advanced stages of their disease and some stroke patients may experience cognitive difficulties, including vascular dementia which may impact on their capacity to make care decisions.

People with stroke, heart failure and other conditions are valuable members of society. The IHF promotes the dignity of people with such conditions, their right to the best level of care and for care to prolong their lives in according with their individual wishes. The IHF supports the rights of people to develop AHDs outlining their treatment and care preferences.

This submission begins with a discussion of AHDs for heart failure and stroke patients, followed by a response to the questions posed by the Department of Health in its consultation document. The document concludes with some additional comments not covered by the consultation questions.

AHDs and end-of-life care for heart failure and stroke patients

The IHF believes that good palliative care should be available to anyone suffering from a progressive, incurable condition. Current palliative care services primarily concentrate on cancer-care. In 2004, only 7.2% of all patients seen in specialist palliative care were non-cancer patients. The most commonly seen non-cancer patients were patients with Motor Neurone Disease, congestive cardiac heart failure, chronic obstructive pulmonary disease, cerebrovascular disease and pneumonia. There is compelling evidence that terminal non-cancer patients in Ireland have unmet physical, psychological, emotional and social needs.¹

The development of an AHD (**which outlines a person's treatment preferences** and which could, should the individual wish, include a refusal of certain treatments) should never be **precipitated by an individual's** concerns about whether they will be able to gain access to palliative care. In order for people to have a real

¹ O'Leary, N. and Tiernan, E. (2008) 'Survey of specialist palliative care services for noncancer patients in Ireland and perceived barriers'. *Palliative Medicine*, 22, 77-83.

choice in their advance care planning, the IHF emphasises the need for the development of palliative care and facilities for all terminal patients.

Heart failure (HF) patients

In most cases heart failure is incurable and patients with heart failure often have a poorer quality of life than those with most other chronic progressive diseases. Between 10–20% of those with incident heart failure die within 30 days of diagnosis, and those with chronic heart failure are subject to a mortality of 50% at four years.² Heart failure, especially in older patients, is characterised by a high prevalence of co-morbidities.³ Only a comparatively small number of HF patients across Europe currently receive specialist palliative care.⁴

Heart failure care has recently seen the development of considerable high tech therapies. Rather than overcoming the need for palliative care, these high tech, life sustaining therapies make the need for palliative care for HF patients more acute. The European Society of Cardiology 2012 HF guidelines⁵ recommend palliative care for HF patients. One of the issues in providing palliative care to HF patients is that they tend to require ongoing interventions much later in their disease trajectory than is the case for cancer patients, i.e. HF patients will be receiving interventions *and* palliative care at the same time. This may require some adjustment to the manner in which hospices and palliative services operate. To investigate the potential of palliative care for heart failure patients, the IHF part funded an action research project providing palliative care for HF patients in hospitals and community settings in North Dublin.

AHDs could assist HF patients in Ireland to make decisions about their end-of-life care. In an editorial in the *European Journal of Cardiovascular Nursing*⁶, Beattie outlines the potential benefits of advance care directives for heart failure patients, as well as the need for **HF-specific issues to be covered in HF patients'** AHDs.

Advance care planning would obviate some of the possible clinical dilemmas that arise in progressive heart failure. Advance directives allow patients to record their preferences for end-of-life care and to appoint a surrogate to undertake decisions on their behalf if they lose capacity. However, heart failure patients appear to have little appreciation of the potential use of advance directives and these instruments are underutilised. A palliative care consultation for those admitted with heart failure may enhance preparedness planning and rates of completion of advance directives. However, even when they are executed, advance directives tend to be relatively generic. They usually address policies such as cardiopulmonary resuscitation, mechanical ventilation, tube feeding and haemodialysis, but frequently do not explicitly incorporate statements on ICD deactivation or the withdrawal of left ventricular assist devices which may be particularly relevant to heart failure therapy.

² Beattie, J.M. (2014) 'Palliative care for heart failure: Challenges and opportunities'. *European Journal of Cardiovascular Nursing*, DOI: 10.1177/1474515114521697.

³ Scottish Partnership for Palliative Care (2008) *Living and dying with advanced heart failure: a palliative care approach*. The Scottish Government and the British Heart Foundation, Scotland.

⁴ Jaarsma, T. *et al.* (2009) 'Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology'. *European Journal of Heart Failure*, 11, 433-443.

⁵ ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012. *European Heart Journal*, 2012. <http://eurheartj.oxfordjournals.org/content/33/14/1787.full.pdf>

⁶ Beattie, J.M. (2014) 'Palliative care for heart failure: Challenges and opportunities'. *European Journal of Cardiovascular Nursing*, DOI: 10.1177/1474515114521697.

People with different conditions will need to consider different treatments and end-of-life care as part of their AHDs. Guidance developed in Australia⁷ to assist advanced care planning with patient groups highlighted the following considerations which may be of benefit to heart failure patients:

- What does the patient understand about the progression of heart failure?
- Are they and their family/carers aware of the unpredictability of this and how it may impact on decision-making?
- Where would they want to be treated in the event of an exacerbation?
- Sometimes all available medication/therapy does not make the patient feel better or relieve the symptoms of their heart failure (and other co-morbidities). For example, shortness of breath, water retention and fatigue. What would be their goals for care at this time?
- Which symptoms bother them most?
- Electronic device implantations are sometimes used for patients diagnosed with heart failure. Would they accept such a device? What do they understand to be the benefits and burdens of these devices (e.g. the need for removal prior to cremation)?
- If the patient has an implantable device, are they aware of the impact this may have on their care at the end-of-life? For example, an Implantable Cardioverter Defibrillator (ICD) can be deactivated at the end of life to prevent prolonging the dying process. Do they wish to discuss this with their specialist?
- Transplantation – this issue may be relevant for a small number of patients with advanced heart failure. Is this something the patient has thought about? Do they have any strong views on this?

A person's preference on many of these issues could be included in their AHDs.

ICDs are a particular issue for HF patients who are dying. If still functioning at the time of death, an ICD will continue to deliver shocks to the patient, which can be very distressing for the patient and their loved ones.⁸ A decision on whether to remove, or turn off an ICD could be included in an AHD.

Stroke patients

Advanced care planning and AHDs are particularly important for people with stroke and other neurological conditions who may face later cognitive change. A significant minority of stroke patients suffer from post-stroke dementia syndrome. Many AHDs will likely focus on end-of-life care but in the case of stroke and other neurological conditions, an AHD may relate to continuing care preferences where the person has progressed dementia, or another condition limiting their capacity. For people in this situation an AHD needs to cover a longer period of time, much in advance of end-of-life. There may also be particular challenges for stroke patients in communicating their care wishes where they are experiencing deteriorating cognition, dysphagia (difficult swallowing) and problems with communication.

⁷ Government of Western Australia, Dept. Health *Advanced Care Planning – a step-by-step guide for healthcare professionals assisting patient with chronic conditions to plan for care towards end of life*. http://www.health.wa.gov.au/advancehealthdirective/docs/acp_guide_health_professionals.pdf

⁸ See, Jaarsma, T. *et al.* (2009) 'Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology'. *European Journal of Heart Failure*, 11, 433-443.

Guidance developed in Australia⁹ to assist advanced care planning with patient groups highlighted the following considerations for stroke and other neurological patients:

- What are the main fears or concerns (e.g. loss of communication, loss of body control)?
- How can they optimise their functional independence?
- Where do they want to live? What has to be done to address these wishes?
- Are they aware of available support (e.g. Home Help)?
- Carer issues – what will happen if the person’s primary carer needs hospitalisation or is no longer able to assist with care? How can the person plan for this?
- What are the patient’s views on artificial feeding and nutrition (e.g. nasogastric, PEG/gastrostomy insertion)?
- Do they have any opinions/thoughts on interventions related to treating complications such as pneumonia/chest infections or urinary tract infections (e.g. using intravenous antibiotics)?

Consultation questions

1. What are your views on requiring an individual to obtain professional advice (e.g. clinical and/or legal) before preparing an advance healthcare directive?

Patients with progressive diseases are frequently concerned about their ability to cope financially and about the impact that this has on their families. The IHF believes that requiring a person to obtain professional services to develop an AHD may place unnecessary financial pressure on people and may reduce the use of AHDs by those who would like to have one in place. The IHF believes that the system must operate at no, or very low cost to ensure that all citizens who wish to have an AHD can do so. There is no point in having a legal facility for AHD if they are only available for those who can pay to have them developed. As discussed in question 3 below, the development of a template AHD may facilitate individuals to draft their own AHDs without the need for paid professional assistance. Doctors and other healthcare professionals will continue to have an important role to play in informing patients about the possibility of making an AHD and in explaining the different treatment options and possible outcomes.

Additional supports should be provided to assist people who have communication difficulties – such as people with asphasia as result of stroke – to develop their AHDs.

2. Is it necessary for the provisions to designate a specific, mandatory time period within which an advance healthcare directive must be reviewed (e.g. every 2 years, every 5 years, every 10 years)?

Every situation will be unique, so a mandated period for review of all AHDs may not be appropriate. However, the IHF recognises that the development of an initial AHD **may not represent a person’s final**

⁹ Government of Western Australia, Dept. Health *Advanced Care Planning – a step-by-step guide for healthcare professionals assisting patient with chronic conditions to plan for care towards end of life.*
http://www.health.wa.gov.au/advancehealthdirective/docs/acp_guide_health_professionals.pdf

wishes and preferences. In advance of drafting an AHD and after it has been drafted people with life-limiting conditions should, if they wish, be involved in an ongoing process of advance care planning. **It isn't therefore enough to introduce a legal basis for AHD, we need to have a process in place to assist people with advance care *planning*.** Such planning will facilitate the initial development of AHD and the making of amendments if and when **a person's** wishes change over time. A continuing dialogue of open communication appropriate **to the patient's wishes and needs should be initiated at the time of diagnosis and maintained throughout all stages of their disease.**¹⁰

People may find it easier to articulate their preferences on outcomes (e.g. the quality of life to be achieved, or the likelihood of a positive outcome from an intervention), rather than focusing on their preferences **regarding specific forms of treatment.** Alzheimer's Europe¹¹ suggests that patients be encouraged to develop a **'Statement of Values'** in addition to an AHD. A statement of values is a non-legal document covering what is important and meaningful to the person writing it. It can provide more detail about a **person's treatment, quality of life, spiritual preferences etc.** than may be required in the legal AHD. This greater detail can then be used to assist the team caring for the person.

3. Should a standard format be developed for advance healthcare directives?

The development of a written AHD could be perceived by individuals as a very complex process and this justifies the development of a template to assist citizens exercise their legal rights.

Explanatory Memorandum Head 4 Subhead (4) states that: *'Given that each individual's will and preferences will vary for different treatments and in different circumstances, requiring all individuals to prepare their directives using the same standard format may place undue procedural constraints on individuals'*.

The IHF recommends that a guidance template AHD – rather than a mandated standard format – be developed. This template, which could be developed by the health service in tandem with patient groups, could be followed, adapted, or completely ignored by an individual when drawing up their own AHD.

4. If a standard format for advance healthcare directives was developed what information should it contain?

The guidance template could include questions people may want to consider in relation to continuing care, invasive treatments, treatments they may wish to refuse, etc. As indicated above, specific conditions will need to consider their preferences with regards to specific treatments. Such condition specific issues should be included in the guidance template. The guidance template could also include a reference to consent beyond death to organ donation, should the person wish to include such consent in their AHD.

Explanatory Memorandum, Head 2 Subhead (2) says that: *'While healthcare professionals have traditionally been tasked with providing such information and discussing various treatment options with their patients, the prevalence of medical information (e.g. via the internet or in book form) has enabled individuals to learn about treatment options in non-traditional methods. Therefore, while the Code of Practice for these provisions will*

¹⁰ See, Scottish Partnership for Palliative Care (2008) *Living and dying with advanced heart failure: a palliative care approach*. The Scottish Government and the British Heart Foundation, Scotland.

¹¹ Alzheimer Europe (2009) *Position paper on use of advance directives*. <http://www.alzheimer-europe.org/Policy-in-Practice2/Our-opinion-on/Advance-directives>

encourage individuals to seek professional advice when preparing an advanced healthcare directive, obtaining such advice will not be mandatory’.

Healthcare professionals will still play a major role in outlining treatment options and should be supported in this role. In addition, the Department of Health and the HSE should provide information on the range of treatments and considerations for specific treatments to make it as easy as possible for an individual to outline an AHD which suits their particular circumstances.

5. Where should advance healthcare directives be kept to ensure that their existence is known about and they can be readily accessed when required?

The IHF recommends that a person’s AHD be linked to their unique health identifier (soon to be provided for in legislation). In this way healthcare staff could check a central registry to find out if a person has an AHD. In addition, copies of the AHD should be given to the patient-designated healthcare representative, family members, the local acute hospitals, the team treating the patient in the community and their GP.

6. What additional measures could be included in the provisions to ensure that healthcare professionals are made aware that an individual has prepared an advance healthcare directive?

There must be an obligation to find out if a person has an AHD before treatment is undertaken. An online registry of AHDs, linked to unique health identifier would likely be the most comprehensive means of ensuring that the existence of an AHD is known to the care team. In Scotland, they have developed a Palliative Care Register for GPs. Patients entered on the register receive better access to palliative care and information and information about their needs and wishes is available to all those they come into contact with in the health service.¹²

7. The provisions enable an individual to make a legally-binding refusal of treatment in an advance healthcare directive, however, requests for treatment in such directives will not be legally-binding. What should be done to ensure that such treatment requests, while not legally-binding, are adequately considered during the decision-making process?

No response.

8. Given that advance healthcare directives relating to mental healthcare and treatment are intended to be used on a recurring basis, as opposed to advance healthcare directives for general healthcare which are predominantly used once, should a different format be used for both types of directive?

No response.

9. What do you think the role of the patient-designated healthcare representative should be? **Should the representative’s role be limited to that of interpreting the individual’s advance healthcare directive? Should the representative have a broader role to advise as to what the individual’s will and preferences regarding treatment are likely to be?**

The IHF identifies some mixing of the decision-making / interpretation powers of the patient-designated healthcare representative within the **text of the general scheme**. This ‘slipping’ of roles may give rise to

¹² Presentation by Prof. Scott A Murray, University of Edinburgh, ‘Relevance of palliative care for diseases other than cancer’, Irish Hospice Foundation Palliative Care for all Conference.

confusion. The IHF believes clarity is required as to whether the patient-designated healthcare representative is solely the communicator / interpreter **of a person's decisions and preferences**, or a decision-maker on behalf of the patient in line with their wishes.

10. What additional safeguards may be required in relation to the provisions for the patient-designated healthcare representative to protect the individual who made the advance healthcare directive and to ensure that the representative carries out his/her wishes?

The IHF recommends that Office of the Public Guardian (to be established under the Assisted Decision-Making Capacity legislation) provides support to patient-designated healthcare representatives and be available to respond to queries regarding their role and actions.

11. Are there any other issues relating to advance healthcare directives that should be included in the legislative provisions?

- The IHF recommends the inclusion of a system to track use of individual AHDs, including a possible requirement to document in medical notes that the AHD has been viewed and followed.
- It will be necessary to monitor the overall use of AHDs. HIQA could be mandated to undertake this monitoring function, including investigation of any specific cases in which an AHD may not have been followed.
- A list of the initial Codes of Practice to be developed should be included in the legislative provisions (a similar approach was taken in the Charities Act).
- The IHF welcomes that an owner or employee of a residential or healthcare facility cannot be a patient-designated healthcare representative. It is also vitally important that people entering nursing homes are not required by the nursing home operators to have an AHD in place. Protections to ensure this and monitoring procedures (likely to be undertaken by HIQA) should be included in legislative provisions.

Additional issues

Raising the public's awareness of the ability to make legally-binding AHDs

Once the legislation is in place, the public must be made aware of the changed legal status of AHDs. The current complicated legal position means that only a minority of people have AHDs. It is likely that once AHDs have legal standing that there will be a large volume of people wishing to draw one up.

Initially media campaigns will be required to ensure that the public is aware that AHDs now have legal force. Ongoing communication will then be required to ensure the public is properly informed about the system, including people taking up residency in Ireland. The state and health system should utilise key engagements with citizens to promote the ability to make AHDs, i.e. including information on AHDs when people are getting / renewing their driving licence, when people register with a GP, as well as providing more general communications about advance care planning in healthcare facilities.

Early review of the impact of the AHD legislation

The IHF suggests that a two year review of the operation of the AHD legislation be undertaken. This review should assess whether there is adequate awareness of the ability to make a legally enforceable AHD and that the process to develop AHDs is straightforward. To ensure a focus on patient quality and patient experience,

the IHF believes that this review should include a strong and independent element of patient oversight. As part of this review we recommend that information sessions / workshops are organised to engage the public and patient representatives in meaningful consultation on the operation of AHDs and to consider any requirements to clarify the legislation, or to adjust its operation in practice.

The process of development of the Advanced Healthcare Directive legislation

AHDs were not included in the Assisted Decision-Making (Capacity) Bill 2013 as originally published, with their inclusion promised at the Committee Stage of the Bill. While welcoming the current consultation on the general scheme for AHDs, the IHF is keen that the full text of the legislation be available as soon as possible. Every effort must be made to ensure that the text, which is crucially important in such a complex legal area, is given proper scrutiny to ensure that it supports a positive approach to capacity and meets the needs of patients developing AHDs.

Training to assist healthcare professionals in the new era of legally-binding AHDs

Doctors and other healthcare professionals will have an important role to play in informing patients about the possibility of making an AHD and in explaining the different treatment options and possible outcomes. Guidance and training for healthcare professionals should be provided, in areas such as advance care planning, the documentation of AHDs, ascertaining whether a patient has an AHD, communicating about an AHD if the patient is transferred to another setting or team and how to assist in a review of AHD.

Conclusion

The IHF welcomes the opportunity to comment on the general scheme for Advance Healthcare Directives and is available for further comment as required.

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