Best laid PLANS

The *Assisted Decision-Making (Capacity) Act 2015* will place advance healthcare directives on a statutory footing and, once commenced, will legislate for their validity and effect. Marie Kinsella and Nicola Harrison carve it in stone

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An advance healthcare directive (AHD) is an advance instruction by a person about how he/she wishes to be treated if certain circumstances arise. It is a mechanism whereby people can voice their wishes around healthcare decisions when they have capacity to do so and for those wishes to take effect when they no longer have capacity.

The validity of AHDs has not been explicitly tested by the Irish courts. However, there have been references made in a number of cases dealing with the issue of the refusal of medical treatment that point to the likelihood that an AHD will be legally binding provided certain conditions are met. These conditions include the requirements that:

- The patient was mentally competent at the time the directive was made, and
- The directive applies to the particular set of circumstances arising.

Case law

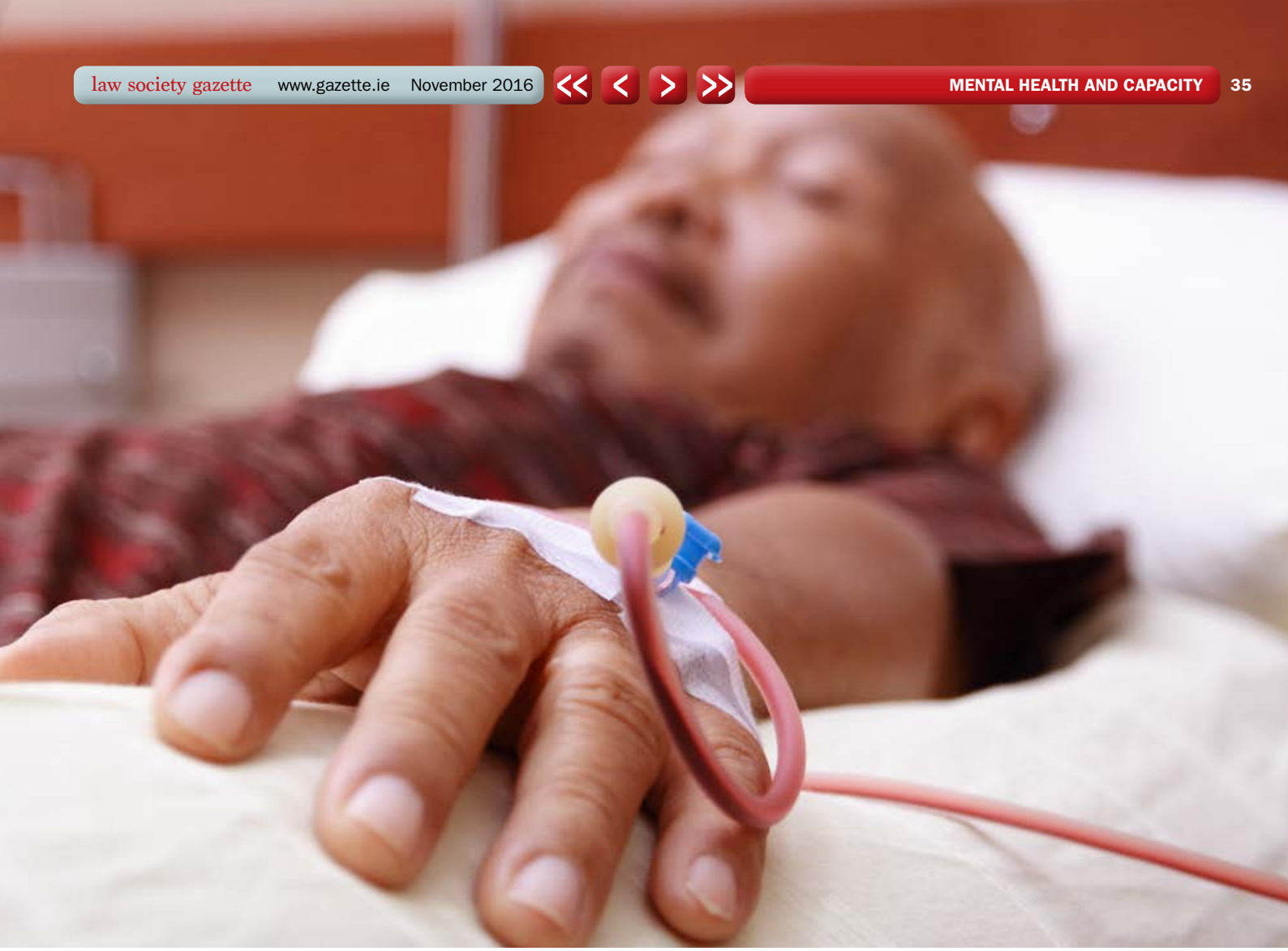
In *Re a Ward of Court* (1996), the Supreme Court considered whether life-sustaining treatment could be withdrawn from a woman in a persistent vegetative state who had sustained profound brain damage following a minor operation at the age of 22. The High Court held that withdrawal of treatment in these circumstances was permissible, and this decision was ultimately upheld by the Supreme Court.

While the main issue for determination in that case was the patient's right to die, the court did comment that a person's right to forego medical treatment or direct that it be withdrawn would be valid provided that the ward was mentally competent and the directive related to her current situation, even if the withdrawal of treatment would result in her death.

A more recent case is that of *Governor of X Prison v PMcD* (2015). This involved a prisoner who began a hunger strike for reasons relating to the conditions of his detention. He made an AHD stating that, if he did end up in hospital, he did not wish to be treated. The prison made an application for orders to validate both his refusal of food and their failure to force-feed

at a glance

- Under the *Assisted Decision-Making (Capacity) Act*, once all the legal requirements are met and an advance healthcare directive is valid, a healthcare professional must comply with it, even if they do not agree with the patient's decision
- Where there is any doubt as to the validity or applicability of an AHD, the healthcare professional must try to resolve this by consulting with the designated healthcare representative (if there is one) or, if there is none, with the patient's family and friends
- Solicitors should be aware that any directions with regard to treatment choices contained in an AHD will take precedence over any such decisions contained in an EPA



him, and the court held that his directive was valid, on the basis that he had capacity at the time it was made.

Professional guidance

The Medical Council's *Guide to Professional Conduct and Ethics for Registered Medical Practitioners* states that clinicians should take reasonable steps to find out if a patient who lacks capacity has made an advance healthcare plan or directive. It also states that an AHD should be followed provided that:

- It was an informed choice,
- It covers the situation that has now arisen, and
- There is nothing to indicate that a patient has changed his or her mind.

In a similar vein, the HSE's *National Consent Policy* provides that a person's advance refusal of treatment should be respected if (a) the decision was an informed choice, (b) it specifically covers the situation that has arisen, and (c) there is no evidence that the service user has changed his or her mind since the advance plan was made.

In terms of international human rights legislation, there have been a number of conventions and directives that have paved the way for legislation in Ireland around the issue of AHD.

In 2006, The UN *Convention on the Rights of Persons with Disabilities* called for states to facilitate people with disabilities to exercise their rights to make choices and express preferences in relation to their care.

In 2009, the Council of Europe issued a recommendation on the *Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*. This provides that states should promote self-determination for capable adults in the event of their future incapacity, by means of continuing powers of attorney and advance directives.

In 2014, the Council of Europe issued a recommendation on the *Promotion of Human Rights of Older Persons*, which states that "member states should provide for legislation that allows older persons to regulate their affairs in the event that they are unable to express their instructions at a later stage".

It is in the context of such obligations that the *Assisted Decision-Making (Capacity) Act 2015* has been enacted. However, it is not yet commenced, so the current common law position still applies.

Part 8 of the act specifically deals with the AHD, which is defined in section 82, in relation to a person who has capacity, as "an advance expression made by the person … of his or her will and preferences concerning treatment decisions that may arise in respect of him or her if he or she subsequently lacks capacity". The AHD must be made in the prescribed form as set out in section 84 of the act.

Designated healthcare representative

While a person can make an AHD without appointing anyone to act on their behalf, one of the features of part 8 is that it provides (at section 87) for persons to appoint a designated healthcare representative to act on their behalf in making treatment decisions or in interpreting the terms of their AHD. Such a representative may have the power to:

- Advise and interpret the directive maker's will and preferences, and or
- Consent to or refuse treatment, up to and including refusal of life-sustaining

treatment, based on the known will and preferences of the directive maker.

The act distinguishes between treatment refusals and treatment requests. In terms of treatment refusals, the act provides (at section 84) that these *shall* be binding, provided the following conditions are met:

- At the time in question, the directive maker lacks capacity to consent to the treatment,
- The treatment being refused is clearly identified in the directive, and
- The circumstances in which the refusal applies are clearly identified.

In terms of treatment requests, however, the 2015 act states that such requests are not legally binding but they *shall* be taken into consideration during any decision-making relating to treatment, provided the specific treatment is relevant to the patient's condition.

When is an AHD not valid?

At section 85, the act sets out the specific scenarios when AHDs will not be valid, which include where:

- The directive was not made voluntarily, or
- The directive maker has acted in a manner that is inconsistent with the terms of the directive while he or she had capacity.

In addition, a directive will not be applicable where:

- The directive maker still has capacity at the time in question, or
- The treatment or the circumstances are not materially the same as that set out in the directive.

As it may be difficult for a healthcare professional to establish that the treatment is 'materially the same' – particularly if there is any uncertainty or ambiguity in the wording of the directive – it is important for the directive maker to ensure that the directive is carefully worded and kept under regular review. However, section 85(5) of the act specifies the steps to be taken where there is any ambiguity in the wording of a directive.

Section 85 also specifies two important scenarios where a directive will not be applicable. First, it provides that a directive will not apply to life-sustaining treatment unless it is specifically provided therein that the directive maker understands the risk to his or her life. Secondly, it provides that a directive will not apply to basic care, which includes warmth, shelter, oral nutrition, oral hydration, and hygiene, but does not include artificial nutrition and hydration.

Section 85 of the act also provides that, where there is any doubt as to the validity or applicability of the directive, the healthcare professional must try to resolve this by consulting with the designated healthcare representative if there is one and, if there is none, with the patient's family and friends.

In addition, they must seek an opinion from a second healthcare professional and, if there is still doubt, the act states that the healthcare professional must resolve the ambiguity in favour of the preservation of life.

The act also provides that, if a dispute arises as to the validity or applicability of a directive, an application can be made to the Circuit Court by any interested party for a declaration as to whether the directive is valid or applicable. Where the application in relation to a directive pertains to life-sustaining treatment, then the application must be made to the High Court (section 89).

Compliance

Under the 2015 act, once all of the legal requirements are met and the directive is valid and applicable, then a healthcare professional must comply with it, even if they do not agree with the patient's decision.

However, the act provides a 'safety net' for healthcare professionals who fail to comply with a directive, provided they had reasonable grounds to believe that it was not valid or applicable. In such circumstances, no civil or criminal liability will apply.

In terms of giving effect to part 8, the act provides for codes of practice to be prepared to support the understanding and implementation of its provisions. In addition, it makes provision for regulations to be made providing for the notification of AHD to the director of the Decision Support Service and the setting up of a national register of AHDs.

Solicitors should note that it is not a requirement for a person making an AHD to consult a solicitor. However, clients will expect solicitors to advise them about the distinction between making an AHD and providing for healthcare decisions that (on the commencement of the 2015 act) may now be contained in an enduring power of attorney (EPA).

Solicitors should be aware that any directions with regard to treatment choices contained in an AHD will take precedence over any such decisions contained in an EPA, regardless as to whether the AHD was made before or after the making of the EPA. Also, any direction with regard to the refusal of life-sustaining treatment must be contained in an AHD, as such decisions cannot be included within the scope of 'personal welfare' decisions in an EPA.

Given that the purpose of AHDs is to provide healthcare professionals with important information about the wishes of the patient and promote patient autonomy, the new legislative framework is a welcome development.

FOCAL POINT

commencement date of section 91(2)

The *Assisted Decision-Making (Capacity) Act 2015 (Commencement of Certain Provisions) (No 2) Order 2016* was signed by the Minister for Health on 13 October 2016.

That order provides for the commencement on 17 October 2016 of section 91(2) of the 2015 act, namely the establishment by the Minister for Health of a multidisciplinary working group to make recommendations to the director of the Decision Support Service in relation to codes of practice pertaining to the advance healthcare directive provisions of the 2015 act.

look it up

Cases:

- *Governor of X Prison v PMcD* [2015] IEHC 259
- *Re a Ward of Court* [1996] 2IR

Legislation:

- *Assisted Decision-Making (Capacity) Act 2015*
- *Convention on the Rights of Persons with Disabilities* (UN, 2006)

Literature:

- Council of Europe (2009), *Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*
- Council of Europe (2014), *Promotion of Human Rights of Older Persons*
- Health Service Executive, *National Consent Policy*
- Irish Medical Council (2016), *Guide to Professional Conduct and Ethics for Registered Medical Practitioners*