

Irish Law Reform Commission Advance Care Directives

Current Legal Approach

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Introduction

- International Dimension
 - UN Convention on Rights of Persons with Disabilities
 - Europe
 - European Convention on Human Rights
 - European Convention on Human Rights and Biomedicine
 - Council of Europe Draft Recommendations
- Case law on Advance Directives

Convention on the Rights of Persons with Disabilities

- Purpose is to promote, protect and ensure the full participation of all persons with disabilities and promote respect for dignity
- Core human rights: dignity, autonomy, equality and independence
- Recognises capacity of persons with disabilities to make own decisions equally with others

European Convention on Human Rights

- Article 8 provides for a right to respect for private life
- *Pretty v United Kingdom* (2002) while refusal of treatment may lead to death, treatment without consent of a mentally competent person is an interference with a person's right under Article 8
- Such interference would have to be justified as necessary and proportionate

Council of Europe Recommendation on Incapable Adults 1999

- Strong promotion of autonomy and self-determination
- Need to provide legal opportunity for people while capable to make provision for possibility of later incapacity
- The least formal arrangements taking, wishes flexibility and proportionality into account
- Defines European standard in the area

Convention on Human Rights and Biomedicine 1997

- Article 9 requires that account be taken of the previously expressed wishes of a person who is unable to express them at the time of the treatment
- Does not mean the wishes will be carried out—depends on circumstances

Draft Recommendation on Continuing Powers of Attorney and Advance Directives for Incapacity 2008(1)

- Urge introduction of AD and provide for choice of a guardian
- Planning for future incapacity
- Self-determination requires opportunity for adults to make decisions for when unable to make them
- Specific principles on advance directives

Effect of AD ⁽²⁾

- Decide to what extent AD would have binding effect or extent statements of wishes to be given due respect
- Address what happens if there is a material change in circumstances?
- Intended to address the situation that has occurred?-interpretation
- AD may not be applicable in such circumstances

Form AD should take⁽³⁾

- AD must be in writing if it is intended to have a binding effect-eg in medical records
- Depends on nature and seriousness of decision
- Depends on length of time before it may become a reality
- May also be expressed orally

Validity of AD₍₄₎

- Mechanisms to ensure validity of binding advance directives
- Advisable to get medical advice to ensure clarity and awareness of consequences
- No value if AD not known to medical staff who are faced with carrying out future decisions
- Need to consider a public register, obligatory or not to enter some decisions or recording in medical notes

Revocation of AD⁽⁵⁾

- Should be revocable at any time without formalities as long as person capable
- No formalities even if directive is binding
- Consider special situations: capable adult with severe physical disability revoke orally or by some clear gesture

Case law relevant to Advance Directives

- Common law decisions mainly
- Address a number of issues including:
 - Content of advance directive
 - Validity, applicability and effect
 - Religion as basis for advance directive

Re A Ward of Court (1996)

- Competent adults has right to refuse medical treatment even if it leads to death
- Right not absolute -eg medical emergencies, contagious disease
- High Court reference to what her wishes might have been
- SC reference to idea of substituted judgement

Re T (1992)

- In principle an advance directive would be binding where:
 - Person had capacity at the time of the decision
 - Anticipated the circumstances that had arisen
 - No undue influence
- Her refusal was not valid

Airedale Trust v Bland (1993)

- Person can refuse medical treatment even leading to death and ...“extends to the situation where the person, in anticipation ... gives clear instructions...”
- Person of sound mind and fully informed can refuse life support; the same principle applies where refusal has been given at an earlier date

Re C (Adult Refusal of Medical Treatment) (1994)

- Injunction to prevent treatment now and in future without written consent
 - Can the person comprehend and retain the information?
 - Is he able to believe it?
 - Is he able to weigh the information, balancing risks and benefits, to arrive at a choice?
- He had capacity to refuse and AD upheld

Content of AD

- Advance Directives can be positive or negative
- *R (on the application of Burke) v GMC* (2005) “Autonomy and the right to self determination do not entitle the patient to insist on receiving a particular treatment regardless of the nature of the treatment.”
- Courts will not compel doctors to act against clinical judgement

Validity of AD

- Change of material circumstances?
- *HE v A Hospital NHS Trust* (2003)
- Must be “convincing and inherently reliable evidence” of the continuing applicability of the advance directive
- Any doubts are resolved in favour of preservation of life
- A lapse in time may create doubt about validity
- AD is inherently revocable

Validity of AD

- Difficult to establish a level of precision regarding future treatment refusal
- *W Healthcare NHS Trust v H* (2004)
- Declaration must be clear and refer to the particular circumstances
- Not an advance directive as she was unaware of the nature of the choice or consequences despite very strong expression of her wishes

Validity of AD

- *Re AK (Adult patient)(Medical Treatment) (2001)*
- “Expressions of AK’s decision are recent and are made not on any hypothetical basis but in the fullest knowledge of impending reality...they genuinely represent his considered wishes and should be treated as such”
- Conditions he stipulated had arisen - unlawful to continue invasive treatment

Validity -*Re AK* (2001)

- Advance directives of patient of full capacity and sound mind are effective
- Care must be taken to ensure directive still represented patient's wishes
- How long ago since it was made
- What level of knowledge involved in decision

Validity-religious beliefs

- *HE v Hospital NHS Trust* (2003)
- Change in circumstances, doubts raised
- Question that no longer professing faith which underlay the advance directive
- *Fitzpatrick v FK* (2008)
- Refused on religious grounds
- Capacity impaired-no capacity to make advance refusal

Conclusion

- Support at many levels for the introduction of advance directives
- Many challenges relate to lapse of time in end of life areas
 - Fully advised about decision
 - Change in circumstances
 - Validity and applying to the particular circumstances anticipated
 - Review of AD?
 - Register of specific types?