



## Advance Care Directives and the Position in Ireland: What lessons can Ireland Learn from the United Kingdom, the United States and Europe?

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### Abstract

An Advance care directive entitles a person to request in advance either the refusal of or consent to certain medical treatment if that person is not competent to consent or refuse at the time such refusal or consent is required. The 2003 Law Reform Commission's Consultation Paper on Law and the Elderly briefly mentioned advance directives. However, the Paper decided to leave the issue to a future Paper that would give a more comprehensive analysis. There is no Irish legislation on the matter and consequently the legal position is unclear. The English Mental Capacity Act 2005 has given recognition to advance directives under section 24. It is interesting to note that only refusal is covered by the Act. The 2005 Law Reform Commission Consultation Paper on Vulnerable Adults discusses the issue of advance directives in more detail. This Paper will examine the Irish position of advance directives. The British Mental Capacity Act and recent case law will provide a comparative analysis. The UN Convention on the Protection of the Rights and Dignity of Persons with Disabilities will also be examined.

**Keywords:** Advance care directives, Medical treatment, Position in Ireland, UK and US

### 1. Introduction

In 2003 the Irish Law Reform Commission (LRC) (Note 1) published a Consultation Paper on Law and the Elderly. The Paper noted the increased longevity and the rise in the numbers of people living to an advanced age. While the Paper acknowledged that this was a welcome development, it warned of potential problems associated with such longevity, including housing, health, financial support and personal social services. The Paper further examined legal mechanisms that were needed for the protection of vulnerably elderly people. Vulnerability is not just associated with elderly people, and with this assertion in mind, the Paper proposed that the issues involved could be adapted without much modification to apply to other vulnerable people such as those with disabilities or of young people (Note 2).

The Paper concentrated on the meaning of legal capacity and its discussion briefly mentioned advance care directives (Note 3). The Commission, however, decided to leave the issue of advance care directives to a future Paper that would give a more comprehensive analysis given the contentious moral, legal and ethical questions that surround the area. Although brief, the mention of advance care directives generated some academic debate.

This article will examine the position of advance care directives in Ireland. Recent case law has brought the issue before the Irish Courts. The case law indicates that the courts recognise advance care directives although there is no specific legislation in place that gives cognisance to such an assertion. The Irish Council for Bioethics released a Report in February 2007 entitled "Is it time for Advance Health Care Decisions?" The Report offered a background discussion and examined the position of advance care directives within Irish society. The Council hope that the Report will generate further discussion. This Report will be examined in more detail in the course of the article. As Ireland has a dearth of case law, a comparative analysis will be conducted. The United States offers an insightful illustration owing to its recognition of advance care

directives since the late 1960s. The United Kingdom will also be examined as a more recent exponent of advance care directives, under section 24 of the Mental Health Act 2005. The article will conclude with some recommendations and suggestions for reform.

No discussion of advance care directives is complete without first looking at the issue of legal capacity under Irish law. As there has been a dearth of case law on the matter in this jurisdiction, the position in England provides some guidelines.

## 2. Legal Capacity

Legal capacity has been described as ‘somewhat of a moveable feast’ (Note 4). As there is no universally agreed definition of legal capacity or incapacity, there are no agreed tests by which legal capacity can be adjudged. Irish law is somewhat confusing on the matter. Various terminology has been used to describe people who lack legal capacity. The Mental Health Act 2001 includes dementia and significant intellectual disability as a form of mental disorder. However, such a term is concerned more with psychiatric care and not legal capacity. The Enduring Powers of Attorney Regulations 1996 uses the term ‘mental incapacity’. The Criminal Law (Insanity) Act 2006 provides that unfitness to plead may be regarded as a form of legal incapacity. Thus Irish legislation does not provide a concrete definition of what constitutes legal incapacity. While mental incapacity or disorder does not mean a person is legally incapacitated, they do however provide convincing evidence of lack legal capacity. It would seem that the line between legal capacity and incapacity is not easy to define. One example where it is possible to identify an extreme stage of legal incapacity is if a person is in a coma. However legal incapacity cannot be ascribed in other situations which lack such exactitude where, for example, there are varying degrees of impaired, restricted or diminished responsibility and in these situations identifying legal incapacity becomes a more arduous task.

There has been no Irish case where capacity to medical treatment has been considered. The English case of *In Re MB* [1997] 2 FLR 426 provides some general principles for assessing capacity to medical treatment. Here the court held (at 437) that a “person lacks capacity if some impairment or disturbance of mental functioning renders that person unable to make a decision whether to consent to or refuse treatment”. Such an inability will arise when the person: “is unable to comprehend and retain the information which is material to the decision, especially as to the likely consequences of having or not having, the treatment in question”; and ‘the patient is unable to use the information and weigh it in the balance as part of the process of arriving at the decision” (at 437). In relation to Ward of Courts, such a ward lacks the capacity to give consent to medical treatment by virtue of the status of ward. However, it would seem that if a ward were to challenge this, the issue could be decided on the basis of specific issue or functional approach (i.e. capacity in relation to the transaction in question) as seen in the case of *Masterman-Lister v Brutton & Co. and Jewell & Home Counties Dairies* [2002] EWCA Civ 1889 and consequently a different outcome may result. In the English case of *In Re C (Adult: Refusal of Treatment)* [1994] 1 ALL ER 819 the court held that although the person was a patient under the Mental Health Act 1983 he nevertheless had the required capacity to refuse the amputation of his gangrenous leg as C believed that he had an international medical career and during his time as a doctor he had never lost a patient. The court (at 824) accepted that while the patient’s general capacity was impaired by schizophrenia, it had not been shown that he did not comprehend the nature, purpose and effect of the proposed amputation. C had been sentenced to prison for stabbing his girlfriend and had been diagnosed as a chronic paranoid schizophrenic. While in Dartmoor Prison, C received drugs and ECT, which improved his condition somewhat. In September 1993 he was moved to an NHS Hospital as he had gangrene in his right foot. The surgeon assessed the situation and believed that C would die if he did not have his leg below the knee amputated. The surgeon gave C a less than 15% chance of survival. C refused to consent to the amputation and instead opted for an alternative treatment, which was successful but there was likelihood that the gangrene would re-occur. Thorpe J. (at 824) found that in the course of proceedings C “seemed ordinarily engaged and concerned. His answers to questions seemed measured and generally sensible”.

## 3. Advance Care Directives and The Position in Ireland

Advance care directives or living wills provide for the wishes of the donor about future medical care. A donor may request that certain medical treatment be refused or should be given in certain circumstances if the donor is not competent to consent or refuse such medical treatment at the time. Advance care directives give an individual control over their health care decisions in the event of them becoming incompetent. There is no Irish legislation on the matter and consequently the legal position is unclear.

After the publication of the 2003 Paper, the Commission decided to hold a public seminar in November 2003. A number of submissions were made and on foot of this, and as a result the Commission were prompted to prepare and publish a second consultation paper which would broaden its terms of reference to encompass legal capacity issues relevant to all adults and not just older adults (Note 4). The Paper, entitled “Consultation Paper on Vulnerable Adults and the Law on Capacity”, was published in 2005. This Paper discussed advance care directives in more detail. The Commission proposed that capacity legislation be amended to provide the Minister for Health with the power to set up a working group to produce guidelines for medical professionals in relation to capacity issues relating to healthcare decisions. While a step in the right direction, the Paper did not elaborate further on the proposal.

In December 2006, the LRC published a Report on Vulnerable Adults and the Law. This Report formed part of the LRC’s *Second Programme of Law Reform 2000-2007* (Note 5). The Report includes the final recommendations of its two

previous papers, namely Law and the Elderly and Vulnerable Adults and the Law, and includes a draft scheme of a Mental Capacity and Guardianship Bill to give effect to these recommendations (Appendix, p.165). Under the heading of Vulnerability Groups and the Law, the Report was divided into two parts, the first dealing with older persons and the second part discussed persons with physical, mental or learning disabilities with the report looking at capacity, guardianship and the right to marry. On the issue of older persons, the Report examined capacity in relation to the transfer of assets and advance care directives. The Report (at paragraph 3.36) alluded to the impending Irish Council for Bioethics Report, which was subsequently published in February 2007. As this Report would be dealing comprehensively with advance care directives, the LRC decided not to propose any recommendations other than certain health care decisions being conferred using an enduring powers of attorney. This limited solution was proposed in light of the more comprehensive analysis contained in the Report of the Irish Council for Bioethics.

The Irish Council for Bioethics (ICB) conducted a public consultation on the legal and ethical issues surrounding advance care directives. A Report was duly prepared and published. The Report recognised the public interest in discussing advance care directives despite the lack of specific legislation. The Report highlighted the need for legislative intervention given that in the next 15 years the proportion of those over 65 will markedly rise. Consequently, end of life decisions will become increasingly important within Irish society. ICB, in taking a libertarian approach, contended that competent adults should have the right to prepare an advance care directive. In referring to patient autonomy and self-determination, the ICB cited the related rights of bodily integrity, privacy and dignity (Note 6). However, the ICB pointed out that these rights are not absolute and would have to be balanced against other principles such as justice and integrity.

As advance directives are not recognised under Irish legislation, the ICB highlighted the ambiguity that surrounds the issue. In referring to the LRC Paper on Law and the Elderly, the ICB suggested that advance care directives should be given legal status so long as the health care decisions within the directive are legal, for example, it would not be legally binding if the directive provided for euthanasia or assisted suicide.

The ICB acknowledged that advance care directives are not confined to end-of-life matters-patient making a decision about treatment or care that their child might receive future, also made by pregnant women. The Report emphasised that individuals should not be obliged to draft an advance care directive but if one wishes to do so there needs to be a legal framework in place to offer guidelines and safeguards. One possible solution proffered by the ICB was the use of the Powers of Attorney Act 1996 as a means of introducing legislative provisions. This would enable both proxies and those nominated under powers of attorney to make decisions on an individual's medical treatment. Although a limited solution, it would provide a framework through which future legislation could be implemented.

### 3.1 Recent Case Law in Ireland on Advance Care Directives

Recent case law indicates that Irish courts would uphold advance care directives. The first reference, albeit oblique, was in the case of *Re a Ward of Court*; [1996] 2 IR 73; [1995] 2 ILRM 401, where the Supreme Court upheld the High Court decision to allow the removal of artificial nutrition and hydration in the case of a patient who sustained irreversible brain damage as a result of cardiac arrest during a minor gynaecological treatment administered in 1972. In 1974 the High Court, on hearing a petition presented by her father, declared her to be of unsound mind and incapable of managing her person or property. Her father was appointed committee of the person and estate of the ward in May 1975. The ward's father died in 1988 and her sister became the appointed committee of the person and estate. She subsequently retired from the position and was replaced by her mother. Following this, her mother applied to the High Court to have the ward's nutrition and hydration withdrawn.

The Supreme Court recognised the ward's constitutional rights to life, privacy, bodily integrity, autonomy, dignity in life, and dignity in death. Grounded within the rights of privacy (Note 7), self determination, and bodily integrity, Hamilton CJ (at 126) held there to be "no doubt but that the ward, if she were mentally competent, had the right, if she so wished, to forego such treatment or, at any time, to direct that it be withdrawn even though such withdrawal would result in her death". To some academic commentators this aspect of the judgment was problematic as it was argued that court failed to take into account what the ward would have wanted prior to her becoming incompetent (Note 8). Hamilton CJ referred to the invasive procedures involved in the feeding of the ward, which in his mind could not be "regarded as normal means of nourishment". O' Flaherty J, obiter, found this approach somewhat unsettling. He found "it impossible to adapt the idea of the 'substituted judgment' to the circumstances of this case". The judge argued that it may only be appropriate to do so "where a person had the foresight to provide for future eventualities".

The case of *Re A Ward of Court* is, according to Campbell, "useful as it sets the foundation for the recognition of the validity of advance directives in Ireland". Madden argues that an Irish court would uphold the validity of an advance care directive "as long as the directive was lawful".

*Re A Ward of Court* was applied in the case of *JM v Board of Management of St. Vincent's Hospital* [2003] IR 321. Finnegan P. in the High Court endorsed the view of the Supreme Court in *Re A Ward of Court* and held that the court must have regard to the right of the person to determine treatment for themselves, provided that they were competent to make such a decision. JM concerned the prior refusal of a medical treatment. The party involved was African and upon marriage she

had adopted her husband's religion and had become a Jehovah Witness (Note 9). She became critically ill and was advised that a blood transfusion and liver transplant were needed to save her life. The hospital staff communicated this to the woman and left her to discuss the matter with her husband. She was lucid at the time. She decided to refuse the blood transfusion but the next day in a noticeable weaker state she consented and as a member of the transplant team returned ten minutes later with a consent form, the party had changed her mind once again.

Finnegan P. (at 325) took the view that the woman had refused treatment on the grounds of her cultural background and her desire to appease her husband. She had not made a clear final decision to have or not have the treatment. With only a 60% chance of survival, the judge ordered the blood transfusion and liver transplant. The judge was also influenced by the fact that the woman had a dependent child and a loving husband.

A similar factor influenced Abbott J. in the case of K in September 2006. This case is the first of its kind in the state and the judgment was delivered in September 2006. K, a Jehovah W's witness from the Democratic Republic of the Congo, suffered severe blood loss following complications arising from childbirth. The woman had suffered 80% blood loss. She was advised of the need for a blood transfusion, but refused in the knowledge that the refusal would result in death. The Coombe Women's Hospital applied to the court for an order directing the provision of the transfusion. Abbott J. acknowledged that K was competent but nevertheless ordered that the court should intervene to protect her and the welfare of her son. He made the point that K had no other family in the state and consequently there would be no next of kin to care for the child. Arguably, had the woman been an Irish national with family in the State, such an issue would not have been raised and thus the court would not have been able to order the provision of treatment on that ground.

### 3.2 Commentary

The K case has created more confusion. In *Re a Ward of Court*, the Supreme Court recognised the validity of the advance care directives so long as the patient competent and informed when the directive was created. In *JM v Board of Management of St. Vincent's Hospital* it was held that the court must have regard to the right of the person to determine treatment for themselves, provided that they were competent to make such a decision. Finnegan P. took the view that the woman had refused treatment on the grounds of her religion and to her desire to please her husband. She had not made a clear final decision to have or not have the treatment. However, in the case of K, Abbott J. acknowledged that the woman was competent but ordered the transfusion on grounds of her health and the welfare of her son.

Such ambiguity has highlighted the need for legislative intervention which would provide clear guidelines for both the courts and patients.

## 4. Advance Care Directives in the United States

The United States has long been a proponent of advance care directives. Since the late 1960s, the US courts have upheld the validity of these directives. Ireland can benefit from 40 years of experience from its American counterparts. The US provides a good starting point for the Irish legislature. Although there are fifty states with differing approaches, there are two seminal cases, namely *Re Quinlan* 355 A 2d 647, 97 ALR 3d 205 (S Ct. of New Jersey) and *Cruzan v Director, Missouri Department of Health* 110 S. Ct. 2841 (1990). These two cases encapsulate the US approach to advance care directives.

### 4.1 Quinlan and Cruzan

In 1967 a US attorney, Luis Kutner, created the first living will. Kutner was a human rights lawyer involved in a right to die organisation, and suggested the creation of a "living will" that would enable patients to give instructions for medical treatment at the end of life. By the 1960s there had been developments in medical equipment such as the development of artificial ventilators and cardiopulmonary resuscitation. This allowed doctors to prolong life in situations where the patient would have previously died. At the same time there was a new awareness of patient autonomy. In the early days advance directives were used for reassurance for family members when faced with a difficult medical decision (Campbell). In the following year the first living will legislation went before a Florida state legislature, a medical doctor by the name of Walter F. Sackett. Dr. Sackett introduced a Bill that would allow patients to make decisions regarding the future use of life-sustaining equipment. However, the bill was not passed and was reintroduced again in 1973 but was once again defeated. Similar developments were taking place in California by Barry Keene, who was elected to the California State senate in 1974. Keene subsequently endeavoured to introduce living will legislation, however this was defeated. He reintroduced the Bill in 1976 and was successful, as the California Natural Death Act was enacted. California became the first state in the US to recognise the validity of living wills. By 1977 43 states were in the process of considering living wills with 7 states passing the legislation. Originally advance directives were non-binding. By 1992 all 50 states had introduced some form of legislation that recognised living wills. Most states have statutes for both living wills and for durable powers of attorney for healthcare. However, the scope varies from state to state.

It is interesting to note that a number of professional organisations such as the American Medical Association and American Bar Association had reservations about giving advance care directives a legal basis. It was feared that financial reasons would force an individual to draft an advance care directive. At federal level, advance directives were given more support. In 1991, the House of Representative enacted the Patient Self-Determination Act. This Act provides that hospi-

tals and other healthcare organisations receiving state funding must inform patients at admission of their right under state law to make decisions about the medical care, including drafting advance care directives. The Act requires that the advance directive is included in the patient's medical record; it also provides that staff should receive education in relation to advance care directives; and perhaps more importantly the Act provides that the presence or absence of an advance care directive does not influence the provision of care.

#### 4.1.2 Re Quinlan

*Re Quinlan* concerned a 21-year-old woman who suffered severe brain damage due to an unknown cause. She was left in a persistent vegetative state and her family wished to disconnect her respirator. The New Jersey Supreme Court granted her father judicial approval for the removal of the respirator. The Court held that the woman had a right to privacy grounded in the Federal Constitution to terminate treatment. Although Quinlan had become incapacitated, the Court argued that had she been competent she would have requested the removal of the respirator. The Court noted the state interest in the case and held that the "only practical way" to prevent the patient's right to privacy due to her incompetence was to allow her guardian and her family to make the decision to remove the respirator. The Court ordered the removal of the respirator. Quinlan continued to breathe on her own for a further nine years until her death.

#### 4.1.3 The Cruzan Case

It was not until 1990 that the US Supreme Court finally gave a judgment on the legality of advance care directives. The Supreme Court had previously been reluctant to hear a case of this nature, as it believed that advance care directives should be regulated by the individual states. In the case of *Cruzan v Director, Missouri Department of Health*, 110 S. Ct. 2841 (1990), the Supreme Court was required to balance the right to die against the interests of the state. Cruzan was rendered incompetent following a car crash in 1983 and suffered severe injuries as a result of the accident. The accident left her lying in a Missouri hospital in a persistent vegetative state. Her family wanted to remove her feeding tube but Cruzan did not have an advance directive and consequently the Supreme Court of Missouri held that there was no clear and convincing evidence of Cruzan's desire to have life-sustaining treatment withdrawn. In the appeal to the Supreme Court, evidence was given by a housemate friend who recalled a conversation with Cruzan in which she stated that if she ever fell ill or injured she would not want to continue her life unless she could live at least halfway normally. This statement suggested that Cruzan would not wish to continue on with her nutrition and hydration in her current condition. The Supreme Court ordered that the patient's nutrition and hydration be removed. Cruzan died subsequently.

This case is important in a number of respects, most notably, the Supreme Court recognised that a patient's previous wishes in regard to future treatment could be used to direct a person's current treatment. The Supreme Court considered the constitutionality of a state requiring clear and convincing evidence of a person's expressed wishes to refuse treatment and while agreeing with the Missouri court, added that that no right is absolute and the right to refuse life-prolonging treatment can be restricted by the state.

The case raised a number of important ethical issues. The Missouri court held that "the right to refuse life-saving medical treatment continued to apply to Nancy Cruzan even though she had become legally incompetent" (Note 10). Cruzan had not drafted an advance care directive and under Missouri law the standard of proof is termed in negative terms in that the family had to prove that Cruzan would not have wanted to be sustained by artificial feeding. By using this standard, "the Supreme Court abandoned the search for accuracy in decision-making and simply made it much more difficult to assert the right refuse treatment for incompetent patients" (Note 11).

#### 4.1.4 The Schiavo Case

Similar ethical concerns were raised in the *Schiavo* (Note 12) case. This case became, in the words of Lazzarini (at 148) a "national political and cultural spectacle" as it attracted the attention of various interest groups, the Florida State Legislature, the Governor of Florida and the President of the United States. With facts medical facts similar to Cruzan, the *Schiavo* case differed fundamentally as her parents challenged her husband's decision to remove feeding. The Florida Court of Appeals considered Schiavo to be incompetent and ordered the removal of her feeding tubes. Her parents considered the decision to be "judicial murder".

The *Schiavo* case has been attributed with the increase in the creation of living wills in the US. According to one source, in 2005 the number of living wills increased from 500 a day to 50,000. By 2006 the number had levelled off to about 2,500 day (Note 13). The case highlighted the struggle between individual autonomy and liberty and that of the interest of the state. Given the sensitive, highly emotive and ethical issues that arose in the case, its filtration into the political domain has received sharp criticism from some commentators, including Lazzarini. Individual decisions on the right to refuse medical treatment are not appropriate subjects for what Dworkin referred to in his works on euthanasia and abortion as "universal, theoretical, abstract judgment born in the stony halls where interest groups manoeuvre and political deals are done" (Note 14).

The United States has provided a rich tapestry of commentary and case law since the creation of advance care directives some 40 years ago. From its humble beginnings in the 1960s to the US Supreme Court decision in Cruzan, advance directives

now enjoy recognition and validity in all 50 states.

### 5. The Position in the United Kingdom

The UK, on the other hand, has recently enacted legislation. The Mental Capacity Act 2005 of England and Wales (which came into force during 2007) has created much debate on the issue. Although advance care directives are recognised under this Act, it does not mean that they are immune from challenge, for example by a patient's family. It is very difficult for a healthy young adult to make decisions on future health care (Note 15).

The Act gives recognition to advance care directives under section 24 (Note 16). Section 24 provides that a person, aged 18 and upward, who at time had capacity to do so, may make an advance decision to refuse treatment. It is interesting to note that only refusal is covered by the Act.

The 2005 Act expressly provides for advance decisions to refuse treatment and for lasting powers of attorney covering health care decisions (Note 17). A valid refusal of treatment is legally binding and decisions made by a person designated as a lasting power of attorney should carry the same weight as if those decisions had been made by the individual who prepared the power of attorney (See Chapter 9 of the Mental Capacity Act 2005).

Under the Act an individual has the right to make an advance request for certain medical treatments. This was considered in the appeal case of *R (on the application of Burke) v General Medical Council* [2005] EWCA Civ 1003. DRC and Others. The applicant suffered from a congenital degenerative brain condition known as spino-cerebellar ataxia, and confined to a wheelchair. He wanted reassurance that the GMC's guidance "*Withholding and Withdrawing Treatment*", a document published in 2002, did not allow or authorise doctors to withdraw life-prolonging artificial nutrition and hydration ("ANH") from him, as a competent patient, in breach of his expressed wish to receive such treatment.

The Court of Appeal concluded that Mr Burke's fears were already addressed by the common law in that there was a positive duty to care for the patient and there was nothing unlawful in the GMC guidance. The Court found while the competent patient has an absolute right to refuse treatment, there is no individual right to demand treatment that is not clinically indicated.

### 6. The European Approach

#### 6.1 European Convention on Human Rights and Biomedicine

The Council of Europe Convention on Human Rights and Biomedicine was created in 1997. This Convention provides for advance care directives under Article 9 concerning previously expressed wishes relating to medical intervention. Article 9 states: "The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account". Twenty European states have signed the Convention; Ireland has yet to do so. However, it is important to note that while these European countries have signed the Convention, it does not mean that there is a legal endorsement of advance care directives. Some countries have enacted legislation, for example most recently Austria (Note 18).

#### 6.1.2 UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities

The final draft of this Convention has been open for signatures at the United Nation's Headquarters in New York since the 30<sup>th</sup> of March 2007. Ireland was one of the first signatories to the Convention. During discussions on the final text of the Convention, a Seminar was held by the National Disability Authority where suggested the use of advance care directives as a mechanism for dealing with incompetence (Note 19). The final draft of the Convention does not mention advance care directives, it was interesting to note that such a suggestion came from the Seminar given that Ireland has no domestic legislation concerning advance care directives.

### 7. Conclusion

Ireland has yet to implement legislation that gives validity and recognition to advance care directives. The case law seems to indicate that the courts will respect an individual's right to self-determination in healthcare decision-making. However, while advance care directives have received judicial recognition, it is uncertain whether an advance care directive would have any legal standing in Ireland. There is a need for some form of legislation that would create a statutory framework for the protection of vulnerable adults. The Irish Council for Bioethics found that the many people within Irish society would like for advance care directives to be recognised and for legislation to be put in place that would provide safeguards. The Law Reform Commission has also brought the issue to the fore and will hopefully devote an entire Consultation Paper to advance care directives.

The right to self-determination and patient autonomy in healthcare decisions have made great progress over the past four decades in the United States. Advance care directives have been recognised since the late 1960s. As they are regulated at state level, the approach differs from state to state, but the overall framework is similar. However, the case law has shown that patient rights are not absolute and may be restricted under state law. Some commentators have argued that patient rights are denigrated in the interest of political agendas (Lazzarini, at 152).

The enactment of the Mental Capacity Act 2005 (Note 20) in the United Kingdom was not without controversy as the Act creates a lasting power of attorney thus replacing an enduring power of attorney. The lasting power of attorney will cover

decisions such as personal welfare; property; healthcare decisions, wills as well as advance care directives (sections 9-14 of the Act). More recently, The Lasting Powers of Attorney, Enduring Powers of Attorney and Public Guardian Regulations went before Parliament and came into force on the 1<sup>st</sup> October 2007. These Regulations set out in detail the procedures for creating a lasting power of attorney, thus augmenting the 2005 Act. Until the 1<sup>st</sup> of October 2007, lasting powers of attorney could not be registered.

The Council of Europe's Convention on Human Rights and Biomedicine 1997 gives cognisance to advance care directives under Article 9, however Ireland has not signed this Convention. Other European countries, such as Austria, the Netherlands and Denmark have enacted their own legislation. Austria enacted legislation in 2006, however it has an earlier Act, the Federal Hospital Law of 1957 (Bundeskrankenanstaltengesetz) which provides for the registration of an individual's medical record in which his or her wishes in relation to the refusal of treatment are stated in the event of later incapacity.

The wardship system is the current recognised system for healthcare decisions on behalf of incapacitated adults in Ireland. Originally the purpose of wardship was to protect and financial assets of the wards for their benefit and their dependants (if any), however the system evolved to provide personal protection (*Law and the Elderly* (LRC CP 23-2003) at paragraph 4.02). It has been argued that Ward of Court system is cumbersome and outdated (at paragraph 6.01). Given the misgivings associated with the wardship system, reform is needed. The legislature needs to introduce statutory protection for those who wish to make future decisions about medical treatment. With increasing public debate on the matter as highlighted by the Irish Council for Bioethics, there is more pressure on the legislature to address the obvious lacuna that exists within Irish law.

## References

### Books

Donnellan, L., The Law Reform Commission's Proposals on Law and Older People. (pp72-103) In E. O'Dell (Ed) *Older People in Modern Ireland Essays on Law and Policy*. pp72-103. (Dublin: FirstLaw, 2005)

Hockton, A., *The Law of Consent to Medical Treatment*. London: Sweet & Maxwell, 2002)

Madden, D. *Medicine, Ethics and the Law* (Dublin: Butterworths, 2002)

### Papers and Reports

Law Reform Commission Consultation Paper *Law and the Elderly* (LRC CP 23-2003)

Law Reform Commission Consultation Paper on *Vulnerable Adults and the Law on Capacity* (LRC CP 37-2005)

Law Reform Commission Report on *Vulnerable Adults and the Law* (LRC 83-2006)

Law Reform Commission Seminar Paper on Consultation Paper: *Law and the Elderly* (LRC SP 2-2003) (November 2003).

The Report of the Irish Centre for Bioethics is available from: <http://www.bioethics.ie/pdfs/AdvanceDirectiveReport.pdf>

### Journal Articles

Campbell, E. (2006). "The Case for Living Wills in Ireland." 12 (1) (2006) *Medico-Legal Journal of Ireland* 12 (1) 5-21

Johnston, C. (2005). "End of Life Decisions". (2005) 155 (7174) *New Law Journal*. 155 (7174). 666-669

Lazzarini, Z., Arons, S. & Wisnieski, A., (2006). Legal and policy lessons from the Schiavo case: Is our legal right to choose the medical care we want seriously at risk. *Palliative and Supportive Care* 4 145-153

### Conventions

Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Oviedo, 4.IV.1997. Available from <http://conventions.coe.int/Treaty/EN/Treaties/Html/164.htm>.

Convention on the Rights of Persons with Disabilities. Available from <http://www.un.org/disabilities/>

### News Paper Articles

Costello, J. (2005). "Medics in legal bind on consent",. *Sunday Business Post*. , 16 January. 2005

Donnellan, E. (2006). 'Woman in court transfusion case recovering in hospital' . *Irish Times*. , 22 September 2006.

### Internet Articles

Rickard-Clarke, P. (2003) Global Trends in Disability Law Reform Setting a Context for Irish Law Reform. [Online] Available from: <http://www.lawsociety.ie/newsite/documents/dispat1.pdf>

"The History of Advance Directives" . [Online] Available: Available from [http://www.medicinenet.com/advance\\_medical\\_directives/page2.htm](http://www.medicinenet.com/advance_medical_directives/page2.htm)

## Notes

Note 1. The Law Reform Commission was established by virtue of section 3 of the Law Reform Commission Act, 1975. It is

an independent statutory body whose main aim is to keep the law under review and to make practical proposals for its reform.

Note 2. The Paper addressed a number of important issues regarding legal capacity, the capacity to make a will, enduring powers of attorney, wards of court, protection against abuse, and new system for protecting vulnerable adults.

Note 3. Advance directives are usually presented in written form and differ from a living will. A living will sets out specific instructions in relation to the refusal of medical treatment in advance. Advance directives allow more flexibility as decisions are not confined to what is written in the directive

Note 4. In the 2003 Paper the Commission acknowledged that while “improvements we recommend are made with elderly people in mind, they are also relevant to other adults with decision making disabilities or who otherwise need protection. The Commission has not analyzed the issues involved for other adults but considers that the proposed system could be adapted to their needs without much modification”.

Note 5. *Second Programme for Examination of Certain Branches of the Law with a view to their reform 2000-2007*, approved by the government in December 2000 under the Law Reform Commission Act 1975

Note 6. Bodily integrity is an unenumerated right under Article 40.3.1° of the Constitution; see *Ryan v. Attorney General* [1965] IR 294. Privacy is also an unenumerated right developed by the courts; see *MaGee v. Attorney General* [1974] IR 274. For a reference to dignity see the Preamble and Article 45.1 of the Irish Constitution.

Note 7. The right to refuse medical treatment falls within the ambit of the right to privacy, which encompasses the right to be left alone. In the oft quoted passage from the case of *Schloendorff v Society of New York Hospital* 2 11 NY 125, 105 NE 92 (1914) Cardozo J. held that “Every human being of adult years and sound mind has the right to determine what shall be done to his own body”.

Note 8. This is a point made by Elizabeth Campbell

Note 9. According to Hockton there were 140, 000 Jehovah Witnesses residing in the UK and Ireland in 2002. While a Jehovah Witness may refuse a blood transfusion, organ transplants are permitted.

Note 10. Lazzarini, Z., Arons, S., Wisniewski, A., (2006) Legal and policy lessons from the Schiavo case: Is our legal right to choose the medical care we want seriously at risk. *Palliative and Supportive Care* 4 145-153, at 148.

Note 11. Lazzarini, Z., Arons, S., Wisniewski, A., (2006) Legal and policy lessons from the Schiavo case: Is our legal right to choose the medical care we want seriously at risk. *Palliative and Supportive Care* 4 145-153, at 148.

Note 12. *In re Schiavo*, 780 So. 2d 176, 177 (Fla. Dist. Ct. App. 2001), reh’g denied (Feb. 22, 2001), review denied, 789 So. 2d 348 (Fla. 2001).

Note 13. Stacy, Mitch, “Schiavo Case Prompts More Living Wills” available at <http://www.uslivingwillregistry.com/Schiavo.shtm>

Note 14. As cited by Lazzarini.. Dworkin, R. (1993) *Life’s Dominion: An Argument about Abortion and Euthanasia and Individual Freedom*. New York: Vintage at 213.

Note 15. Take for example; a 25-year-old unmarried man makes an advance care directive which provides that all life-sustaining treatment is to be refused in the event of him becoming mentally incompetent. However, in the intervening years, there are advances in medicine and by the time the woman reaches his seventies, he is married, has a supportive family and suffers from mild dementia. However, as the man is no longer deemed competent, he may no longer change her mind. Donnelly, M. (2002) *Consent Bridging the Gap between the Doctor and Patient*. Cork: Cork University Press, at 66. See also Section 24 (3) of the Mental Capacity Act 2005 which provides that a patient may withdraw or alter an advance decision at any time when he has capacity to do so. Again, capacity is the important factor.

Note 16. Advance wills had been recognised at common law, for example, in the case of *Re C (adult: refusal of treatment)* [1994] 1 All ER 819 and *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649.

Note 17. This can be contrasted with the Irish position where health care decisions cannot be taken under the Enduring Powers of Attorney Act 1996. See Chapter 9 of the 2005 Act, available at <http://www.opsi.gov.uk/acts/en2005/2005en09.htm>

Note 18. Federal Act on Living Wills (Patientenverfügungs-Gesetz - PatVG) 2006. *Federal Law Gazette of the Republic of Austria* 55 (1): 1-3. Finland has the *Act on the Status and Rights of Patients* 1992); Denmark has an Act entitled the *Law on Patients’ Legal Status* 1998 and the Netherlands enacted legislation in 1994, the *Medical Treatment Contracts Act* (WGBO) 1994.

Note 19. Capacity and the Convention: Report of National Disability Authority (NDA) seminar on the draft UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities 15 June 2006.

Note 20. See also the Safeguarding Vulnerable Adults Act which received Royal Assent on the 8<sup>th</sup> of November 2006