Patients have both moral rights and legal rights which must be respected in healthcare decision-making. This includes decisions about the end of life. Rights make an important contribution to patient care because respect for patient rights makes the patient central to the decision-making process and allows a patient to exert a degree of control over how and when he or she dies.

The following case study is based on the facts of an important Irish Supreme Court decision on end of life, In re a Ward of Court. As you read the case study, pay attention to the way in which the law understands patients’ rights and tries to protect them.

**In re a Ward of Court**

This case came before the Supreme Court in 1995. It concerned a woman who had been in a near-Persistent Vegetative State for 23 years. She was unable to communicate, move or swallow and was fed by gastrostomy (PEG) tube. The Ward’s family asked the court to have the PEG tube removed. The institution where the Ward was cared for had ethical objections to discontinuing life supports especially discontinuing the PEG tube because they understood this as aiding the progression towards dying.

In reaching its decision in favour of removing the tube, the Supreme Court regarded as relevant a number of rights protected under the Irish Constitution. These included the right to autonomy or self-determination, the right to privacy, the right to dignity, the right to bodily integrity, the right to life and the right to die and the right to equality.

The Court stated that the fact that the woman lacked decision-making capacity did not diminish her rights. To distinguish between people with capacity and people without capacity would be ‘invidious’.

Bearing in mind the significance of the woman’s rights, the Supreme Court decided that decisions such as this should be made on the basis of the best interests of the person taken from the point of view of a ‘prudent and loving’ parent. In their decision to allow the withdrawal of the PEG tube, the Supreme Court took the view that the provision of nutrition and hydration via the artificial means of PEG feeding was equivalent to medical treatment and, as such, could be justifiably withdrawn because it was considered to be ineffective and burdensome to the Ward.

(In re a Ward of Court [1996] 2 IR 79)

**Discussion**

One of the reasons why the case, In re a Ward of Court, is important is because it involves the Supreme Court setting out in the clearest terms that patients have rights in respect of dying and that these rights do not stop simply because a person lacks or loses capacity. The fact that the woman was in a near PVS did not diminish her rights. She still had rights to autonomy, bodily integrity, dignity and privacy. These rights arise under the Constitution and all people and institutions who deal with her (and with other patients) have a legal obligation to respect these rights. Failure to do so would leave the healthcare professional/institution liable for failing to respect individual rights.

Another reason why In re a Ward of Court is important is that the Supreme Court did not differentiate between withdrawal of artificial nutrition and hydration (ANH) via PEG and other forms of treatment withdrawal (e.g. dialysis or chemotherapy). In general, withdrawing treatment that has already begun is legally and ethically justified if it can be shown that the burdens of continued treatment for a particular patient outweigh the benefits. If a patient is competent and if they so wish, they should be central in the determination of what
constitutes a ‘burden’. Withdrawal is normally a decision taken with the patient and/or the patient’s family through conversation about the patient’s sufferings and prognosis. If a patient lacks capacity, such as happened in this case, then the health professionals, usually in conjunction with any family or proxy, determine what is in the ‘best interests’ of the patient.

There was clearly a strong disagreement between the health professionals looking after the Ward and family members in relation to what was considered in the ‘best interests’ of the Ward and the status of ANH among other things. There is a suggestion that the Ward’s family had attempted to communicate about the possibility of discontinuing life supports including re-insertions of the PEG tube and use of antibiotics and resuscitation many times after their loved one arrested and that these efforts at communication were resisted.

Following the Supreme Court Judgement, the Irish Medical Council and Nursing Board issued statements that they viewed ANH as an ordinary and humane requirement of care and they claimed that it was a duty of their members to continue the provision of nutrition and hydration. That nutrition and hydration have a special status is reflected in the current Medical Council Code of Ethics (2009) which states that ‘Nutrition and hydration are basic needs of human beings. All patients are entitled to be provided with nutrition and hydration in a way that meets their needs’ (par.19.1). However, the Code has moved away from the more absolute position of earlier Codes, which had required that ‘all reasonable and practical efforts should be made to maintain’ nutrition and hydration. Rather, it now states that

If a patient is unable to take sufficient nutrition and hydration orally, you should assess what alternative forms are possible and appropriate in the circumstances. You should bear in mind the burden or risks to the patient, the patient’s wishes if known, and the overall benefit to be achieved. Where possible, you should make the patient and/or their primary carer aware of these conclusions.’ (Medical Council of Ireland (2009) Guide to Professional Conduct and Ethics for Registered Medical Practitioners, 7th ed. Dublin: Medical Council, 19.1).

Notice that the Medical Council suggests that doctors take a number of things into account when considering the provision of ANH:

- the burden and risk to the patient
- the patient’s own wishes if known
- the overall benefit to the patient
- the sharing of clinical conclusions with the patient and/or their primary carers

In light of your reading and understanding of re a Ward of Court; discuss your response to the following suggestions in relation to professional responsibilities and consider any others that you think should be added.
**Suggested Professional Responsibilities**

1. **Maintain good communication with family:** It is essential to maintain good communication with family members. This does not mean that family members’ views should take precedence over the legal and ethical obligation of health professionals to provide care to the patient. However, appropriate communication can alleviate family concerns and can sometimes prevent confrontational situations developing.

2. **Competently assess the patient’s best interests:** In cases such as *In Re a Ward of Court*, an assessment of the patient’s ‘best interests’ should be made. This assessment should take into account any benefits, burdens and risks involved in life prolonging treatments and it should be communicated to the patient and/or the patient’s family where appropriate. See definition of ‘best interests’ below.

3. **Facilitate team decision:** Any disagreements that may arise within the healthcare team should be aired and constructively resolved based on careful evaluation of benefits and burdens of continuing any form of life prolonging treatment.

4. **Document decisions:** The decision in terms of the process and the final determination made about continuing or withdrawing a life prolonging treatment should be documented.

5. **Seek advice:** If in doubt about the legal rights implicated in a particular decision, health professionals should seek advice as to how to proceed. This is especially important in the event of disputes between family members or between health professionals and family members.

6. ??

**Key Terms**

**Rights**

When thinking about the role of rights in healthcare decision-making, it is important to distinguish between moral rights and legal rights. A moral right, if accepted within a community, is a claim that entitles us to demand that other persons act or desist from acting in certain ways. For example, we have a moral right to be treated with dignity and that people do not act in a way which is degrading or inconsistent with our dignity. A legal right is a right which is legally enforceable in a court of law. Legal rights create legal obligations in another person or the State. Sources of legal rights include the Irish Constitution, European Convention on Human Rights and United Nations Conventions.

**Best Interests**

Acting in someone’s best interests involves an assessment of the appropriateness of treatment and care options for that person. It is not solely a clinical judgement about the potential medical benefits, burdens and risks of treatment options that lacks reference to the particular patient. Quite the contrary: ‘best interests’ based decisions need to take into account:

- The patient’s known or ascertainable wishes, including information about previously expressed views, feelings, belief and values and whether those views might still be the same.
- Information received from those who are significant in the person’s life and who could help in determining his or her best interests.
• Aspects of the person’s culture and religion that would influence a treatment decision.

As well as:
• The likely clinical outcome and the level of recovery that can realistically be expected after successful treatment.
• The risks involved with treatment and non-treatment.
• The patient’s human rights, including the right to life and the right to be free from degrading treatment.
• The likelihood of the patient experiencing severe pain or suffering as a result of the treatment.

Activities

1. Reflect back on the particulars of In re a Ward of Court. In your view, is it a good or a bad thing for cases like this to come before the courts? In your view, what should the Supreme Court have done when faced with this case? The Supreme Court listed a set of rights, including the right of autonomy, dignity, bodily integrity and dignity. How do you think that these rights were relevant to the circumstances which arose in In re a Ward of Court? Can you think of any other rights which may have been relevant in the facts arising in this case?

2. There is broad consensus that, if a patient is able to take food in the conventional way, then food should be offered and the patient encouraged to eat. However, when a patient is no longer able to take food in a conventional way, the difficult issue of deciding on ANH arises. If you were one of the health professionals involved in this case, would you have taken a similar position in relation to ANH to theirs? If so, why; if not, why not?

3. The Supreme Court left many questions unanswered. For example, what does it mean to respect the right of autonomy of a woman who clearly lacks the ability to make decisions and who has not left any clear indication of what she would have wanted to happen in the situation which arises? What do you think might be required of health professionals who try to respect the autonomy of a patient who currently lacks the capacity to make decisions about their treatment and care?

4. Few, if any, rights are absolute. Even rights which we think of as fundamental, such as the right to life, may be restricted in certain circumstances. The most common basis upon which rights are restricted is that respect for one person’s right will have a negative impact on another person’s right. In some circumstances, societal interests may also justify interfering with a person’s right. Can you think of an example of a case where a person’s right to autonomy could be overridden on the basis of other people’s rights?
Key Readings


Study Session 3

Healthcare Decision-making and the Role of Rights