Module 3
Healthcare Decision-making and the Role of Rights
### Module 3 Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Key Points</td>
<td>121</td>
</tr>
<tr>
<td>1.1 Patient Rights</td>
<td></td>
</tr>
<tr>
<td>1.2 Moral Rights and Legal Rights</td>
<td></td>
</tr>
<tr>
<td>1.3 Positive and Negative Rights</td>
<td></td>
</tr>
<tr>
<td>1.4 All Patients have Rights</td>
<td></td>
</tr>
<tr>
<td>1.5 Limited Views of Rights</td>
<td></td>
</tr>
<tr>
<td>1.6 Rights are not Absolute</td>
<td></td>
</tr>
<tr>
<td>1.7 Advantages of a Rights-based approach</td>
<td></td>
</tr>
<tr>
<td>1.8 Limits of an Exclusive Focus on Rights</td>
<td></td>
</tr>
<tr>
<td>1.9 Good Care Requires More than Respect for Rights</td>
<td></td>
</tr>
<tr>
<td>2. Module 3 Definitions</td>
<td>123</td>
</tr>
<tr>
<td>2.1 Positive Rights</td>
<td></td>
</tr>
<tr>
<td>2.2 Negative Rights</td>
<td></td>
</tr>
<tr>
<td>2.3 Moral Rights</td>
<td></td>
</tr>
<tr>
<td>2.4 Legal Rights</td>
<td></td>
</tr>
<tr>
<td>2.5 Constitution of Ireland</td>
<td></td>
</tr>
<tr>
<td>2.6 European Convention on Human Rights</td>
<td></td>
</tr>
<tr>
<td>2.7 Charter of Patient Rights</td>
<td></td>
</tr>
<tr>
<td>2.8 The United Nations Convention on the Rights of the Child</td>
<td></td>
</tr>
<tr>
<td>2.9 The United Nations Convention on the Rights of Persons with Disabilities</td>
<td></td>
</tr>
<tr>
<td>2.10 Council of Europe Recommendation</td>
<td></td>
</tr>
<tr>
<td>3. Module 3 Background</td>
<td>125</td>
</tr>
<tr>
<td>3.1 Medical Ethics and the Rise of Rights</td>
<td></td>
</tr>
<tr>
<td>3.2 Different Kinds of Rights</td>
<td></td>
</tr>
<tr>
<td>3.2.1 Positive Rights and Negative Rights</td>
<td></td>
</tr>
<tr>
<td>3.2.2 Moral Rights and Legal Rights</td>
<td></td>
</tr>
</tbody>
</table>
4. The Scope of Rights
   4.1 Rights and Absolutes
   4.2 Rights and Responsibilities
   4.3 The Contribution of a Rights-Based Approach
   4.4 The Limits of a Rights-Based Approach

5. Rights in Practice
   5.1 Sources of Moral Rights
   5.2 Sources of Legal Rights
   5.3 Legal Rights as Citizens
      5.3.1 Rights and the Irish Constitution
      5.3.2 Rights under the European Convention on Human Rights
   5.4 Other Sources of Rights
      5.4.1 Charter of Patients’ Rights
      5.4.2 International Human Rights Instruments

6. Cases: Exploring Rights in Action
   6.1 Case 1: The Limits of Negative Rights
      6.1.1 Discussion
      6.1.2 Suggested Professional Responsibilities
   6.2 Case 2: A Case Study on Constitutional Rights
      6.2.1 Discussion
      6.2.2 Suggested Professional Responsibilities
   6.3 Case 3: Children, Rights and Healthcare Decision-Making
      6.3.1 Discussion
      6.3.2 Suggested Professional Responsibilities
   6.4 Case 4: Rights, Incapacity and Decision-Making
      6.4.1 Discussion
      6.4.2 Suggested Professional Responsibilities
      6.5.2 Professional Responsibilities
7. Module 3 Further Discussion 152

8. Module 3 Summary Learning Guides 153
   8.1 The Nature of Rights
   8.2 The Contribution of Rights
   8.3 Sources of Legal Rights
   8.4 Positive Rights Implicated in End of Life Care
   8.5 All Patients Have Rights

9. Module 3 Activities 155

10. Module 3 References and Further Reading 157
1. Module 3 Key Points

1.1 Patients have rights and these must be respected in healthcare decision-making:
Patients have both moral rights and legal rights which must be respected in healthcare
decision-making. This includes decisions about the end of life.

1.2 Moral rights and legal rights are different:
A person may have a moral right to something but this moral right may not be enforceable
in a court of law. This does not mean that the moral right is less important than a legal right.
However, it can mean that a moral right is more difficult to enforce.

1.3 Rights are both positive and negative:
Rights can be seen as a right to something – a positive right and a right that someone does
not do something to you – a negative right. Most legal rights tend to be negative rights. This
does not mean that negative rights are more important than positive rights. However, the
enforcement of positive rights can be more difficult to achieve. In particular, positive rights
may require the allocation of resources.

1.4 All patients have rights:
Rights are not restricted to certain patients only. All patients have rights. Patients who are
children, patients who have disabilities, patients who lack the capacity to make decisions
for themselves all have rights and these must be respected in healthcare decision-making in
respect of these patients.

1.5 Rights can sometimes be viewed in too limited a way:
Rights should not be thought of as negative rights or as legal rights only. This is too limited a
view. It is essential to remember that people have positive rights and moral rights.

1.6 Rights are not absolute:
Rights may be restricted for a number of reasons, including the protection of the rights
of others or the protection of societal interests. The extent to which a person’s rights may
legitimately be restricted varies depending on the circumstances.

1.7 A Rights-based approach offers important possibilities in respect of patient care:
A rights-based approach to decision-making can have important advantages for patient care.
It places the patient at the centre of the decision-making process. In an end of life context, it
recognises that all decisions must centre on the patient and his or her needs.
1.8 An exclusive focus on rights can be problematic:
A focus on rights without reference to the social situation in which people live (and die) can provide too narrow a focus.

1.9 Good care requires more than just respecting people’s rights:
It is not enough simply to respect patients’ rights. Good care requires more than this. Yet, while respect for rights does not provide the whole basis for care, it is an important aspect of appropriate patient care.
2. Module 3 Definitions

2.1 Positive Rights:
an individual’s right to some social or personal or institutional benefit or provision.

2.2 Negative Rights:
the right to demand that a person or persons desist from doing something to you

2.3 Moral Rights:
a justified claim that entitles us to demand that other persons act or desist from acting in certain ways.

2.4 Legal Rights:
rights enforceable in a Court of Law

2.5 Constitution of Ireland:
A legal instrument which provides the foundation for all laws in Ireland. The Constitution was adopted in 1937 and sets out certain fundamental rights. All laws must comply with the Constitution and if a law is found to be unconstitutional, it must be repealed. The Constitution may be amended only by a referendum of the people.

2.6 European Convention on Human Rights:
A human rights instrument adopted by the Council of Europe in 1950 to protect human rights and fundamental freedoms in Europe. Until 2003, Ireland was a signatory to the European Convention on Human Rights but judgments of the European Court of Human Rights in Strasbourg were of persuasive effect only. The European Convention on Human Rights Act 2003 made the Convention part of domestic Irish law. This means the Convention can be argued in an Irish court.

2.7 Charter of Patient Rights:
The European Charter of Patient Rights agreed in Rome in 2002 sets out 14 rights of the patient. The Charter is not legally enforceable but is an important indicator of best practice.

2.8 The United Nations Convention on the Rights of the Child:
An international human rights instrument adopted by the United Nations in 1989 which sets out the human rights of children. Ireland has signed and ratified the Convention. This means that Ireland is bound by the Convention.
2.9 The United Nations Convention on the Rights of Persons with Disabilities:
An international human rights instrument adopted by the United Nations in 2006 which sets out the human rights of persons with disabilities. Ireland has signed the Convention but has not ratified it. This means that Ireland is not bound by the Convention.

2.10 Council of Europe Recommendation Concerning the Legal Protection of Incapable Adults:
A recommendation adopted by the Council of Europe in 1999 covering the protection of adults lacking decision-making capacity. This Recommendation is not legally binding but is an example of best practice in this area.
Module 3  Healthcare Decision-making and the Role of Rights

3. Module 3 Background

3.1 Medical Ethics and the Rise of Rights
For much of the history of medicine, the most important imperatives were doing good for the patient, frequently referred to as beneficence and the protection of life, often referred to as the sanctity of life principle. This ethical view derives from the Judaeo-Christian tradition whereby life was seen as having an intrinsic value unrelated to the individual’s views regarding his own life. The principle is based, in Paul Ramsey’s words, on the fact that ‘[e]very human being is a unique, unrepeateable opportunity to praise God. His life is entirely an ordination, a loan and a stewardship’ (Ramsey, 1971, p.11). The matter of patient rights was largely irrelevant. However in the late 1960s, attitudes began to change. Medical ethicists, especially in the United States, began to emphasise the importance of patient rights and in particular to draw attention to the role of patient autonomy. The right of autonomy is of such significance in the context of healthcare decision-making that it is considered in more detail in Module 4.

It has now become commonplace to speak about patient rights in the context of healthcare decision-making. As the philosopher Onora O’Neill writes, since the mid-1970’s ‘no themes have become more central in large parts of bioethics, and especially in medical ethics, than the importance of respecting individual rights and individual autonomy’ (2002, p.2). However, as O’Neill has also argued, this focus on rights is not unproblematic. She points to the cost to other values, including trust, which derives from a fixation with rights. Others, (Callahan, 2003) have argued that the individualistic focus on rights fails to recognise the social context within which individuals operate.

In this module, we look at the issues which arise in respect of a rights-based approach to healthcare decision-making in decisions made towards the end of life. The goal is to understand the possibilities and limits of a rights-based approach to decision-making at the end of life and to appreciate how a rights-based approach operates in practice.

3.2 Different Kinds of Rights
In order to appreciate the role of rights in decision-making at the end of life, it is important to distinguish between different kinds of rights. The first distinction is between positive rights and negative rights. The second distinction is between moral rights and legal rights.

3.2.1 Positive Rights and Negative Rights
Rights impose either negative or positive duties or obligations on others. We develop this distinction in the context of what we mean by ‘a right to die’.

Negative rights: the right to demand that a person or persons desist from doing something to you. Applied to the ‘right to die’, this means, for example, that we have a negative right to refuse treatments or life prolonging therapies.

Positive rights: the right to some social or personal or institutional benefit or provision. Applied to the ‘right to a good dying’, this means that we can claim or expect some state or health care institutional provisions that would facilitate a ‘good dying’, for example, adequate pain relief, appropriate information, a caring and private environment.

A positive right to die might also be interpreted to mean a right to have active steps taken to end a person’s life or to assist a person in ending his or her own life. The term ‘euthanasia’ is often used to refer to these situations. Additionally, the term ‘assisted-suicide’ is sometimes used (where a person seeks assistance in ending his or her own life). The legal and ethical issues to which these issues give rise are discussed in more detail in other modules. For present purposes, the important point is that neither is permissible under Irish law.

Under Irish law, any person who deliberately ends the life of another person is potentially guilty of murder. It makes no difference that the person consented to the action or even that he or she requested that this should happen. The law does not permit a person to consent to his or her own death. A person who assists another person in ending his or her own life is also criminally liable. Under Irish law, suicide ceased to be a criminal offence under the Criminal Law (Suicide) Act 1993. However, the Act states that anyone who ‘aids, abets, counsels or procures’ the suicide of another person commits a criminal offence which is punishable with a possible maximum sentence of 14 years.

Therefore, a positive right to die in the sense of a right to have active steps taken to end one’s life or to assistance in ending one’s life would run contrary to the law. This is not the meaning of positive rights adopted in this module. However, other aspects of positive rights, such as a right to a ‘good dying’ are lawful and are very significant if we are to develop the best way to ensure that people have the most appropriate care and treatment at the end of their lives.

### 3.2.2 Moral Rights and Legal Rights

When thinking about 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 justified 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. Moral rights are politically important. The existence of a moral right is empowering for the individual whose right is recognised and the recognition of the right can have powerful rhetorical force. However, the existence of a moral right does not create a legal obligation in others to respect that right.

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. Some legal rights are also moral rights but not all moral rights are legal rights.

To date, most legal interventions in respect of rights in an end-of-life context have involved the cessation of unwanted interventions rather than the delivery of appropriate care. This means that most legal rights have tended to be seen as negative rights rather than positive rights.

The fact that legal rights tend to be negative rather than positive, means that the contribution of the law in this area is inevitably limited. This means that, while law is important in decisions about treatment at the end of life, the law provides only a small part of the picture in developing an appropriate framework for end-of-life care.
4. The Scope of Rights

Both legal and moral rights are important in thinking about decisions at the end of life. As will be seen below, there are advantages in a rights-based approach to patient care. However, it is also important to recognise the limited scope of a rights-based approach. Rights are not absolute and may justifiably be subject to limitations. Nor can it be expected that a simple reference to rights will resolve difficult ethical questions. Rights may also be in conflict. There may be a conflict between the rights of the dying person and those of other people or a conflict between different rights of the dying person. There may also be a conflict between individual rights and broader societal interests. A classic example of this conflict in action has been the debate surrounding assisted suicide. There may also be a conflict between respect for individual rights and a societal commitment to the principle of sanctity of life.

An exclusive focus on rights as the basis for a framework for a good dying is overly limited and does not, of itself, provide an appropriate approach to patient care. Other matters, including beneficence and care, are also essential components of an appropriate framework.

4.1 Rights and Absolutes

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. For example, as discussed in Module 4 in various legal cases in respect of a right to assisted suicide, the courts have held that the person’s right to autonomy (in choosing when to end his or her life) could be overridden on the basis of a societal interest in protecting vulnerable people from possible pressure to end their lives. The difficult question is when such justifications will arise and how an appropriate balance may be struck between competing rights and interests. With legal rights, these questions are decided by courts. Increasingly commonly, courts adopt a proportional approach to the resolution of these kinds of question. If a right is found to exist, the court asks whether interference with the right can be justified and whether the degree of interference is proportional in light of the justification. With moral rights, resolution of the appropriate balance depends on informed debate and discussion.
4.2 Rights and Responsibilities

Patients have rights but they also have responsibilities. Brazier (2006, p.401) identifies the direct link between increased recognition of patient rights and an increased recognition of patient responsibilities: ‘In a relationship where the recipients of medical care were infantilised, patients’ responsibilities seem to me to be of a much lesser order.’ Thus, she argues that ‘it is the empowerment of patients that brings responsibilities’.

Freedom of choice (which is central to a rights-based approach centred on the right of autonomy) brings with it a moral responsibility to consider the impact of one’s choice on others. For example, a person’s decision to decline life saving treatment places an ethical obligation on the person to consider the impact of his or her decision on family members or others. Again, a distinction must be made between moral obligations and legal obligations. As Brazier (2006, p.422) reminds us, ‘identifying when and how these moral obligations become legally enforceable remains difficult’. We may argue that a person has a moral obligation to take account of the impact of his or her decisions on others but imposing a legal obligation to do this is a different matter.

4.3 The Contribution of a Rights-Based Approach

A rights-based approach to decisions taken at the end of life has important advantages for patient care. It places the patient at the centre of the decision-making process and allows a patient to exert a degree of control over how and when she dies.

The value of this approach can be seen in one of the narratives outlined by Quinlan and O’Neill (2008, p.19):

‘Rita had a very peaceful happy death. She refused some treatment and her wishes were granted. She never discussed death with any staff, but in the end had a very peaceful pain-free death in the company of her family.’

Here, Rita’s rights, in particular, her right not to have treatment which she did not feel appropriate was respected and Rita’s death was peaceful and pain free.

Arguments based on positive rights can also make a very significant contribution to delivering appropriate care and in particular, in respect of the important matter of access to necessary resources. In end-of-life care, there are repeated concerns about resources to make a ‘good dying’ a more likely outcome.

As Quinlan and O’Neill’s (2009, p.29-30) interviews show, the pressure on resources, even when people are dying, was evident. There is pressure for beds. A hospital may need the
bed for the next patient and practitioners recount how, even when a patient is still dying, staff may come to the ward and asking if the patient has gone to the mortuary yet. There is resource pressure in providing access to appropriate treatment and diagnostic processes at an appropriate time. There is resource pressure in facilitating dying people, both adults and children, in spending their last days at home. One incident recounted by Quinlan and O’Neill (2009, p.30) reminds us that, when someone has a short time to live, even relatively short delays can have a huge impact on the patient’s quality of life and death. The practitioner describes a young man who had to spend over five weeks in hospital in order to have routine procedures because resource pressures led to delays. For a young man with a limited life expectancy, this was time which he would have been happier and better to spend elsewhere.

The impact of limited resources is also felt in respect of communication. Communication is fundamental if a patient’s right to a dignified dying is to be a reality. Yet, based on practitioner interviews, one of the most consistent frustrations experienced is in respect of communication. This frustration stems in large part from shortage of staff and lack of time on busy wards.

Resources have to be pleaded for in social and political arenas. While positive rights may not necessarily be legally enforceable, the rhetoric of rights ensures that the issue of resources is recognised as an ethical issue as well as a political one. As Munro (2001, p. 463) notes, ‘the rhetorical value of rights discourse must not be underestimated.’ It is essential that rights are understood as encompassing both positive and negative rights and that it is recognised that people have positive rights to a ‘good dying’.

4.4 The Limits of a Rights-Based Approach

While a rights-based approach makes an important contribution to an appropriate framework (and in respect of legal rights, is a legal obligation), an exclusive focus on rights is limited in several respects. First, rights are formulated in an abstract way and, sometimes, the rhetoric of rights may seem far removed from the reality of treatment decisions in practice. It is one thing to say that a patient has rights, it is quite another to understand what respect for a patient’s rights requires in any particular situation.

Secondly, while rights can be both positive and negative, very often, a rights based approach will be seen to extend only to negative rights. This is in part because the law has tended to recognise negative rights rather than positive rights. This approach to rights can lead to a rights-based approach which protects a patient’s right to refuse unwanted treatment but does little in furthering the provision of appropriate treatment (in the broadest sense including medical treatment but also an appropriate environment, communication, etc).
Thirdly, an exclusive focus on rights omits important aspects of the ethical picture. Beauchamp and Childress’ influential four principles approach to ethics identifies beneficence, nonmaleficence and justice alongside autonomy. An appropriate framework for decisions at the end of life requires more than simply respecting patients’ rights. If we look at the example of Rita’s situation discussed earlier, the fact that her right to refuse treatment was an important aspect of her peaceful death but so too was the fact that her family were present and the care of the professionals involved. Focusing on rights alone fails to accord sufficient recognition to these broader but equally essential aspects of patient care at the end of life.
5. Rights in Practice

Rights must have a basis or source. It is not enough simply to assert that a person has a right to something. There must be a means whereby the existence of the right may be asserted.

5.1 Sources of Moral Rights

Moral rights derive from our membership of the moral community. In this sense, moral rights may sometimes be contested. For example, some people may argue for a moral right to choose to die even if this requires active steps, such as euthanasia, while others may equally vigorously contest the existence of such a moral right.

5.2 Sources of Legal Rights

In relation to legal rights, the rights derive from a more tangible source. For a right to be legally enforceable, it must for the main part derive from some form of legal instrument. Like moral rights, legal rights can be contested. However, with legal rights, the final determination of whether or not a legal right exists, what the right means and whether interference with the right may be justified is made by a court. Legal rights tend to be more limited in scope and will often tend to be negative rather than positive rights. For this reason, it is important to remember that legal rights should not be thought of as providing the whole basis for patient rights in respect of healthcare decision-making (and that rights alone do not provide a full basis for care).

Nonetheless, legal rights provide the foundation for healthcare decisions and therefore it is necessary discuss the sources of patients’ legal rights in more detail.

5.3 Legal Rights as Citizens

Patients at the end of life have the same rights as any other members of society. Therefore the human rights frameworks which apply to all citizens in general also apply to these patients. In Ireland, these rights derive first, from the Irish Constitution (Bunreacht na hÉireann) and secondly, from the European Convention on Human Rights. Both of these human rights instruments impose obligations on others to respect rights and a patient may assert his or her rights in a court. These rights are practically important because a patient can take steps to enforce them and because health professionals are legally obliged to respect them.

5.3.1 Rights and the Irish Constitution

The Irish Constitution was introduced in 1937. It provides the basis for protection of individual rights. All legislation must comply with the provisions of the Constitution.
The ‘fundamental rights’ part of the Constitution is found in Articles 40-45. Of these Articles, the most important source for patient rights is Article 40.3.1. This Article states as follows:

The State guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate the personal rights of the citizen.

From this general statement, the Irish courts have identified a range of rights (often referred to as ‘unenumerated’ or unstated rights). The rights identified by the courts have included a right to autonomy or self-determination; a right to privacy; a right to dignity; a right to bodily integrity; a right to freedom from inhuman and degrading treatment. The Irish Constitution also expressly protects the right to life. Article 40.3.2 states that the State shall protect as best it may from unjust attack and, in the case of injustice done, vindicate the life of every citizen.

Two other articles of the Constitution are relevant in respect of children. Article 41 protects the authority of the family (based on marriage) while Article 42 protects parents’ rights in respect of their children. Article 42.5 can be especially important in relation to healthcare decision-making involving children. This article states that, in exceptional cases, where parents for physical or moral reasons fail in their duty to their children, the State may endeavour to supply the place of the parents but always with due regard to the rights of the child. Other than this, there is currently no express statement of the rights of the child in the Constitution.

The Irish Constitution is much less strong in its endorsement of positive rights. Article 45 sets out ‘directive principles of social policy’. This states that justice and charity must inform national institutions and that the vulnerable must be protected. However, these principles cannot be enforced in a court of law. Therefore, the other positive rights discussed above, these are matters for political and ethical engagement rather than legal enforcement.

### 5.3.2 Rights under the European Convention on Human Rights.

Since 2003, the European Convention on Human Rights (ECHR) has been incorporated into Irish law. This means that the ECHR is directly enforceable in the Irish courts. However, if there is a conflict between the Irish Constitution and the ECHR, constitutional rights take priority. The ECHR was adopted in 1950 to protect human rights and fundamental freedoms in Europe. A number of the rights protected by the ECHR are important in the context of end-of-life decisions. These include: the right to life which is protected by Article 2; the right to freedom from inhuman and degrading treatment which is protected by Article 3; the right to respect for private and family life which is protected by Article 8; and the right to freedom of thought, conscience and religion which is protected by Article 9.
5.4 Other Sources of Rights

5.4.1 Charter of Patients’ Rights

In addition to general rights under the Irish Constitution and the ECHR, there is a specific Charter of Patient Rights. Unlike rights protected under the Irish Constitution and the ECHR, these rights are not directly enforceable in a Court. They are also stated in general terms and many are aspirational in nature. However, they are important indicators of best practice. The European Charter of Patient Rights agreed in Rome in 2002 sets out 14 rights of the patient. The following rights are most important in the context of healthcare decisions, including decisions at the end of life.

Right to Information: Every individual has a right of access to all kinds of information regarding their state of health.

Right to Consent: Every individual has a right of access to all information that might enable him or her to actively participate in the decisions regarding his or her health; this information is a prerequisite for any procedure and treatment.

Right of Free Choice: Each individual has the right to freely choose from different treatment procedures and providers on the basis of adequate information.

Right to Privacy and Confidentiality: Each individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic or therapeutic procedures.

Right to Avoid Unnecessary Suffering and Pain: Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness.

5.4.2 International Human Rights Instruments

There are also a number of international human rights instruments which have a broader remit than application to patients but which relevant to certain kinds of patients. Among the most important of these instruments are:

The United Nations Convention on the Rights of the Child:
This Convention was adopted by the United Nations General Assembly on 20 November 1989 and entered into force on 20 September 1990. Ireland signed the Convention on 30 September 1990 and ratified it without reservation on 21 September 1992. This means that Ireland is bound by the Convention. The Convention sets out the human rights of children which must be observed by states. The Article of the Convention which is most relevant to healthcare decision-making is Article 12. This says that:
States parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

This requires that, in healthcare decisions, including decisions about dying, the child has a right to participate in the decision-making process and his or her views must be taken into account increasingly as he or she becomes older and/or more mature (Kilkelly and Donnelly, 2006).

United Nations Convention on the Rights of Persons with Disabilities:
This Convention was adopted by the United Nations General Assembly in December 2006 and entered into force on 3 May 2008. The Convention was signed by Ireland on 30 March 2007. However, it has not yet been ratified by Ireland. This means that the State has not agreed to be bound by the Convention. It is likely that, when legislation relating to adults lacking capacity is introduced (expected to happen in 2010), the State will ratify the Convention and it will then be bound to observe the rights set out in the Convention.

The Convention sets out a framework to protect the human rights of people with disabilities – both physical and mental/intellectual disabilities. Among the Articles of most relevance to healthcare decision-making, and in particular to decisions at the end of life are:

- Article 3 sets out general principles underpinning the Convention. These include respect for inherent dignity and individual autonomy, including the freedom to make one’s own choices, and independence of persons
- Article 10 reaffirms the inherent right to life of all persons with disabilities
- Article 17 states that every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others

Council of Europe Recommendation Concerning the Legal Protection of Incapable Adults:
This Recommendation was adopted by the Council of Europe in 1999. The Recommendation adopts as its fundamental principle ‘respect for the dignity of each person as a human being’. It requires that the laws, procedures and practices relating to the protection of adults lacking capacity should be based on respect for their ‘human rights and fundamental freedoms.’ The Recommendation is an indicator of best practice and is not legally binding.
6. Cases: Exploring Rights in Action

It is a relatively straightforward matter to list the rights relevant to end-of-life decisions. The most obvious of these are the right to life, the right to autonomy or self-determination, the right to bodily integrity, the right to dignity, the right to freedom from inhuman and degrading treatment. However, it is a much more complex and difficult matter to determine how rights apply in practice and how a rights-based approach to end of life decisions should work. This section will explore some of the issues through four case studies. These show the contribution which a rights-based approach can make but they also show the limits of a rights-based approach and remind us that good care requires more than simply respect for rights.

6.1 Case 1: The Limits of Negative Rights - refusing pain relief

Consider the following case which is based on a narrative from a practitioner recounted by Quinlan and O’Neill (2008, p.18) and which shows some of the limits of the rights-based approach to care. As is clear from the narrative, the incident described did not occur in Ireland. Nonetheless, the issues to which it gives rise are applicable here:

**Refusing pain relief**

*In Australia, a young mother in early 30’s had an inoperable tumour at back of her nose and throat. In the end stages, this girl refused pain relief or sedatives. She did not want much medical intervention. It was the most distressing death I ever witnessed as she could not breathe and depended on a nasal tube as her only airway. This frequently blocked and needed regular suctioning. It was very distressing for her, her family and staff. She was from a very poor social background and had little or no education. Staff tried to assist her as much as possible but it was an awful death for her. (Quinlan and O’Neill, 2008, p.18)*

6.1.1 Discussion

This case shows the limits of an approach to rights which is based simply on negative rights. Here, the patient refused pain relief or sedatives. In this, she was exercising her right to autonomy by refusing medical intervention/treatment. This right is recognised under the Irish Constitution (In re a Ward of Court, 1995; Fitzpatrick v K, 2008) and under the European Convention on Human Rights (Pretty v UK, 2004). The right is undoubtedly very important and is discussed in more detail in Module 4.
However, the striking thing about this narrative is how very limited the right of autonomy can be. The young woman’s right to refuse treatment was respected but, on the basis of this narrative, very little was done in a positive way to improve the dying process for her. Respect for the patient’s autonomy here raised conflicts with the healthcare staff’s concern about the well-being of the patient and yet they believed that the value of autonomy as expressed by the patient should have priority.

Arguing that something positive should have been done to improve the dying process for this patient does not mean that the woman’s autonomous wishes should not be respected. However, if one thinks about the circumstances, there may have been positive ways in which the woman’s right to make her own choices and decisions could have been respected while at the same time helping to ensure that her death was made as bearable for her as was possible in light of her circumstances.

For example, the narrative states that the woman was from a very poor social background and had little or no education. Presumably, also, she was very frightened and distressed. In addition to her physical pain, it is highly likely that she suffered ‘soul pain’ (discussed in detail in Module 5). It may be that, if it had been possible to talk with her, to explain and discuss her situation and to provide her with the support she needed, she might have been able to choose a way of dying which was less difficult for her (and less traumatic for her carers and family members). The choice should not be between respecting her right to refuse treatment and imposing treatment she does not wish. Rather it should be possible to find ways to provide positive help suitable for her situation.

Contrast the very different approach evident in the following example, also drawn from Quinlan and O’Neill (2009, p.32):

‘A couple of years ago now when I was in Palliative Medicine in another centre, adult Palliative Medicine, we came across a gentleman who was referred to us after he had attempted to commit suicide and he had thrown himself into the local river, was referred to us then. The reason that he had tried to commit suicide was that he had a diagnosis of cancer which he’d lived with well for about eight years at this stage but was developing increasing pain and he was worried that if his pain was so bad at this stage and not controlled, how bad was it going to be when he was closer to death and it was really his fear about symptoms, you know, not being controlled. So he was able to relay all this to us, we then got his pain under control, relatively easily I suppose, it’s what we do every day, and we were able to reassure him that his pain would never have to be out of control as it had been and thereby his suicidal ideation completely resolved.’
Because the health professionals were able to reassure this man, he was able to live out his life in the best way possible in the circumstances. Rather than ending his life by suicide, he felt content to live out his life to the end because he knew that his pain could be controlled.

If one contrasts this example with Case 1, this example shows the contribution to be made by positive rights to a ‘good dying.’ This approach to rights is much broader in scope and much more significant for many patients than simply respecting patients’ decisions.

Of course, respect for patients’ decisions is very important but so too is respect for the positive rights needed to ensure that patients’ decisions are made in a way which maximises patient control. Empirical research shows unanimity on the significance of adequate pain relief. As one hospice worker commented ‘the main thing is that it’s just pain relief. Our big thing in the unit is pain relief, that person is never in pain.’ (Quinlan and O’Neill, 2008) Without adequate pain relief, it is very difficult for patients to have and to retain control of their situation. It is just as important to remember that patients have a positive right to appropriate pain relief and to appropriate explanations and communications from professionals as it is to remember that patients have a negative right to refuse treatment.

6.1.2 Suggested Professional Responsibilities

- Where a person refuses treatment, especially pain relief, efforts should be made to engage with the person and to understand the basis for the decision. Patients’ decisions may be based on fear or lack of understanding and communication may help to alleviate these factors. The person may still wish to refuse the treatment and if he or she does so and he or she has the necessary degree of decision-making capacity, his or her wish to do so should be respected.

- Where possible, where a person refuses a particular treatment, alternative options should be made available to the person. Reasonable choice requires the availability of more than one option.

- Efforts should be made to engage with the patient in a way which is accessible to him or her in light of education level, background etc. Different people require different kinds of communication and in many instances, a blanket approach based on simple provision of information will not suffice.

- Every effort should be made to ensure both that adequate pain relief is made available and that patients are reassured in this regard. Even if patients have not actively sought reassurance, they may have fears about pain which they find difficult to articulate. Sometimes it may be necessary to repeatedly provide reassurance about pain relief for patients.
6.2 Case 2: Constitutional Rights - In Re a Ward of Court 1995

One of the reasons why rights tend sometimes to be thought of as negative rather than positive – with the limits which this involves – is that the law’s approach to rights usually focuses on negative rights rather than positive rights. This is evident in the following case study which is based on the facts of an important Irish Supreme Court decision on end of life. In the case study, we can see legal reasoning at work and we also see the possibilities and the limits of a law-focussed approach to rights.

In Re a Ward of Court 1995

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 although she may have had minimal ability to recognise and track people with her eyes. She was unable to move or swallow and was fed by gastrostomy (PEG) tube.

The Ward’s family asked the court to have the PEG tube removed which removal would, inevitably, lead to the woman’s death. 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 the circumstances, the PEG tube should be removed.

6.2.1 Discussion

The decision in In re a Ward of Court is important for many reasons. The fact that the case came before the court at all is striking. There was clearly a strong disagreement between the health professionals and family members. 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 when their loved
one arrested and that these efforts at communication were resisted. 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.

Sometimes, disagreements between health professionals and family members will be inevitable; there may be very good reasons why family members and health professionals do not agree. If this is the case, it well may be that a situation such as this may only be resolved through recourse to courts. However, there may be situations where better communication between health professionals, family members and patients would resolve some of the difficulties and avoid the need for the engagement of the legal system. In particular, knee-jerk reactions by professionals to family requests must be avoided. Resolution is much more likely in a context of engagement, communication and explanation rather than dogmatic assertions by professionals. And, even if resolution is not possible in the particular circumstances, a process of communication and engagement enhances the experience for all concerned: the patient, the family and the health professionals.

In re a Ward of Court is also important 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.

While the recognition that people have rights, regardless of capacity, was a very important contribution, the Supreme Court was less clear in setting out what exactly the rights actually meant in the circumstances of the case before them. In fact, the Court did little more than list the rights implicated and provided no analysis of how they operated and interacted with each other and with the principle of sanctity of life. The decision has been criticised for its lack of conceptual coherence (Keown, 1996; Hogan and Whyte 2004, p.1397-1401).

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? This means that health professionals trying to provide rights based end-of-life care are left with limited legal guidance regarding what exactly is required. Patients’ rights have to be respected but the detail of what respect for patient rights requires
is more difficult. This is why a focus on legal rights alone provides too limited a basis for a rights based approach to a good dying. This case reminds us that a meaningful rights-based approach to healthcare decision-making must encompass positive as well as negative rights and moral as well as legal rights.

In In re a Ward of Court, the Supreme Court did not differentiate between withdrawal of artificial nutrition and hydration (ANH) and other forms of treatment withdrawal. However, following the decision, both the Medical Council and An Bord Altranais issued statements making a clear differentiation on these grounds. This special status of nutrition and hydration 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 previous Codes, which had required that ‘all reasonable and practical efforts should be made to maintain’ nutrition and hydration. Rather, it now states that ‘[i]f a patient is unable to take sufficient nutrition and hydration orally, you should assess what alternative forms are possible and appropriate in the circumstances.’ Medical professionals are reminded that they should ‘bear in mind the burden or risks to the patient, the patient’s wishes if known, and the overall benefit to be achieved.’ The ethical issues to which withdrawal of ANH give rise are discussed in detail in Module 6.

The decision of the Supreme Court in In re a Ward of Court shows both the potential and the limitations of legal rights. Recognising that patients have legally enforceable rights places patients in a stronger position in asserting their rights. However, legal rights are just the first part of the picture. Good care requires more than just respecting people’s legal rights.

6.2.2 Suggested Professional Responsibilities

- 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 the healthcare professional to provide care to the patient. However, appropriate communication can alleviate family concerns and can sometimes prevent confrontational situations developing.
- If in doubt about the legal rights implicated in a particular decision, professionals should seek advice as to how to proceed. This is especially important in the event of disputes between family members or between professionals and family members.
Good care requires more than just respecting people’s legal rights. This is shown in the next case study which is also based on a legal case but which shows a range of factors relevant to good decision-making which go beyond simply respecting legal rights.

Decisions involving children, especially decisions where children are dying, are very traumatic and difficult for all parties involved. As Quinlan and O’Neill (2009, p.56) remind us:

‘A sick child in a family is as much at the mercy of the family dynamics as any sick person within a family. Sometimes the dynamics are good and sometimes they are not so good. Where the not so good family dynamics interfere with the care of the child the clinicians may need to intervene, and facilitate a resolution, as they intervene in any such family. Such interventions are often unwelcome and as such they can be difficult and challenging for the clinicians as well as the families. All of this goes to further the complexity of the situation of the patient in hospital and expressions and experiences of patient autonomy and practices around patient autonomy in hospital care settings.’

The challenges involved in making decisions where children or young people are very ill or dying are very clear in the case discussed below. This case came before the European Court of Human Rights in 2004. The case had first been brought before the courts in the United Kingdom and these courts had held that there had been no breach of rights in the circumstances (which are outlined in more detail below). The family were unhappy with the conclusion and brought the case to the European Court of Human Rights. As in Ireland, the European Convention on Human Rights is part of domestic law in the United Kingdom and decisions of the European Court of Human Rights are binding on citizens and the State.

Glass v UK 2004

David Glass was a teenager with severe intellectual and physical disabilities and with a very poor life expectancy. He had been admitted to hospital many times in the past with respiratory failure and this was a pattern which was likely to continue.

David was admitted to hospital following respiratory failure. The health professionals responsible for his care considered that his condition had reached the point where any further resuscitation was futile. They put a DNR (do not resuscitate) order on his file without consulting with his family.
The health professionals also believed that David was in pain and they provided him with palliative care in the form of morphine, again without consulting his family. David’s family objected to the placing of the DNR on this file and to the administration of morphine which they feared would speed up his death. They attempted to remove the DNR from the file and to disconnect the morphine feed. A fracas ensued between family members and the health professionals and family members were physically ejected from David’s room by security staff. David’s mother (acting as representative for the family) first brought the case before the English courts arguing that the placing of the DNR and the administration of morphine without the consent of David’s family was a breach of the family’s rights and also of David’s rights. The action was unsuccessful before the English courts. Mrs Glass brought the matter to the European Court of Human Rights. She argued that the hospital had failed to respect both her own right and David’s right to private and family life as protected by Article 8 of the European Convention on Human Rights.

The European Court held that the hospital authorities had breached David’s right to private and family life. The professionals involved should have consulted with David’s family before reaching the decisions on his care. The Court did not consider that the family’s views should have decided the matter. Ultimately, the important question was whether the decision made was in David’s best interests. This could be decided by the professionals involved or in the event of a dispute, by a court. However, David was entitled to have his family consulted before a decision regarding his best interests was reached. The Court did not offer any view on whether Mrs Glass’s rights were breached.

6.3.1 Discussion

This case is important for a number of reasons. First, even if one does not consider the matter from a perspective of legal rights, it is very obvious that the hospital’s way of dealing with the Glass family was inappropriate. Cases like this can come to litigation precisely because of failures on the part of health care staff to communicate in an on-going way and assure families that they are being heard. This case also arose in part because the resuscitation process was neither clarified nor documented on the ward and the family’s wishes or family expectations were not documented. Once again, a failure of communication by staff with family intensified the family’s frustration.

Some of the practitioner perspectives recounted by Quinlan and O’Neill (2009, p.81) remind us of how important it is that resuscitation status is clear and that patients and family members are aware of the position. Failure to clarify can result in the patient, family and staff being insecure and anxious about a DNR (Do not resuscitate) order.
This can be made more difficult because some consultants may be reluctant to document the existence of a DNR order. The position may also raise difficulties when, as happened in Case 3, families may insist on resuscitation and a conflict arises on the ward.

More than anything, Case 3 serves as a reminder of the need for good communication. This does not mean that families and professionals will always agree. But it does maximise the chances of agreement and an appropriate resolution and it ensures that, even if the participants fail to reach agreement, the discussion takes place in the best possible way for the patient, the family and the health professionals.

The second reason that Case 3 is important is that it recognises that patients are members of families. It was David’s right that his family be consulted. Respect for patient rights requires family involvement. In Ireland, family rights are further enhanced by Articles 41 and 42 of the Irish Constitution. Here, the rights recognised are the rights of the family and of parents. In North Western Health Board v HW and CW (2001), the Irish Supreme Court held that parents had a constitutional right to make healthcare decisions for their children (in this case, the parents sought to refuse the routine PKU test aimed at detecting certain genetic abnormalities). The right is not absolute. The State can intervene where parents fail in their moral duty but this may arise only in an ‘exceptional case’ (as set out in Article 42(5) of the Constitution of Ireland).

A great deal has been written about the way in which families have been treated in healthcare decision-making in respect of children (for example, Bristol Royal Infirmary Inquiry, 2001; Kilkelly and Donnelly, 2006). In the inquiry into practices surrounding children’s heart surgery at the Bristol Royal Infirmary, it became clear that some professionals dealing with parents were not giving clear indications to parents about their children’s situations. Sometimes this was a deliberate practice, aimed at ensuring that parents maintained hope or did not communicate distress to children. However, as the Bristol parents recognised (2001, p.282): ‘I think you need to know. It hurts … It hurts to hear it, but you need to know the truth. I do not want to be told that everything is going to be jolly and fine. It is a fact of life … You do not want people to be cruel to you but you need honesty in a situation like that.’

Case 3 reminds us that children and their families have a right to full information and appropriate communication. Families have to be consulted in decisions at the end of life of their children and their views must be taken into account in reaching decisions. This does not mean that family views will or should always prevail but consultation, communication and engagement is essential.
Case 3 is also important because, while it recognises that patients are members of families, it also reminds us that patients are individuals too. David had a right to have his family consulted as regards what was in his best interests. But the decision was not wholly that of David’s family. Rather the decision had to be what was best for David. His family were an important part of this decision but ultimately it was David’s best interests which were at stake. These were to be determined by the health professionals in consultation with his family and if a dispute continued, by the Court.

Family involvement is, of course, not just an issue in respect of children. It can equally arise in the context of elderly people as the following example from Quinlan and O’Neill (2009, p.37) makes clear:

‘I have a very recent experience that upset me greatly and that I’m still trying to have conversations with the individuals concerned and it was for a patient who had, whom I happened to come across on their admission to the hospital four days previously. So I knew their history very well. They had had palliative radiotherapy for CA of the lung, a gentleman in his early 80s, and he had a chest infection on admission to hospital. I met up with the family about three days later when I took a report from a colleague at 5 pm in the evening, to hear that the patient’s condition had deteriorated. His oxygen saturations had dropped. He was on the medical unit and had been transferred to the high care unit and he was disimproving. I asked what the plan of care was for him and I was told that the family wanted him to have every possible chance. The consultant was not on duty that day. There was someone acting for him until 5 pm in the evening and as far as they were aware, the gentleman was to be resuscitated. I asked had the fact that he had a chest infection as well as CA of the lung, (he knew what was wrong with him), been discussed with the patient and I was told no, because the family wanted him to have every chance. Before I got to the end of that report the emergency bleep went off and it was for this patient. When I got to the unit the patient was intubated. I asked the nurses about it. They said yes the family wanted - the doctor had discussed it with the family and they did want resuscitation measures taken if anything happened. They knew that their father was getting worse. The father himself had expressed that he didn’t want tubes or anything like that, so I was very annoyed really. I couldn’t understand how it had gotten to this stage.’ (2009, p.34)

Here, it would seem that the family’s views took precedence over those of the patient (who died an hour later). Quinlan and O’Neill’s study of practitioner perspectives suggest that this is not unusual. One practitioner quoted states:
Sometimes their wishes may not be respected. You might like have a patient and you might know the patient quite well and know that they probably want conservative treatment or palliative care. The families might want this done or want them transferred to (named acute hospital). The next thing they’re getting bloods and x-rays and the whole lot done and know in your heart and soul, this is not what this patient wants. (2009, p.37)

It is easy to understand why families respond in these kinds of ways. Families may find it difficult to ‘let go’ of a loved one; they may be suspicious of medical professionals perhaps doubting that the professionals have their loved one’s best interests at heart; they will often be frightened and traumatised by the impending death. With these difficult challenges around life support decisions, one contributor suggests that perhaps a Palliative Care Team would be of great benefit to sound decision-making. This team would deal specifically with end-of-life families. The contributor suggested:

‘…if there was a system there or there was services there, that we actually had a team that were able to approach a family and say: ‘Listen, this is what we’ll do over the next few hours’ or ‘listen, this is what you have in the weeks ahead’.

Once again, communication does not solve all the difficulties which may arise but good communication provides the basis for the best experience possible.

As discussed above, the challenges for a rights-based approach to decision making are significant when family members are involved. Patients who are children have a right to have their families involved in decisions about their dying. But ultimately, the patient must be central. His or her views must provide the basis for decisions about care. Of course, it will not always be possible for a patient to express his or her views. In Case 3, David had very serious intellectual and physical disabilities and very limited abilities to communicate. Very young children may also have difficulty communicating what they want although most children are able to express preferences from a relatively young age (Alderson and Montgomery, 1996; Kilkelly and Donnelly, 2006; Bridgeman, 2007). The issue of children’s autonomy and respect for children’s choices will be discussed in more detail in Module 4.
6.3.2 Suggested Professional Responsibilities

- Professionals should maintain communication with family members. This is especially important in respect of highly charged situations such as the recording of a DNR on a patient’s file.
- Where possible health professionals should inform families about what to expect in the dying process. Many families will not know what to expect and informing them of what is likely will make the process easier and reduce the possibilities of conflict between families and health professionals. This may also involve reassurance about pain relief and distress.
- Professionals should think about the time at which they talk to family members and the environment in which discussions take place. Rushed conversations in public places cannot provide the kind of reassurance needed and may lead to feelings of resentment and anger among family members which may create further difficulties for the patient, the family and the health professionals involved.
- Resuscitation status should be made clear to family members and, if a DNR is recorded on a patient’s file, the reason why a DNR is considered appropriate should be made clear. The meaning and limits of a DNR should be explained in full to family members.
- While families should be informed and involved and their views should be sought and weight should be accorded to these, the duty to act in the best interests of the patient must always remain central.
- When dealing with children and young people, professionals should make efforts to explain what is going on in a way that is accessible and should involve children and young people in decisions about their care insofar as this is possible in light of the child’s age and maturity.
6.4 Case 4: Rights, Incapacity and Decision-making – why resuscitation?
This case study explores the rights issues which arise where patients have difficulty formulating their views or communicating their preferences, perhaps because they have dementia, Alzheimer’s disease, intellectual disabilities or other conditions which limit their decision-making abilities. The role of advance healthcare directives in such circumstances will be discussed in more detail in Module 4. However, even if these measures are legally provided for, they will not apply in all situations. The question which then arises is how are patient rights to be respected when there is no indication of what the patient would have wanted and he or she is not in a position to communicate. The final case examined in this module on the role of rights in healthcare decision-making looks at rights, incapacity and decision-making.

This case study is based on a case adapted from Quinlan and O’Neill. It is based on a real experience as recounted by a practitioner – however, as recounted it is not clear whether the patient had given any indication of preference or, indeed, whether or not he had the capacity to do so. The facts have therefore been adapted in order to allow discussion of the situation where a patient clearly lacks capacity and is nearing the end of life.

**Why Resuscitation?**

‘I’m on the resuscitation team, when we arrived at the scene, you know, the first thing I could see, God, this is such an unethical resuscitation, if it was my relative in the bed I’d be so upset. It was an 86 year old gentleman with Alzheimer’s disease that was admitted that night by a medical registrar that had not consulted with his consultant, and had not consulted with the anaesthetic consultant, to review this patient. He had end stage chronic obstructive airway disease that was on maximum medical treatment and home oxygen. So, I mean, the sort of thing we’re talking about - resuscitation, that’s why often patients and relatives are not explained to properly, or talking about will they benefit from their heart being shocked or will they benefit from being put on a life support machine? Now, this gentleman would not have benefited from that because he would never come off of the life support machine, research would have shown with end stage COPD. The poor little gentleman was very skeletal and he had a pigeon chest as well. You know, and the first thing I could say - I arrived at the scene the same time as the anaesthetist and the medical registrar that called the rest of us there - and I said,'
This gentleman is for resuscitation, is he? And yes - and we were going through with it, and all his ribs were cracking as we were doing the procedure. And I said, God, this is very unethical, has this been discussed with the gentleman or relatives? And the registrar said, ‘No’ and the anaesthetist just chimed in as well, he said, ‘This is quite unethical.’ And he just was continuing leading on, and he just said, ‘Oh well, we won’t compress as much on the chest compressions, we’ll do it gentler.’ But the thing with resuscitation, you either do it properly or you don’t do it at all. There are no half measures; we don’t act out the role. He died; once the resuscitation was called off he died. He wasn’t going to survive resuscitation” (Adapted from Quinlan and O’Neill, 2009, p.31).

6.4.1 Discussion
This case raises the issue of rights outside of the situation where a patient has given a clear indication of his or her treatment preferences. It raises a number of ethical issues regarding futility, the use of life-prolonging methods and moral distress which are explored in more detail in Module 6. The present discussion is concerned with the issue of rights and whether intervention in a situation such as this is respectful of the patient’s rights.

A number of rights are relevant to a discussion of Case 4. First, the patient had a right to life. As discussed above, the right to life is protected by the Irish Constitution, the European Convention on Human Rights as well as under United Nations human rights instruments. The right to life is one of the most fundamental rights. It derives from the ethical principle of the sanctity of life and it is a right which is universal. A person cannot be deprived of his or her right to life because he or she is disabled or because he or she lacks capacity. It would be both unlawful and unethical to deny treatment to a patient on this basis. Yet, the right to life is not absolute. It is generally accepted that treatment is not required where treatment would be futile or in Keown’s words, ‘not worthwhile’ (Keown, 1997, p.485). Keown, (1997, p.485) describes a treatment as not worthwhile in this sense ‘either because it offers no reasonable hope of benefit or because, even though it does, the expected benefit would be outweighed by burdens which the treatment would impose, such as excessive pain.’

Other rights are also at stake. A person has a right to dignity, a right to freedom from inhuman and degrading treatment and a right to bodily integrity. The patient in Case 4 had his ribs cracked during the administration of resuscitation. By any standards, this is an invasion of his right to bodily integrity and by many standards, it constitutes inhuman treatment. His right to dignity was also compromised. His last moments of life were spent having his ribs broken during a highly invasive process.
Of course, in many cases, if a person had his or her ribs cracked during the administration of CPR, we would accept that, while this was an invasion of his or her right to dignity or bodily integrity, it was justified because it saves his life. Imagine if the man in Case 4 had been 30 years younger and had been admitted following a heart attack. Nobody would argue that CPR should not be administered even if there was a risk of broken ribs and of loss of dignity during the process. However, in a case such as Case 4, a real question arises as to whether the administration of the CPR was worthwhile and whether the violation of the patient’s right to dignity, bodily integrity and freedom from inhuman and degrading treatment could be justified on the basis of the patient’s right to life.

The interplay of rights in these kinds of situation was explored in an English case of R (Burke) v the General Medical Council and Others (2004). Although the Irish courts might act differently, this case is helpful in showing how complex the interplay of rights can be and how difficult it is to reach appropriate conclusions. The case concerned a 44 year old man named Leslie Burke who had motor neurone disease – a progressive condition which would ultimately lead to his death. The likely progression of the disease was that a time would come when Mr Burke would be completely unable to move or to communicate with his carers but he would still be sentient. Mr Burke was concerned that, under the General Medical Council (GMC) Guidelines: Withholding and Withdrawing Life- prolonging Treatment: Good Practice in Decision-Making (2002), at this stage of his illness, the medical professionals caring for him would be able decide that it was in his best interests to have artificial hydration and nutrition removed. He would not be able to object to the decision. Mr Burke considered that death from deprivation of ANH would be undignified and he was very concerned that he should not die in this way. He wanted an express confirmation that this would not occur.

In the English High Court, Judge Munby found that the GMC Guidelines failed to protect the patient’s right to autonomy in determining when ANH should be withdrawn. In his view, where a patient has made his or her views known (in a case like this, by means of an advance instruction), this should determine when ANH should be withdrawn. Where a patient has not made his or her views known, Judge Munby held that the relevant factor in deciding when life-sustaining treatment should be withdrawn was ‘intolerability’. It was only if life was intolerable for the patient that the withdrawal of treatment leading to the patient’s death should take place. Judge Munby’s decision was overruled by the English Court of Appeal which approved the GMC Guidelines. The Court of Appeal considered that it was for the medical professionals acting in a patient’s best interests and not for the patient to decide when ANH should be withdrawn. The Court also rejected the use of a standard based on intolerability where the patient’s views are not known and said instead that a simple best interests test should apply.
The decision in Burke is a reminder that, in end-of-life situations, while the right to life is very important, it does not ‘trump’ other rights in all circumstances and sometimes treatment should be withheld or withdrawn depending on the circumstances. Following Burke, and taking account of other developments, including the introduction of the Mental Capacity Act 2005, government strategies on end-of-life care in England and Scotland, new GMC guidance on Consent: Patients and Doctors Making Decisions together (2008), and new research, the GMC has issued new draft guidance on withholding and withdrawing treatment (GMC, 2009). This draft guidance lays down a framework in respect of decisions on life prolonging treatment for patients with and without capacity. The guidance advises doctors to encourage patients to plan for end-of-life care in respect of both advance requests for treatment and advance refusals of treatment. The role of advance planning is discussed in more detail in Module 4. In a substantial change from the current GMC guidance (which was at issue in the Burke case), doctors are advised that ANH may be withdrawn from a patient who lacks capacity, where death is not imminent, if provision of the treatment would be ‘intolerable in all the circumstances’ (Dyer 2009, p.875).

6.4.2 Suggested Professional Responsibilities

- Professionals have an ongoing duty to respect the right to life of a person who lacks decision-making capacity. However, this duty must be balanced with the duty to protect the patient from inhuman or degrading treatment and the duty to respect the patient’s right to dignity and bodily integrity.

- Patients should be encouraged to plan for end of life care while they have the capacity to do so. In this respect, communication and (appropriate) reassurance is essential to ensuring that patients can make decisions which are informed and which represent their considered views.
7. Module 3 Further Discussion

Rights are important tools in the provision of appropriate care for patients at the end of their lives. The rights to autonomy, to dignity, to bodily integrity, to freedom from inhuman and degrading treatment as well as the rights to information, to consent and to free choice are powerful ideals and, in some cases, legal obligations. To state the rights applicable in decisions at the end of life is easy enough but, as the practitioner interviews show, giving practical effect to rights is much more difficult. Patients may get little information about their condition and so are unable to form realistic expectations or they may get no information or, indeed, misinformation. Decisions may be made in emergency situations by professionals who have not had the opportunity to reflect on the rights involved or indeed who may not have a full picture of the circumstances at issue.

There is a recognisable gap between these rights and their application in end-of-life care. This is not meant to be pessimistic but rather to signal the need to take account of the practical operation of patient rights in developing a framework for end of life care. It is essential that resources are allocated to allow for patient-focussed communication and for education and training to ensure that professionals who are involved in these important decisions are aware that patients have rights and to ensure that these rights are respected in one of the most important decision-making situations that any of us will encounter – that is, decisions about care at the end of life.
8. Module 3 Summary Learning Guides

8.1 The Nature of Rights

- There are different kinds of rights. The rights discussed in this module have been:
  - Positive Rights: Right to something
  - Negative Rights: Rights that someone should desist from something
  - Moral Rights: Rights justified on the basis of membership of the moral community
  - Legal Rights: Rights enforceable in a court of law
- Each aspect of rights is important. An appropriate framework for rights in respect of decisions at the end of life must recognise positive as well as negative rights and moral rights as well as legal rights. It is especially important that, in discussing rights, the discussion is not limited to (largely negative) legal rights.

8.2 The Contribution of Rights

- Rights make an important contribution to patient care because
  - Respect for patient rights makes the patient central to the decision-making process
- Arguments based on positive rights provides a basis for essential resources
- There is a legal obligation to respect patients’ legal rights
  - But good patient care requires more than just respect for rights.

8.3 Sources of Legal Rights

- Irish Constitution
- European Convention on Human Rights
- European Charter of Patients’ Rights (not legally enforceable)
- United Nations Conventions
8.4 Positive Rights Implicated in End of Life Care

- Right to information
- Right to pain relief
- Right to communication
- Right to a ‘good dying’

These rights have a basis in legal rights, including the right to dignity, to protection from inhuman and degrading treatment and the right to bodily integrity. They are also moral rights. An appropriate framework for end of life care requires that these rights be recognised.

8.5 All Patients have Rights

Rights are not restricted to adult patients with decision-making capacity. All patients have rights.

Children’s rights include:
- The right to participate in decisions about their care – including end of life care – in accordance with their age and maturity
- The right to have their family consulted and involved in the decision-making process
- The right to have treatment decisions made in their best interests
- The right to life, to dignity, to protection from inhuman and degrading treatment

Adults who lack decision capacity have rights. These include:
- The right to participate in decisions made insofar as this is possible
- The right to life
- The right to dignity
- The right to protection from inhuman and degrading treatment

The right to life is not absolute but must be balanced with other rights.
9. Module 3 Activities

9.1 Recall the distinction between positive and negative rights:

a. Would you add anything further to these points on the distinction?

b. Which kind of rights seem to you to contribute best to appropriate decision-making at the end of life?

c. Which negative rights do you think are most relevant to treatment decisions at the end of life?

d. Which positive rights do you think are most relevant to treatment decisions at the end of life?

Reflect back on the particulars of Case 1:

a. In reading Case 1, jot down your first, unanalysed response to the facts set out.

b. Do you think that health professionals should have done more for the woman in this case?

c. What kind of structures would facilitate health professionals in doing more in a case along the lines of Case 1?

d. Compare Case 1 with the contrasting example given. Is the approach taken in the contrasting example a better way of protecting patient rights than the approach outlined in Case 1? If so, why?

Reflect back on the particulars of Case 2:

a. In your view, is it a good or a bad thing for cases like this to come before the courts?

b. In your view, what should the Supreme Court have done when faced with this case?

c. 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 Case 2?

d. Can you think of any other rights (both positive and negative) which may have been relevant in the facts arising in Case 2?

e. If you were the health professionals involved, would you have taken a similar position to that taken by the health professionals? If so, why; if not, why not?

f. Was the Supreme Court correct in the approach taken to ANH?; Would you take a similar approach? Is the approach taken by the Medical Council Guide consistent with the approach of the Supreme Court?
9.4 Reflect back on the particulars of Case 3:

a. Were the health professionals wrong in placing a DNR order on the patient’s file without consulting his family?; were they wrong in administering morphine without consulting his family? Is there any difference between the two decisions?

b. How involved should parents be in end-of-life decisions about their children?

c. Is it justified to retain information about a child’s situation from parents in order to preserve hope/prevent the parents from distressing the child?

d. How would you resolve a conflict where you believe that parents are making inappropriate decisions about their dying child? What factors would influence you in resolving the conflict?

9.5 Reflect back on the particulars of Case 4:

a. What are the rights at risk in this case?

b. How should the right to life be balanced against other rights where a patient lacks the capacity to make his or her own views or preferences known?

c. Do you agree with a standard for withdrawing or withholding treatment based on whether the treatment is ‘worthwhile’ or based on whether the patient’s life would be ‘intolerable’? Can you think of other possible standards which might be used in resolving the conflict between rights in making decisions about end-of-life care for patients lacking capacity?
References and Further Reading


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