# Module 4 Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Key Points</td>
<td>164</td>
</tr>
<tr>
<td>1.1 Autonomy</td>
<td></td>
</tr>
<tr>
<td>1.2 Respect for Autonomy in Hospital</td>
<td></td>
</tr>
<tr>
<td>1.3 Autonomy is a Contested Notion</td>
<td></td>
</tr>
<tr>
<td>1.4 A Capable/Competent Patient</td>
<td></td>
</tr>
<tr>
<td>1.5 There are Three requirements for Autonomous Decisions</td>
<td></td>
</tr>
<tr>
<td>1.6 The Legal Right of Autonomy</td>
<td></td>
</tr>
<tr>
<td>1.7 Information is Key</td>
<td></td>
</tr>
<tr>
<td>1.8 Legal Capacity is a Threshold</td>
<td></td>
</tr>
<tr>
<td>1.9 Every Adult</td>
<td></td>
</tr>
<tr>
<td>1.10 The Legal Test for Capacity</td>
<td></td>
</tr>
<tr>
<td>1.11 Capacity Assessment</td>
<td></td>
</tr>
<tr>
<td>1.12 Respect for the Principle of Autonomy</td>
<td></td>
</tr>
<tr>
<td>1.13 Autonomous Decisions</td>
<td></td>
</tr>
<tr>
<td>1.14 Advance Directives</td>
<td></td>
</tr>
<tr>
<td>1.15 Autonomy and Incapable Adults</td>
<td></td>
</tr>
<tr>
<td>2. Definitions</td>
<td>166</td>
</tr>
<tr>
<td>2.1 Autonomy</td>
<td></td>
</tr>
<tr>
<td>2.2 Absolute Right</td>
<td></td>
</tr>
<tr>
<td>2.3 Advance Directive</td>
<td></td>
</tr>
<tr>
<td>2.4 Capacity/Competence</td>
<td></td>
</tr>
<tr>
<td>2.5 Duty to Disclose</td>
<td></td>
</tr>
<tr>
<td>2.6 Enduring Power of Attorney</td>
<td></td>
</tr>
<tr>
<td>2.7 ‘Living will’</td>
<td></td>
</tr>
<tr>
<td>2.8 Paternalism</td>
<td></td>
</tr>
<tr>
<td>2.9 Principle of Autonomy</td>
<td></td>
</tr>
<tr>
<td>2.10 Principle of Beneficence</td>
<td></td>
</tr>
<tr>
<td>2.11 Right to Refuse Treatment</td>
<td>161</td>
</tr>
</tbody>
</table>
Module 4 Patient Autonomy in Law and Practice

2.12 Sanctity of Life
2.13 Self-determination

3. Background
3.1 A Matter of Policy
3.2 Defining Patient Autonomy
3.3 The Nature of the Right of Autonomy
3.4 Autonomy is Not an Absolute Right
3.5 Autonomy as a Positive Right

4. Ethical Debates Regarding the Status of Autonomy
4.1 Critiques of Autonomy
4.2 The Importance of Autonomy

5. The Legal Right of Autonomy
5.1 The Scope of the Legal Right
   5.1.1 A Right to Refuse Treatment
   5.1.2. The Right in Practice
5.2 Limits on the Legal Right

6. Cases: Exploring Rights in Action
6.1 Case 1: Applying the Legal Right of Autonomy – Re B
   6.1.1 Discussion
   6.1.2 Suggested Professional Responsibilities
6.2 Case 2: Informed Consent – Information in Practice
   6.2.1 Discussion
   6.2.2 Suggested Professional Responsibilities
6.3 Case 3: Capacity, a Pre-requisite for Autonomy? – Re C
   6.3.1 Discussion
   6.3.2 Suggested Professional Responsibilities
6.4 Case 4: Voluntariness and Decision-Making Freedom – Families and Patients
   6.4.1 Discussion
   6.4.2 Suggested Professional Responsibilities
Module 4 Patient Autonomy in Law and Practice

6.5 Case 5: Preserving Patient Autonomy – Advance Directives in Practice

6.5.1 Discussion

6.5.2 Suggested Professional Responsibilities

7. Further Discussion

7.1 Implications of the Positive Right of Autonomy
7.2 Participation by People Lacking Capacity
7.3 Traditional Views of Autonomy
    7.3.1 Autonomy and Rationality
    7.3.2 Autonomy and Individuality
7.4 Relational Autonomy

8. Summary Learning Guides

8.1 The Nature of Autonomy
8.2 The Legal Right of Autonomy
8.3 Information is Key to Autonomy
8.4 The Role of Decision-Making Capacity and Freedom
8.5 Advance Decision-Making
8.6 Autonomy and the Person without Capacity

9. Activities

10. References and Further Reading
1. Module 4 Key Points

1.1 Autonomy is not just about the right to say no:
The right of autonomy is not just about refusing treatment or procedures; it is also about the positive right to be involved in decisions about treatment.

1.2 Respect for autonomy is especially important in a hospital setting:
A patient in a hospital setting is in an inherently vulnerable position; he or she is part of a big and sometimes impersonal institution and is inherently restricted in many of the choices which he or she can make.

1.3 Autonomy is a contested notion:
There is ongoing debate among healthcare ethicists and others regarding the proper status for autonomy. For some, autonomy provides the basis for patient rights and is the most important of all the ethical standards. However, this claim is disputed by others who place importance on values such as trust and maintaining personal and social relationships.

1.4 A capable/competent patient has the right to refuse treatment:
This is a legal right which is protected under the Irish Constitution and the European Convention on Human Rights.

1.5 There are three requirements for autonomous decisions:
Information, Capacity and Freedom: Not all decisions are autonomous: an autonomous decision is one which is made with adequate information; where the patient has decision-making capacity and where the patient is not unduly influenced or pressured by others.

1.6 The legal right of autonomy does not extend to allow patients assert a ‘right to die’:
Courts in a number of countries have rejected the argument that the right of autonomy gives people a ‘right to die’ in the sense of 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.

1.7 Information is key to autonomous decision-making:
Without adequate information, a patient cannot make autonomous decisions. Protection of patient autonomy imposes a positive duty to provide information in an appropriate way. However, simply providing information does not ensure autonomous decision-making.
1.8 **Legal capacity is a threshold and not a comparison:**
A person's legal capacity is decided according to whether or not he or she meets a designated standard.

1.9 **Every adult is presumed to have capacity to make decisions:**
Regardless of age, intellectual disability, mental illness, all adults are presumed to have the capacity to make decisions.

1.10 **The legal test for capacity asks three questions:**
Can the patient understand the information relevant to the decision? Can he or she believe this information? Can he or she make a decision based on the information?

1.11 **Capacity assessment:**
Respect for the principle of autonomy requires that capacity be assessed in a way which is fair and appropriate and which is free from prejudices based on external factors such as old age, mental illness or intellectual disability.

1.12 **Respect for the principle of autonomy requires efforts**
to be made to develop and enhance patients’ capacity and to facilitate them in making decisions where this is possible.

1.13 **Autonomous decisions are decisions which are freely made:**
The positive right of autonomy requires that efforts be made to ensure that patients are free to make their own decisions and that patients have the maximum control possible over the manner of their dying.

1.14 **Advance Directives provide vital control for patients over their dying:**
An Advance Directive can prolong lives as well as decide when life should end.

1.15 **Autonomy and incapable adults:**
It should not be presumed that simply because a person lacks the capacity to make an autonomous decision, his or her views should simply be disregarded: An autonomy centred approach to end of life decisions requires that efforts must be made to facilitate the participation of patients lacking capacity in making decisions.
2. Module 4 Definitions

2.1 Autonomy
is the capacity of self-determination; it is a person’s ability to make choices about their own life based on their own beliefs and values.

2.2 Absolute Right:
A right which cannot be interfered with in any circumstances. Autonomy is not an absolute right

2.3 Advance Directive:
a decision made by a person while he or she has decision-making capacity regarding the medical treatment which he or she would wish to receive (and more frequently not to receive) if he or she subsequently loses capacity.

2.4 Capacity/Competence:
The ability to make decisions based on designated standards.

2.5 Duty to Disclose:
The duty of a medical professional to disclose material risks to a patient in advance of treatment

2.6 Enduring Power of Attorney:
Power which a person grants while he or she has capacity giving another person the power to make certain designated decisions if the person granting the power of attorney subsequently loses capacity.

2.7 ‘Living will’:
Another term for an Advance Directive.

2.8 Paternalism:
involves an action that overrides a person’s decision or controls their actions in the interests of what is considered to be their own good.

2.9 Principle of Autonomy:
requires that, in a healthcare context, health professionals recognize and support the unique values, priorities and preferences of patients.
2.10 Principle of Beneficence:
Doing good for the patient.

2.11 Right to Refuse Treatment:
A legal and ethical right of a patient.

2.12 Sanctity of Life:
A principle whereby life is seen as having an intrinsic value unrelated to the individual’s views regarding his or her own life.

2.13 Self-determination:
Another way of saying ‘autonomy’ – sometimes used in legal discussions.
3. Module 4 Background

3.1 A Matter of Policy
One of the goals of the Irish Health Service Executive Strategic Plan for 2008-13, is ‘to develop the role of the “expert patient”, especially those with long-term illnesses, in developing their own care plan and in looking after their own condition’ (p.14).

Two of the related actions to achieve this goal are; the promotion of patients as ‘partners with health professionals’ and; the education of staff on the ‘importance of patient involvement in their care’ (National Strategy for Service User Involvement in the Irish Health Service 2008-2013). The document defines ‘involvement’ as:

‘A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change’ (2008, p.6).

In emphasizing the idea of individual patient participation in care planning and self-care, this HSE strategic plan brings Ireland in line with international efforts to change the way in which illness is managed in the 21st century by health professionals and, increasingly, by patients themselves. This focus on patient-directed and patient-centred care is construed as giving expression to patient autonomy and it is articulated in the 7th Edition of the Irish Guide to Professional Conduct and Ethics for Registered Medical Practitioners (2009) in relation to the requirement of the informed consent of patients to medical treatment:

‘You should ensure that informed consent has been given by a patient before any medical treatment is carried out. The ethical and legal rationale behind this is to respect the patient’s autonomy and their right to control their own life. The basic idea of personal autonomy is that everyone’s actions and decisions are their own. Therefore, the patient has the right to decide what happens to their own body.’ (Section 33.1, p.34)

The notion of patient autonomy is particularly relevant to one particularly vulnerable group of individuals: patients who are dying.
3.2 Defining Patient Autonomy

The term, autonomy, derives from the Greek words, autos (‘self’) and nomos (‘rule’, ‘law’, ‘governance’), and originally referred to the self-rule of Greek independent city-states. Today, however, autonomy is associated, not just with nations but also with persons, decisions and actions and it is linked with other meanings such as self-governance, liberty, self-authorship, free will and self-determination.

The moral principle of autonomy requires that, in a healthcare context, health professionals recognize and support the unique values, priorities and preferences of patients. In end-of-life care, they can do this by enabling patients to direct their own journeys from living to dying and death. This requires that patients be encouraged to participate in decisions relating to their treatment and care.

Respecting patient autonomy does not mean that health professionals only respect the choices of persons who are deemed autonomous. It requires that they respect whatever level of autonomy the person is capable of. Where the dying person is incompetent or impaired or suffers from some psychological, emotional, physiological or social disability, the principle of autonomy obliges health professionals and organizations to create the conditions that foster capacity. They do this through, for example, the early provision of treatment or care plans and consulting with family members and friends about what the person would have wished in the circumstances.

3.3 The Nature of the Right of Autonomy

The right of autonomy or self-determination protects the individual’s ‘interest in making significant decisions about his or her own life’ (Buchanan and Brock, 1989, p.36). This right is often seen as being encapsulated by John Stuart Mill’s ([1859], 1991, p.4) words, ‘Over himself, over his own body and mind, the individual is sovereign’.

Respect for autonomy requires that autonomous decisions must be respected even if we do not agree with them. In the words of Ronald Dworkin, ‘[w]e allow someone to choose death over radical amputation or a blood transfusion, if that is his informed wish, because we acknowledge his right to a life structured by his own values’ (1993, p.27).

The right of autonomy is both a moral right and a legal one. As members of the moral community, we have a moral obligation to respect our fellow citizens’ right of autonomy. We also have a legal obligation to respect the right. In this sense, autonomy may be seen as a negative right (see discussion on positive and negative rights in Module 3). It is a right not to
be interfered with. This has often been the legal response to the right and in the healthcare context; the legal right of autonomy is often viewed as simply the right to refuse treatment.

### 3.4 Autonomy is Not an Absolute Right

Autonomy is not an absolute right. The most commonly recognised justification for interference with autonomy is that respect for the right will cause harm to another person (often described as the ‘harm’ principle; see Further Discussion). For example, where a person has a contagious and dangerous disease, say tuberculosis, a degree of interference with his or her autonomous rights (to refuse treatment, to freely interact with others) may be justified on the basis of the harm which would be caused to others who might well become infected with the disease if the person’s right of autonomy were respected.

Respect for autonomy is also premised on ‘all the persons concerned being of full age, and the ordinary amount of understanding’ (Mill, [1859], 1991 p.84). Children and people without decision-making capacity do not have the same right of autonomy as capable adults. However, this does not mean that their views are irrelevant. Insofar as is possible, account should be taken of the views of people lacking capacity in healthcare decisions, including decisions at the end of life.

### 3.5 Autonomy as a Positive Right

The right of autonomy should also be viewed as a positive right. Respect for the right is as much about empowering patients as about patients refusing treatment. Many in the healthcare profession would argue that the right of patient autonomy should be accompanied by more positive help to enable patients to die in a context that protects their dignity and privacy. This is clear in the range of practitioner responses to Quinlan and O’Neill’s request to define patient autonomy (2009, p.44-45). Practitioners responded:

‘I suppose it’s the right and the ability of the patient to make a choice.’

‘It’s the choice of what kind of treatment the patient is going to receive and the degree of treatment, if it’s going to be just like minimal or more aggressive.’

‘I suppose it’s more the patients’ right to make choices around that and, you know, that we would be respectful to the patients’ wishes […]’

‘[…] that we would take their wishes into consideration and act on them at all times […]’

‘It’s to do with, maybe not just the treatment, but things like patients’ family involvement and special particular requests that the patient might have as to whether we can, you know, the balance between whether we can have whatever the patient wants from a practical point of view.’
This means that autonomy is not just about the right to say no; it is also about the right to be involved in decisions about how one’s treatment proceeds and the environment in which one dies.

This is the view of autonomy developed in this module – a view of autonomy as a positive right to be involved in decisions at the end of life and to have the steps taken to ensure that this happens.
4. Ethical Debates Regarding the Status of Autonomy

As discussed in Module 3, the principle of autonomy has traditionally played a very limited role in medical ethics. Historically, healthcare decisions were based on the principles of beneficence (doing good for the patient) and sanctity of life (recognising an intrinsic value in life) with little or no reference to the patient’s own views of their interests or of the value of their lives. However, from this position of insignificance in traditional medical ethics, in recent decades, the principle of respect for patient autonomy has come to be widely recognised in healthcare decision-making.

Autonomy is now regarded as a fundamental ethical principle (Beauchamp and Childress, 2008) governing healthcare decisions. However, it is a contested notion. For some, it is the most fundamental ethical principle governing the relationship between medical professional and patient (Gillon, 2003). For others (O’Neill, 2002; Callahan, 1984, 2003), autonomy provides, ‘a thin gruel for the future of bioethics’ (Callahan, 2003, p.499).

4.1 Critiques of Autonomy

The elevated role of autonomy has been criticised for a number of reasons. Critics argue that the autonomy principle is too individualistic and that it fails to take account of the essential interconnectedness of people or the complexity of the ways in which people make healthcare decisions (Schneider, 1998; Callahan, 1984, 2003; O’Neill, 2002). Many argue that a broad and more concrete understanding of autonomy is required.

One significant deficiency in the way that autonomy is usually understood is that it supports an abstract view of persons as independent, self-sufficient centers of decision-making. When associated with free market economies such as ours, this view of autonomy conjures up an image of an independent individual who chooses from amongst an array of commodities; in the healthcare arena, the patient is a consumer and the commodity is a medicine or treatment. It could be argued that this distorts the relationship between the patient and the professional, and between the citizen and the state which has responsibility for healthcare provision.

Daniel Callahan puts his criticism as follows:

‘[Autonomy] buys our freedom to be ourselves, and to be free of undue influence by others, at too high a price. It establishes contractual relationships as the principal and highest form of relationships. It elevates isolation and separation as the necessary starting point of human commitments.’ (1984, p.41)
Onora O’Neill (2002) identifies the cost to other values and in particular, the important value of trust, which is exacted by the elevation of autonomy. Contrasting the different features of trust and autonomy, she notes, ‘[t]rust flourishes between those who are linked to one another; individual autonomy flourishes where everyone has “space” to do their own thing’ (2002, p.25).

Rather than fostering trust between patients and professionals, it is argued that elevating autonomy pits the patient and professional against one another. In situations in which disagreements engender conflicts and disputes, these are increasingly referred to the courts or Fitness to Practice Committees to resolve. Such a narrow a view of autonomy conceives of the obligations of health professionals in terms of what they cannot do. This reinforces the already widespread culture of demoralization and fear of litigation which focuses the minds of health professionals on expedience, pragmatism and self-protection.

It must also be remembered that not all cultures adopt identical views of autonomy or take an individualistic view of the person (Blackhall, 1995; Gaylin and Jennings, 2003). Thus, while respect for autonomy may be in line with western liberal thinking, it may be wholly alien to people from other cultural backgrounds.

While identifying important questions about the status accorded to autonomy, critics of the principle do not advocate a return to old-style paternalism. In Callahan’s words, there cannot be a ‘return to those good old days that understood doctors to be good old boys who could work out moral problems among themselves in the locker room’ (1984, p.42). If autonomy is to be preserved and to have relevance, it is argued that a broader account is needed to provide substantive basis for decision making. One such account is described by George Agich as ‘actual autonomy’ which focuses on paying attention to concrete actions carried out in everyday shared social life (Agich, 2003, p.19). This perspective; pays attention to the conditions which foster capacity, provides treatment or care plans from which patients choose, and tries to ensure that available options are meaningful to the patients involved. See Further Discussion for philosophical supports for, and critiques of, the notion of autonomy.
4.2 The Importance of Autonomy

Although the elevated role of autonomy can be criticised and the cultural context in which autonomy is valued must be recognised, the principle provides an important foundation for decisions about healthcare, including at the end of life. Autonomy is a more complex ideal than simply respecting the right to say no. The right to say no – to refuse interventions – is important but so too is the more positive right of autonomy in the sense of facilitating patients in exercising control over how they live, and how they die. One practitioner recounts:

‘I’ve yet to remember when a patient had full, you know, control over what they exactly wanted. We feel we’re doing what’s best for the patient and we do, we do what’s best, but I don’t know whether we question enough by asking the patient “is this what you want”. So I think as yet patients haven’t got great control over end-of-life decisions’ (Quinlan and O’Neill, 2009, p.52).

The especially strong need for protection of autonomy in this broader sense in a hospital context is evident when we consider one the practitioner responses recounted by Quinlan and O’Neill (2009, p.69):

‘Once you put your foot in the door of the hospital as a patient you lose that power, that power you have as an individual. A hospital is an institution and it has to tick, it has to keep going, staff come and go, there’s rotas, there’s crises, there’s personalities, there’s conflict, there’s tension. People who are dying usually want to go home and they want to die at home. The journey they have had with cancer – could have involved a number of hospitals - and then they end up let’s say in this facility here. My experience of working here for nearly 2 years is that, and I’m sure it’s no different to any other institution or hospital, a lot of stuff gets lost, the emotional stuff doesn’t get dealt with. That could be because of a combination of family dynamics and ward dynamics and hospital dynamics. So my experience is that people lose an awful lot of autonomy and I’ve seen a lot of people die who have been totally disempowered […] and people have good deaths I’m sure as well - but it’s kind of sad’.

Autonomy in this sense might be seen as an aspiration or a goal. In many cases, it will not be possible for patients to be fully autonomous; the circumstances of their illness and their hospitalisation may limit this. But recognising that respect for autonomy and the empowerment of patients are important values is an essential component of an appropriate framework for end of life decision making.
5. The Legal Right of Autonomy

Autonomy is an important ethical principle. It is also a recognised and enforceable legal right. While the existence of a legal right does not, of itself, guarantee that an ethical principle will be respected, legal endorsement allows patients to make ethical principles enforceable in their individual situations (Donnelly, 2008, p.34). An understanding of the legal right is essential in order to appreciate health professionals’ legal obligations. However, it is crucial that the legal right is not seen as the only relevant factor in providing appropriate protection for patients’ autonomy. Respect for the right of autonomy also imposes positive obligations to enhance patient autonomy and to ensure that patients are able to control to the maximum extent possible their own living and dying.

5.1 The Scope of the Legal Right

The legal right of autonomy has sometimes tended to be viewed primarily as a right to say ‘no’; a right to refuse treatment rather than a positive right to appropriate treatment.

5.1.1 A Right to Refuse Treatment

The Irish Constitution protects the right to refuse treatment. This has been recognised by the Irish Supreme Court in a number of cases, beginning with the decision in In re a Ward of Court (1995). In this case, the Supreme Court recognised the right of a patient to refuse medical treatment. The right to refuse treatment was again recognised by the Irish courts in JM v Board of Management of St Vincent’s Hospital (2003) and in Fitzpatrick v K (2008). Speaking in Fitzpatrick v K (2008), Judge Laffoy said that it ‘could not be argued that a competent adult is not free to decline medical treatment’.

The right of autonomy is also protected under the European Convention on Human Rights. In Pretty v UK (2002), Mrs Pretty was an English woman who suffered from motor neuron disease. She was concerned that a time would come when she would wish to end her life. She did not wish to die by withdrawal of ventilation – which she would be legally entitled to request – as she had a fear of suffocation and did not wish to die in this way. Instead, she wished her husband to assist her in bringing her life to an end. She was concerned because assisted suicide is against the law in England (as is also the case in Ireland). She was worried that, after her death, her husband might be prosecuted for assisting her. She did not wish this to happen and sought a reassurance from the public prosecutor that it would not happen. The prosecutor declined to give this reassurance because the law on assisted suicide in England did not allow for any exceptions. Mrs Pretty applied first to the English courts. She argued that the blanket prohibition on assisted suicide was a breach of her human rights.
arising under the European Convention on Human Rights. The English courts rejected her case and she brought her case to the European Court of Human Rights.

The European Court recognised that a person has a right of autonomy which is protected under Article 8 of the European Convention on Human Rights which protects the right to private and family life. The Court also found that respect for the right of autonomy required that people have the right to refuse medical treatment. The Court also accepted that the prohibition on assisted suicide was a breach of Mrs Pretty’s right of autonomy (although as discussed below, it found that interference with this right could be justified in the circumstances).

5.1.2. The Right in Practice

Perhaps the most striking feature of the Irish cases on the right to refuse treatment is that, in all cases, while the right to refuse treatment was recognised, the right did not actually apply in any of the cases (Donnelly, 2008, p.36). In In re a Ward of court (1995), the woman had been in a near PVS for 23 years and evidently lacked decision-making capacity. Nor had she given any prior indication of how she would have wished a situation like this to be dealt with. The decision to withdraw ANH from the woman was made on the basis that withdrawal was in her best interests and not on the basis of her right to refuse treatment.

In JM v Board of Management of St Vincent’s Hospital (2003), the woman had refused a blood transfusion on the basis of her religious beliefs (she was a Jehovah’s Witness). The woman had made her views known and then she lost consciousness. The issue for the court was whether her advance instruction should apply. The woman’s husband gave evidence to the Court that the woman had converted to become a Jehovah’s Witness on her marriage to him and that she did so because her cultural background meant that she was culturally disposed to adopt her husband’s religion. On this basis, the Court held that the woman’s decision was not a ‘real’ or ‘true’ decision. Because the decision was not a real or true one, the Court considered that it was not autonomous and therefore the woman’s advance refusal of the blood was not upheld and a blood transfusion was administered.

Fitzpatrick v K (2008) also concerned refusal of a blood transfusion for religious reasons. Here, the woman, who had recently given birth, refused a blood transfusion. She suggested that her condition should be treated instead with tomatoes and coca cola. Judge Laffoy found that the woman lacked the capacity to appreciate the seriousness of her situation and held that the administration of blood was justified in such circumstances. The role played by capacity and decision-making freedom in end of life situations will be discussed in more detail below. For present purposes, the important point is that the Irish courts have recognised the right of autonomy in the sense of the right of the competent adult to refuse
medical treatment but, in practice, a case has not yet come before the courts in which the right has actually been held to apply.

### 5.2 Limits on the Legal Right

The legal right to refuse treatment is not absolute. The right of autonomy may sometimes be limited because of duties owed to other people – so for example, it may be justified to interfere with a person's right to refuse treatment if the person has a contagious disease which may infect other people.

A more unusual example of duties owed to others may be seen in one Irish case, Re K, (2006). Here, a woman was not permitted to refuse a blood transfusion on the basis of her religious beliefs (she was a Jehovah’s Witness) because, if she died, her infant son would be left without a parent. Judge Abbott held that child's welfare should take priority over the woman's right of autonomy. This case was later reconsidered by the Irish courts under the name Fitzpatrick v K, (2008). Judge Laffoy found that the woman had, in fact, lacked the necessary capacity to make the decision to refuse the blood transfusion and for this reason, her decision was not an autonomous one. This meant that there was no need to consider the question of whether or not the child’s welfare should take priority over the woman’s right of autonomy and Judge Laffoy did not consider the matter.

In Pretty v United Kingdom (2002), the European Court held that the protection afforded to the right of autonomy under the European Convention was not absolute. It was permissible to interfere with a person's right of autonomy if it was necessary for the protection of the rights and freedoms of others. The Court held that the United Kingdom had made a reasonable case that its prohibition on assisted suicide was intended to protect the rights and freedoms of others (in particular vulnerable people who might feel pressured into ending their lives if assisted suicide were lawful). For this reason, the prohibition on assisted suicide was a permissible breach of Mrs Pretty’s rights.

The effect of the decision in Pretty is that the right of autonomy does not extend to allowing a patient assert a right to die in the sense of a right to have active steps taken to end his or her life or to assist him or her in ending his or her life. Courts in Canada and the United States have reached similar conclusions on largely similar grounds (Rodriguez v British Columbia, 1993; Washington v Glucksberg, 1997; Vacco v Quill, 1997). It is highly probable that the Irish Supreme Court would reach a similar conclusion. This does not mean that a country could not bring in legislation to allow for assisted suicide. For example, the Netherlands, Belgium and Luxembourg (all of which are subject to the European Convention on Human Rights) have done this in recent years. However, this is seen as a matter for politicians, following public debate, and not for the courts.
6. Cases: Autonomy in End of Life Contexts

As is often the case with rights, it is one thing to state the existence of a right of autonomy, it is quite another to determine what it means in practice in end-of-life contexts. This can be made more difficult because legal conceptions of the right of autonomy are often developed in once-off, usually dramatic situations such as the Jehovah’s Witness refusing blood products. This can create a very unrealistic view of what autonomy in practice means for most patients who are not proposing to make dramatic decisions or to refuse possibly life-saving treatments. Most patients are simply trying to find the best way possible to deal with their illness and the end of life decisions which they must make.

In the cases to follow, the practical application of the right of autonomy in end of life contexts will be explored. This includes an exploration of the way in which autonomy has operated in the law; the requirements for autonomy and how these may be used to further autonomy as a positive right as well as a right to refuse and a discussion of ways to preserve and protect autonomy even after a patient has lost capacity.

6.1 Case 1: Applying the Legal Right of Autonomy – Re B
This case, which is based on the facts of an English case which came before the courts in 2002, shows the strength of the legal right of autonomy in those cases where the right is held to apply. The case is concerned with the withdrawal of ventilation. There has not been a similar case in Ireland. In an unreported case in 2001, ventilation was not withdrawn from a pregnant woman because the withdrawal would have ended the life of the foetus also. Because information on the facts of the case is restricted (the newspaper report provides only limited information), it is not possible to draw any conclusions from this.
Re B (Adult: Refusal of Medical Treatment), (2002):

Ms B was a 43 year old woman who was quadriplegic following a stroke which had occurred in the previous year. She also required artificial ventilation and had been hospitalised in an ICU since her illness began. She brought an application to court for ventilation to be withdrawn saying that she had decided that she did not want to live any longer in her condition. Ms B had earlier asked the court to have ventilation withdrawn. She had been severely depressed at the time and had been found not to have the capacity to make this decision. At the time of this case, however, there was no dispute regarding her capacity to make the decision.

The medical professionals caring for Ms B expressed some concerns about her decision. In particular, some carers pointed out that she had never had the opportunity to experience life outside of the restrictions of the ICU environment. There was a possibility that she could successfully complete a ventilation weaning programme and that she would be able to live a much more independent life. Therefore, some of her carers argued that she had not had the opportunity to make an informed decision about her future and that her decision should not be respected until after she had had such an opportunity.

The English High Court held that the ‘personal autonomy of the severely disabled patient’ should be recognised and that Ms B should be permitted to have ventilation withdrawn. The judge asked Ms B to reconsider her decision but she said that she could not require Ms B to do so. Ms B remained committed to her decision and shortly afterwards, she moved to another hospital because her carers could not bring themselves to participate in the removal of ventilation. She had ventilation removed and shortly afterwards, she died.

6.1.1 Discussion 4

Case 1 shows that, when the right of autonomy arises in the context of treatment refusal, it is a very powerful right. It takes priority even when the effect of the refusal is the death of the person. In these circumstances, the right to refuse treatment ‘trumps’ or outweighs the ethical principle of the sanctity of life. The nature of the legal right is perhaps best summarised by Lord Donaldson in the English case of Re T (1992) who stated:

An adult patient who … suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered…. This right of choice is not limited to decisions which others
might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent (1992, p.486).

The judge in Case 1 could implore Ms B not to refuse treatment and she did so in the strongest terms. However, because of Ms B’s right of autonomy, she could not be forced to accept treatment which she did not wish to have.

Case 1 also shows that decisions which implement the right of autonomy can be difficult and painful. The judge and Ms B’s carers were all very anxious that she should continue to live. Some of Ms B’s carers strongly believed that her situation could improve in many ways and that she had not had the opportunity to avail of all the possibilities available to improve the life of a person in her situation. But ultimately, the court held that it was Ms B’s decision whether or not to avail of these possibilities.

Case 1 also reminds us of the difference between engagement and discussion on the one hand and force on the other. There was nothing inappropriate in people caring about Ms B and wanting her to have the opportunity to experience life outside the unit. Indeed, it may be argued that Ms B’s carers had an ethical obligation to engage with her and to seek to persuade her to continue to live (Mclean, 2009). Healthcare provision would be much poorer if health professionals did not have an interest in the person they cared for or if carers simply accepted decisions such as Ms B’s without engaging closely with her and seeking to persuade her to change her mind. However, there is a very significant difference between engaging with, discussing, seeking to persuade and actually forcing a person to accept a treatment which the person rejects. In Case 1, Ms B’s carers did the right thing in engaging with her decision but the ultimate decision was for Ms B to make and her carers were bound, both legally and ethically, to respect this decision.
6.1.2 Suggested Professional Responsibilities 4

- If a person seeks to refuse treatment, especially life-saving treatment, health professionals should consider whether the person has the capacity to make this decision (capacity is discussed further below). If in doubt about capacity, professionals should consult a professional with expertise in this respect (perhaps a psychiatrist or geriatrician). Ultimately, if doubt remains, legal advice should be sought.
- Professionals can and should engage with patients who refuse treatment. If professionals believe that it would be in the patient’s best interests to have treatment, they can and should seek to persuade the patient to consent to the treatment. This attempt should be on the basis of dialogue and discussion which should be conducted in a way which is honest and which does not attempt to manipulate the facts.
- A distinction must be made between honest persuasion and force. While persuasion is legitimate, the use of force is not (unless the person lacks the capacity to make the decision).
6.2 Case 2: Informed Consent - Information in Practice

In order to be maximally autonomous, decisions must be fully informed. Tom Beauchamp (1997, p.194) describes informed consent as follows:

'A person gives an informed consent … if and only if the person, with substantial understanding and in substantial absence of control by others, intentionally authorises a health-care professional to do something.'

Ethicists, Ruth Faden and Tom Beauchamp point out that informed consent requires the patient to be fully informed about the nature of the decision and also that any information of particular relevance to the patient should be available (1986, p.302). A patient who makes a decision on the basis of inadequate information cannot be said to have made an informed decision. This is especially true where the decision has life-changing consequences. For example, if a patient refuses life-saving treatment, he or she must be aware of the probable consequences of this decision and of the likelihood that this will occur.

However, simply providing information does not of itself comprise a complete basis for autonomous decision-making. Nor is more information necessarily better (Manson and O'Neill, 2007). Neil Manson and Onora O'Neill argue that a narrow focus on the disclosure of information can serve to obscure the issue of ‘effective communication and commitments between the parties’ (2007, p.184). For this reason, we should not simply focus on disclosure of information in an end of life context, for example, simply telling a person that he or she is terminally ill or providing information about treatment options, risks and outcomes. Instead, it is important to recognise broader issues of communication and engagement.

In some situations, also, failure to provide adequate information in respect of material risks in advance of consent to a medical procedure will leave a health professional potentially liable in the tort of negligence (Fitzpatrick v White, 2007). However, the legal duty to disclose information falls far short of what is required for genuine informed consent (Donnelly, 2002). The legal duty has focussed primarily on risks and has paid little attention to the other important information for a patient, such as side-effects or alternatives. There has also been a tendency to focus on the detail of the information conveyed without paying much attention to the method of communication. Respect for the positive right of autonomy requires that much greater effort at communication be made than is required under the law of negligence.

The importance of communicating information in the broader sense is evident is Case 2 which draws on a practitioner narrative provided in Quinlan and O’Neill (2009, p.49-50):
‘I did have the experience of a gentleman, you know, I got a referral to say that he was, you know, quite anxious and, you know, he needed to speak to somebody. He wasn’t really consenting to his treatment and, you know, I went to see him and his biggest thing was that he said he had got no information from the team as to what the treatment was, why he was getting it or what his outcome was going to be. Now he did say to me ‘I understand it’s not going to be good news but I’d rather know.’

I think if people know good or bad they’ll find a way to deal with that or they’ll find a way to cope with that, it mightn’t be the best way but I suppose then you can come in and try and offer some support with that. But for that man, at that time, he just felt ‘I don’t know what they’re talking about’ and at the same time he had a sense, he knew it wasn’t going to be good, ‘but just tell me so I can get on with it’, so those sorts of things.

I think just people being fully aware at all times of what’s going on. I suppose that they feel that their wishes are respected, that we’re not running off and ringing the family to say well ‘they’ve said no but we really think …’, you know, and I would always feel that – I would always go and see a patient first and say to them ‘listen, is it okay if I call such and such?’, if they say ‘no’, that’s fine, that’s their decision and the team mightn’t like that or, you know, a lot of people don’t like that but that’s – I feel that they should know that their wishes were respected. And then, you know, I suppose just the amount of dignity they have around that as well.’

6.2.1 Discussion 4

This case as recounted by a practitioner shows a number of important issues in respect of the role of information in protecting patient autonomy. It reminds us that patients can respond in two different ways to lack of adequate information. Many patients will not object; they will go ahead with treatment and comply with their health professional’s directions. But, these are not autonomous decisions. Although the patient has given consent, the patient’s positive right of autonomy is not being respected.

Patients may also respond like the gentleman in Case 2. He refused to consent. It turned out, when the practitioner investigated further, that the reason for the refusal was his lack of information. In a sense, he was using his refusal as a plea for information. However, not all patients will be as forthcoming as this gentleman. Some may withdraw or refuse treatment without ever explaining (or perhaps sometimes without even understanding) why they
are doing do. If, in a case like this, the professional is not open and prepared to discuss with the patient and simply accepts the refusal at face value, the patient may continue to refuse treatment. If this happens, it would represent a failure to respect the patient’s rights, including his right of autonomy. Thus, Case 2 reminds us that respect for the patient’s right of autonomy requires more than simply not interfering with a patient who seeks to refuse treatment. In addition, respect for the right imposes a positive obligation to inform the patient and to discuss treatment options with him or her.

Communication (giving information and listening to patients) is central if patients are to be sufficiently informed about their diagnosis and prognosis. Lack of information and even misinformation can leave patients without power to make choices. One practitioner narrative notes ‘it is not unusual that people are let out of here with misinformation because we use language like ‘a shadow on the lung’ and patients don’t know that he had lung cancer. (Quinlan and O’Neill, 2009). It is not always easy to achieve good communication especially where a patient is dying. However, respect for patient autonomy requires positive efforts to be made. (The difficulties with honest engagement are explored in Module 2.)

A second notable aspect of Case 2 is the recognition which this practitioner clearly shows that autonomy is not a right respected in a once-off situation only, and that information is something which must be relayed on an ongoing basis. The practitioner says ‘I would always go to the patient first.’ The positive right of autonomy in the sense of control over one’s decision-making requires more than once-off information. Facilitating autonomy in patients requires on-going communication. Conversation to nurture autonomy is stressed as an indispensable ethical value in discussions on end-of-life care.

But good information and listening take time. There is a serious lack of time for communication with patients to find out their preferences, desires or wishes. Where this communication doesn’t happen, staff can’t help patients to be autonomous. Practitioners remind us that, ‘if we’re intent on nurturing and encouraging patient autonomy, then we need time to communicate with patients, with family and with each other on a ward’ (Quinlan and O’Neill, 2009).
6.2.2 Suggested Professional Responsibilities

- In order to ensure that patients’ decisions are as fully informed as is possible, health professionals must ensure that patients receive adequate information in respect of their condition.

- Health professionals should address broader issues of communication rather than focusing simply on the information communicated. This requires that they understand the emotional and social context in which the information is conveyed.

- Health professionals should recognise that information is not simply conveyed in a once-off way but that repeated efforts need to be made to engage with the patient.

- Adequate communication requires listening as well as speaking; each patient has unique informational concerns and these can only be addressed if the professional is aware of what these are.

6.3 Case 3: Capacity, a Pre-requisite for Autonomy? – Re C

Respect for autonomy principle is inherently linked to the requirement for capacity. The right of autonomy presumes that the person whose right is respected has the capacity to make the decision in question. Decision-making capacity is a requirement for the moral or ethical right of autonomy. It is also a requirement for the legal right. Legal autonomy, in Buchanan and Brock’s words is ‘a threshold concept, not a comparative one’ (1989, p.27). The law sets the required standard for capacity and asks simply whether the patient reaches the designated threshold. This means that the law is not concerned with whether someone is a good decision-maker as we might think of the concept in other contexts. The law does not ask whether the person is reflective and careful or impulsive and careless. The only matter of interest to the law is whether or not the person reaches the legal standard.

A person may lack the capacity to make decisions at the end of life for two reasons. First, she or he may be too young to make the decision or secondly, she or he may lack the necessary decision-making abilities. This may be because the person is unconscious or because of intellectual disability, mental illness or dementia. In both cases, the law sets out a threshold point at which a person has capacity. In order to understand the legal right of autonomy, it is essential that these thresholds be appreciated. However, it is also important to remember...
that, just because a person lacks formal legal capacity does not mean that his or her views and preferences can simply be ignored. This point will be returned to in the Further Discussion.

First, however, it is necessary to consider Case 3. This case provides an example of the relevant threshold for legal capacity to make decisions for adults. This is based on an English case from 1993. In the Irish case of Fitzpatrick v K (2008), the Irish courts have held that the same standard applies in Ireland.

### Re C (An Adult) 1993

Mr C had been detained in a mental hospital for many years. He developed gangrene in one leg and medical advice was that his leg needed to be amputated. Mr C resisted this and said that he would prefer to die with two legs than to live with one. Mr C also offered the view that God would save him and he referred to his own (delusional) belief that he was a world-famous surgeon.

The Court held that Mr C had the necessary capacity to refuse the amputation even if the refusal would lead to his death. It was not relevant that Mr C had a mental illness. Everyone must be presumed to have capacity regardless of their underlying circumstances.

The test for capacity related to his capacity to make this particular decision and not to his overall situation. The Court identified three questions as relevant in deciding if Mr C had legal capacity:

1. **Could he understand the information relevant to the decision (to refuse the amputation)?**
2. **Did he believe the information?**
   Could he use this information to make a decision?

   The Court found that Mr C understood the information relevant to his decision – including that if he did not have the surgery, he could die. He was also found to believe this information ‘in his own fashion’ and to be able to use this information to reach a decision. Therefore Mr C was permitted to refuse the amputation.
6.3.1 Discussion 4

Although Case 3 happened in England, the test for capacity set out in Case 3 applies in Ireland as well. A Bill on Mental Capacity is due to be published and this is likely to become law in 2010. The standard for capacity set out in the Bill is likely to be more or less the same as that in Case 3. There are a number of features of the test for capacity as set out in Case 3 which merit further reflection in an end of life context.

First, all persons are to be presumed to have capacity. Just because a person is very old, or mentally ill, or intellectually disabled does not mean that a person can be presumed to lack the capacity to make his or her own decisions. It is especially important to remember this when dealing with older patients or patients with intellectual disabilities. Quinlan and O’Neill (2009, p.48) note the following view offered by one practitioner:

‘I think the most obvious place where patient autonomy falls down is with ageism. If somebody is 30 or 40 or 50 we are much more likely to pay heed to what they’re saying and involve them. If somebody is 70 or 80 or 90 we’re much less likely to so. As a sweeping statement I think patient autonomy tends to decrease with age and I don’t think there’s a good reason for that but I think that is the practice of what happens.’

A second important aspect of the test for capacity as set out in Case 3 is that, in most cases, it will be health professionals who will decide if a patient has capacity or not. This places an onus on health professionals to acquaint themselves with the legal test. As Shaun O’Keefe notes, this also presents challenges for many professionals (2008, p.44) who may be unfamiliar with the test for capacity or who may be unsure of what exactly is required. Respect for the principle of autonomy requires that capacity be assessed in a way which is fair and appropriate and which is free from prejudices based on external factors such as old age, mental illness or intellectual disability (Donnelly, 2009b).

A final point about Case 3 is that capacity should be seen, not just as a characteristic which must assessed, but as a characteristic which must be developed. This view of capacity is consistent with the positive right of autonomy which is put forward in this module. Research shows that patients’ capacity can often be enhanced by quite simple steps, such as breaking down information into smaller ‘bites’ or making efforts to talk to patients in a way that they will understand (Gunn 1999, p.276). Clearly, this requires effort on the part of health professionals and, like many of the other efforts which delivering on the positive right of autonomy requires, this needs resource allocation. Time and commitment are crucial in deciding what can be achieved in terms of helping a person make autonomous decisions.
In relation to young people, the starting point for capacity is section 23 of the Non-Fatal Offences Against the Person Act 1996. This states that:

‘The consent of a minor who has attained the age of 16 years to any surgical, medical or dental treatment which, in the absence of consent, would constitute a trespass to his or her person, shall be as effective as it would be if he or she were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be necessary to obtain any consent for it from his or her parent or guardian.’

This means that once a person is 16 years old, she or he can consent to treatment and the consent of her or his parents is not required.

Section 23 does not mention the refusal of treatment. This leads to the question of whether a person aged 16 or more can refuse treatment in the same way as she or he can consent to it. This issue has not come before the Irish courts. It might be argued that consent and refusal are clearly two sides of the same matter and that the right to consent automatically includes the right to refuse treatment. However, the English courts, working with a broadly similar legal position, have held that the refusal of treatment is not the same as consent to treatment. This meant that a young person (below the age of 18) may have the automatic right to consent to treatment but does not have an equivalent right to refuse treatment. Instead, if a young person proposes to refuse treatment, the court must determine if this is in the best interests of the young person.

There is a strong possibility that the Irish courts would adopt a position similar to that taken by the English courts. In such a situation, the young person’s views would have to be taken into account in deciding if treatment should be given.
6.3.2 Suggested Professional Responsibilities

- If a question arises in respect of whether a person has decision-making capacity, it is the responsibility of the professional/s involved to investigate capacity.

- If in doubt in this respect, the professional should seek a second opinion from another professional with expertise in the area of capacity assessment (perhaps a psychiatrist or a geriatrician depending on the circumstances).

- If doubts remain, legal advice should be sought.

- Professionals should familiarise themselves with the legal test for capacity as this is the relevant test to determine whether or not a person is legally entitled to make decisions.

- Professionals should presume that patients have decision making capacity and should assess capacity in a way which is fair and free from prejudices based on old age, mental illness or intellectual disability.

- Professionals should seek to facilitate people of borderline capacity in making decisions for themselves insofar as this is possible. This may require breaking information down into more easily understandable ‘chunks’ and making efforts to talk to patients in a way which they can understand.

6.4 Case 4: Voluntariness and Decision-Making Freedom – Families and Patients

Respect for the positive right of autonomy requires that necessary efforts are made to ensure that patients are free to make their own decisions. This does not mean that professionals should not engage with patients or seek to inform them. Nor does it mean that professionals should not offer their own views as to what is the most appropriate treatment option or seek to persuade patients in this regard. The positive right of autonomy requires professional engagement not professional withdrawal. But, ultimately, the patient must be facilitated in feeling that he or she is free to make decisions and that decisions are not made simply to keep the relevant health professionals happy.
Interviews with hospital staff make clear that the role of family in decision making is among the most challenging of all ethical and legal topics. The challenges for a model of respect for autonomy of the patient while at the same time recognising the importance of families are evident in Case 4 which is taken from Quinlan and O’Neill (2009, p.59).

Families and Patients’ Decision-Making Freedom

I can think of an example a few weeks ago where this man just used to do the answering for his wife and, you know, like he did respect her decisions but he kind of – she had a brain tumour and he kind of used to answer the question before you’d get a chance to hear her answer and when we were offering her – her balance was very unsteady and we were offering her a place in the hospice and he said ‘no, no she can go home, we’ll manage at home.’ And, you know, I suppose he was just not ready to let her go to the hospice and really keen to take her home and she went along with that but I felt that deep down, you know, if he was more open to the idea she’d have been more open to it as well because she was fearful that if she was at home the dogs would knock her over and that, you know, or that she’d be for periods on her own in the house – things like that.

6.4.1 Discussion 4

Keeping contact and communication with family is an essential component of a good framework for end-of-life decisions. Family input can be especially valuable with dementia patients. As one practitioner noted:

‘We depend a lot on the relatives, you know, for the information we receive as well. Communication with family is a big thing really in the elderly. They know the person better. And I think it’s right that we listen to the family […] that’s one good thing here, that the family are always welcome all day and they’re involved a lot in the care.’ (Quinlan and O’Neill, 2008).

However, the position may not always be so straightforward. Another practitioner notes:

‘There’s nieces an nephews who would know very little […] they turn up and make decisions that sometimes we know in our heart and soul the man would never have wanted.’ (Quinlan and O’Neill, 2008)
Case 4 reminds us that sometimes family members can limit patient autonomy. This can sometimes have negative effects for the patient and can lead to a patient being deprived of treatment which could make his or her dying easier or more pain-free. One palliative care physician explains in Quinlan and O’Neill (2009) that family can exert pressure to the point of not allowing their relative access to palliative care because they pressurise physicians to agree not to tell patients their diagnosis (See Module 2). Patients in this situation may also be placed in a very lonely and frightening position with nobody to talk to about their concerns. Respect for the positive right of autonomy requires that efforts are made to engage with the patient him or herself as an individual and not simply to deal with the patient through family members.

6.4.2 Suggested Professional Responsibilities 4

- Professionals have an obligation to provide honest advice to patients, including about treatment options. However, advice should not be allowed to become coercive. Patients should not be in any doubt that decisions are his or her to make.
- Professionals should recognise the pressures which families can place on patients in end-of-life contexts. While recognising the importance of communication and engagement with family members, professionals should make efforts to ensure that the patient is not pressured into making decisions about end-of-life care which do not accord with what he or she wants or needs in order to keep family members happy.

Health professionals may need to reassure both the patient and the family that the primary duty is owed to the patient. While this needs to be done sensitively, it is essential that this primary duty is maintained and that all parties involved are aware of it.

6.5 Case 5: Preserving Patient Autonomy - Advance Directives in Practice

While the role of patient autonomy where a patient has capacity is fairly straightforward, the issue becomes more complex when a patient lacks the capacity to make healthcare decisions. A lack of capacity can arise in two circumstances. A patient who formerly had capacity to make decision may have lost capacity, perhaps in an older patient due to conditions such as dementia or Alzheimer’s disease. Other patients may never have had capacity to make decisions. These may include very young patients or patients who have significant intellectual disabilities.

For patients who once had capacity, it is possible in some circumstances to preserve patient autonomy, to a degree at least, even after a patient has lost capacity. There are two main
ways in which this can be achieved. These are Advance Directives/Decisions and Enduring Powers of Attorney.

An Advance Directive or decision (sometimes known as a ‘living will’) is a decision made by a person while he or she has decision-making capacity regarding the medical treatment he or she would wish to receive (and more frequently not to receive) if he or she subsequently loses capacity. An Advance Directive may be stated in very general terms: i.e., ‘I would not wish to receive treatment for cancer’ or in much more specific terms: i.e., outlining specific treatments that a person would not wish to receive, for example, a patient may request a DNR or do-not-resuscitate order to be placed on his or her notes stating that he or she would not wish to be artificially resuscitated in certain circumstances. Advance Directives are usually made in writing and this is advisable because it provides a clearly indication of the person’s wishes.

An Enduring Power of Attorney is a document, again drawn up when a person has legal capacity, which gives another person (sometimes known as the donnee of the power) the power to make certain kinds of designated decisions if the person who drew up the Enduring Power of Attorney subsequently loses capacity. The principle behind this model for decision-making is that the substitute decision-maker will act in a way which represents the views of the person who has lost capacity. In this way, the autonomy of the person is preserved even though he or she has lost decision-making capacity.

The advantage of the Power of Attorney model for decision-making when compared with the Advance Directive model is that it allows for a more nuanced and complex approach to decision-making. The person granting the power does not have to make firm advance decisions (although he or she may do so and communicate these to the person to whom the Power of Attorney is given) but can rely on his or her representative to act on his or her behalf. The substitute decision-maker can take account of all the factors, including developments in medical science, past wishes and current attitudes and situations in order to reach a decision about healthcare, including when life-sustaining treatment should be withdrawn. Clearly, however, this model requires a good deal of trust to be placed with the person granted the Power of Attorney. Depending on the circumstances, he or she has enormous control over the health and possibly even the life of the person who now lacks capacity.

Legislation regarding Advance Directives has been common place in the United States since, at least, the mid 1990s. More recently, in England and Wales, the Mental Capacity Act 2005 allows for advance refusals of treatment (but not for advance requests regarding treatment) and for the appointment of Enduring Powers of Attorney. There is no legislation in Ireland.
However, it is likely that in a non-contentious case, especially where a patient had a terminal illness, an Advance Directive would be considered to be binding. Certainly, there is a strong ethical imperative to respect the stated wishes of the person in the Advance Directive.

Three recent Irish reports have called for the introduction of Advance Directives in legislation (Irish Council for Bioethics, 2007; Law Reform Commission, 2008; Law Reform Commission, 2009).

This view seems to be shared by healthcare practitioners, one of whom says:

“I actually think that we should start bringing in Living Wills, I really do because by the time it comes to the end of their lives, most of our patients don’t have a say because they’re either confused or they’re not comatosus. You will try and listen to the ones that are and if you can make it possible you will make it possible but I do think we should bring in some sort of Living Will.’

(Quinlan and O’Neill, 2009, p.47)

The Law Reform Commission (2009) proposes the introduction of legislation dealing specifically with Advance Directives. The Commission’s Report sets out a draft Mental Capacity (Advanced Care Directives) Bill 2009. It proposes that this would apply to refusals of treatment only. However, the Commission recommends that a person should not be able to refuse basic care, which includes warmth, palliative care, nutrition and hydration.

The draft bill also provides for the nomination of a healthcare proxy to carry out the wishes of the person.

Current Irish law does not permit Enduring Powers of Attorneys to be made in respect of healthcare decisions (although it does allow them in respect of property and welfare decisions). It is likely that a limited Enduring Power of Attorney to make healthcare decisions will be included in the forthcoming Mental Capacity Bill. However, it is unlikely that this will extend to decisions at the end of life.

As matters currently stand, very few people provide advance instructions as regards how they would wish to be treated towards the end of their lives (Weafer, McCarthy and Loughrey, 2009). One practitioner notes that ‘a lot of people in Ireland don’t discuss or think about end-of-life decisions. I haven’t really had any experience where people have made a decision beforehand’ (Quinlan and O’Neill, 2009, p.42). In fact, research in other countries shows that this is not a uniquely Irish phenomenon (Francis 2001, p.561). In the United States, where legislation on Advance Directives has been in effect for many years, a relatively small number of people make Advance Directives.
There are many reasons why people, even people who are serious ill or elderly, may not choose to take this step. There may be an inherent privacy and reticence. Or there may be an understandable reluctance to face up to the unhappy prospect of death, serious illness or dementia. However, there are strong reasons why people who wish to make these kinds of decisions should be facilitated in doing so.

An Advance Directive allows patients to direct their care even beyond incapacity. As Case 5 shows, this allows patients a degree of control which would otherwise be impossible. Case 5 is based on the facts of an English decision.

**Advance Directives in Practice**

AK was a young man with progressive motor neuron disease. While he still had the ability to communicate, he made an Advance Directive setting out what should happen when he lost this ability. The directive stated that, when he signalled an intention – by blinking his eye in a particular way – this was a communication that ventilation should be withdrawn.

The English Court approved the directive and when AK indicated that ventilation should be withdrawn, this was carried out with appropriate palliative care.

**6.5.1 Discussion 4**

Case 5 is somewhat unusual in that AK did not lose the capacity to make treatment decisions as is normally the case where Advance Directives are employed. Rather, he lost the ability to communicate these decisions. However, from a practical point of view, loss of the ability to communicate decisions is similar in effect to loss of the ability to make decisions.

Case 5 also reminds us that Advance Directives can serve to preserve life as well as decide when life should end. AK could have declined ventilation when it became necessary through a straightforward exercise of his right to refuse treatment. However, he was a young man who did not want to die at that time. He wanted to gain the maximum from his life for the time he had left. Because he could make an Advance Directive, he was able to avail of the possibilities for a longer life offered by ventilation while still ensuring that, at a time of his choosing, the treatment could be withdrawn. In this very sad situation, also, the knowledge that he had a means of control may have given the young man in Case 5 some consolation and fortitude and helped him to get the maximum benefit from the time he had left.
However, while Advance Directives are important tools in furthering patient autonomy, they are not without ethical, or indeed legal, complexity. The liberal legal philosopher, Ronald Dworkin, himself a strong proponent of Advance Directives, uses an example based on a woman called Margo to explore the challenges to which Advance Directives give rise (1993, p.201).

In the example, Margo has Alzheimer’s disease and has no long term memory and minimal short term memory. She is very contented and spends her days listening to music, reading (choosing pages at random) and painting pink circles. Her doctor described Margo as ‘the happiest person I know’. Dworkin imagines that Margo has made an Advance Directive stating that if she develops Alzheimer’s disease, she wishes to decline all medical interventions. He also imagines that Margo now develops a form of cancer which is easily treatable and for which treatment is relatively un-invasive and has a high likelihood of success. In other words, it is clearly in Margo’s current best interests that she should receive treatment. He asks whether Margo should receive the treatment notwithstanding her Advance Directive.

Dworkin himself argues that Margo should not receive the treatment. He argues that her prior expressed wishes should take priority because respecting the autonomy of a capable person is the most important value. Other commentators such as Dresser (1986) disagree. She argues that Advance Directive are important but that they do not justify overriding the current best interests of a person who now lacks capacity. Dresser argues that the person lacking capacity should not be bound by the decisions of his or her former, capable self. Rather the current person’s best interests should take priority over his or her previously expressed views. Court cases on advance refusals of treatment have tended to support Dresser’s view rather than Dworkin’s.

The ‘Margo’-type situation is unlikely to occur frequently. Most of the time, in end-of-life contexts, there will not be a clear conflict between what a patient’s Advance Directive proposes and his or her best interests. Rather, as in Case 5, the Advance Directive will dictate at a level of detail how the person should be treated. In this, Advance Directives can play an important role in allowing patients to retain control over their future care.
6.5.2 Suggested Professional Responsibilities

- Although the legal framework for advance decision making is still limited in Ireland, professionals should engage with patients where possible in order to ascertain the treatment they would wish to receive if they lose capacity.

- Most of the time, there will not be a clear conflict between the patients’ wishes expressed while capable and his or her best interests. In such a situation, the professional should take account of the previously expressed wishes in making decisions about treatment.
7. Module 4 Further Discussion

Autonomy is an important legal and ethical principle. The view of autonomy taken in this module is of autonomy as a positive right to control together with the steps required to make this meaningful, as well as a negative right to refuse treatment. This ethical conception of autonomy is broader than the legal conception. But this broader view is more helpful in thinking about decisions at the end of life.

7.1 Implications of the Positive Right of Autonomy

Autonomous decisions must meet three requirements: the patient must have adequate information; he or she must have capacity and he or she must act freely without undue pressures from health professionals, family members or others. In respect of each of these requirements, there is a positive obligation to assist the patient in making autonomous decisions. This means that autonomy requires a good deal from health professionals and a commitment to autonomy will require resources. It is much less likely that pressured staff with limited resources and facilities will be able to dedicate the time and energy necessary to deliver autonomy as a positive right.

7.2 Participation by People Lacking Capacity

An important final point to note relates to those patients who lack the capacity for autonomous decision-making, whether because they are too young or because they have dementia or another capacity-impairing condition. It should not be presumed that, simply because a person lacks the capacity to make an autonomous decision, his or her views should simply be disregarded. Patients who lack decision-making capacity have a right to participate in decisions made about them.

As discussed in Module 3, the United Nations Convention on the Rights of the Child requires that children be permitted to participate in decisions in accordance with their age and maturity (Kilkelly and Donnelly, 2006). The United Nations Convention on the Right of Persons with Disabilities and Council of Europe Recommendation on Incapable Adults impose similar requirements in respect of adults lacking capacity. It is highly likely that the proposed Mental Capacity Bill will also include a requirement to this effect in respect of adults.

It is not always easy for professionals to find a way to facilitate participation in end of life decisions by patients lacking capacity. As one professional interviewed by Quinlan and O’Neill (2009, p.54) recounts:
'A child who is on the cusp of having their own autonomy, you’re looking at teenagers, and we see children here from premature babies up to 18, 19 and sometimes 20. We see children with intellectual disabilities as well and the whole role of autonomy for somebody with an intellectual disability and the challenges that poses, in terms of can they be autonomous? Are they allowed be autonomous? Whether that is from their parents’ side of things or from the medical point of view or the child’s own abilities. That’s a huge challenge.'

This professional identifies the challenges involved. However, there are ways in which patient participation can be facilitated notwithstanding the fact that a patient lacks capacity. The Code of Practice to the English Mental Capacity Act (2007) provides a useful resource in setting out ways to facilitate participation by adults lacking capacity. These include using simple language, speaking at the appropriate volume and speed, using appropriate words and sentence structure, breaking down information into smaller points, and using illustrations and/or photographs to help the person understand the decision to be made. Where a person has communication or cognitive problems, possibilities are offered by the use of picture boards, Makaton, signing, technological aids. For some people who are restricted to non-verbal methods of communication, their behaviour and, in particular, changes in their behaviour may provide indications of their feelings (Donnelly, 2009a).

In making end-of-life decisions for patients lacking capacity, it is also possible to take account of the patient’s past wishes and preferences and to ask what the patient would have wanted if he or she had had capacity. Even if a person has not made a formal Advance Directive, there should be room for his or her prior preferences to be taken into account in determining what is in his or her best interests. In England, the Mental Capacity Act 2005 requires that, in making decisions about the best interests of a person lacking capacity, account should be taken of the person’s past and present wishes and feelings (and in particular any written statement made by the person when he or she had capacity) and of the beliefs and values that would be likely to influence the person’s decision if he or she had had capacity. It is likely that the proposed Irish legislation on capacity will contain a similar requirement.

It is not always easy to find ways to take account of the prior views of a person when these have not been formally stated in an Advance Directive. It is crucial to consult with families and friends as to what the person was like before this illness and to ask what he or she would have wanted in the situation that now arises. It is essential that a space be created where the person who is now without decision-making capacity can influence the process to the maximum extent possible (Donnelly, 2009a).
7.3 Traditional Views of Autonomy

Because of the significance attached to autonomy, respect for autonomous choice is a core element of many different philosophical and political theories. Two philosophers, the eighteenth century German, Immanuel Kant (1724-1804), and the nineteenth century Englishman, John Stuart Mill (1806 - 1873), have greatly influenced the way in which we understand what respect for autonomy involves.

7.3.1 Autonomy and Rationality

Kant appealed to the deontological belief that some things are intrinsically or inherently good, and that each person is intrinsically valuable or has unconditional worth because they have the capacity to be autonomous (See Module 1 for explanation of the deontological moral theory). For Kant, human dignity resides in the fact that each person has a free will which they can follow independently of their passions or desires. On his view, human beings can be distinguished from many other sentient creatures because, unlike animals, they are not wholly determined by their own immediate desires.

Believing that human beings are able to act freely and independently of personal desires, loves and hates, Kant argued that they are capable of prescribing general moral rules or principles for themselves to follow. They can legislate for their own conduct. The neo-Kantian, Thomas Hill, takes this to mean that:

\[
[T]he\text{\,}\text{autonomy\,of\,a\,moral\,legislator\,means\,that,\,in\,debating\,basic\,moral\,principles\,and\,values,}\text{\,}\text{a\,person\,ideally\,should\,not\,be\,moved\,by\,blind\,adherence\,to\,tradition\,or\,authority,\,by\,outside}\text{\,}\text{threats\,or\,bribes,\,by\,unreflective\,impulse,\,or\,unquestioned\,habits\,of\,thought[\ldots]\text{.\,}must\,try\,not\,to\,give\,special\,weight\,to\,his\,or\,her\,particular\,preferences\,and\,personal\,attachments\,[\ldots]\text{.\,}In\,other}\text{\,}\text{words,\,at\,the\,level\,of\,deliberation\,about\,basic\,principles,\,morality\,requires\,impartial\,regard\,for\,all}\text{\,}\text{persons}\text{\,}(\text{Hill, 1991, p.45})
\]

On the Kantian view, human beings have a capacity for free, rational and impartial decision-making. This means that they are able to decide a course of action on the basis of careful reflection, and in the absence of coercion from authority or custom. In addition, they can decide the best course of action independently of their own personal preferences or inclinations.

It is on the basis of this kind of autonomous capacity that each human being has a special status that deserves protection and respect for Kant. In his terms, failing to respect a person's autonomy would involve treating that individual merely as a means to another's ends, and not in terms of their own ineliminable value:
7.3.2 Autonomy and Individuality

In his well-known thesis in On Liberty ([1859], 1991), John Stuart Mill also promoted respect for individual autonomy (or liberty), but on grounds different from those suggested by Kant. Mill viewed each person as worthy of respect, not because of their rationality or impartiality, but because of their unique individuality. He appealed to the utilitarian view – that an action is morally good if it gives rise to more good than evil – to support his position (See Module 1 for an explanation of the utilitarian theory). For Mill, respecting individual autonomy gives rise to more good than evil; society ought to respect autonomy because, in the long term, society benefits from doing so:

‘The worth of a State, in the long run, is the worth of the individuals composing it… a state which dwarfs its men in order that they may be more docile instruments in its hands even for beneficial purposes – will find that with small men no great thing can really be accomplished.’

(Mill, [1859], 1981, p.187)

In other words, on the Millian view, individual freedom is compatible with, and contributes towards, the good of society as a whole. It follows that a person ought to be allowed to act according to their own life’s plan and their own beliefs and values, whether or not their actions are considered wise or good or foolish by everyone else. (One needs to read Mill’s text as referring to both genders when he uses the language of ‘small men’ etc.)

For Mill, autonomy is not an absolute right. On his view, a state, or an individual, is justified in interfering with a person’s liberty when their action causes harm to others (this is known as the harm principle). He distinguishes between public and private morality, between those actions which affect others in society; ‘other-regarding’ actions, and those which affect only ourselves; ‘self-regarding’ actions. This is a classic liberal position which holds that the freedom of the individual can be compromised only when it is in competition or conflict with the rights and freedoms of other individuals. Respect for autonomy requires, on this view, that we refrain from interfering with the self-regarding acts and decisions that people make.

‘[T]he only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better
for him to do so, because it will make him happier, because, in the opinions of others, to do so would be wise, or even right. These are good reasons for remonstrating with him, or persuading him, or entreating him, but not for compelling him, or visiting him with any evil in case he does otherwise.’ (Mill, [1858], 1981, p. 68)

(See Module 7 for an example of the application of the harm principle in relation to patient confidentiality.)

7.4 Relational Autonomy

While, the principle of autonomy is one of the cornerstones of contemporary bioethics it is a highly complex and problematic one. Some thinkers repudiate the concept altogether, while others accept its value but dispute the meaning which has been attached to it. For example, some thinkers refuse to accept the concept of the autonomous self central to modern Western philosophy – namely, the depiction of the self in abstract, asocial terms as an independent and rationally self-sufficient individual – and demand a new conception of autonomy which recognises the inherently social nature of human beings (MacIntyre, 1981; Sherwin, 2008; Taylor, 1989). According to this interpretation, the self is essentially social:

‘We are not isolated atoms, or islands, or self-contained entities, but rather products of historical, social, and cultural processes and interactions. The existence of any person is dependent on the existence and social arrangements of many others. Our interests are discovered by and pursued within social environments that help to shape our identities, characters, and opportunities. […] relational autonomy […] requires us to examine the types of options on offer and ask questions about how these have arisen and also about options that are not available or accessible.’ (Sherwin, 2008, p.12)

One of the implications of viewing the self as profoundly social is to accept that one’s actions are determined or influenced by one’s social context. Secondly, one’s social attachments may motivate one’s actions, and, finally, one’s very identity may be constituted by these social attachments (Barclay, 2000).

In the first of these senses, the relational autonomy position rejects the idea of autonomy as simply a matter of deciding what one wants or desires. Relational theorists insist that attention is paid to the social circumstances which inform or ground desires of any kind. Such social circumstances include social norms and oppressive patterns. The skills and competencies for the exercise of choice to begin with include self-trust, self-understanding and self-direction, self-worth – and these may be undermined or made possible in the
company of others. On this view, the actions of individuals are framed and contrained by the opportunities available to them. In addition, the ability to imagine and pursue a course of action depends on options available.

Autonomous capacity, on the relational view, can be understood as the ability to negotiate the effects of socialisation by actualising certain capacities, including the capacity to choose preferences, goals and projects and make them one’s own (Barclay, 2000, p.54-5). The implication of this view for health professionals and organisations is to enable patients to develop their capacity to direct their care: autonomy is not simply something that is assessed but it is something that is developed (Barclay, 2000, p.57).

A second implication of viewing the self as social is to see the self as ‘motivationally social’; that is, primarily motivated to act, not by rational self-interest or by a striving for self-sufficiency – as caricatures of the modern ideal of autonomy would suggest – but by a sense of solidarity and by deep attachments to other people (Barclay, 2000, p.60). This view, is supported by international and Irish research with patients and families who are terminally ill and who often prioritize the interests of their loved ones over their own (Quinlan 2009a; Weafer, McCarthy and Loughrey, 2009).

The third sense in which the self may be described as social – the ‘constitutively social’ self – involves understanding one’s identity as a product of one’s social relationships and attachments. On the view of the philosopher, Michael Sandel, for example, the goals and ends which define us as who we are, are not private, but shared; they are the goals and ends of the communities of which we are a part and they are formed by participation in these communities. We don’t so much choose these ends as discover them when we reflect on who we are and what we aspire to (Barclay, 2000, p.65). For Sandel, the classic expression of the rational exercise of autonomy involves a person ranking their desires and choosing that plan of action which will satisfy as many of their principal desires as possible. Against this, Sandel argues that even the evaluation of our desires presupposes a set of socially-shared values which constitutes who we are; it is this set of ‘constitutive values’, rather than our desires per se, which forms the foundation for our choices and actions.

Finally, it has been suggested feminists such as Barclay (2000) and Sherwin (2008) that the fact that our choices are socially determined and our identities are socially mediated opens up the possibility of change and liberates us to choose reflectively which values to endorse and which goals to prioritise. And this reflection upon which relationships and attachments we choose to promote does not undercut, but reinforces, the importance of the capacity for autonomy, understood as relational.
### 8. Module 4 Summary Learning Guides

#### 8.1 The Nature of Autonomy

- The right of autonomy protects a person’s interest in making significant decisions about his or her own life
- Autonomy is not just a negative right – a right to say no but also a positive right – a right to be facilitated in taking control of one’s dying to the maximum extent possible
- Autonomy is especially important in a hospital setting
- Concern with autonomy is to some extent a cultural phenomenon which is especially associated with Western liberalism

#### 8.2 The Legal Right of Autonomy

- This right is protected under the Irish Constitution and the European Convention on Human Rights
- The legal right is very often seen as a negative right – a right to refuse treatment
- As part of protection of the legal right of autonomy, capable adults have the right to refuse medical treatment even if the refusal leads to their death
- But there are some limits: duties to others may arise – the extent of these duties is not clear

#### 8.3 Information is Key to Autonomy

- The positive right of autonomy requires that patients are informed
- ‘Informing’ in this sense requires more than simply passing on information: communication is essential
- ‘Informing’ is an ongoing process – it is not a once-off event
- Legal requirements in respect of information provision are insufficient in protecting a patient’s positive right of autonomy
8.4 The Role of Decision-Making Capacity and Freedom

- Legal capacity is a prerequisite for the legal right of autonomy
- For adults, legal capacity requires that the person can understand information relevant to the decision; believe the information and use the information to make a decision
- Young people can consent to treatment from the age of 16
- There is still legal uncertainty regarding whether young people from the age of 16 can refuse treatment (if the refusal is not considered to be in the young person’s best interests)
- To be autonomous, decisions must be freely made

8.5 Advance Decision-Making

- An Advance Directive or ‘Living Will’ is a binding instruction made by a person with capacity about the treatment that the person would wish to receive or to refuse if he or she subsequently loses capacity
- There is no legislation in respect of Advance Directives in Ireland. However, the courts have approved Advance Directives in principle
- An Enduring Power of Attorney allows a person with capacity to designate a person to make decisions on his or her behalf if he or she subsequently loses capacity.
- Although there is legislation on Enduring Powers of Attorney in Ireland, it does not currently include healthcare decisions
- Advance Directives and enduring powers of attorney provide a means of preserving autonomy after losing capacity
8.6 Autonomy and the Person without Capacity

- The fact that a person lacks capacity does not mean that his or her views should be completely disregarded.
- It is important that a person without capacity be facilitated in participating in decisions about end-of-life care where possible.
- Efforts must be made to take account of the past preferences of a person without capacity and of what he or she would have wished to happen in a situation like this. Consultation with family and friends about what the person would have wanted is essential.
9. Module 4 Activities

9.1 Recall the distinction between the positive right of autonomy and the negative right of autonomy:

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

b. What actions on the part of health professionals are needed to give effect to a negative right of autonomy?

c. What actions on the part of health professionals are needed to give effect to a positive right of autonomy?

d. Which form of autonomy is easier to deliver?

e. Which form of autonomy is most important? Or are both equally important?

9.2 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 the woman in this case should have been required to experience life outside the confines of the ICU before her decision to have ventilation withdrawn was respected?

c. In your view, is there a conflict between health professionals’ ethical duty to care on the one hand, and legal duty to respect a patient’s refusal of treatment, on the other? If there is a conflict, how should this be resolved?

9.3 Reflect back on the particulars of Case 2:

a. In your experience do patients often actively seek information towards the end of life?

b. Why is information essential to the positive right of autonomy?

c. Set out the information which, in your view, is most important for patients to receive in order to help them make autonomous decisions?

d. Do communication breakdowns occur often in practice; if so, what steps can usefully be taken to avoid this occurring?

9.4 Reflect back on the particulars of Case 3:

a. What are the requirements for the legal test for capacity? Do these requirements strike you as sensible? Try to imagine yourself applying these requirements to a real patient that you have met in the course of your work?

b. Does it strike you as sensible that the law regards capacity as a threshold concept and not a comparative one? Can you see any reasons for the law’s approach? Can you see any difficulties with applying this approach in practice?
c. In your view, do professionals in practice make assumptions about capacity in respect of certain categories of patient? If so, which categories?

d. Do you believe that a patient’s capacity can be enhanced? If not, why not? If so, what in your view are the most appropriate ways to enhance patient capacity?

9.5 Reflect back on the particulars of Case 4:

a. In your view, is it ever possible for a patient to make a wholly independent decision? If not, why not? If so, why?

b. At which point, in your view, does a professional begin to exert an inappropriate degree of influence on patients in decision-making at the end of life?

c. To what extent does a professional have an obligation to protect a patient against the pressures of family members? What difficulties do you think professionals experience in this kind of context?

9.6 Reflect back on the particulars of Case 5:

a. What role, in your view, should Advance Directives play in end of life care?

b. Reflect on the case of Margo. In your view, should Margo have had the treatment for cancer notwithstanding her express statement in an Advance Directive that she did not want this treatment? If so, why; if not, why not?

c. Do you think that many Irish people are likely to make Advance Directives? If so, why? If not, why not?

d. Which form of advance decision-making do you think works best: Advance Directives or Enduring Powers of Attorney? What are the limitations in each model?


a. Is participation important even for patients who lack decision-making capacity? If so, why? If not, why not?

b. Can you think of ways to enhance the autonomy of adults who lack decision-making capacity?

c. Can you think of ways to enhance the autonomy of children who lack decision-making capacity?
10. Module 4 References and Further Reading


Council of Europe Committee of Ministers. (1999). Recommendation no. R (99) 4 of the committee of ministers to member states on principles concerning the legal protection of incapable adults. Strasbourg: Council of Europe.


Fitzpatrick v K [2008] IEHC 104.


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


JM v Board of Management of St Vincent’s Hospital [2003] 1 IR 321.


Mental Capacity Act 2005 (England and Wales).


Re AK (Medical treatment: consent) [2001] 1 FLR 129.


Re C (Adult: Refusal of Medical Treatment) [1994] 1 WLR 290.

RE K ex tempore High Court Abbott J 22 September 2006.


