Module 6

The Ethics of Life Prolonging Treatments (LPTs)
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1. Module 6 Key Points

1.1 Advance Care Planning (ACP)
is at the centre of efforts to promote patient-centred care. ACP offers choice and respects the
right of persons to consent to or refuse treatment and care offered. At present, legislation
in Ireland covering advance care plans such as advance directives is not available though in
2009 the Law Reform Commission published a report recommending that provisions be put
in place to recognise validly drawn up advance directives. Nothing in ACP can authorise a
health professional to do anything that is illegal.

1.2 Withholding and Withdrawing LPTs
such as ventilators, dialysis machines, chemotherapy and the sophisticated technology of the
intensive care unit are ethically and legally accepted practices that should ideally be specified
in advance care plans or directives.

1.3 Withholding a Particular Treatment
for a particular patient is generally viewed as morally justified if the treatment is considered
futile (without benefit) or unnecessarily burdensome. It is often recommended that
decisions by a healthcare team to withhold life supporting treatment require the consent
of the patient and/or the patient’s family. However, such a viewpoint about the obligation
to achieve consent of patient/or family is contested. This would especially be the case
when the treatment under consideration is, on the basis of clinical evidence, deemed futile.
However, where conversation with patient/and or family is pursued, an essential element in
that conversation is that it must provide information on the nature of the treatment under
consideration, the likely consequences of its use, and the benefits and/or burdens expected
in the use of a particular LPT. This level of information is essential to help achieve patient
and/or family understanding so that they are better positioned to give genuine and valid
authorisation for refusal of LPTs.

1.4 Withdrawing Treatment Already Begun
is legally and ethically justified if it can be shown that the burdens of continued treatment for
a particular patient outweigh the benefits. If a patient is competent and if they so wish, they
should be central in the determination of what constitutes a ‘burden’. Withdrawal is normally
a decision taken with the patient and/or the patient’s family through conversation about the
patient’s sufferings and prognosis. If a patient lacks capacity, then the health professional,
usually in conjunction with any family or proxy, determines what is in the ‘best interests’ of
the patient.
1.5 A Common Misconception on the Topic

of withholding and withdrawing LPTs is that it is morally more serious to stop a LPT than it is to withhold it. This perception is explained by the belief that ‘stopping’ a life support is an ‘action’ and ‘withholding it’ is only an ‘omission’. Add to this perception, the belief that ‘actions’ are much more serious than ‘omissions’ and we can see how misunderstandings occur. However, omitting a therapy can be morally just as serious as any action taken in treating a patient. Whether something is an act or an omission is never adequate to determine the morality of the action.

1.6 Judgements of ‘Futility’

of treatments in end-of-life care are part of everyday life especially in ICU settings. Doctors have come to accept patients’ rights to refuse treatment yet they have increasingly encountered patients, or more commonly the families of incompetent patients, demanding treatment that the health professionals judge to be futile.
Module 6 Definitions

2.1 Advance Care Planning (ACP):
Is a process of discussion between an individual, their care providers and often those close to them, about their values and preferences for ongoing healthcare. This process may lead to formulation of an advance directive, an advance decision to refuse treatment or the appointment of a personal proxy to help interpret a person’s advance directive preferences.

2.2 Artificial Nutrition and Hydration (ANH):
Is a term commonly used in medicine to refer to methods for preventing or treating malnutrition and dehydration where a patient has a problem taking fluids or food orally. ANH requires invasive procedures supplied through the patient’s nose and throat (nasogastric tube), veins (IV line), stomach (gastrostomy), intestine (jejunostomy) or major vessel into the heart (hyper-alimentation). ANH is ethically controversial. Viewpoints differ about whether ANH is a form of universal human care and so always morally obligatory or whether it can be considered an optional treatment based on a benefit-burden judgement.

2.3 Cardiopulmonary Resuscitation (CPR):
Is a group of treatments used when someone’s heart and/or breathing stops. CPR was developed as a treatment intervention for cases of sudden unexpected cardiac or respiratory arrest. CPR is used in an attempt to restart the heart and breathing. It may consist of mouth-to-mouth breathing; chest compression, bag-and-mask positive-pressure ventilation, intubation and defibrillation. Electric shock and drugs are also frequently used to stimulate the heart.

2.4 Do Not Resuscitate (DNR):
A DNR order may generally be described as a note primarily written and signed by a doctor but which could involve the patient, healthcare team and family, stating that in certain circumstances should the patient suffer from cardiopulmonary failure, cardiopulmonary resuscitation (CPR) should not be attempted. Such an order is only relevant to not attempting CPR and not to the withholding of any other treatment.

2.5 Euthanasia:
Is a deliberate act or omission whose primary intention is to end another person’s life. Literally, it means a gentle or easy death but it has come to mean a deliberate intervention by one person with the clear intention of ending the life of another. This is often described as ‘mercy killing’ of people in pain with terminal illness. Decisions to withdraw or discontinue LPTs are not equivalent to euthanasia if they are validly authorised by a competent patient’s
consent or if a clinical decision is made that further life supports, based on all available evidence, would be futile – lacking in benefit for the patient and merely prolonging the dying process.

2.6 Life Prolonging Treatment (LPT):
is any medical intervention, technology, procedure or medication that is administered to provide benefit for a patient and to forestall the moment of death. These treatments may include, but are not limited to, mechanical ventilation, artificial hydration and nutrition, cardiopulmonary resuscitation, haemodialysis, chemotherapy, or certain medications including antibiotics.

2.7 Physician Assisted Suicide (PAS):
Assisted suicide is the act of helping a person to die by providing the means for them to take their own life. An example of physician assisted suicide is the act of giving a prescription or supply of a lethal dosage of drugs to a patient who has requested this. The doctor providing the lethal dosage thus enables a patient to end his or her own life.

2.8 Principle of Double Effect (PDE):
is an ethical rule which holds that effects of treatment which would be morally wrong if brought about intentionally are permissible if they are foreseen but unintended. The principle is often cited to explain why certain forms of care at the end of life which may risk and/or hasten death are morally permissible while others are not.

2.9 Principle of Proportionality:
states that whether or not a particular LPT for a patient is morally required should be evaluated in terms of its potential risks or burdens and probable benefits. If the risks or burdens to the patient outweigh the benefits, then the treatment is clinically inappropriate and not morally required. A fundamental ethical question in applying the principle concerns the issue of who takes part in any decision that determines the relative burdens and benefits of an LPT? If a patient has capacity and wishes to participate in decision-making, then their input is important in any judgement about benefits and burdens of treatments proposed.
Module 6 The Ethics of Life-Prolonging Treatments (LPTs)

3. Module 6 Background

In times past, people died from minor illnesses because science had not yet developed medical cures. Today, an impressive range of medical therapies and life-support technologies offer not only amelioration of disease but, at times, a considerable extension of good quality of life. A key ethical challenge that these medical and technological advances present is to determine whether there is always an obligation to prolong human life simply because it possible to do so.

In The Patient as Person (1970) Paul Ramsey claims that there are limits to our moral obligations to sustain life. Questions arise such as the following.

‘Must a terminal cancer patient be urged to undergo major surgery for the sake of a few months’ palliation? What of fragmented creatures in deep and prolonged coma from severe brain damage, whose spontaneous cerebral activities have been reduced to those arising from the brainstem but who can be maintained “alive” for years by a combination of artificial activators and by nourishment? Is there no end to the doctor’s vocation to maintain life until the matter is taken out of his hands?’ (Ramsey, 1970, p.115).

Admittedly, new treatments often benefit patients, restoring them to well-functioning lives. However, such treatments can also be used in situations where they may be neither a benefit to, nor wanted by, patients. Once pneumonia was an ‘old man’s best friend’ and was one way that nature ended a life that had become debilitated. Now the technology of LPTs brings new ethical decisions to decide when such technology is warranted and respectful of patient autonomy. In considering decisions to prolong life, one is also considering postponing the dying process. If decisions about the use of LPTs are made without attempting to understand the values and preference of patients in this regard, then such use of LPTs may be imprudent, inhumane and certainly unethical in failing to respect the patient’s own views of what should happen.

3.1 Autonomy and its Limits

In most European jurisdictions, it is well established that a patient with capacity has an unequivocal right to refuse medical treatment. This right of refusal is ethically defended by the principle of respect for patient self-determination or autonomy. Such a principle recognises that people have a right to act freely according to a self-chosen set of values and plan of life (See Module 4). This right to refuse treatment imposes limits on medical interventions and curtails judgements of clinicians to provide LPTs. Patients may request that a particular treatment not be given or, if it is already in place, that it should be withdrawn. The cases in this module illustrate this point.
Refusals by patients can be stressful for doctors and nurses especially if their own judgement would indicate a contrary decision to that given by the patient. However, it is generally accepted that unless health professionals have concerns about a patient’s capacity or consent, they should respect these refusals even contrary to their expertise, their best judgement and their emotional response.

Autonomy has its limits too. In law and to a great extent in ethics, the principle of autonomy confers mainly a negative right, a right to non-interference as explained in Modules 3 and 4. If patient autonomy were interpreted as conferring a positive right to treatment, this could entitle individuals to any requested treatment while ignoring medical advice and judgement and ignoring alternative claims for scarce healthcare resources (Gedge, Giacomini and Cook, 2007). A patient’s request for LPT does not have to be granted if health professionals judge the request to be without benefit for this patient in this particular condition. In brief, the clinician does not have to grant what he/she judges ‘futile treatment’. However, it is important that informative conversation with any competent patient be offered to ensure understanding of why a clinician refusal is given. Such communication is also an important opportunity to give hope to the patient and/or the family that a medical refusal of the patient’s request for an LPT or other therapy does not mean that they will be abandoned by health professionals or left without optimal palliative care.

### 3.2 Advance Care Planning (ACP)

Advance Care Planning (ACP) has become the gold standard for patient-centred care. The ACP might include an advance statement of wishes and preferences (Advance Directive), and/or an advanced decision to refuse treatment (ADRT) in a predefined potential future situation. The ACP may also include the appointment of a personal-proxy representative who would interpret the stated wishes of a patient when/if they lose capacity. This personal representative is not currently part of an Enduring Power of Attorney in Irish legislation but could be an informal provision requested by a patient and/or their family. ADC has been strongly recommended by numerous societies and medical and nursing colleges. National UK guidelines published by the Royal College of Physicians (2009) state the role of ACP in achieving the ethical objective of patient-centred care.

‘At the core of current health and social care are efforts to promote patient-centred care, offer choice and the right to consent to or refuse treatment and care offered. This can be difficult to achieve when an individual has lost capacity – the ability to make one’s own, informed decision. ACP may help in such scenarios.’ (Royal College of Physicians, 2009, p.2)
The objective of encouraging the use of ACP is not yet matched with reality in the uptake. In many countries, most deaths in intensive care are preceded by a decision to withdraw or withhold life support. However, clinicians, sometimes in conjunction with families, generally make the decisions about life support in intensive care as most patients are too ill to participate. Unfortunately, research indicates that few patients have ever discussed their life support preferences with a family member or their family doctor. This means that decisions by proxy or surrogate decision makers about end-of-life care and use of life supports may not accurately reflect patient’s wishes (Way, Back and Curtis, 2002).

3.3 Goals of Care

If healthcare decision making is be truly patient-centred and respectful of a patient’s wishes, then the goals of care must be clarified. The conversations toward patient consent discussed above are an essential part of establishing the goals of care. In fact, decisions about futility or starting or withholding life supports are impossible, in any case, without defining what the goals of caring for a patient are. It is necessary to consider such questions as: Should the focus be on pursuing curative therapies? On prolonging life? On palliating symptoms?

Determining the goals of care needs to consider the stage of a patient’s disease or prognosis and uncertainties related to this. What are the realistic treatment options and, very importantly, does the patient understand what these options are? What are the personal hopes, values and understandings of the decision-maker and the patient? The goals of care for any patient are not set in stone. They are dynamic and can change rather quickly. On-going reassessment of goals and on-going documentation is necessary to ensure quality of care that is clinically judged feasible and in keeping with the particular patient’s preferences.
4. Central Issues and Concepts in Decisions about LPTs

The moral concepts that are discussed in this section are guiding concepts in the process of making decisions at end of life. In the discussion of the concepts, readers may notice that there are certain recurring insights that reinforce elements of moral reasoning.

4.1 Starting and Stopping LPTs

Is the decision to stop an LPT morally more serious than the decision not to start an LPT? Health professionals sometimes feel morally uneasy about stopping a treatment that has been started. What explains this un-ease? In part, it is because stopping a treatment or therapy seems to ‘feel’ like ‘killing’ the patient. Stopping a treatment seems more akin to an active move that will certainly have consequences. In contrast, not starting a therapy or treatment seems more acceptable, apparently because it involves an omission rather than an action. Health professionals may believe that decisions to stop treatments are more momentous and consequential than decisions not to start them. Stopping a respirator, for example, seems to cause a person’s death, whereas not starting the respirator does not seem to have this direct causal role. In fact, both actions and omissions can have a causal role in a patient’s demise.

If we adopt the view that treatment, once started, cannot be stopped, or that stopping requires much greater justification than not starting, then it is likely this view will have serious adverse consequences. Treatments might be continued for longer than is optimal for the patient, even to the point where it is causing positive harm with little or no compensating benefit. An even more troubling wrong occurs when a treatment that might save life or improve health is not started because the healthcare personnel are afraid that they will find it very difficult to stop the treatment if, as is fairly likely, it proves to be of little benefit and greatly burdens the patient. Fear of being unable to stop treatment can lead to failure to treat. Ironically, if there is any call to draw a moral distinction between withholding and withdrawing, it generally cuts the opposite way from the usual formulation: greater justification ought to be required to withhold than to withdraw treatment. (President’s Commission 1983: 75-6)

Morally speaking, then, in some circumstances, it may be more serious to withhold than to withdraw treatments. It may be highly uncertain whether a particular treatment will have positive effects before it has been tried. Therefore, if we decide not to start a treatment for a particular patient who is not imminently dying, we may be losing the opportunity to glean evidence of patient response – perhaps even improvement from the treatment.
‘If a trial of therapy makes clear that it is not helpful to the patient, this is actual evidence (rather than mere surmise) to support stopping because the therapeutic benefit that earlier was a possibility has been found to be clearly unobtainable.’ (President’s Commission 1983: 76).

Feelings of reluctance about withdrawing treatments are understandable but ‘not starting’ and ‘stopping’ can both be justified depending on the circumstances of a particular case.

‘We conclude that the distinction between withholding and withdrawing is morally untenable and can be morally dangerous. Decisions about beginning or ending treatment should be based on considerations of the patient’s rights and welfare, and, therefore, on the benefits and burdens of the treatment, as judged by a patient or authorised surrogate.’ (Beauchamp & Childress 2001: 122)

### 4.2 Ordinary and Extraordinary Treatment

A Spanish Dominican theologian, Francisco De Vitoria (1486-1546), offered the first explicit treatment from the Catholic tradition about one’s obligation to prolong life by providing food and medicinal drugs. However, it was Domingo Bañez (1528-1604) who introduced the terms ‘ordinary’ and ‘extraordinary’ into the discussion of morally obligatory and morally optional means of preserving life. In a short time after this terminology was introduced, the distinction became firmly established in both the Catholic moral tradition and secular contexts of medical practice. This distinction still operates today and is often used as a rule of thumb by health professionals.

#### 4.2.1 Ordinary Means

Ordinary means are all medicines, treatments, and operations, which offer a reasonable hope of benefit and which can be obtained and used without excessive expense, pain, or other inconvenience. Such treatments would normally be considered morally obligatory.

A medical treatment, usually considered ordinary, such as antibiotics, or medically assisted nutrition and hydration, might be judged extraordinary for an individual because it will be ineffective or without benefit given the person’s poor medical condition and dismal prognosis. The immanence of dying can render ordinary therapies extraordinary. The goal then moves to palliative care and accompanying the dying (Panicola, 2001, p.18).

#### 4.2.2 Extraordinary Means

Extraordinary means are all medicines, treatments, and operations, which cannot be obtained and used without excessive expense, pain or other inconvenience, or which, if used, would not offer a reasonable hope of benefit.
In conclusion, one is normally morally required to use only ordinary means – according to circumstances of persons, places, times and cultures: that is means that do not involve any grave burden. Ordinary means must also give reasonable hope of benefit to a particular patient.

In the 20th century it was the American Jesuit theologian, Gerald Kelly (1902-1964), who studied the Catholic tradition on one’s moral responsibility in end-of-life decisions. It is revealing that when clarifying the position, Kelly prefaced it by saying that ordinary and extraordinary means are always to be understood in terms of the patient’s duty to submit to various kinds of therapeutic measures. (emphasis added. Kelly 1950: 550). The point here is that the interpretation of what treatments are ordinary or extraordinary, obligatory or optional is always patient-specific. There are no lists of treatments that are labelled ‘ordinary’ or ‘extraordinary’. It is how proposed treatments are assessed vis-à-vis a particular patient that makes the judgement difficult. Kelly’s emphasis is that the role of the patient in such decision-making is primary. The reason for this emphasis is that, traditionally, the Catholic moral teaching on end-of-life decisions gives authority first to patients in decision-making, then family members and finally health professionals.

4.2.3 Clinically Difficult Judgements

The concepts of ordinary and extraordinary treatment are indicators to be considered in making decisions but still rely firmly on the understanding and judgement of health professionals and patients where appropriate. While these concepts have a long tradition they cannot be viewed as a facile method for determining precisely which means are obligatory and which optional. The determination of treatment obligations is clinically difficult in concrete cases. The reason for the difficulty is that, included in the definitions of the concepts, are several external factors, specifically relevant to a particular patient, that need to be considered such as: circumstances of medical and personal information available, value considerations about benefits and burdens, information gleaned from available advance directives.

The distinction between ordinary and extraordinary means of treatment does not remove disagreements. The differences of interpretation are especially apparent on the issue of prolonging lives of patients with the use of artificial nutrition and hydration (ANH). These disagreements persist today as we see in the discussions of ANH in case 6.5 below. On the topic of ANH in particular, a consensus is lacking among the general public, religious leaders and health professionals. It remains a matter open for discussion (Panicola, 2001, p.20-21).
4.3 Principle of Proportionality

The principle of proportionality is a central principle when considering whether or not to utilise a LPT with a particular patient.

“In clarifying goals, health professionals in conversation with patients or their proxies have the sensitive task of determining the benefits or burdens of procedures or treatments. This task requires a direct application of the proportionality principle. The proportionality principle states that a medical treatment is ethically mandatory to the extent that it is likely to confer greater benefits than burdens upon the patient.” (Lesage and Portenoy 2001:122)

The text just quoted needs qualification: a medical treatment might be judged ethically required unless a competent patient has refused the treatment. The right of self-determination of a competent patient to refuse a medical treatment is a fundamental ethical value in Ireland, even if a clinician judges the treatment necessary to save the patient’s life (See Module 3 and Module 4).

The principle of proportionality requires that the decision process about treatments should follow the general rule to maximise benefit and avoid undue burden. In conjunction with the ordinary/extraordinary distinction, this principle is widely cited a moral rule of thumb as the basis for decision-making about withholding or withdrawing LPTs.

4.3.1 Benefits and Burdens

While the principle of proportionality seems clear or perhaps self-evident, what is not obvious is that the patient with capacity should have a voice in determining, (according to their values), what should be understood as a ‘benefit’ and what constitutes a ‘burden’ (General Medical Council, 2009).

If a benefit must accrue to one for a medical treatment to be considered morally obligatory, what constitutes a benefit? A holistic understanding of benefit means that one views the human person as a physical, psychological, social and spiritual being.

“In the medical context, a treatment is considered beneficial if it restores one’s health, relieves one’s pain, improves one’s physical mobility, returns one to consciousness, enables one to communicate with others and so on.” (Panicola, 2001, p.22-23)

A claim that an LPT offers no hope of benefit simply means that the goods for which one seeks medical therapy are not forthcoming from the therapy. An ‘excessive burden’ means
that any benefits forthcoming from use of a therapy are outweighed significantly by the burdens. Given the holistic view of persons, it follows that burdens may also be spiritual, psychic, and economic as well as physiological.

This holistic understanding of benefit and burdens has not been endorsed by everyone because it is too demanding in specifying the results of treatments. The effect of the holistic view would be that more physically or mentally impaired patients might have treatments withheld.

4.3.2 Competence and Incompetence
Where competent patients are involved, making a concerted effort to try and understand how they interpret ‘burdens’ and ‘benefits’ demonstrates respect and commitment to shared decision-making with the patient whose life is at stake (See Case 3 and Case 5 below). Coming to know how a patient understands ‘benefits’ and burdens’ is not the result of a single conversation with the patient. A patient’s judgement of what is beneficial or burdensome may change over time, when the patient’s medical condition either improves or increases in severity. Similarly, the goals of care are not set in stone but may change with the patient’s experience of their condition.

Where the patient is not competent, the process of clarifying goals involves a process of communication and consultation between the healthcare team and the family to determine if any input about patient preferences may be relevant for a decision. Few decisions are more momentous than those to withdraw or withhold a medical procedure that sustains life. In some cases it is morally unjustified for surrogates and clinicians to begin or continue a therapy knowing that it will produce a greater balance of suffering and pain for a patient who lacks the capacity to choose for or against such therapy. Taking cognisance of any advance directive the patient may have aids understanding of a patient values and preferences. In brief, what is required if the patient lacks capacity is a decision conforming to the ‘best interests’ of the patient (Joyce and The British Psychological Society, 2007; See Module 3 and Module 4).

4.4 Killing and Letting Die
Many distinctions and rules about LPTs derive from the distinction between killing and letting die.

The killing-letting die distinction often underpins distinctions between:
1) suicide and foregoing treatment and,
2) euthanasia and so-called ‘natural’ death.
'Killing' and 'letting die' are terms often used in bioethics literature as if they are clear and undisputed in their meanings. However, these terms are vague and widely contested as the extensive amount of literature on the topic testifies. The concepts are discussed briefly here because they often arise in the context of decisions about LPTs as well as public policy debates. Clarification may help to dispel some misunderstandings about 'killing' and 'letting die' in treatment decisions at the end of life.

4.4.1 Conditions of Judgement

'Letting die' is generally acceptable in medicine where one or more of the following three conditions apply:

a. Patients or their chosen surrogates have validly refused an LPT. A valid authorisation to refuse an LPT alters the obligation of the health professional to treat.

b. A best interest judgement is made by the healthcare team in cases where a patient lacks capacity and where a valid surrogate may or may not be present to contribute to the decision.

c. An LPT is judged to be 'futile' because it yields no benefit for a particular patient and only postpones an imminent dying. The task of giving reasons for the 'futility' judgement and discussing the judgement with the patient and/or family is the responsibility of the healthcare team. This condition is the most contentious of the three. What if a competent patient or authorised surrogate does not accept the health professional’s or team’s futility determination? If a patient is competent and does not accept the futility judgement, then it is usually advisable to continue the LPT and hope to glean further evidence that it is without benefit (See discussion of Futility below).

In these circumstances (a-c), letting a patient die (following a decision to withhold or withdraw LPTs) is normally considered legally and morally acceptable. If none of the three conditions above are satisfied, then letting a patient die following withdrawal of treatment may involve negligence and be a form of unjustified killing.

In conclusion: Valid authorisation by a patient, validly designated surrogate, or a reasoned argument from health professionals supporting a judgement of futility are conditions that morally justify a clinical decision to forego a LPT or to stop a treatment already begun.

‘Although the shortening of the patient’s life is one foreseeable result of an omission, the real purpose of the omission was to relieve the patient of a particular procedure that is of limited usefulness to the patient or unreasonably burdensome for the patient and the patient’s family or caregivers. This kind of decision should not be equated with a decision to kill or with suicide.’

(O’Rourke and Norris, 2001, p.204).
Withholding LPTs without valid authorisation that result in a patient dying can be both as intentional and as immoral as actions that involve direct interventions to bring about death (and both can be forms of killing). Everything depends on other elements in the case and not whether the withholding or stopping of LPTs are omissions or actions.

The importance of ‘valid authorisation’ in assessing the morality of decisions at the end of life will be discussed below under Further Discussion. Suffice for now to conclude that the distinction between letting die and killing often suffers from vagueness and moral confusion.

- ‘Letting die’ is not always morally justified by saying it is an ‘omission’ of treatment.
- Neither is ‘killing’ always morally unjustified by saying it is an ‘action’ taken by the health professional to bring about death.

‘Nothing about either killing or allowing to die entails judgements about actual wrongness or rightness, or about the beneficence or non-maleficence of the action. Rightness and wrongness depend on the merit of the justification underlying the action, not on the type of action it is. Neither killing nor letting die, therefore, is wrongful per se. Accordingly, a judgement that an act of either killing or letting die is justified or unjustified requires that we know something else about the act besides these characteristics. We may need to know about the actor’s motive (is it benevolent or malicious?), the patient’s or surrogate’s request, or the act’s consequences. These additional factors will allow us to place the act on a moral map and make a normative judgement about it. In short, whether letting die is justified and whether killing is unjustified are matters in need of analysis and argument, not matters that medical tradition and legal prohibition have adequately resolved.’ (Beauchamp and Childress, 2001, p.141-142)

It is increasingly clear that laws and policies about end of life decision-making are often vague and unclear because of the confusions discussed above about acts and omissions, killing and letting die. The discussion above is meant to clarify the ethical nature of these distinctions and is not making claims about the law (See Module 3 and Module 4).
4.5. Quality of Life Judgements

Thus far in these discussions, considerable weight is given to quality-of-life judgements in deciding whether treatments are ordinary or extraordinary, optional or obligatory, proportionate or disproportionate. The central premise in these discussions has been:

“When quality of life is sufficiently low and an intervention is likely to produce more harm or burdens than benefits for the patient, it is morally justified to withhold or withdraw treatment. But such judgements require evidence based and defensible criteria of burdens and benefits in order not to reduce quality of life to arbitrary judgements of personal preference and the patient’s social worth.” (Beauchamp and Childress, 2001, p.136).

This latter point from Beauchamp and Childress is pivotal in understanding decisions based on estimated quality of life. It is also fundamental to objections to quality of life judgements. What worries all opponents of quality of life positions is that the view appears to define and prescribe the ‘good life’ in terms of the qualities necessary to live a minimal human and worthwhile existence. If this is an accurate reading of quality of life views, then the position becomes entrapped within the ‘exclusionary’ use of quality of life judgements. The lack of certain valued qualities in a patient’s life becomes a way of positively excluding potential patients from the normal standards of medical and moral treatment (Walter, 2004, p.1391).

There is an apprehension and fear that decisions based on quality of life considerations could descend into an appraisal of a patient’s place in a society, or discriminatory assessment of a patient’s ethnicity or intelligence etc. It is fundamentally important that the involvement of patients and/or authorised surrogates in decisions about LPTs can help to address concerns that clinical decisions in assessing benefits and burdens may discriminate against some patients.

Decisions based on quality of life considerations are judgements about what the likely outcomes (benefits or burdens) are for a patient if a particular treatment is given. It is impossible to determine what will benefit a patient without presupposing some quality of life standard and some conception of the life the patient will likely live after a medical intervention

‘Accurate medical diagnosis and prognosis are indispensable, but a judgement about whether to use life prolonging measures rests unavoidably on the anticipated quality of life, not merely on a standard of what is medically indicated.’ (Beauchamp and Childress, 2001, p.137)
Those who oppose quality of life judgements often propose a ‘sanctity of life’ position that emphasizes the inherent dignity of every human being regardless of ability or status.

4.6 Sanctity of Life

The sanctity of life tradition is associated with the major world religions. In Genesis from the Christian Holy Bible, for example, human life is seen as having an intrinsic value independently of the individual’s own view of it. Each life is viewed as unique, on loan, made in the image of god with an unrepeateable opportunity to praise god. Similarly, in the Islamic tradition, the Holy Koran (Al-An’am, Verse 151) states that human life has intrinsic value, that it is made sacred by Allah. It is a divine trust, created to discover god’s work and serve god’s plan.

Historically, the sanctity of life position holds that the value of human life is not dependent upon its being valued by the individual themselves or by others or by the presence of certain functional capacities such as relationality or rationality. On this view, if the valuing of human life requires certain kinds of capacities, then their absence (for example, with patients who are considered to be in a persistent vegetative state) implies a different (lesser) kind of valuing. Conditions placed on the respect owed human beings results in an ethics of exclusion based on certain properties that some persons may lack through no fault of their own.

4.6.1 Challenges to the Sanctity of Life Position

A first challenge to the sanctity of human life commitment claims that it is intrinsically idolatrous. In talking of the ‘sanctity’ of human life this view overstates the nature of human essence in its insistence that human life is sacred and this is an attribute reserved only for God. Adherents of sanctity of life dispute this interpretation and claim that sanctity of human life only means that humans are set apart by God and are distinct in the created order. However, this response means that the special status attributed to humankind still requires a theological foundation and such religious reliance will not persuade those of different or no religious faith.

A second challenge to the sanctity of life view is the charge of medical vitalism:

‘the notion that all means must be utilized to keep a human being alive in the face of death. Because human life has incalculable worth a commitment is required to keep patients alive at all costs. Many critics of the sanctity of life perspective have assumed that vitalism is an inherent part of the tradition’ (Hollinger, 2004, p.1404).
However, those who propose the sanctity of life position reject vitalism as part of their position. They claim that there is a natural cycle to human life that must be accepted.

### 4.6.2 Inalienable Human Rights

A respect for the inherent dignity of human persons central to a sanctity of life view also supports communal life in society.

> ‘If laws were permitted to embody the idea that in some circumstances life loses its worth, or that some people lack sufficient worth to have their lives protected, individuals would no longer enjoy equal protection of the law so far as their lives are concerned’ (Hollinger, 2004, p.1404).

Others argue that religious arguments are not required to defend belief in the ‘sanctity of human life’.

> ‘It is enough simply to say that all human lives are deserving of equal respect not because of what they have to offer or have offered or potentially will offer, but because they exist. The notion of inalienable human rights attributes force to the value of human life with the assertion that it needs no justification. This is the primary merit of the sanctity of life ethic – that a life requires no justification’ (Schwartz, Preece and Hendry, 2002, p.116).

The sanctity of human life position emphasizes that medical termination of life does require justification. In this sense the principle acts as a powerful bulwark against the devaluing of human life. Article 3 of the United National Declaration of Human rights asserts simply that: ‘Everyone has the right to life, liberty and security of person’ (Schwartz, Preece and Hendry, 2002, p.116).

### 4.6.3 Compatibility of Quality of Life and Sanctity of Life

If one removes a religious foundation as a requirement for acceptance of the sanctity of life view, then its essential meaning is compatible with quality of life judgements. Human life needs no justification if we once agree to the commitment that all human lives are accorded equal respect not because of what they can offer to society but because they simply exist. This respect for the dignity of human beings is harmonious with the belief that quality of life judgements are necessary when making decisions about LPTs. Those quality of life judgements deliberate on the possible efficacy or futility of LPTs in the life of the patient. Health professionals, in company with patients or authorised surrogates can acknowledge when further life supports are greater burdens than benefits for a particular patient. This acknowledgment, in unison with expert palliative care, allows patients to achieve the dignity of a good dying.
5. Futility

Judgements of ‘futility’ of treatments in end-of-life care are part of everyday life especially in ICU settings. Physicians have come to accept patients’ rights to refuse treatment yet they have increasingly encountered patients, or more commonly the families of incompetent patients, demanding treatment that the clinicians judge to be futile.

Historically, the debate about what constitutes ‘futile’ treatments began with decisions relating to the stopping of cardiopulmonary resuscitation but with increasing medical technology, it has expanded to other forms of life prolonging care. Paradigms of futile care often involve efforts to resuscitate a patient who is imminently dying as well as life prolonging intervention for patients in a persistent vegetative state. Other paradigms include the use of aggressive therapy such as surgery, chemotherapy and haemodialysis for patients with advanced terminal illness and without a realistic expectation of improvement. Even the use of less invasive treatments such as intravenous hydration or antibiotics in near-moribund patients might be considered ‘futile’ treatment.

The impression may be that such judgements about futility are based on clinical criteria and can result in objective decisions that provide a certain and warranted basis for discontinuing further LPTs. The discussion that follows indicates that this is not the case.

5.1 Debates on the Meaning of ‘Futility’

A central issue in the futility debate has been how to define futility.

'Some try to narrowly restrict it [futility] to only those treatments known with certainty not to achieve their goal. The attempt is to eliminate value judgements from futility determinations and to make them only an empirical matter about which the physician should be expert. But others have pointed out that it is not possible to eliminate all value judgements. Others have more broadly characterised futility to include cases where the probability of benefit is considered too low, or the size of benefit too small, to warrant the burdens of treatment.' (Brock, 2004, p.1418).

‘Futility’ judgements are typically used to express a combined value judgement and scientific judgement. There is a considerable subjective element in judgements that further treatment is ‘futile’ – precisely because decisions that weigh up benefits and burdens are not based on rocket science. It is easy to see how clinicians and patients might disagree about whether or when further treatment is beneficial for improving one’s function or one’s quality of life. The value judgement seems in most cases appropriately left to the patient or surrogate, not the physician.
‘In some situations a physician can determine that a treatment is ‘medically’ futile or non-beneficial because it offers no reasonable hope of recovery or improvement or because the person is permanently unable to experience any benefit. In other cases the utility and benefit of a treatment can only be determined with reference to the person’s subjective judgement about his or her overall well-being. As a general rule, a person should be involved in determining futility in his or her case. In exceptional circumstances such discussions may not be in the person’s best interests.’ (Canadian Nurses Association, Canadian Healthcare Association, Canadian Medical Association and Catholic Health Association of Canada, 1999, p.4).

In discussing ‘judgements of futility’, it should not be people’s lives that are judged futile. In making judgements of futility, a health professional (often in company with patient or family) is not (or should not be) making a value judgement about the significance or worth of this person’s life. This point is most important to stress with family members where, for example, a Do Not Resuscitate (DNR) has been signed. Respect for the patient’s worth and concern to protect their dignity means that, if a patient has a DNR in their chart, they need reassurance that all pain management and compassionate care will continue.

### 5.2 Evolution of the Concept of Futility

What is beyond doubt is that the notion of futility is disputed and that it is very much a concept in evolution. For over twenty years now ‘futility’ has been debated in the hopes that a clear and determinate set of criteria might be formulated that would help doctors make decisions about providing or withholding LPTs. The concept of medical futility surfaced in the 1980’s largely in response to concerned families who insisted on LPTs for their loved ones while caregivers or health professionals deemed these treatments to be inappropriate. Clinicians felt providing futile treatment was cruel while studies of patients and families consistently stated that such care was valued and wanted (Burns and Truog, 2007).

The debate on ‘futility’ can be divided into three segments or three generations that mark the evolution of the concept.

1. A first generation was taken up with efforts to define futility in terms of definite clinical criteria. This process seemed guaranteed to give objectivity and certainty to futility judgements. However, these efforts failed because they recommended ‘limitations to care based on value judgements for which there is no consensus among a significant segment of society’ (Burns and Truog, 2007).

2. The second generation in the debates on futility offered a procedural approach that gave power to hospitals, utilising their ethics committees, to decide whether interventions...
demanded by families were futile. However, this procedural approach failed as it seemed to try and distance the decision from health professionals by transferring it to ethics committees. Failure also resulted because it gave hospitals authority to make decisions that health professionals desired but any national consensus on what is ‘beneficial treatment’ remained under intense debate.

3. Burns and Truog (2007) predict the emergence of a third generation that should focus primarily on negotiation at the bedside and on-going communication. This third view places importance on developing and deepening understanding between patients, families and professionals. In addition, it acknowledges that conflict can surface among health professionals if families demand what is judged futile treatment and wish ‘all that can be done to be done’. While considerable stress can then be experienced by healthcare teams Burns and Truog advise that, rather than initiate an adversarial encounter with the patient and/or their family, the health professionals should support each other to help deal with the stress of ‘futility’ judgements and ensuing conflicts (2007, p.1992).

5.3 Divergent Views about Futility Judgements
There are diverse approaches to making judgements that certain kinds of treatments are futile.

1. One position thinks that ambiguity is fostered by the use of the term to refer to both quantitative and qualitative components.

‘Those who question the use of futility judgements to limit the treatment options offered to patients often argue that what effects are deemed desirable or beneficial may depend on whether the patient’s or the clinician’s perspective is adopted. They express concern that assertions of futility may camouflage judgements about the comparative worth of patients’ lives. It must be acknowledged that even seemingly objective claims about the likelihood that an intervention will produce some effect are tinged with uncertainty; for some patients, a vanishingly small probability of success will be viewed as preferable to foregoing the treatment.’

(Centre for Bioethics, 1997b, p.5).

2. A second position about futility debates claims that it would be more helpful if we just abandoned the term ‘futility’ in preference for more concrete and precise descriptions of a clinical situation being considered. The amount of divergence in subjective, and even apparently objective clinical estimates of futility, should suggest that the resulting confusion can be remedied by more accurate accounts of specific situations where treatment seems contraindicated because earlier efforts at therapy indicate that no further patient-benefit is expected.

‘The term ‘futility’ is used to cover many situations of predicted improbable outcomes, improbable
success, and unacceptable benefit-burden ratios. This situation of competing concepts and great ambiguity suggests that we should generally avoid the term ‘futility’ in favor of more precise language.’ (Beauchamp and Childress, 2001, p. 134)

3. A third area of diverging perspectives pertains to the obligations of health professionals to consult patients and/or their families in making decisions about the use of LPTs, most especially where there is clinical agreement that a particular therapy would be futile for the particular patient. Some clinicians and commentators on the topic of ‘futility’ judgements do not agree that a clinician must respond positively to a patient’s insistence on a treatment that is judged to be without any discernible benefit. The argument is given that if a treatment is futile for a particular patient, this fact changes the doctor’s obligations to seek agreement from patients or surrogates. Health professionals may not even have an obligation to discuss such a treatment as if it were a realistic option.

‘The physician is not morally required to provide the treatment (and in some cases may be required not to provide the treatment) and may not even be required to discuss the treatment[…] Increasingly hospitals are adopting policies aimed at denying therapies that physicians judge to be futile, especially after trying them for a reasonable period of time[…] respect for the autonomy of patient or authorized surrogates is not a trump that allows them alone to determine whether a treatment is required or is futile.’ (Beauchamp and Childress, 2001, p.134).

A recent study in one Dublin hospital seems to give credence to the above viewpoint that communication with patient and family is not always required when deciding on use of LPTs that are considered futile. The research focussed on communication with families of patients in intensive care. The study of end-of-life care in one Dublin hospital by Collins, Phelan, Marsh et. al. (2006) showed that the involvement of families with clinicians when making end-of-life decisions was low. Overall, almost a quarter of patients’ families studied were not involved in the decision to limit life prolonging therapy. Patients’ input in the decision-making was not discussed because all of the patients whose end of life condition was discussed lacked capacity.
The Collins et al. (2006) study, explains that when a clinical judgement is made that further therapy or treatment would be futile because the patient is unresponsive to maximum medical therapy, health professionals tend not to consult a family about the possibility of providing such a treatment or discontinuing the treatment. The explanation given was that where a clinical judgement is made of acute physiological futility, consultation with family would be redundant. One might add that consultation with family may not even be obligatory. If a family were consulted and insisted on continued futile treatment, clinicians would face a serious conflict of conscience in believing that they would then have to provide futile treatment that may well harm the patient (Collins et al., 2006, p.318; See Cases 1, 2 and 4 below).
6.1 Case 1: When is Treatment Futile? – Do Everything You Can

Do Everything You Can

Ms. R., a 52-year-old woman with severe rheumatoid arthritis and chronic immobility, was brought to the emergency department. Her health was poor, although stable, until the morning of admission when she became disoriented and lethargic. She was admitted to intensive care and put on a ventilator while being treated for septic shock secondary to decubitus ulcers and for acute renal failure. On the day after admission she required increasing doses of vasopressor drugs and developed acute respiratory distress syndrome. Some members of the intensive care team became increasingly concerned about the ‘futile’ care they felt they were providing. The patient’s family requested that the medical team ‘do everything’ to keep her alive.

After several days of observation of Ms. R. and following conversations with the family, an ICU clinician agreed to meet with them to explain that Ms. R.’s underlying immune suppression and general health was such that she was most unlikely to recover from the progressive septic shock but if improvement were not possible, the aim and value was to ensure patient comfort. The clinician was sensitive to the family’s anxiety, sense of impending loss and fear of Ms. R.’s impending death.

At the conference the family was asked to say how they understood the patient’s condition? The team learned from the conversation that Ms. R. was known for her energy and readiness to take on all challenges. The family expressed an unrealistic optimism about her condition and genuinely believed (or wanted to believe) that Ms. R. could recover to an earlier mobile and healthy self. Careful listening by the clinician and expressions of interest about the person of Ms. R. reassured the family that this conversation was not just a formality to be quickly concluded.

The team continued in their efforts to help the family to adjust their hopes to more realistic care goals for Ms. R. The family were reassured that they would have time to think everything over. Life support would continue as long as the family believed it was what Ms. R. would want. After a few days, the family decided Ms. R. would probably not want ongoing life support. Here the team took time to explain the process of withdrawing life support while being careful not to alarm the family about Ms. R.’s ensuing pain. All drugs were stopped for Ms. R. except morphine.
Module 6 The Ethics of Life Prolonging Treatments (LPTs)

6.1.1 Discussion

Many deaths in intensive care occur after withholding or withdrawing life support. In ICU situations, the decisions are often made by health professionals and families since the patient is frequently too ill to participate. But conflict can arise due to disagreements among healthcare staff in ICU or disagreements about treatment decisions by family members.

‘Conflict surrounding decision-making in intensive care units is common. Conflict can arise about issues such as communication styles, interpersonal interactions, pain control as well as about treatment decisions […] The evidence on the best way to resolve conflicts suggests that communication, negotiation and consensus building are the most important tools.’

(Way et. al., 2002, p.1343).

In Case 1, there is consensus on the part of the healthcare team that further provision of treatments aimed at cure would be futile.

The case here illustrates a general rule of thumb in ICU care: When diagnosis and prognosis is unclear, it is preferable to commence treatment and keep the patient under observation. Before an LPT is started, it is not certain whether it will bring the hoped-for-benefits to the patient. Once it has been tried and it becomes clear that it does not produce the benefits sought, clinical evidence exists to justify stopping therapy that did not exist for not starting the ventilator. The principle supports the use of time-limited trials of LPT, with the understanding that if the treatment does not prove to be beneficial it will be stopped.

‘Few decisions are more momentous than those to withhold or withdraw a medical procedure that sustains life. But, in some cases, it is unjustified for surrogates and clinicians to begin or to continue therapy knowing that it will produce a greater balance of pain and suffering for a patient incapable of choosing for or against such therapy.’

(Beauchamp and Childress, 2001, p.135-6).
When the team observed the progression of Ms. R.’s illness, they may have clearly realised that continued ventilator support and increasing vasopressor drugs served only to prolong the dying process. Their responsibilities now were to provide appropriate palliative care for Ms. R.

Justified ‘Allowing to Die’?
A clinical decision to intentionally withdraw an LPT is often construed as a doctor’s ‘letting die’ rather than killing. The argument is that if the decision is validly authorised then it is morally justified. A valid authorisation can often transform what might be a maleficent act of killing into a nonmaleficent (and perhaps beneficent) act of allowing to die. Normally valid authorisation is provided by a competent patient who refuses or perhaps requests continued life support assistance. Ms. R. lacks capacity to decide for herself or provide authorisation for a decision. The team’s effort to involve the family in assessing benefits and burdens of continuing ventilator support, demonstrates attempts to achieve surrogate authorisation for the decision to discontinue ventilation and commence palliative care.

Assessing the burdens and benefits of further LPTs for Ms. R. involves reasonable medical judgements and quality-of-life judgements:

“We conclude that competent patients and authorized surrogates can use controlled quality-of-life considerations with medical input to legitimately determine whether treatments are optional or obligatory.” (Beauchamp and Childress, 2001, p.139).

Abandonment
In conversations with the family of Ms. R. an important point was stressed throughout; if some treatments were to be discontinued because they lacked discernible benefit for the patient, good care and pain management would continue to be provided. For example, therapeutic sedation to ameliorate symptoms of breathlessness and anxiety are essential in end of life weaning from ventilator support.

Families often fear abandonment by health professionals once a patient is no longer seen as curable or as responsive to LPTs. Expert guidelines on caring for patients at the end of life emphasize the importance of not allowing the patient to feel abandoned especially when the care plan includes withdrawal of disease-modifying treatment (Cherny, Radbruch and The Board of the European Association for Palliative Care [EAPC], 2009, p.581; Lesage and Portenoy, 2001, p.125). Non-abandonment has been cited as a primary tenet of medicine and a key value in professionalism. Despite the professed importance of non-abandonment to end-of-life care, surveys show that patients and family care-givers still experience abandonment around the time of death (Back, Young, McCown, et. al., 2009, p.474).
The family of Ms. R. felt their concerns were heard. The team did not appear rushed in their conversations and the family appreciated knowing the now revised care plans for Ms. R. Most of all, the family felt relieved that they had not been pressured into accepting withdrawal of life support.

6.1.2 Suggested Professional Responsibilities

- Communicate with the family to help them to realistically understand the clinical condition of Ms. R. including likely prognosis.
- Give time and provide a proper atmosphere of privacy for the family to digest the reality of Ms. R.’s illness. In this context, be aware of imminent grieving of family.
- Document in case notes the basis for a judgement that further ‘curative efforts’ were deemed ‘futile’. This includes clinical and quality of life judgements about burdens and benefits for the patient.
- In an effort to minimise distress for the family and patient, the healthcare team can show they are partners with the family in trying to make the right decision for Ms. R. When relatives feel the team are partners in the decision, they may feel less marginalized and/or burdened by guilt.
- Provide understanding and reassurance for the family that all comfort needs and pain management of Ms R will be carefully provided for in the dying process.
- Make every effort to accommodate the religious perspective of the patient and family.
6.2 Case 2: DNR and Family Disagreement – When God Might Intervene

Case 2 presents a rather ordinary situation of advanced and complex illness in an elderly gentleman. His wishes have not been expressed and his family voice their serious concerns about the clinician’s suggestion that they agree to a Do not Resuscitate Order (DNR) for their father.

When God Might Intervene

Mr. W. is 82 years old and has many serious medical problems, including ischemic heart disease, hypertension and diabetes mellitus. He has had a series of debilitating strokes that have left him severely disabled and unable to communicate his wishes. His health care providers feel that he would not benefit from resuscitation attempts if he were to suffer a cardiac arrest and suggest to his family that a DNR be placed on his chart.

The devout Christian family is quite upset and reject this suggestion. They can’t see that continuing to live is any burden on them or their father. They believe that God could still heal their father and they accuse the health care providers of trying to ‘play God’. They ask to see the hospital Chaplain. (Smith, RCSI Residency Programme case no.12, 2008, p.52)

6.2.1 Discussion

Normally, unless a specific order to the contrary (e.g. DNR) has been recorded on the person’s health record by the responsible doctor or a valid patient Advance Directive, CPR is used as a standard intervention in virtually all cases of sudden cardiac or respiratory arrest.

What is a DNR Order?

A DNR order may generally be described as a note primarily written and signed by a doctor but which could involve the patient, healthcare team and family, stating that in certain circumstances should the patient suffer from cardiopulmonary failure, cardiopulmonary resuscitation (CPR) should not be attempted. Such an order is only relevant to not attempting CPR and not to the withholding of any other treatment.

What is Involved in CPR?

Cardiopulmonary resuscitation (CPR) was first developed as a treatment intervention for cases of sudden unexpected cardiac or respiratory arrest. CPR includes chest compression, bag-and-mask-positive-pressure ventilation, mouth-to-mouth resuscitation, ventilation,
intubation and defibrillation. During CPR the chest is pressed on forcefully. Electric stimulation to the chest and special medicines may be used. This is usually done for 15 to 30 minutes. A tube may also be put through the mouth or nose into the lung. This tube is then connected to a breathing machine. (American Academy of Family Physicians (AAFP), 2000)

Judging Disproportionate Means

While very aware of the grief experienced by the family the doctor explains to the family that prolonging life with CPR would not benefit their father and the distress of the process itself is sometimes more cruel than compassionate. In the case of Mr. W., health professionals have judged CPR inappropriate and are relying on their benefit-burden judgement known as the principle of proportionality discussed above.

‘It needs to be determined whether the means of treatment offered are proportionate to the prospects for patient improvement. To forego disproportionate means is not equivalent to suicide or euthanasia: it rather expresses acceptance of the human condition in the face of death.’ (Ashley and O’Rourke, 1997, p.419).

The family disagree. They cannot see what is so burdensome about continued life for their father. They might believe that prolonging their father’s life benefits him because:

a. Recovery of awareness by Mr.W. is remotely possible, perhaps by a miracle;
b. Their father is better off alive than dead.

Here, as in Case 1, it is essential that the healthcare team engage in conversation with Mr. W.’s family. This is not only out of respect for the family who are wondering about Mr.W.’s condition but the conversation also needs to ensure that the family understands the CPR procedure as realistically as possible. This understanding is seldom the case with families.

In their research with practitioners in Irish hospitals, Quinlan and O’Neill (2009) found that patients and families often lacked knowledge and understanding about active treatments mentioned. They didn’t know what was meant by ‘PEG feeding’, ‘subcut fluids’, ‘defibbing’ and ‘shocking hearts back to life’ (Quinlan and O’Neill, 2009, p.36). It is easy to see how patients or families end up confused and are intimidated about asking ‘what does this mean?’ when hearing abbreviated jargon from doctors or nurses.

Guiding principles about CPR and DNRs recur in statements offered by international medical and nursing associations (British Medical Association [BMA], Resuscitation Council UK, and Royal College of Nursing [RCN] 2007; General Medical Council, 2009; New South Wales Department of Health, 2005; Royal College of Paediatrics and Child Health, 2004).
These guidelines all agree that health professionals find it difficult to discuss CPR with their patients and part of that difficulty is a result of the point made above that it is a complex procedure and very dependent on the precise clinical condition of the patient (O’Keefe, 2001).

Some patients may ask that CPR be attempted should they arrest, even if the clinical evidence suggests that, in their case, there is only a very small chance of success. Health professionals may doubt whether the risks and burdens associated with CPR are justified with such a small chance of success but the individual – if properly informed, and whose life is at stake, may be willing to accept that chance.

Research continues to show that patients are not adequately informed:

a. Most patients are not aware or knowledgeable of possible risks and adverse effects of CPR in order to make an informed decision about whether or not they would want CPR.

b. Many people, patients, families and even some health professionals have unrealistic expectations about the likely success and potential benefits of CPR and lack detailed understanding of what is involved.

c. This failure of understanding makes it very difficult to achieve genuine informed consent to a DNR or to CPR in the event of cardiac arrest (BMA, Resuscitation Council UK, and RCN, 2007).

In the health professional-family conversation, it is important to find out whether the family understands what is actually involved in CPR, what likely outcomes can be anticipated, and what possible suffering might be involved for Mr. W. if it is attempted. The potential benefits and risks of CPR need to be discussed with the family.

The Benefits of CPR
For a patient with an advanced life-threatening illness who is dying, the single benefit of CPR is that it may defer dying. CPR may prolong life if it’s done within 5 to 10 minutes of when the person’s heart stopped beating or breathing stopped.

The Risks of CPR
Attempted CPR carries a risk of significant side effects (such as sternal fracture, rib fracture and splenic rupture) and most patients require either coronary care or intensive care treatment in the post resuscitation period. If there is delay between cardiopulmonary arrest and the resuscitation attempt, there is a risk that the patient will suffer brain damage. Some resuscitation attempts may be traumatic meaning that death occurs in a manner the patient
and people close to the patient would not have wished (Sheikh, 2001, p.7). These full, graphic details of potential risks of CPR may not have to be provided to Mr. W.’s family but, on the other hand, without some explanation, the family may have a very unrealistic perception or image of what CPR involves. A possible misunderstanding such as this can obstruct a decision that could ‘benefit’ Mr. W.

‘Information should not be forced on unwilling recipients and if patients indicate that they do not wish to discuss CPR this should be respected. All of these efforts in attempting to discover if the patient wishes to discuss CPR as well as the outcome of these attempts should be documented.’ (BMA, Resuscitation Council UK, and RCN, 2007, p.2).

Based on interviews and narratives of Irish hospital staff, such conversations with patients and families to provide helpful information and aid understanding are uncommon occurrences. Documentation of such decisions with the circumstances and reasoning for the decision noted is also uncommon. Certainly, patient records do not show evidence of such conversations aimed at discovering patient wishes (Quinlan & O’Neill, 2009, p.37). The Irish Ethicus data with intensive care patients and families, show that documentation of end-of-life decision making is sparse. This was especially the case with respect to CPR (Collins et. al., 2006, p.317).

Ethical and Legal Status of DNR in Ireland

As is the case with many other areas of medicine, there is a serious lack of ethical and legal certainty regarding DNR orders. There exist no Irish medical guidelines and there is neither legislation nor judicial wisdom to assist medical practitioners in this emotionally sensitive and legally uncertain area of medicine. (Sheikh, 2001, p.4)

In the absence of policy guidelines or legislation it is not surprising that health professionals may decide to ‘walk slowly’ if a patient arrests and CPR is thought to be a futile therapy for that individual. But in the absence of policies or legislation, families also have little recourse if they believe that they have been overlooked in a decision to provide or withhold CPR. The following report explains why a policy is required:

‘Because for every person there comes a time when death is inevitable, it is essential to identify patients for whom cardiopulmonary arrest represents a terminal event in their illness and in whom attempted CPR is inappropriate. It is also essential to identify those patients who do not want CPR to be attempted and who competently refuse it’ (Sheikh, 2001, p.6).
In the Best interests of the Patient

When patients and their families are consulted, decisions about attempting CPR raise sensitive and potentially distressing issues for patients and people emotionally close to them. Initially it is most important to determine the competence or incompetence of patients who are deciding on DNR or CPR. When an incompetent person’s wishes are not known, treatment decisions must be based on the person’s best interests as discussed above. This best interests judgement is not solely a clinical or legal judgement that lacks reference to the particular patient. Quite the contrary: ‘best interests’ based decisions need to take into account:

a. The patient’s known or ascertainable wishes, including information about previously expressed views, feelings, belief and values and whether those views might still be the same.

b. Information received from those who are significant in the person’s life and who could help in determining his or her best interests.

c. Aspects of the person’s culture and religion that would influence a treatment decision.

As well as:

d. The likely clinical outcome, including the likelihood of successfully re-starting the patient’s heart and breathing for a sustained period, and the level of recovery that can realistically be expected after successful CPR.

e. The risks involved with treatment and non-treatment.

f. The patient’s human rights, including the right to life and the right to be free from degrading treatment.

g. The likelihood of the patient experiencing severe pain or suffering as a result of the treatment.

CPR can also be viewed as harmful and offensive to the dignity of a patient. The explanation above of the potential ‘risks’ involved in CPR is translated into reality in this anonymised Irish case cited in Quinlan and O’Neill (2009).

“I’m a nurse on the resuscitation team and, to this day, a case still bothers me. An 84 year-old gentleman with end stage chronic obstructive airway disease (COPD) was admitted at night by a medical registrar who had not discussed this man’s case with her consultant and had not discussed it with the anaesthetic consultant to review this patient. The patient was on maximum medical treatment and home oxygen. He would not have benefitted from his heart being shocked nor will he benefit from being put on a life support machine because, with end stage COPD, he would never come off the life support machine.
This gentleman was very skeletal and he had a pigeon chest as well. I arrived at the scene the same time as the anaesthetist and the medical registrar who called me […] I asked: “Is this gentleman for resuscitation?” “Yes.” So we were going through with it and all his ribs were cracking as we were doing the procedure. I said: “God, this is very unethical!” Has this been discussed with the gentleman or relatives? The registrar said: “No.”

(Quinlan & O’Neill, 2009, p.31)

This decision to apply CPR is made without the consensus from the healthcare team. It also shows no effort to consult the family. It appears to be an unjustified decision to apply CPR since it was, on all the medical evidence, futile treatment. Finally, even a brief consideration of benefits and burdens of the LPT for this gentleman would show that CPR is not only proving to be a ‘futile’ treatment; it is also harmful – the burdens are overwhelming. Justification for this medical decision is wholly lacking. This case provides a good example for documentation of all decisions in patient records. If documentation were provided, it would have required the clinical team to reflect on their actions and see if any warrant for their decision could reasonably be provided.

6.2.2 Suggested Professional Responsibilities

- Given the difference of perspective that exists between the healthcare team and the family in Case 2, it is important to allow time to observe the progress of Mr. W’s condition and continue conversations among health professionals and family.
- The nature, benefits and risks of CPR as they apply to Mr. W’s situation should be explained to the family.
- The family should be reassured that a DNR decision applies solely to CPR. All other treatment and care which are appropriate, including palliative care are not precluded and will not be influenced by a DNR decision.
- All the health professionals in the team and the family members should be clear that while they have a duty to protect life, they must also balance this value with the obligation not to subject the patient to inhuman or degrading treatment.
- Any decision that CPR will not be attempted for an incapacitated patient should be documented on the patient’s records and details given of components that went into the ‘best interests’ judgement.
6.3 Case 3: Requesting Ventilator Withdrawal – ‘My Life has Lost Value for Me’
Decisions to apply a ventilator are difficult and, often in the busy days in ICU, patients may be ventilated as a stop gap until further review of the case can be provided. Research in Irish hospitals indicate that health professionals question the decision to provide ventilation in cases where the patient is ‘trying to die’:

‘At the moment, a gentleman is ventilated up in ICU. He has been diagnosed with Motor Neurone Disease. He’s ventilated and sedated. I suppose if things had been reviewed at the time when he was diagnosed, he probably would not have been put on the ventilator. Now that we’re there, he’s trying to die and just can’t die. That ventilator is keeping him alive up there. He took a turn on Friday and is now on his second syringe driver and the wishes of his wife are that he wouldn’t suffer any more. ICU is very curative and proactive. That’s a huge dilemma, a huge ethical dilemma really for that patient. At Christmas when he was able to talk he clearly said “I don’t want anything else.”’ (Quinlan & O’Neill, 2009, p.33-34).

Difficult challenges for health professionals are particularly acute when active or ‘aggressive treatment’ may be provided even when it seems inappropriate.

‘A patient might be end stage COPD, and they’re on continuous oxygen nebulizers and not able to do any kind of movement and then when they come in to ICU, they’re ventilated and end up with a tracheotomy and maybe full care at that stage. And then down the road often they die from an infection.’ (Quinlan & O’Neill, 2009, p.34).

The case of Katherine that follows tells the narrative of a patient with capacity to request the withdrawal of the ventilator required for her to live. She makes a quality of life judgement about her life prospects and chooses to discontinue ventilation. Katherine’s judgement is that this life support is posing a greater burden than any benefit for a functioning life that she wishes to live.
My Life has Lost Value for Me’

Katherine Lewis is a single, 40-year-old woman suffering from Guillain-Barre’s syndrome, a painful neurological illness that leaves its sufferers paralysed for unpredictable lengths of time. Many people recover from the syndrome more or less completely and live long, relatively healthy lives. However, Katherine’s case became severe. She has been paralysed in her limbs for three years now. Ten months ago, it was recognised that she was having increased difficulty in swallowing and speaking.

The consultant had explained to Katherine that, due to swallowing difficulties, they may consider feeding intravenously or through a tube. Katherine was saddened to hear this but felt it was almost inevitable. She gradually found it was very difficult and painful to move or breathe on her own due to the extent of damage to her nerves and muscles. She now needs a ventilator to help her breathe.

You are a nurse on the ward who has come to know Katherine and develop methods of communicating with her during the night watch with her when all is quiet. You explain this prognosis to Katherine in a gentle but clear manner. Last week Katherine indicated that she wanted to communicate with you privately. She signals in her halting mode of communicating that she has considered her options and decided that she no longer wanted to continue living this way. She said her life held no value for her if it meant being in constant pain and without the freedom to move, eat or even breathe on her own. She said she discussed this with her family and they have accepted her wishes to have the ventilator removed.

(Edited from Schwartz et al., 2002, p.9).

6.3.1 Discussion

Ventilation is essential for life when a person cannot breathe on their own. Given the seriousness of this decision in Katherine’s case, the withdrawal of ventilator support may well be ethically and clinically difficult for members of the healthcare team, family and even the patient.

For Katherine, life is no longer bearable. Ventilation is a burden and not a benefit to her. Katherine believes that, according to her values, continued use of the ventilator is futile. As discussed above, futility judgements are profoundly value laden, in part because the specification and choice of goals are so variable. The case of Katherine illustrates this...
subjective dimension of ‘futility’ judgements. What Katherine deems ‘futile’ is met with confusion and disagreement among health professionals. But Katherine does not see the goal of living with ventilator dependence as a positive personal value. The consideration that ‘merely being alive’ is a benefit would most likely not persuade Katherine to rethink her decision to remove the ventilator. Katherine seems to take the view that there is a profound difference between continued ‘biological life’ (merely being alive) and living a narrative of choices, relationships and opportunities that would be a ‘biographical life’.

‘There is a deep difference between having a life and merely being alive. Being alive, in a biological sense, is [on its own] relatively unimportant. One’s biographical life, by contrast, is immensely important; it is the sum of one’s aspirations, decisions, activities, projects, and human relationships. […] The doctrine of the sanctity of life can be understood as placing value on things that are alive [only in the biological sense]. But it can also be understood as placing value on ‘lives’ and on the interests that some creatures, including ourselves, have in virtue of the fact that they are subjects of lives. […] The sanctity of life ought to be interpreted as protecting lives in the biographical sense, and not merely in the biological sense. (Rachels, 1986, p.24-27).

The value of simply being alive may be considered a ‘benefit’ to observers of Katherine’s suffering. But it is Katherine who is making a judgement about the quality of her life, about her prospects for her future which concludes that living in this way is no longer a ‘benefit’. The burden for Katherine is that, for her, this current existence is not a ‘life’. It is biological endurance. Stress, frustration and relentless anxiety arise from the awareness that continuing to live in this way offers no prospect to make human choices, to relate to her family and friends outside the confines of her ventilatory context. In making the choice to request removal of the ventilator, the patient is effectively choosing her ‘good dying’. A life of anticipated incapacity and unremitting pain is of negligible value for her. Having reflected for ten months on the continuing distress of ventilator reliance is not tantamount to a hasty or ill-thought through decision.

It is understandable that, initially, if a doctor or nurse were faced with Katherine’s request they might be reluctant to simply agree. Points that the healthcare team might discuss as a team are:

• If Katherine is not ‘terminally ill’ or ‘imminently dying’, should her refusal of the LPT be respected?
• If they agree to respect this patient’s request to remove her ventilator, would they be complicit in assisted suicide?
• Because of the seriousness of this request, should they review the evidence that Katherine has capacity to consent to withdrawal of the ventilator?
There is no qualification such as ‘imminently dying’ on a competent patient’s right to refuse life prolonging therapies. Katherine’s reasons for refusing the ventilator are important for the health professionals to discuss with her but ultimately, they need to be assured of Katherine’s valid refusal.

If Katherine’s capacity to make this decision is, in any way in doubt, one option would be to seek a consultation by an expert psychiatrist to assess Katherine’s claimed competence. However, in this case, the behavioural symptoms that Katherine shows would not normally cause alarm sufficient to request a psychiatric assessment. It is rather the doubts and possible disagreements of staff about her choice that begin to engender reluctance to accept it.

Is Ventilator Removal Assisting in Suicide?
In a situation such as the case of Katherine, there can be a lingering belief and emotional response from family and health professionals that this withdrawal decision (stopping the ventilator) is equivalent to actively taking the patient’s life. The question may haunt health professionals: Is it always wrong to withhold or withdraw life supports such as a ventilator, artificial nutrition and hydration from a patient? Is this not euthanasia by omission?

‘Euthanasia must be distinguished from the decision to forgo so-called “aggressive medical treatment” in other words, medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and the patient’s family […] One can in conscience refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted […] It needs to be determined whether the means of treatment available are objectively proportionate to the prospects for improvement. To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death.’

(Ashley and O’Rourke, 1997, p.419-420).

One objection to the removal of the ventilator might be that a ventilator is not medical treatment but basic humane care that is universally required. Denying basic and humane care, the argument claims, would be tantamount to physician-assisted suicide or euthanasia. However, this objection overlooks an important ethical and legal right of this patient. When a competent patient has refused the use of a life prolonging therapy, its use would be legally tantamount to assault and, morally, would be a denigration of the competent patient’s liberty of choice and right to privacy and dignity. Katherine has the right, both legally and ethically to refuse medical treatment even if such refusal leads to death. (See Module 4,
The support of the family for Katherine’s decision is a positive feature of this case that the medical team can draw on to aid them in their understanding of Katherine’s choice. Much of contemporary writing has spoken of autonomy in highly individualistic terms but this case illustrates how a woman like Katherine who is judged competent and autonomous has involved her family as supportive companions in her choice and her approaching death (Donchin, 2000). The form of autonomy illustrated in this case could be termed ‘relational autonomy’ which takes into account others who have been important in one’s life and now, however haltingly, support one’s choice to die (See Further Discussion, Module 4 for more on relational autonomy). The family have offered support and respect for Katherine’s sense of the ‘good life’ that seems no longer available to her. While the family support is apparent, they will undoubtedly still need reassurance, comfort and support in the period when ventilator removal occurs.

Not everyone would agree with Katherine’s decision and some would clearly voice the concern that compliance in this request is assisting suicide. In this case narrative, the patient wants to exercise control over her dying so some semblance of human dignity remains for her. The concept of human dignity encompasses a range of human sentiments with regard to people’s place in this world, their relatives, the environment in which they live and their conception of the past, the present and the likely future. For sick people, the concept of human dignity includes a desire not to become a burden and the desire that their own suffering will not cause their loved ones to suffer (Cohen-Almagor, 2001).

Patients often express fear of developing dependency on others or on machines; they want their death to somewhat reflect the way they lived. Katherine chose to control the process of dying as much as possible. Perhaps she feared dying without control over her body and feared relentless suffering. Katherine’s suffering was physical but also emotional and psychological in that she could anticipate the progression of her illness and knew what that would mean for her daily living. Health professionals who become poignantly aware of this can seek to reassure the patient that dying with dignity is a realistic possibility.
6.3.2 Suggested Professional Responsibilities

• In view of the seriousness of this decision and the healthcare team’s commitment to respect human life, the health professionals should take measures to ensure competence, understanding and valid consent on the part of Katherine to withdrawal of the ventilator. It would also be reasonable for the clinician to encourage the patient to have a waiting period to see if her decision remains firm, reassuring her that this is not ignoring her distress and concerns but rather ensuring a careful and reflective decision.

• If Katherine continues in her determination to have the ventilator removed, then the healthcare team should agree to do this in moral recognition of her autonomy as a competent person to choose the meaning of her life in such illness. Health professionals need to show respect for Katherine’s decision, even if they do not agree with it.

• The process of ventilator removal should be done with clinical care and expertise. Careful attention to pain management is vital if the patient is not to experience profound suffering from ventilator withdrawal. The process needs to be discussed with at least the family and, in this case, with the patient in order for them to achieve a clear understanding of what they are requesting but also to receive assurance that effective pain management will be provided.

• Given the stress that may be experienced by health professionals in situations such as this, it is important that collegial support be provided.

• Katherine and her family need to receive comfort, human presence and continued reassurance of care to company her in her dying days. It is important for Katherine that she does not feel abandoned by health professionals because of this choice she is making.

• For future reference in the healthcare unit, the full account of this decision needs to be documented. Included in such documentation is the evidence of the process seeking patient informed consent. Also for documentation are the specific measures taken to inform the family and patient of the actual process of removal of ventilator and promised follow-up care.
6.4 Case 4: Withholding LPT in a Neonatal Unit – A Low Birth Weight Baby

As with adults, decisions about the limitation of therapy and life supports for neonates are based on clinical prognoses but also ethical considerations about future suffering and profoundly diminished quality of life. The following case illustrates the clinical and ethical challenges involved in such complex decision-making.

A Low Birth Weight Baby

Jan C. was admitted to the labour ward in advanced labour at 23 weeks gestation. This was her fourth pregnancy, the others having ended in miscarriages before 20 weeks. At 43 years of age she felt time was running out for her to achieve a successful outcome and Jan was desperate for this baby to survive. Baby C was born with a severe spina bifida, malformation of the brain stem, hydrocephalus, vocal cord paresis and severe deformities of the lower limbs. He was relatively unresponsive, had little spontaneous movement and had difficulty swallowing, sucking and breathing. If baby C survived he would be unable to walk, be doubly incontinent, have no sexual function and probably require an artificial airway. He would certainly require multiple operations on his spine and lower limbs. The quality of his future life was estimated to be extremely poor.

The healthcare team agreed that no active treatment was warranted. Feeding was restricted to that on demand and the baby was given paracetemol and phenobarbitone. The consultant obstetrician told Jan C. and her husband that, given the prognosis of baby C, the hospital’s special care unit would not be able to offer more than basic care to the baby. In spite of the couple’s pleas for everything possible to be done, when baby C was born, weighing 400g, he was wrapped in a blanket and given to his parents to cuddle until he died about half an hour later.

(Tibballs, 2007, p.231. Edited variation on case of Baby M)
6.4.1 Discussion
Within the last few decades, developments in life prolonging technology have meant that it is now possible to contemplate the survival of babies born at extremely low gestation and size. However, clinical and family decisions to withhold or withdraw LPTs can be very stressful and challenging in these circumstances. Disagreements can occur between parents and health professionals, and within the healthcare team itself. In these circumstances, differences of ethical opinion and feelings of being emotionally overwhelmed are usually important factors that need to be addressed. This is especially clear in the case of Baby C.

While the healthcare team agree on withholding LPTs in the case of Baby C, the family do not have the background of neonatal experience that health professionals share. Moreover, the case of Baby C is particularly tragic for the parents since they have already suffered the grief of several previous miscarriages. A key challenge is that the health professionals do not usurp the parents’ input into the decision but, at the same time, the parents cannot be left without the full details of the newborn’s likely future.

The UK Royal College of Paediatrics and Child Health (RCPCH) (2004) suggests the circumstances that may involve the withholding or withdrawal of treatment in the case of children:

The Brain Dead Child – when brain stem death is confirmed the patient is, by definition dead. All life supports may be withdrawn with full emotional support for family and staff involved. (This condition does not apply to Case 4.)

The Permanent Vegetative State – in such circumstances treatment, inclusive of tube feeding, may be withdrawn while making the patient comfortable with nursing care. (This condition does not apply to Case 4.)

The ‘No Chance’ Situation – Prolonging treatment in these circumstances is futile and burdensome and not in the best interests of the patient; there is no legal obligation for a doctor to provide it. Indeed, if this is done knowingly it may constitute an assault or ‘inhuman and degrading treatment’ under Article 3 of the European Convention on Human Rights. An example would be a child with progressive metastatic malignant disease whose life would not benefit from chemotherapy or other forms of treatment aimed at cure. (The extent of serious impairment of Baby C would definitely be considered here as part of the clinical discussions with the parents.)
The ‘No Purpose’ Situation – In these circumstances the child may be able to survive with treatment, but there are reasons to believe that giving treatment may not be in the child’s best interests. The child may not be capable now or in the future of mobility, speech or taking part in decision-making and other self-directed activity. (This condition applies as it is a component of the ‘best interests’ judgement being discussed with Baby C’s parents.)

‘The Unbearable Situation’ – This situation occurs when the clinician and family believe that further treatment is more than can be borne and they may wish to have treatment withdrawn or to refuse further treatment irrespective of the medical opinion that it may be of some benefit. (Parents in Baby C’s case may not consider further treatment unbearable.) (RCPCH, 2004, p.28-29).

In addition, European Specialists in Paediatrics offer the following ethical principles to guide decision making:

1. In the event of futile treatment, the primary obligation of the paediatrician is to counsel the parents and let the patient die with minimal suffering. The decision lies primarily with the physician

2. The opinion of parents should be included in all medical decisions. Doctors treating the sick infant first should come to the conclusion on the basis of comprehensive facts. This should then be discussed with parents in thoughtful dialogue.

3. In the case of unclear situations or controversial opinions between members of the healthcare team and parents, a second expert opinion can be helpful.

4. Every form of intentional killing should be rejected in paediatrics. However, giving medication to relieve suffering in hopeless situations which may, as a side effect, accelerate death, can be justified.

5. Decisions must never be rushed and must be based on evidence as solid as possible (Sauer, 2001, p.365-367)

Recent research indicates that supports and values that parents find most important during neonatal decision-making regarding use of LPTs are religion, spirituality, hope and compassion. These supports and values are not routinely acknowledged or incorporated by physicians. Parents in this research needed doctors to convey hope and compassion when discussing resuscitation options even when the infant’s outcome was likely to be poor (Boss et.al., 2008, p.585).
'Physicians who were perceived as providing hope were not necessarily more likely to predict survival; in fact, some of the physicians whom parents described as hopeful predicted nearly certain death. These physicians gave parents hope because they expressed emotion and showed the parents that they were touched by the tragedy of the situation. […] Expressing their own emotions during intense patient interactions can be uncomfortable for physicians. Nevertheless, there is evidence that parents value physicians’ emotional reactions when the physicians communicate bad news.’ (Boss et. al., 2009, p.586)
6.4.2 Suggested Professional Responsibilities

- The healthcare team may need to reiterate to the family how they determine the likely burdens and benefits that make up a judgement to withhold LPTs and promise provision of optimal palliative care.
- With the decision to withhold and withdraw treatments, all members of the healthcare team should have an opportunity to voice their opinions and feelings. The final decision should be made in consultation with parents though the team must take the main responsibility for the decision. This can help alleviate the burden of guilt that some parents feel.
- If the family disputes the decisions being taken, a procedure needs to be made available for another opinion (another independent clinician, the hospital ethics committee etc.)
- Baby C’s parents need time to be with their baby. They also may need reassurance that withholding LPT does not make them complicit in euthanasia.
- Withholding LPT signals a change of focus to palliative care and the parents need to feel that they are not abandoned in their grief and their efforts to understand why this happens.
- The family should be asked if they would like a member of the clergy or other spiritual support to be available.
- With a view to keeping on-going records for occasional review by the healthcare team, the decision taken needs to be documented and the actions evaluated. The evaluation should include not simply the decision but the manner in which the decisions were made and the follow up with parent(s).
- Following the death of the baby, the consultant in charge and the nurse most involved should offer to see the parents, to discuss the death and the result of the post mortem examination if it were available.
- Given the parent’s history of multiple miscarriages, the healthcare team should offer suggestions about professional assistance for infertility difficulties.
6.5 Case 5: Artificial Nutrition and Hydration (ANH) – Is PEG Feeding Optional?

Is PEG Feeding Optional?

Nora is 62 years old and has had multiple sclerosis for 25 years. Initially the disease followed a relapsing and remitting course and Nora would have long periods of good health in between months of various disabling side-effects, such as temporary paralysis and visual problems. For the past ten years, however, her condition has become more disabling and Nora has had to move into a nursing home. The staff are friendly and she is well cared for. However, as a result of the insidious effect of her illness, most of her bodily functions have ceased to work. She is doubly incontinent. On the days when she is well enough to be aware of her surroundings, she finds her condition extremely distressing. She is embarrassed by her lack of bodily control and the fact that she has to have 24-hour nursing care. Her swallowing is unsafe and the decision was made a year ago to feed her via percutaneous endoscopic gastrostomy (PEG). She gets no pleasure from eating or drinking.

She does not have relatives or visitors. Some days she is described as barely conscious. Staff had a conference yesterday to discuss the continued use of the PEG tube wondering if withdrawal of ANH would be right. Wouldn’t comfort care be more compassionate and appropriate? There was no consensus among the staff about withdrawal: some felt that providing ANH was a gesture of solidarity and wanted to ensure that Nora would not be abandoned. Others wondered if there is a moral or legal obligation to maintain life at all cost regardless of the quality of the life?

(Edited case from Johnston and Bradbury, 2008, p.161)

6.5.1 Discussion

An important consideration throughout the discussions on LPTs thus far is that any judgement about withholding or withdrawing treatments including ANH must be patient-specific. Abstract principles alone will not be sufficient. Even accepting this advice, health professionals and ethicists differ on the moral evaluation of ANH. There is broad consensus that, if a patient is able to take food in the conventional way, then food should be offered and the patient encouraged to eat. However, when a patient is no longer able to take food in a conventional way, the difficult issue of deciding on ANH arises.
In Case 5, Nora has had the PEG tube in place for a year so the question is about whether this form of ANH should be removed. Case 5 is especially challenging because Nora’s competence is diminished though she experiences intermittent awareness and lucidity. Some days she is described as barely conscious and when she is aware of her environment, her lack of bodily control is a cause of distress and embarrassment. The questions that arise include:

1. Why do clinical doubts arise, after a year, about the wisdom of continuing the PEG tube?
2. Is the withdrawal of ANH justified in this case?
3. Is it in the ‘best interests’ of Nora to continue or withdraw ANH?
4. Is withdrawal of ANH equivalent to euthanasia?

1. Why question the continuing of the PEG tube after a year?

The health professionals notice Nora’s distress with her disability and general condition. On days when she has intermittent awareness she seems particularly embarrassed by the ‘insidious effect of her illness’. Chronic disability makes her daily life a struggle and she is often ‘barely conscious’. With the PEG tube she derives no pleasure from eating or drinking. The reasons the health professionals wonder about continuing ANH are not obvious and there is not consensus among the staff about withdrawal. They need to continue their conversation about their reasons for considering withdrawal of ANH at this point in Nora’s life. Comfort care might be more compassionate and perhaps even more comforting but, in what sense is it more appropriate? Withdrawal of ANH will result in the death of Nora within a relatively short time, perhaps 10 days to two weeks.

2. Is withdrawal of ANH justified?

One issue that looms large in the debate about the ethics of feeding and often influences individuals in objecting to withholding or withdrawing of feeding is the powerful symbolism of feeding the hungry and giving drink to the thirsty. Feeding the hungry has been cited as the most fundamental of all human relationships and a perfect symbol of the fact that human life is inescapably social and communal. Food and water are undoubtedly powerful symbols of comfort and human care in our society. Through their provision we communicate such care and concern for others. Some people feel concern that withholding or withdrawing artificial nutrition and hydration will undermine our commitment to the values of comfort and care in medical institutions and society at large. On this view one would find it difficult to justify withholding feeding even if in the form of ANH (Centre for Bioethics, 1997a).

However a focus on the symbolic value of providing food and water might mask several important differences. ANH is provided to treat malnutrition and dehydration. But these
medical conditions are not invariably accompanied by hunger and thirst. In addition, hunger and thirst can sometimes be treated without having recourse to ANH, e.g., the sensation of thirst associated with a dry mouth can be alleviated by moistening the patient’s lips and mouth with glycerine swabs or ice chips (Meidl, 2006, p.335). Importantly, ANH requires invasive procedures that strain the symbolism of offering food and drink to those in need.

For patients unable to take food or liquid orally, feeding and hydration are often supplied through the nose and throat (nasogastric tube), veins (IV line), stomach (gastrostomy), intestine (jejunostomy), or major vessel into the heart (hyperalimentation). All of these options highlight the profound difference between feeding the hungry with a meal and receiving nutritional support. It is also shown in some patients that withholding or withdrawing ANH may actually contribute to their sense of comfort. In brief, withholding or withdrawing ANH should not too readily be equated with ‘starving the patient to death’. It may even be considered by some to be a form of compassionate treatment (Meidl, 2006).

3. Is it in Nora’s ‘best interest’ to continue or withdraw ANH?

This method requires the decision-makers to consider what the ‘best course of action’ is for a particular (incompetent) person in a particular situation. See Case 2 above and Module 4 for a discussion of ‘best interests’.

Special Legal Challenges in Ireland

In the Ward of Court case in Ireland (1995), a central ethical and legal issue that arose was the question of whether it was justified to discontinue the ANH that was being provided to the Ward via a PEG tube. The moral reasoning involved in that case highlights the contentious terms of the ethical and legal debate about ANH.

After a High Court judgement that allowed withdrawal of the PEG tube from the Ward, an appeal followed with a Supreme Court judgement upholding the High Court decision. The removal of ANH was defended by Justice Lynch in the High Court as a ‘best interests’ judgement. In their decisions to withdraw ANH from the Ward both the High Court and the Supreme Court took the view that ANH was equivalent to medical treatment and, as such, could be justifiably withdrawn because it was considered to be ineffective and burdensome.

However, following the Supreme Court Judgement, the Irish Medical Council and Nursing Board issued statements that ANH is an ordinary and humane requirement of care and they claimed that it was a duty of their members to continue the provision of nutrition and hydration. In 2009, the Irish Medical Council has updated its position statement on feeding.

The Medical Council new guidelines offer more qualified and nuanced advice than that provided in 1995.
Nutrition and hydration are basic needs of human being. All patients are entitled to be provided with nutrition and hydration in a way that meets their needs. If a patient is unable to take sufficient nutrition and hydration orally, you should assess what alternative forms are possible and appropriate in the circumstances. You should bear in mind the burden or risks to the patient, the patient's wishes if known, and the overall benefit to be achieved. Where possible, you should make the patient and/or their primary carer aware of these conclusions. 

(Medical Council, 2009, p.20).

The 1995 statement of the Nursing Board has not been updated as yet and remains as follows:

‘The ethical principle requires that so long as there remains a means of nutrition and hydration of this patient it is the duty of the nurse to act in accordance with the Code and to provide nutrition and hydration. In this specific case, a nurse may not participate in the withdrawal and termination of the means of nutrition and hydration by tube. In the even of the withdrawal and termination of the means of nutrition and hydration by tube the nurse’s role will be to provide all nursing care.’ (An Bord Altranais, 18th August, 1995, cited in Dooley and McCarthy, 2005, p.284). (See Module 4, section 5.1.2 for reference to the Ward of Court Case and ANH)

4. Is withdrawal of ANH equivalent to euthanasia?
If the decision to remove ANH is made with the clear intention of hastening Nora’s death, then there is reason to pause and consider that this may be an act of euthanasia, a deliberate act or omission whose primary intention is to end another person’s life.

However, decisions to withdraw or discontinue life supports are not equivalent to euthanasia if they are validly authorised by a competent patient’s consent or if a clinical decision is made that further life supports including ANH would, on the basis of all available evidence, be futile – lacking benefit for the patient and merely prolonging the dying process.

The following text offers one method of reasoning for decisions on ANH:

‘We should not assume that all or most decisions to withhold or withdraw medically assisted nutrition and hydration are attempts to cause death. To be sure, any patient will die if nutrition and hydration are withheld. But sometimes, other causes are at work. For example, the patient may be imminently dying, whether feeding takes place or not, from an already existing terminal condition. At other times, although shortening of the patient’s life is one foreseeable result of an
omission, the real purpose of the omission was to relieve the patient of a particular procedure that is of limited usefulness to the patient or unreasonably burdensome for the patient and the patient’s family or caregivers. This kind of decision should not be equated with a decision to kill or with suicide.’ (O’Rourke and Norris, 2001, p.205-6).

The position of O’Rourke and Norris combines application of the principle of double effect, the principle of proportionality as well as the ordinary extraordinary distinction. The text does not provide an answer about the decision in the case of Nora but it highlights the questions that health professionals must reflect on and provide some answers for before a decision is taken and before they are confident that they can morally defend a decision to remove ANH.

The above arguments, reasoning and questions about the morality of ANH are representative of an expanding literature on this topic. The following sources offer an opportunity to reflect on viewpoints that are widely discussed among theologians, ethicists, doctors and nurses alike (Center for Bioethics, 1997a, 1997b; GMC, 2009; Dooley and McCarthy, 2005; Lesage and Portenoy, 2001; Meidl, 2006; Meisel, 1992; O’Rourke and Norris, 2001; Panicola, 2001).

### 6.5.2 Suggested Professional Responsibilities

- The intermittent awareness that Nora experiences is mostly dominated by the distress felt in relation to her condition. During the brief periods when Nora might show partial awareness, a conversation could be initiated with her about possible withdrawal of the PEG tube. However, such a conversation might be very distressful and may not provide reliable evidence of Nora’s capacity to take part in this decision.
- In the absence of family or designated proxies, an assessment of Nora’s ‘best interests’ should be made. For a patient with an advanced life-threatening illness who is dying, there may not be many benefits. Admittedly, continued existence might be seen by some as an important ‘benefit’.
- The burdens of providing ANH in Nora’s case should be assessed. There is always a risk to a patient being fed through a feeding tube. Feeding tubes may feel uncomfortable. They can become plugged up, causing pain, nausea and vomiting. Feeding tubes may also cause infections.
- Any disagreements that may arise within the healthcare team should be aired and constructively resolved based on careful evaluation of benefits and burdens of continuing ANH in Nora’s case.
- The decision in terms of the process and the final determination made about continue or withdrawing ANH should be documented.
7. Module 6 Further Discussion

7.1 Euthanasia and Physician Assisted Suicide

‘Euthanasia’ derives from the ancient Greek, ‘eu’, meaning good and ‘thanatos’ meaning death, thus a ‘good death’. Today, the term ‘euthanasia’ refers to the administration of death, the active intentional ending of life.

In the medical context, ‘active euthanasia’ is the act of purposely ending the life of someone. This might be done by a health professional injecting a patient with a lethal dose of drugs that directly causes his or her death.

The withholding or withdrawal of LPT is sometimes described as ‘passive euthanasia’. However, it is argued that describing the withholding/withdrawing of treatment as passive euthanasia is not accurate. In such cases, it is argued that the person involved is not killed in the usual sense, nor is the death of the person intended by the withholding of additional treatment. Terms such as ‘allowing natural death’ are increasingly used as an alternative to ‘passive euthanasia’.

Consent for euthanasia would be said to be voluntary if it were carried out at the patient’s request.

If someone does not explicitly request euthanasia this does not mean that they do not want it; it would be reasonable, however, to assume that they do not. Euthanasia in such a case would be involuntary, and, even more obviously, it would be if someone had clearly expressed a wish to live as long as possible, whatever the circumstances.

Newborn babies do not yet have, and comatose or severely brain-damaged adults have lost, the capacity to request or refuse euthanasia. In such cases neither consent nor the lack of it can be said to be a factor, so euthanasia, if considered, is neither voluntary, nor involuntary, but non-voluntary.

Assisted suicide is defined as the act of helping a person to die by providing the means for them to take their own life. An example of physician assisted suicide is the act of giving a prescription or supply of a lethal dosage of drugs to a patient who has requested this. The doctor providing the lethal dosage of drugs thus enables a patient to end his or her own life. The patient or individual may never use the drugs to end their life but it is suggested that having the means at their disposal, offers a patient the security of knowing they have the means to end their life and suffering if they choose.
The following discussions consider the legal and ethical implications of euthanasia and physician-assisted suicide (PAS). International discussion of these topics has not abated but there are still relatively few countries that have legalised the practices. Reasons of public interest and threats to physician integrity are raised as justifications for unwillingness to legally endorse the practices. In the legal discussions (7.2 See Module 5, section 6.4. for discussion of the R v Cox case) that follow, the position in law on euthanasia and PAS is explained for a selection of countries.

In the ethics discussion (7.3 and 7.4) positions are distinguished that (1) offer reasons and arguments that serve to morally justify the practices of euthanasia or PAS and (2) reasons and arguments to show that moral justification is lacking for the practices.

7. 2 Legal Positions: Euthanasia and Physician Assisted Suicide

7.2.1 The Law – Ireland

In Ireland, any person who takes active steps to end the life of another person is in breach of the criminal law. In this respect, a distinction may be made between assisting a person in ending his or her own life – perhaps by providing medical assistance – and actually taking the final step of ending the patient’s life. The first situation involves assisting the suicide of the person. Under Irish law, suicide ceased to be a criminal offence under the Criminal Law (Suicide) Act 1993. However, the Act states that anyone who ‘aids, abets, counsels or procures’ the suicide of another person commits a criminal offence which is punishable with a possible maximum sentence of 14 years.

The situation which is sometimes termed ‘euthanasia’ involves the deliberate action of ending the life of the person. Under Irish law, this is legally categorised as murder. The law does not allow a person to consent to his or her own death and for this reason, the fact that the patient has consented to, or even requested, the action is irrelevant. A person who is convicted of murder is punishable on conviction by a mandatory life sentence. This means that the court cannot choose to give a lesser sentence because of a person’s underlying motivations.

There have been no prosecutions of Irish health professionals in relation to either assisted suicide or euthanasia. It is thought that the position taken in the English case of R v Cox (1992) is likely to be followed in Ireland effectively legally prohibiting euthanasia. (See Module 5 for discussion of the R v Cox case)

A number of efforts have been made in other countries, including the US, Canada, the UK and under the European Convention on Human Rights, to assert a legal right to die through the courts (See Module 4, section 5.2 for discussion of the UK Ms Pretty case involving an attempt to receive assurance that an act of assisted suicide would not be prosecuted.)
7.2.2 Switzerland

Although the law in most countries legally prohibits suicide and active euthanasia, there have been some moves in recent years to introduce measures to permit one or both practices. Both practices are permitted in Switzerland where they are not contrary to the criminal law and are largely unregulated. Because of the liberal regime in Switzerland, this is the most common country for people to travel to in order to avail of euthanasia. However, recent reports claim that the Swiss government is considering restricting or even banning organised assisted suicide in an attempt to reduce so-called ‘death tourism’. Concerns stated that their current laws on assisted suicide could be open to abuse. A study in 2008 suggested more and more people seeking help to die in Switzerland did not have a terminal illness (Pidd, 2009).

7.2.3 The Netherlands

Both euthanasia and physician assisted suicide have been permitted by legislation in the Netherlands since 2001, in Belgium since 2002 and in Luxembourg since 2008. In these countries, the practices are more regulated than in Switzerland. In the Netherlands, for example, the Dutch Criminal Code states that a physician who terminates a patient’s life or who assists a patient’s suicide will be exempt from criminal liability provided that he or she complies with two conditions. These are, first, he or she must practice in accordance with the due care criteria and secondly, he or she must report the cause of death to the municipal coroner.

The due care criteria apply to both euthanasia and physician assisted suicide. These criteria require that the attending physician must:

- be satisfied that the patient has made a voluntary and well considered request
- be satisfied that the patient’s suffering is unbearable, and that there is no prospect of improvement
- have informed the patient about his or her situation and prospects
- have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient’s situation
- have consulted at least one other physician, who must have seen the patient and given a written opinion on the due care criteria referred to above, and
- have terminated the patient’s life or provided assistance with suicide with due medical care and attention.
7.2.4 United States

Physician assisted suicide is also permitted in the American states of Oregon since 1996 and Washington since 2008, although in much more restricted circumstances than in the European models. In Oregon, the Death with Dignity Act 1996 requires that the patient must have a terminal illness with a life expectancy of less than six months. The Act also requires the patient to have made two separate requests for assisted suicide and imposes a 15 day delay between the first and second requests.

7.2.5 United Kingdom 2009: The case of Debbie Purdy

Debbie Purdy, from Bradford was 46 and was diagnosed with MS in 1995. As her condition progressed and she knew of the likely prognosis, she considered going to Switzerland to end her life. However, she feared that her husband might be charged on his return to the UK. She wanted assurances from the DPP that her husband, Omar Puente, would not be prosecuted.

Ms. Purdy believed that, unless the law was clarified, she might be forced to end her life earlier than she planned because her husband would be unable to help her, without risking prosecution, if she became totally dependent. If the risk of prosecution was sufficiently low, she could wait until the very last minute before travelling with her husband’s assistance. If the risk of prosecution was high, Ms. Purdy would have to go earlier while she was still fit enough to travel without assistance.

Purdy took her case to the House of Lords after the High Court and the Court of Appeal held that it was for Parliament, not the courts, to change the law which makes assisted suicide illegal in the UK. The offence of assisting suicide is a criminal offence under Section 2(1) of the Suicide Act 1961 and carries a maximum penalty of 14 years imprisonment. The act defines assisting a suicide as ‘aiding, abetting, counselling or procuring’ the suicide of another. Committing or attempting to commit suicide is not a criminal offence. No individual to date has been prosecuted for assisting a suicide in relation to suicides committed abroad, including the Dignitas clinic in Switzerland.

The Law Lords agreed that changes were a matter for Parliament but upheld Ms Purdy’s argument that the DPP, Keir Starmer QC, should put in writing an ‘offence-specific policy’ identifying the facts and circumstances he would take into account in deciding whether it was in the public interest to prosecute under the Suicide Act.
The Director of Public Prosecutions, Keir Starmer QC has called for public participation in a 12-week consultation on the factors he had identified which will be taken into account when considering whether prosecutions will be brought for the offence of assisting a suicide. Starmer stated:

‘Assisting suicide has been a criminal offence for nearly fifty years and my interim policy does nothing to change that. There are also no guarantees against prosecution and it is my job to ensure that the most vulnerable people are protected while at the same time giving enough information to those people, like Ms. Purdy, who want to be able to make informed decisions about what actions they may choose to take.’ (Crown Prosecution Service, 2009).

Details of the interim policy on prosecuting assisted suicide can be found on this Crown Prosecution Service website: www.cps.gov.uk/news/press_releases/144_09/.

7.3 Ethical Positions: Euthanasia and Physician Assisted Suicide

Consciously deciding to end a person’s life is a profound and grave matter and actions which do, while motivated by compassion, are widely, intensely and heatedly considered and debated around the world. They engender strong feelings about

- the right to demand one’s choice of dying

and

- that life is so precious there is a duty to preserve it at all costs.


Considerable professional and public attention has focussed on voluntary euthanasia. This has partly been spurred by the publicity of the practice of euthanasia in the Netherlands and it is considered in this section.

7.3.1 Arguments in Support of Euthanasia

In general there are two kinds of arguments that support euthanasia. The first kind is a duty based argument:

- Public support for euthanasia reflects recognition that the same values of patient self-determination and well-being that have been accepted as guiding treatment decision making in general, and decisions about LPT in particular, can, in some cases support voluntary euthanasia as well. For example, it is argued that permitting (voluntary) euthanasia respects patient autonomy and provides a more peaceful and humane death for some patients than they would otherwise have.
The second kind of argument appeals to anticipated (likely good) consequences of permitting euthanasia in addressing the fear and the reality of suffering.

- In significant part, the public interest in and support for euthanasia reflects fear of loss of control and dignity while dying.
- This fear includes concerns that, especially in acute care settings, aggressive use of life prolonging technologies would allow one to linger in a semi-comatose state, unable to relate to others or communicate the extent of one’s suffering.
- There is strong belief that, even with the best of palliative care, pain cannot be fully relieved in terminal illness.

The belief is that the availability of euthanasia will contribute to lessening these kinds of fears and concerns.

7.3.2 Arguments Opposing Euthanasia
In general there are also two kinds of arguments that oppose euthanasia. The duty based argument usually takes the following form:

- Any individual instance of euthanasia is morally wrong because it violates the duty not to kill innocent human beings. For some, even the consent of the one killed does not make the killing permissible.

The second kind of argument appeals to anticipated (likely bad) consequences of permitting euthanasia. On this view:

- Although it might be morally justified in some individual cases, it would nonetheless be bad public policy to permit voluntary euthanasia. Among potential bad consequences opponents cite are: its seeming incompatibility with the proper aim of medicine to protect life in all its frailty; the erosion of the trust of patients in their caregivers; the erosion of the social commitment to provide appropriate care to the dying if euthanasia is seen as an acceptable alternative; the fear that providing voluntary euthanasia would, in time, lead to involuntary euthanasia or non-voluntary euthanasia of incompetent patients.

Evaluating and assessing the relative seriousness or likelihood of these consequences of permitting voluntary euthanasia is both controversial and difficult.

7.4 Physician-Assisted Suicide (PAS)
The difference between active euthanasia and aiding in a terminally ill patient’s suicide is essentially that in active euthanasia the doctor determines the eventual course of action, whereas in PAS she merely assists the patient to realise his decision to end his life.

It should be said at the outset that some commentators claim we should change the terminology of PAS and refer rather to physician-assisted death (PAD) in order to clearly
distinguish it from the usual meaning of suicide. Others like Debbie Purdy ask why assisted suicide should be only physician assisted?

It is sometimes said that, similar to the distinction between ‘active’ and ‘passive’ euthanasia described above, withholding or withdrawing LPTs from a patient who has capacity to request this is equivalent to PAS. However, it could be argued that this is placing an emotive label on an action that is legally and morally valid. When a society prohibits PAS and a case of discontinuing LPT is labelled PAS, both the doctor and competent patient seem implicated in a legal and moral offence. However, the point to be noted is that, based on a fundamental respect for a person’s autonomy, competent patients have the moral and legal entitlement to discontinue LPT (See Module 3 and Module 4). If such decisions are labelled as PAS, this could be viewed as disrespecting the competent patients’ right to refuse unwanted treatments.

7.4.1 Arguments Supporting PAS
Arguments in support of PAS include those that are put forward in support of euthanasia. They centre on respect for patient autonomy and are perceived to address some patient’s fears about the possibility of a painful, distressful and/or undignified death.

- Specifically, supporters of PAS argue that the provision of PAS is consistent with the aim of medicine which is to: respect the patient’s autonomy; ease the patient’s suffering; and do what is in the best interests of the patient (Dieterle, 2007).

- It is also claimed that PAS differs greatly from the wrongful killing of innocent persons. Proposals to allow PAS do so on the assumption that the patient requests the medication – usually a number of times, the patient is terminally ill with less than 6 months to live and the patient is convinced over time that death would be far preferable than the life he or she is living. In brief ‘death is not a harm to those who seek and are granted PAS’ (Dieterle, 2007, p.138).

The philosopher, Tom Beauchamp, claims that PAS may be a morally justified action. On his view, valid requests and authorisation for assistance in dying can legitimate PAS. This means that a doctor would not be obligated to honour all requests but that valid requests make it morally permissible for them, or some other person, to lend aid in dying. A doctor might refuse to honour a particular request if there is good moral reason for doing so: autonomy of person seeking PAS may be impaired; excessive influence is being exerted on the individual requesting; the desire to avail of PAS is not stable over time; public trust in doctors would suffer etc:
‘If letting die based on valid refusals of treatment does not wrong or harm persons or violate their rights, how can assisted suicide or voluntary euthanasia harm or wrong a person who died? In each case, persons seek what for them in their bleak circumstances is the best means to the end of quitting life. Their judgement is that lingering in life is worse than death.’

(Beauchamp, 1999, p.438)

7.4.2 Arguments Opposing PAS

Arguments against PAS are, similar to euthanasia, duty based and consequential. A first duty based argument opposing PAS derives from the perceived aims of medicine in the same way as the argument supporting PAS does. On this view, the intent of the doctor is said to offer grounds for rejecting PAS:

- Doctors should not kill; this is prohibited by the Hippocratic Oath. The doctor is bound by their profession to save life, not take it. The idea behind this argument is that the intent of a doctor should be always to heal or cure.

A second argument considers the inherent wrongness of killing.

- Killing an innocent person is inherently wrong. The doctor indirectly kills the patient in cases of PAS by providing the lethal medication. So the doctor does something inherently wrong.

One of the most common forms of argument against PAS (similar to euthanasia) cites the possible negative consequences of the practice as a reason not to legalize it. These arguments rely on empirical claims about the future and, as a result, their persuasiveness depends on how likely it is that the predictions will be realised.

Seven consequences are most typically cited as the basis for opposing legalisation of PAS and similarly would be cited to claim that PAS could not be morally justified.

1. PAS could start us on a slippery slope to non-voluntary euthanasia.
2. Abuses of the law are likely; patients might be pressurised by family to seek PAS and vulnerable groups would be more susceptible to persuasion to accept PAS.
3. Allowing or encouraging PAS would corrupt medicine and health professionals.
4. Acceptance of PAS will weaken the prohibition on killing.
5. Patients will give up too easily and abandon hope.
6. Improvements in palliative care will cease or diminish.
7. Citizens will begin to fear hospitals and health professionals.
In some research which assessed this list of possible consequences against the backdrop of the legalization of PAS in Oregon (US) and the Netherlands, it was found that the overwhelming majority of predicted consequences of PAS laws have not come to pass (Dieterle, 2007). This does not mean that concerns about the consequences of legalizing PAS have no basis in reality because these findings may be contested by findings from other research. What is important to note is the contribution that empirical research can make to informing ethical and legal debates on euthanasia and PAS.

7.5 Insights from Oncologists on Euthanasia and PAS

One robust piece of research, carried out in the US in 2000, surveyed 3,299 oncologists on the subject of euthanasia and PAS. Four insights were gleaned from the study:

1. Concern among oncologists about performing euthanasia or PAS may limit their willingness to prescribe opioids, thereby leading to inadequate pain management. This reticence may reflect fear that increasing opioid dose increases the risks for respiratory depression and death and might be construed as a form of euthanasia. (See Module 5)

2. There seems to be a relationship between the likelihood of performing euthanasia and PAS and the inability of physicians to obtain adequate end-of-life care for their patients. Worry was voiced that inadequate access to palliative care might make euthanasia and physician-assisted suicide attractive alternatives.

3. Physicians who reported receiving better training in end-of-life care seemed less likely to perform euthanasia or physician-assisted suicide.

4. Results suggest that among US oncologists support for PAS and euthanasia has decreased substantially. Between 1994 and 1998, oncologists’ support for PAS declined by half, from 45.5% in 1994 to 22.5% in this study (Emanuel, Fairclough, Clarridge, et. al., 2000) This decline may reflect expanding knowledge about how to facilitate a ‘good death’ making PAS and euthanasia no longer appear as necessary or desirable (Emanuel, Fairclough, Clarridge, et. al., 2000).
Cognisant of the arguments to support PAS that suffering and inadequate palliative care are often contributing factors, the Irish Association for Palliative Care strongly recommends the continued appropriate development of specialist palliative care services throughout Ireland. It is the clear duty of the doctor to ensure that a patient dies with dignity and with as little suffering as possible (O’Brien et. al., 2000, p.1). In addition the Irish Association holds the position that the legalisation of euthanasia has potential adverse effects on the patient-health professional relationship, society’s expectations of health care and resources available to address serious illness (O’Brien et. al., 2000, p.2).
8. Module 6 Summary Learning Guides

8.1 Central Issues and Concepts in Decisions about LPTs

- Decisions to start or stop treatment should be based on the benefits and burdens of the treatment, as judged by a patient or authorised surrogate.

- The distinction between ordinary and extraordinary treatment is often used as a rule of thumb by health professionals to distinguish between medicines, treatments, and operations, which offer a reasonable hope of benefit without excessive pain or other inconvenience and those which do not.

- The principle of proportionality requires that the decision making process about treatments should follow the general rule to maximise benefit and avoid undue burden.

- The meaning of the distinction between killing and letting die is widely contested and often underpins distinctions between: 1) suicide and foregoing treatment and, 2) euthanasia and so-called ‘natural’ death.

- It is impossible to determine what will benefit a patient without presupposing some quality of life standard and some conception of the life the patient will likely live after a medical intervention.

- Historically, the sanctity of life position holds that the value of human life is not dependent upon its being valued by the individual themselves or by others or by the presence of certain functional capacities such as relationality or rationality.
8.2 Futility

- The notion of futility is a disputed concept that is still evolving.
- The debate about what constitutes ‘futile’ treatments began with decisions relating to the stopping of cardiopulmonary resuscitation but it has expanded to other forms of LPT.
- Futility judgements are typically used to express a combined value judgement and scientific judgement.
- There is a considerable subjective element in judgements that further treatment is ‘futile’ – precisely because decisions that weigh up benefits and burdens are not based on rocket science.
- The debate on ‘futility’ can be divided into three approaches:
  the first defines futility in terms of definite clinical criteria.
  the second is a procedural approach that gives power to hospitals, utilising their ethics committees, to decide whether interventions demanded by families were futile.
  the third approach focuses primarily on negotiation at the bedside and on-going communication with patients, families and the healthcare team.
9. Module 6 Activities

9.1. Reflect back on the particulars of Case 1:

a. Ms. R. was put on a ventilator when she was admitted to intensive care. The family asked that everything should be done to keep their loved one alive. Do you agree with the ICU team that further LPTs for Ms. R. would be ‘futile’?

b. The team took time (a few days) to provide life support and on-going conversation with the family. In what way was this process therapeutic for the family?

c. Based on your experience caring for patients, what is it in the procedures of the hospital setting that might contribute to a patient’s sense of abandonment?

9.2 Reflect back on the particulars of Case 2:

a. Mr. W.’s life in the balance: Would CPR provide benefit?

b. The family of Mr. W. are experiencing the grief of potentially losing their loved one. They believe that providing CPR may give them a reprieve from this grief. What information or conversation would you provide that might give the family of Mr. W. reason to believe that CPR might be more harmful than helpful for their loved one?

c. Can you understand how the family of Mr. W. think that biological life can be construed as a benefit even if there is no realistic opportunity for Mr. W. to continue having a biographical life?

d. From your clinical experience, what is the likely outcome for Mr. W. if CPR proceeds?

e. What means would you suggest for resolving the disagreements between the family, doctors and nurses? When faced with continued resistance to clinical advice, is it ever legally or morally justified to simply go ahead and write up a DNR without family consent?
9.3 Re-read Case 3
where Katherine requests removal of the ventilator and discuss the following with your colleagues:

a. Even if Katherine is competent, given the seriousness of this request, are there any further complications among health professionals that you anticipate?

b. You are the clinician in charge where Katherine is a patient. Explain what kind of information or understanding you would want to provide for Katherine. Since she had already approached a staff nurse about her desire to discontinue ventilator use, what conversation would you have with her?

c. Who should participate in the decision: family? The entire clinical team? Hospital ethics committee? On-site hospice clinician?

d. How would you explain your choice of participants?

9.4 Reflect back on the particulars of Case 4:

a. In this time of grief and desolation, can you suggest further clinical advice for Jan and her partner who have already experienced three miscarriages before 20 weeks?

b. What appropriate after-care for the family’s grief can be provided in the confines of the hospital setting? Is this available in your work context?

c. Based on your experience and study, who do you think should be responsible for final decisions about CPR and DNR?

d. Are guidelines for CPR and DNR available in your work context? If so, what do they include? If not, is there a reason?

9.5 Reflect back on the particulars of Case 5:

a. How would you evaluate the benefits and burdens of continuing ANH for Nora?

b. In your experience, how would a clinical team deal with a case such as Nora’s? Who would be involved in the decision-making on the case?

c. Do you think there is realistic basis for clinical disagreement about what is in the ‘best interests’ of Nora?
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