

The background of the page is white with two large, overlapping blue triangles. One triangle is in the top-left corner, and the other is in the bottom-left corner, meeting at a diagonal line that runs from the top-left towards the bottom-right.

A Report on Euthanasia for the NZMA

Grant Gillett

Grant Gillett

MBChB (equivalent to U.S. MD); MSc (Psychology); D.Phil (Oxon); FRACS (equivalent to U.S. Board Certification in Neurosurgery); FRS NZ.

Grant Gillett is a qualified neurosurgeon and practised until 2006. He also has a D.Phil (Oxon) and was a fellow in philosophy at Magdalen College, Oxford. He is now a Professor of Medical Ethics at the Bioethics Centre of the Otago University Medical School, and a fellow of the Royal Society. He is author of *The Mind and its Discontents* (2009), *Subjectivity and Being Somebody: human identity and neuroethics*. (2008), *Bioethics in the clinic: Hippocratic reflections* (2004) and over 350 articles in medical ethics, philosophy, bioethics, the philosophy of psychiatry and neuroscience. An abiding area of writing and research has been end-of-life care and euthanasia and he worked closely with the euthanasia report group of the BMA in 1988 and 1989. He continues to teach and write extensively on ethical issues and medical law in New Zealand and Australia, and the philosophical basis of contemporary clinical ethics.

This report was prepared for the New Zealand Medical Association, 2017

A report on euthanasia for the NZMA

I.	Executive summary	1
II.	Preamble	5
III.	Hippocratic traditions.....	5
3.1	The <i>pause</i>	5
3.2	Narratives, lives, deaths and human sensibility	7
3.3	The sanctity of life	8
3.4	Whose life is sacred?	9
3.5	The unique challenge of mortality	10
3.6	Suicide and its relevance to euthanasia	12
IV.	Care and intervention: our role as professionals and clinicians.....	14
V.	International ethical-legal perspectives	16
5.1	The Netherlands	17
5.2	Belgium.....	21
5.3	United Kingdom.....	22
5.4	United States	23
5.5	Canada.....	24
5.6	South Africa: an about turn against legal assistance in dying	24
5.7	The European Association of Palliative care	25
VI.	Letitia Seales and aid in dying in New Zealand.....	25
VII.	Severely damaged human lives.....	37
VIII.	Futility.....	40
8.1	Varieties of futility	41
8.2	Decisions about futility and benefit	42
IX.	Other cultures and faith traditions: some tentative thoughts	43
X.	Children: potentiality and human interests	45
10.1	The potentiality principle—further thoughts.....	46
10.2	Severely impaired newborns and transplant decisions	48
10.3	Children and clinical decisions.....	49
XI.	Ending the narrative in a fitting way	52

11.1	The RUB: the worst possible end to the story.....	55
XII.	Euthanasia broadly speaking: pulling the threads together	58
12.1	Professional morality and legal reform	58
12.2	A sense of life in the midst of the clinic.....	59
12.3	Inspir(it)ed persons with a sense of life	61
XIII.	Concluding remarks and convergences.....	62
XIV.	References (Alphabetical)	65

I. Executive summary

A report on euthanasia for the NZMA

This report is an update on the debate about euthanasia as it affects the medical profession in New Zealand. It examines ethical arguments and codes, personal and professional commitments, and the current state of the law. The report includes commentary from a variety of sources and tries to strike a balance in alignment with traditional ethics, New Zealand law, and international codes of medical ethics. It has been prepared by Professor Grant Gillett, MBCHB, D Phil (Oxon); FRACS; FRSNZ *Bioethics Centre, University of Otago*, and was commissioned by the New Zealand Medical Association's Board.

The Hippocratic tradition

I will not give a fatal draught to anyone if I am asked, nor will I suggest such a thing.

The Hippocratic tradition is committed to a version of the sanctity of life principle: that each human life is of unique value and ought to be protected and cherished on that basis alone. It is moderated by other considerations in clinical practice.

Clinical intuitions, illness and end-of-life decisions

Clinical decisions draw on our character as moral agents. End-of-life procedures, significantly differ from one another. Active voluntary euthanasia generally denotes intentionally ending a patient's life at the patient's explicit and competent request; physician-assisted suicide and physician aid in dying (where lethal drugs are prescribed to a patient for the purposes of self-administration) also involve an active intervention and differ from the limitation of life-prolonging treatment.

Palliative care shares the widespread clinical intuitions of many doctors and leaves the profession holding to the traditional position and our duties to protect life.

Human death has many and diverse meanings and requires caring attention and non-abandonment of a dying patient, in ways that often go beyond clear-cut policies or objective guides to action.

The sanctity of life and its limits

Medicine is not committed to a doctrine of the sanctity of life requiring that we prolong life whatever the condition of the patient concerned, but rather focuses on the supreme value of each human life. That allows voluntary euthanasia to be distinguished from the decision to forego "aggressive medical treatment" by applying certain helpful concepts:

- I. *substantial benefit* is an outcome that, now or in the future, the patient would consider worthwhile
- II. the *risk of unacceptable badness* or the RUB.

These two concepts contribute to a patient-centred concept of medical futility in end-of-life care.

The unique challenge of mortality: our role as professionals and clinicians

Death is a certainty for all of us and, when confronting it, we meet as person-to-person such that medical technology *per se* has a limited, albeit vital, role.

When any patient dies, the healthcare team feels the burden of that loss so that, if a patient is helped to die by a doctor at a given time and place, that doctor assumes a heavy moral burden. Those in hospice practice see such a solution to the problem of death and dying as a poor second best to careful attention to the needs of the patient and any despair or desperation induced by those needs.

International ethico-legal perspectives

Law or policy has specifically sanctioned active voluntary euthanasia in a number of settings (eg, Netherlands, Belgium, Luxembourg, Colombia, Canada) and in others active physician aid in dying is allowed (eg, Switzerland and the US states of Oregon, Washington, Montana, Vermont and California).

Opponents of a law change have deep misgivings about acceding to a wish to actively end a patient's life. It happens with patients who are deeply distressed and fearful and whom we, as healthcare professionals, tend to find troubling and distressing. That strains the Hippocratic ethos founded on trust and reverence for life, and the attitudes we have developed during our training and professional experience.

Extant evidence as to professional and societal opinion are universally inconclusive, and published works tend to conclude with remarks supporting the prior convictions of those who write them. For that reason, the well-researched opinions by such bodies as the UK Supreme Court, the Scottish Parliament, and the European Association of Palliative Care (EAPC) deserve special regard.

The EAPC has formulated a position reflecting a wide range of European palliative care opinion and has settled on what it regards as a consensus position in relation to euthanasia, physician-assisted suicide, and palliative sedation. It affirms, "the intrinsic value of each person as an autonomous and unique social individual" and asserts "requests for euthanasia and PAS [physician-assisted suicide] require respect and careful attention, together with open and sensitive communication in the clinical setting" but that "the provision of euthanasia and PAS should not be included in the practice of palliative care and that palliative care is ... never futile."

Aid in dying in New Zealand

It is clear that a doctor in Australasia is under no obligation to provide care to prolong life if a reasonable body of medical opinion would deem that the patient's journey towards death should be neither prolonged nor hastened.

Given the disproportionate rate of suicide in marginalised and disempowered groups in contemporary society, the links between decisions to hasten death and attitudes of helplessness, hopelessness, disaffection with life and low self-worth are worrying.

Proper care of severely damaged human beings

Clinicians cannot afford to be complacent about this area. The sometimes wasteful and futile use of expensive clinical resources that are desperately needed elsewhere needs to be weighed against a respect and care for the individual patient and the avoidance of an ethos in which some human lives are deemed of less worth than others. In particular the concept of futility is sometimes regarded as a guise for medical paternalism, in that it rolls together medical and value judgments. Using two concepts—*substantial benefit* and the *risk of unacceptable badness*—supports the application of a patient-centred view of benefit and futility.

Other cultures and faith traditions: some tentative thoughts

We should note that societal intuitions are not nearly as clear-cut in relation to life and death as some pronouncements make them out to be.

Most faith traditions reject the right of human beings to end their lives when they wish to.

Indigenous perspectives are almost universally aligned with a set of guiding concepts closely linked to the sanctity of human life. Traditional ways of thinking regard human life in the wider context of relatedness and connection to others, so that the untimely taking of one's own life is rejected as a response to suffering because it damages not only oneself but brings evil into the lives of others. The grief caused by the loss of a human life is prominent here so that—even in what seem like empty and worthless moments of a given human life—there are goods to be discovered by those who touch and are touched by that life.

Children: potentiality and human interests

The birth of a severely compromised child is a profound tragedy for all involved and must be dealt with in a compassionate and sensitive manner, perhaps informed by *the potentiality principle*: the life due to each and every child is a life in which its potential is given the best chance of being actualised. That principle condemns a rejection of disabled children or those among us who are vulnerable and need extra support to have the best chance of fulfilling their inherent potential.

In end-of-life decisions, the need for sensitivity and inclusion is higher than in other situations. The twin considerations of substantial benefit and an unacceptable prospect of burdensome treatment may assist in making an ethical decision for treatment withdrawal.

Euthanasia broadly speaking: pulling the threads together

Having taken part in many end-of-life decisions and spoken to colleagues about their own similar experiences, it seems that doctors are somewhat reluctant to take on the weight of the burden that we are asked to assume by legalising active euthanasia. Every time a doctor

is closely involved with a patient's death—even where that is agreed by all to be the inevitable and perhaps best outcome of the treatment regimen—that doctor feels a moral burden.

Professional morality and legal reform

We should recall that the law and professional codes do not merely reflect the moral standards of a society but, in fact, have a profound influence on them. So there is a significant difference between the arguments that bear on the morality of an individual act of euthanasia and those shaping social or legislative policy. Many doctors feel secure in seeing the patient's journey through to its end and seeking neither to hasten nor delay that end.

The right to decline medical treatment is a basic right of the patient and the physician does not act unethically if respecting such a wish results in the death of the patient.

The debate about the legalisation of euthanasia is complex and the medical profession should remain cautious about any change in law that would interfere with principles that have guided medicine and general healthcare to good effect for most people throughout the centuries. The WMA's resolutions on euthanasia and physician-assisted suicide reflect this tradition; its clear opposition is sound and worthy of support.

II. Preamble

This report is an update on the current literature and state of the debate about euthanasia as it affects the medical profession in New Zealand. The profession is affected by ethical attitudes, personal and professional commitments, and the current state of the law. This report therefore includes reference to recent legal decisions in New Zealand and elsewhere that are likely to apply to ongoing medical practice and its legal and ethical governance. The report summarises and includes a large amount of commentary from a variety of sources, and the author is convinced that it has achieved a level of saturation (in the qualitative sense) in which further reading or coverage is unlikely to adduce any new material or considerations that would substantially affect the position outlined.

III. Hippocratic traditions

*I will not give a fatal draught to anyone if I am asked, nor will I suggest such a thing.*¹

The Hippocratic tradition has always been committed to some version of the sanctity of life principle. Clint Eastwood's character 'Will Munny', in the film *Unforgiven*, puts it thus: "*It's a helluva thing killing a man; you take away everything he's got and everything he's gonna have*". The principle enunciates the intuition that there is an intrinsic value in human life, quite apart from whether it is currently thought to be valuable by the person concerned, or indeed by anyone else. In part, this is because nobody quite knows what the future will bring, even in the last days of an illness. The principle that each human life is of unique value and ought to be protected and cherished on that basis alone is widely accepted, to the point where it rules our treatment decisions when we intervene in an emergency department to prevent suicide—although any patient of sound mind may refuse any treatment even if that decision results in his or her death. It could be argued that a suicide attempt is a *prima facie* refusal of treatment, but we do not treat it that way for reasons to which we will need to return.

The Hippocratic commitment is, however, weighed alongside and moderated by other considerations when treatment becomes too burdensome and a person wants to let nature take its course; but, even here, many of us are conflicted, as is marked by 'the *pause*'.² This medical conflict is, arguably, a reflection of a lifetime dedicated to caring for human beings as they face the trials of illness and the uncertainties of the illness journey.

3.1 The *pause*

The *pause* occurs when, despite acknowledging that death is perhaps the right option for one's patient based on very good moral reasons, a doctor hesitates—under the joint prompting of a commitment to a version of the sanctity of life principle, and a sense of care for the individual human being who is the patient. That commitment may be particularly strong in the case of a new-born child who will, almost certainly, never recover to the point where it can respond to those around it or develop its human potential. But, even in such an extreme case, at the moment of recommending that no further intensive efforts be made to keep the child alive, one might experience the *pause*. This springs, we could say, from our

being drawn into the nexus of human relationships that surround life, death and mortal illness—a context in which doctors are always entwined.

Such decisions make us delve deeply into our character as moral agents and the ways we have been formed by our extended clinical experience—and rightly so. The ability to heed complex inner voices resulting from a series of challenging experiences and the way we have negotiated them is, arguably, fundamental to the caring professions. In the light of a considered discussion of clinical intuition, perhaps such moments confront us with the mismatch between informed and astute judgement (underpinned by careful attention to evidence and sound reasoning), and a kind of unstable quasi-certainty in the face of diverse imagined futures, when we bow to what seem like rational arguments accessible to lay commentators and non-medical experts to whom apparent certainties can seem persuasive.

The *pause* alerts us to the seriousness of the decision being made (the dimensions of which are indicated by ‘Will Munny’), particularly for those at the coalface; the clinicians who feel responsible for them. It asks that one reflect on any lingering misgivings or unresolved questions at the back of one’s mind in coming to such decisions, and the climate within which we practice end-of-life care. In this way, the *pause* can indicate that the apparently clear-cut reasons leading to an apparently straightforward ethical decision may not have done justice to everything at stake in that decision (at least for creatures of our moral stripe when we see it from up close).

End-of-life procedures, although often broadly included under the banner of ‘euthanasia’ involve significant differences, as extensively discussed in a United Kingdom Supreme court judgment on three patients.³ Voluntary euthanasia (VE) generally denotes intentionally ending a patient’s life at the patient’s explicit and competent request.⁴ Other methods/terms include physician-assisted suicide (PAS) or physician aid in dying (PAiD) whereby lethal drugs are prescribed to a patient for the purposes of self-administration.

A different category altogether involves the withdrawal of life-sustaining treatment voluntarily at a patient’s request (VWT); or medically initiated treatment withholding of treatment, based on a clinical decision (MIWT).

The practice of actively ending the lives of patients has, in the Dutch setting, been extended to other categories where an explicit request is not made. This occurs at about half the rate, when surveyed, as those fitting the criteria laid down for active voluntary euthanasia and is usually non-voluntary euthanasia (the patient lacks competence), referred to as the “termination of life without the patient’s explicit request” in Netherlands, Belgium or other European countries.⁵ As such, it takes one step further a type of management (allowing to die) often used for persistent vegetative states (PVS) (and related states) by making the termination of such states an active decision to intervene with a lethal technique.

The Australian and New Zealand Society of Palliative Medicine (ANZSPM) defines euthanasia as: “the act of intentionally, knowingly and directly causing the death of a patient, at the request of the patient, with the intention of relieving intractable suffering. If someone other than the person who dies performs the last act, euthanasia has occurred.”

Medical intuitions and legal determinations are generally weighted heavily against actively ending human life, thereby capturing the roots of our moral sensitivity in general, but also, and particularly, our moral sense as healthcare professionals.⁶ What is more, those things touch each of us at a personal level—elusive, evocative and inchoate but disturbingly resonant—and engage with our ‘sense of life’, particularly when that is awakened by an imagination schooled by clinical experience to exhibit a narrative sense of the values that life trades in.

First we ought to be clear that this is, in the sense of being hard to rationally articulate, a ‘gut level reaction’ that cannot establish the morality or immorality of active euthanasia but deepens our focus on the unique and complex nature of human death. When we are trying to decide how we should act in the middle of such a situation, our intuitions can be sensitive guides to the right choice of action. But they must be weighed against other considerations, particularly in end-of-life scenarios, according to some form of proportionality—a sense of the balance to be struck.⁷

Palliative care has made significant advances in end-of-life care and on a much wider front than purely biomedical and legal arguments might encompass. Even if considerations based on the values guiding medicine tell definitively against active euthanasia, we can recognise the strength of arguments from patient rights and human rights for its permissibility. It remains to be seen whether an inquiry into euthanasia couched in terms that pay philosophical attention to the widespread clinical intuitions underpinning the *pause* and a narrative or more care-based patient-centred approach might still leave the profession inclined towards a slightly more traditional conclusion.

3.2 Narratives, lives, deaths and human sensibility

Human death is unique with respect to all those things that make a human being what he or she essentially is. Many and diverse meanings (some cultural and some more local or personal), aspects of relationships, and passages of life are disrupted by a range of medical techniques designed to avoid human suffering of any kind when life is clearly ending and death becomes the preferred option (eg, heavy or terminal sedation that blunts a patient’s ability to respond to loved ones). A viewpoint that mandates reacting to extreme contingencies of pain and perceived worthlessness by complying with a patient’s request to have his or her life ended becomes uncomfortable for doctors when ‘the final solution’ is waiting in the wings. We are uncomfortably aware that measures such as active euthanasia or other forms of aid in dying are almost too clean and rational to engage with the tragedy of a dying person, because the decisions here are not as simple as they are in other cases of relieving pain.⁸ Human narrative and the sensibilities it enhances do not furnish any easy options or recommend functional solutions if we are to remain, as Martha Nussbaum has it “finely aware and richly responsible”.⁹

Nussbaum discusses a sense of life informing the moral perceptions that guide our sensibilities at intense and conflicted moments of our moral journeys. She explores the territory of moral reflection and moral perception in complex human situations, arguing that such a stance “speaks about us, about our lives and choices and emotions, about our social

existence and the totality of our connections”.¹⁰ She urges “the vigilant and responsive imagination that cares for everyone in the situation and refuses ... to ‘simplify’ for the sake of purity and safety in the midst of wonderful puzzling mysteries”. The sensibility and imaginative capacities she explores are not likely to be satisfying to many with a penchant for clearly premised arguments leading to rationally coherent and clear-cut moral conclusions. Those more clear-cut terms are seemingly being forced on us by a more open and transparent context for professional standards and policies in health care. However, the need to reflect on patients’ experiences and respond to evolving clinical realities in a way that is sensitive to human pain and the subtle guidance of practical wisdom can encourage us to proceed in a slightly different vein¹¹ reflecting the difficult proportionality unavoidable in end-of-life choices.¹² The need for proportionality may, therefore, be unavoidable, as the ethical (or even ethically informed) life was never meant to be easy, and for doctors who deal with life, death and human fragility as their daily work, it is not easy at all.

What seems particularly hard when making general policy statements for wider groups and sectors is achieving caring attentiveness to a clinical situation as it is lived and looks from up close. Doctors and nurses have no choice but to reflect on things from “up close” where “our own experience and our intuitions” must do a lot of ethical work for us as caring professionals. The proximity to human life and death, amidst the smell of the clinic, is where one’s neural networks sniff out those nuances and styles of interaction and conversation that tell one how one ought to behave so that things are resolved in a way that all of us will be able to live with now and hereafter.¹³ And the ability to do what is fitting in complex situations such as those encountered clinically does not reduce itself neatly to a set of policies or objective guides to action.

3.3 The sanctity of life

If that is true, then a sense of life is not, in any flatfooted way, committed to a doctrine of the sanctity of life—whatever the condition of the human being concerned—but rather regards it as something to indicate the supreme value of every human life in the light of human subjectivity.¹⁴ Seen that way, voluntary euthanasia must be distinguished from the decision to forego so-called “aggressive medical treatment”.¹⁵ In other words, medical procedures that no longer correspond to the real situation of the patient—either because they are disproportionate to any expected results, or because they impose an excessive burden on the patient or his family—should not be used to merely prolong death. They are different from those employed as part of a regimen of palliative care sensitively applied that stops short of actively ending life.¹⁶

The following concepts may assist in interpreting and elaborating some deeply held intuitions about the sanctity of life:

- (i) *substantial benefit* or an outcome which now or in the future the patient would consider worthwhile¹⁷
- (ii) the *RUB* or the *Risk of Unacceptable Badness*.¹⁸

These two concepts are more or less self-explanatory and spell out what we are aiming at when we hold on to respecting the life of a human subject as sacred in the context of decisions regarding limitation of treatment in end-of-life care.

3.4 Whose life is sacred?

A human being lives a life that forms a story. A discussion of the fitting end to a human life can usefully begin with a narrative perspective to which the idea of the sanctity of life contributes a framework that some regard as one of the “most fundamental of all human social values...common to all civilised societies...all developed legal systems and all internationally recognised statements of human rights”.^{19,20} That fundamental value is inflected by an individual’s narrative and life project, which jointly determine what counts as doing the right thing for that person. But the centrality of the unique value of an individual life can be made vivid in a thought experiment (one commonly used in the Early Learning in Medicine ethics teaching in Dunedin).

A young man, Nigel, is admitted to hospital to investigate headaches and epilepsy. He has a CT and an MRI scan that show a malignant brain tumour. He is told his diagnosis and that he has a life expectancy of a few months. He is shattered so the neurosurgeon suggests he talk to a nurse or chaplain.

Two days later the neurosurgeon comes back saying he has good news. He talks about brain transplants and says that a young motorbike rider has been seriously injured in an accident with a train. They have kept his brain alive but the rest of his body is beyond saving. Nigel is told he can have a brain transplant and therefore need not die from his malignant brain tumour. Nigel is, momentarily, overjoyed but just as the neurosurgeon goes to leave, he asks “Hold it, who is going to wake up from this operation?”

Now most people do not believe that Nigel will wake up, because most of us believe that the brain is the crucial seat of the soul—the life of a person as the distinct person he or she is, with a distinct story, personality and set of memories. It is clear that an adequate level of brain function is required both to support conscious life and to keep a cumulative record, enabling a lived narrative to be inscribed in the person so that it is the basis of the integrated subjective life of the person as a person rather than merely a ‘biological remnant’. The uniqueness of each human life as the ground of the sanctity of life principle is a *sine qua non* of caring health services and the laws that govern them.

Some prominent philosophical themes emerge from this story including *personal identity*, a story of one’s own *conscious awareness* of the world around one, and an ongoing *intentional interaction* with others.

Personal identity is an autobiographical idea of the unique individual living **this** life among **these** people, and it is open-ended. Therefore, one’s life story is not finished until death, because everything prior to that is part of the remembered story of a given lived life.

Second, *conscious awareness or lived experience* is a human being's response to the world and others. Locked-in Syndrome,²¹ the condition affecting Nicklinson, for instance, leaves the person in the position of a moral agent/patient reliant upon others for the quality of their experiences. Consciousness is, therefore, an active, interactive and exploratory cognitive function of embodied human beings, and its persistence in Locked-in Syndrome leads to vastly different appraisals of living in the locked-in state by different patients. So even circumscribed conditions require careful, nuanced and individual appraisal rather than the application of broad policy moves that may have mortal impact on those suffering them, making concepts like 'unacceptable' or 'intolerable' quality of life very demanding to determine for healthcare professionals and institutions or legal bodies.²²

Third, *intentional action and interaction* expresses an individual's conceptions and interests.²³ Even where the individual concerned is markedly different from others, there is a quality of interaction that those who know the person discern and respond to in complex and nuanced ways. But once the possibility of any such action or interaction is irrevocably lost (eg, because of severe, widespread and irrecoverable brain damage), the person's life as a person has ended. (This is discussed further below.)

At this point we are subscribing to a commonly shared view that the human soul is best thought of as a holistic set of functions and capacities realised in the human body through its interaction in rational and social/political activity, so that there is a close link between brain function and the integrity of a unique psychological being.²⁴ Therefore, once the body that instances or supports the soul has been effectively destroyed, the life of the person *as a person* is ended, even though an attenuated bodily life may continue. That remnant cannot have the same significance as the life of a person as a conscious subject among us, a fact with profound ethical implications (to which we shall return).

3.5 The unique challenge of mortality

Death is a certainty we will all face, some suddenly and others of us after a period of preparation (nowadays, one often knows one has a terminal illness). At that point in our lives, most of us need others to help us in our journey. All sorts of small kindnesses ease the way; conversations need to be had, things need to be said that have not been said, loose ends need to be tied up, and others untied and retied so that those left behind can carry on. For these things to happen, the person who is dying must both be in a sufficiently clear-minded condition to attend to them, and must also be cared for. The need for a good dying makes many fear the worst, where one is reduced by illness to an impaired and pathetic condition and is left alone with nobody to care.

Despite all that we know, death is and will remain the great unknown, as a person quits all that is familiar, some say for another kind of life, some say for oblivion. There is no knowledge, in the ordinary sense, to be had this side of death. Death is a final break with the relationships and everyday familiar things that fill the hours and days of human life. In the face of this unknown, many people need support and reassurance that they are not being abandoned. A doctor is not a deliverer of technology, but a vital and acknowledged witness

to a course of treatment, perhaps at the end of life, and someone who can therefore figure in the story of a fitting death rather than a hastened end.

The feeling of being no longer of any worth is, it seems, is one of the worst aspects of dying for many patients. But, for many people, the time before death has much greater meaning and intensity than any other time of their lives. Many patients and relatives spontaneously say, in their last days or hours, “Our last time together has been one of the happiest and closest of our lives”. Often it is only the threat of loss that impresses on us the true value of what we have. This re-evaluation of one's values is a very common experience both in serious sickness in general and in the time before death.

Many of our beliefs about what is worthwhile are seen in a different light under the personal challenge of a serious illness. It is therefore important that healthcare professionals dealing with a patient help create an atmosphere in which such questions can be raised and worked through. Rather than just ‘pills and potions’—or, even worse, a lethal intervention bringing the process to a tidy end—in existential terms, a time of tragedy should be given the best chance it can to be a time of healing and the appreciation of a person's intense personal worth at a level beyond physical disease and suffering. Good end-of-life care, sensitively adjusted to a clinical relationship and the insights it engenders, therefore embeds a vital moral task for the patient whose life is ending and for the doctor who attends, rather than just a role in easing the way of death.

The doctor is often a pivotal figure in the final twists and turns of the illness journey, but medical training, in its scientific and technical aspects, sadly may do very little to explore the resources most needed to deal well with death and dying. Reflection on human life and what makes it go well may only become clear as we spend time in the presence of human fragility, and with those who are dying, when we seek to help where we can and be a witness to the last days and weeks of the lives in our care with as much dignity and patience as possible.

The dying experience can, however, become a lonely nightmare. The knowledge that someone has a terminal disease may cause other people to avoid that person and can lead to a strange fabric of evasion and deceit that isolates him or her from those who are most needed at a crucial passage that all must face. Guilt, embarrassment or awkwardness can threaten to cut a person off from his or her normal supports at that point. This is sometimes the case with AIDS patients who can be rejected by many of those to whom they ought to be reconciled before they die, such as family or estranged ‘straight’ friends. It is only by realising that our attitudes and actions can convey rejection and worthlessness that we can ensure that dying is no more painful and desolate than it need be for those who must face death and conduct themselves in a manner that is fitting in the light of their life story.

There is, unfortunately, nothing we can do for some people, but not usually because of uncontrollable pain. Some cannot approach death with any peace despite us minimising pain, offering respectful treatment, acknowledging their views, and preserving their personal dignity as much as possible. Some are driven to search for some way out and all we can do is make a commitment not to abandon them, to try to provide the sense of worth and reassurance that may help. Wittgenstein, a philosopher, remarks, somewhat harshly,

“Fear in the face of death is the best sign of a false, ie, a bad life”.²⁵ We, however, are called to be more understanding, to find why that remark does not capture the whole story, and to appreciate that anxiety and fear sufficient to drive a person to seek an early death must signal some need for healing but perhaps of a kind about which medical textbooks and research papers do not have a lot to say.

What is clear is that, in the face of death, we meet as person-to-person and that medical and health care techniques *per se* have a vital but limited role. For this reason, some of us are deeply suspicious of any so-called 'technological hijacking' of death. It sometimes happens that a person can be rushed off to hospital, admitted to an intensive or acute care bed, and treated with drips and drugs before anybody takes stock as to where it is all heading. This is worse in some countries than in others but it is particularly cruel when it is demanded in the misguided name of not denying older people the best medical care.

For each of us, medical care is only good when it offers what is fitting and realistic at that point in life's journey. It is clear that many people who suffer a really serious illness late in life want peace and comfort-care rather than futile (but state-of-the-art) medical techniques. Here we cannot evade the real need for the understanding, wisdom and sensitivity that are part of the art of medicine and that reveal to us what would be of substantial benefit to a given patient. It is in the light of the delicate uncertainties that this complex area involves that many judicial opinions have opted for a very conservative legal process safeguarding those who are vulnerable.²⁶

3.6 Suicide and its relevance to euthanasia

Suicide is a growing problem in many Western societies and there are some points that seem to carry over to the euthanasia debate. The first is the well-known association between suicide and depression; the second is the phasic nature of the desire to suicide. So closely are these phasic aspects of mood, attitude and cognition linked that Boldt remarks “with rare exceptions, suicide is constrained by an urgent and intense need to relieve an intolerable life situation. This renders the notion of an autonomous, voluntary, or free choice about suicide, inappropriate”.²⁷

There can be a number of reasons for believing that death is more attractive (or less unattractive) than going on living. It may be that the person concerned feels that nobody loves or values them; or life may seem to be of no value at all; or anything may seem better than some state of physical or emotional suffering. The person may feel cut off and afraid of the future; or a state of grief or impending loss may seem too much to bear so that the person just wants to “get it over with”. No doubt there are many other stories that could be mentioned here but, in every case, we must try and understand the person concerned and see why he or she wanted their life to be cut short; a challenge captured by such questions as ‘Why did you not tell us?’, ‘How did we fail you?’ or ‘Why did you not want to live out your time among us?’

These thoughts should give us pause when we find that terminal illness is associated with a high rate of clinical depression, which in many cases responds well to directed therapy.²⁸ In

fact, clinical depression does seem to be a significant factor among patients with terminal illness who desire an early death.²⁹ For instance, a patient thinking about 'getting it all over with' may have poorly controlled pain and real fears that it is going to get worse. In fact, up to 98% of patients who fail pain treatment in other institutions can be well-controlled in an experienced hospice setting where pain, as an affliction of the whole person, is well-understood and expertly handled.³⁰ Many of these patients will leave the hospice on lower doses of pain relief medication than those with which they were admitted, but with better control of their pain. Thus it is perhaps not always just the pain itself but the fear of what is happening and is going to happen that may push a person toward a certain type of choice. This fear, the anxiety with which one faces unknown prospects, and pain itself all enhance one another and contribute to a malignant psychic cocktail that is part of the hospice ethos to recognise and address. The hospice attitude—that death should neither be hastened nor delayed—provides the kind of framework within which patients and staff can be given time to take care of the pain, fear and anxiety of dying, without the background pressure of having to make a decision about a possible intervention such as voluntary euthanasia.

It is understandable that a patient with a terminal illness who knows he or she is going to die might feel unsure whether others still want them around. Even a glance at the disability literature can make vivid the idea of marginalisation—that one may feel worthless when severely debilitated. For this reason alone, it seems wise to encourage the attitude that death must take its own time, and that we can only ease it and make it as 'gentle' as possible. If a doctor were to enquire whether you wanted to be helped to die or to offer to help you to die (or actually to hasten your death) then that doctor, perhaps unwittingly, is conveying something about whether it is worth you still being around.

This last worry has drawn our attention to the fact that any patient, and particularly one who is seriously ill, is vulnerable to subtle coercions. On admission to a hospital for a procedure, there arises a definite obligation to go through with the course of treatment planned. Many patients will say something like "Well, I've come this far, I can't really back out now". This may not reflect genuine uncertainty but only be a way of avoiding a painful topic once some kind of decision has been reached. For most patients and most decisions about health care there are good reasons to stay on track, which have been adequately discussed (to the patient's satisfaction) so there is no real reason why the discussion should be reopened.

However, an end-of-life decision is less clear and somewhat painful for all of us to think and speak about. A tendency to not 'want to go over all that again' or burden other people with doing so might make some vulnerable patients just go along with what is planned or what they think might be expected of them. Most people want to do the right thing and if euthanasia is legalised, 'the right thing' can be complicated by feelings that you don't want to be a burden or cause too much fuss for others—which are quite common.³¹

The complex, conflicting and often-unclear ideas we all have about death and dying create a further problem. On the one hand, there are obvious things to be considered, such as the fact that a person is dying, the fact that he or she suffers pain, disability and so on, and the

possibility of it just ending without further ado. These are easily stated and evident to all so they can be thought of as the only *real* features of the decision being made. Some even argue that, from a philosophical perspective, there is nothing bad about death per se—leaving the considerations of present and prospective suffering, compassion and autonomy to carry the day.³²

On the other hand, the more subtle and complex thoughts appreciated by those who must care for people through the process of death and dying tend to cause certain misgivings that can be thought to be indistinguishable from “a gut reaction” and therefore discounted, even though they reflect the voice of those most experienced in this area. That may account for the hospice position as much as any prior commitments.

The ill-defined and poorly articulated feelings and perceptions that contribute to a felt hesitancy are difficult to lay out in any cogent, forthright way. Therefore, faced with such 'hard facts' and readily understandable arguments on the one side and a 'fuzzy discomfort' on the other, supporting the traditional 'respect for the sanctity of life' can feel a bit irrational. This issue poses a difficult ethical challenge for the profession, because it is often hard to put into words why we tend to be against it. We want to be as clearly reasoned in our ethics as in other areas of clinical decision-making (given that many traditional codes of belief are not part of a modern liberal debate). The idea of narrative can help, but does not clearly weight one side over the other in the debate about what matters here, even if some traditional stances may have more than just history on their side.

The clear and desperate remedy of the suicide victim has some of the same cognitive qualities—a plethora of seemingly compelling reasons why it is the only thing to do, such that they tend to overpower the voice that speaks for life. Of course, we should try to reason clearly about such mortal decisions, but perhaps we should also listen to the voices and the silences that alert us to the defects inherent in a purely rational analysis of what matters. We have, after all, a powerful cultural trope for the “still small voice heard within” that resonates with one’s sense of life and deep commitment to other human beings—however desperate and disparate they are.

IV. Care and intervention: our role as professionals and clinicians

One of the impulses served by a practice of voluntary euthanasia and physician aid in dying is to do something for a suffering person. But doing something is not always the right thing and, even if it is right to do something, we need to be very clear about what needs we are meeting. Cicely Saunders and Frances Dominica are both highly experienced in the care of the dying and their comments are illuminating at this point.

Cicely Saunders remarks on the patient who asks a team just to “Let me die”:

The team needs to discover what it is that makes continued life so grievous ... reassurance and explanation about the likely nature of the final coming of death may well be needed if anxious fears are to be eased.³³

'I want to die' expresses anguish that demands attentive and experienced listening.... It often arises when past treatment for distress has been inept and listening cursory.³⁴

The specific request 'Kill me'...is still extremely uncommon in spite of all the (often confusing) attention of the media to this subject... We need to give a clear answer, and a definite stance of this kind gives its own security.³⁵

She goes on to discuss the need for a caring and supportive atmosphere in which the patient's value as a person is affirmed, and unresolved problems surrounding their life and relationships can be addressed. She counsels judicious use of pain-relieving drugs, as these are often used to compensate for inadequate listening and support. In her wide-ranging and sympathetic work, the narrative of the patient is framed in words that need to be heard and she notes one patient who suffered from a widespread inoperable cancer that she needed "open and frank discussion and patience as she found her own way ... to a final peace that at one time seemed unlikely".³⁶

Frances Dominica, from a similar tradition, writes on death in childhood, noticing our discomfort with tragedy and our tendency to try and get an expert to step in and handle it.³⁷ She remarks:

I condemn a society which prefers to have such things dealt with at a safe distance clinically and antiseptically, and seems to absolve itself from the responsibility for making itself available to be alongside and to stay alongside and to take on board some of the suffering and grief of others.

Here is one who does not abandon even though the pressure of life, clinical demands and one's sometimes irresistible desires to be doing, intrude and displace our best intentions. She also observes, "despite society's fear of death and ineptitude in the face of death, I believe that every individual has the potential to meet death with a severe beauty which in no way denies grief".³⁸

These revealing glimpses into the insights of those who care for and have extensive first-hand knowledge of the experience of care-in-dying are relevant to a discussion of active euthanasia in that the events surrounding death have a different rhythm from the interventionist mode of much modern medicine in a "have-a-problem-fix-it" society.

When a patient is helped to die by a doctor at a given time and place, a great weight is placed on those who make the decision (particularly the doctor who actively causes that death at that time). It is not the same with the withdrawal of life-prolonging treatment, because our actions have the dynamic of appropriate treatment for the dying or terminally ill. We all acknowledge the tragedy of death and the limitation of human action in the face of it and the legal perspective that clearly identifies the disease and not the cessation of treatment as the cause of death.³⁹ How to accommodate giving active assistance to hasten death—without changing the doctors who do it into technologists who control life and death in a way that poses deep moral burdens—is a serious question that many of us have

confronted and found quite onerous, demanding a wisdom beyond the reasoning available to most Hippocratic professionals to answer. The fairly bright line of our dedication to saving lives where it is reasonable to do so tends to lighten that burden.

When we intervene to alter a process at work in the patient's body, we intrude on what could be regarded as a *natural* change inherent in human life and mortality. Of course, medicine does this all the time but a person usually seeks active medical help so that she might enjoy continued life as far as possible and be rescued from suffering or danger to her health. Even if a patient gets to the point where they say 'I have had enough' or 'I don't want to fight it anymore' or 'Is that really going to do me any good, Doctor?' their remarks reflect a sense of the *fittingness* or *naturalness* of the death that is coming and that perhaps it is time not to treat death as an enemy any more. This is consistent with a traditional recognition that each of our lives has a natural and mortal form and that medicine has its limitations.

At such points, the patient—and the wise health professional—tends to 'listen to the wisdom of the body' rather than wheeling in yet more technology to try and fix things. This may mean that the moral discussions in medicine need not apologise for phrases like 'allowing to die', 'letting nature take its course' or 'not prolonging the dying process'. Such phrases, when they take their rightful place in the stories we tell about life and death, are sympathetic to our realistic appraisals of what we can achieve, the feelings of the patient, and the rhythms of mortality. They call into question the assumption that in life and death situations we are required to act always as decision-making autonomous agents with clearly formulated reasons for our actions who need—and should have—a wide range of choices.

There are times when it is better just to be taken care of and to have one's sufferings relieved and witnessed as they play themselves out. Those in hospice practice often argue that a lethal, fix-it solution to the problem of death and dying is a poor second best to careful attention to the needs of the patient and attention to any despair or desperation induced by those needs. Stepping in "to end it all" is, they claim, not what is needed. If we answer the real needs, rather than do away with them by killing the patient, we shall come to see that using technology to hasten death is not always the best way to serve the calling of the good life.

V. International ethical-legal perspectives

In some cases, law or policy has specifically sanctioned active voluntary euthanasia (eg, Netherlands, Belgium, Luxembourg, Colombia and Canada) and PAiD is allowed in an increasing number of settings (eg, Switzerland and the US states of Oregon, Washington, Montana, Vermont and California).

Restrictions on access to euthanasia/PAS vary in these different contexts. For example, patients requesting euthanasia/PAS in Canada and Luxembourg, or PAS in the US states listed, must be 18 years old or over. In contrast, the Netherlands allows children as young as 12 to request euthanasia or PAS, while Belgium permits euthanasia and PAS irrespective of age as long as the person has 'capacity for discernment'.⁴⁰ The five US states require that

terminally ill patients undertaking PAS have a prognosis of less than 6 months, whereas the Netherlands, Belgium and Luxembourg require that adult patients requesting euthanasia/PAS have “unbearable physical or mental suffering” without prospect of improvement.

It is useful to consider those settings and variations in discussing the implications of these somewhat unclear ethical reflections for the profession as it contemplates a compassionate and sound position in this area of our clinical life.

5.1 The Netherlands

The approach to euthanasia and PAS in the Netherlands has evolved from case law that set out guidelines for medical practitioners, and is now set out in the statutory Termination of Life on Request and Assisted Suicide (Review Procedures) Act introduced in 2002.

The process set out under the law is described in a very recent article⁴¹ that states:

...the Dutch regional euthanasia review committees (Regionale Toetsingscommissies Euthanasie [RTE]) review all EAS reports regarding whether the notifying physicians (physicians of record for performance of EAS) have conformed to the due care criteria laid out in legislation...

There are 5 regional committees, but the goal is to provide uniform guidance. The RTE has a strong commitment to transparency, and its publication committee publishes a selection of case reports that are deemed “important for the development of standards” to provide “transparency and auditability” of EAS practice and “to make clear what options the law gives physicians”.⁴²

The Euthanasia and Physician-Assisted Due Care Criteria:⁴³

The committees examine retrospectively whether the attending physician acted in accordance with the statutory due care criteria laid down in section 2 of [the Termination of Life on Request and Assisted Suicide (Review Procedures) Act]. These criteria determine that physicians must:

- a. be satisfied that the patient’s request is voluntary and well-considered
- b. be satisfied that the patient’s suffering is unbearable, with no prospect of improvement
- c. have informed the patient about his situation and his prognosis
- d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient’s situation
- e. have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled
- f. exercise due medical care and attention in terminating the patient’s life or assisting in his suicide.

It is accepted by the Dutch medical profession that a doctor is under conflicting duties when faced with a patient who is suffering intolerably. In this situation, the doctor is held to have a duty to relieve suffering (as the patient's caregiver) and a duty (as a citizen) to obey the law and not commit murder.⁴⁴ The former duty was, historically, thought to create a defence of *force majeure* or "necessity" whereby the doctor found that he was bound by the greater demand to do his duty as a caregiver and, acting under that necessity, ended the patient's life to relieve her suffering even though that required him to fail in his duty as a citizen not to take the life of another citizen.

When the law, as it currently stands, was being developed, the defence of doctor-assisted VE could be sustained if the doctor acted under the following conditions:

1. There was a request by the patient
2. The patient was properly informed about his or her condition
3. The patient's wish was sustained or durable
4. The doctor considered the patient's condition to involve intolerable suffering without hope of relief
5. A colleague agreed with the doctor concerned.⁴⁵

The crucial conditions clearly involved a free and informed request from the patient, thereby ruling out other forms of end-of-life decisions, apart from that involved in active voluntary euthanasia. However the assurance that this was the general case was dispelled by the Rummelink Report of 1991.⁴⁶

The Rummelink report noted that, in addition to voluntary euthanasia, cases of involuntary and non-voluntary euthanasia were occurring and that assisted suicide was also widely being used as a means of helping patients to die. It therefore fuelled the already existing worries about abuse of the provisions in the Dutch legislation.⁴⁷ This showed that, all in all, about 3% of deaths occurred because of euthanasia, assisted suicide, or "life terminating acts without specific request". It therefore seems clear that the original very stringent guidelines have loosened slightly as the practice has spread.

The Chabot Case concerned a 50-year-old woman, Mrs B, who was supplied, at her request, with lethal drugs that she consumed in the presence of her doctor; she died within half an hour.⁴⁸ Mrs B had a particularly complex psycho-social history. She had had an unhappy marriage and had separated from her husband three years previously. She had lost both her sons; the older son had committed suicide in the army two years prior to her separation and she had lost her second son from cancer four months before her death. She was diagnosed as having no major psychiatric illness but was judged by her psychiatrist, who gave her the lethal drugs as suffering "intense, long-term psychic suffering that, for her, was unbearable and without prospect of improvement."⁴⁹ The case was heard in the District Court, The Court of Appeals and the Dutch Supreme Court.

The first two hearings concluded that the doctor acted under the necessity to relieve the patient's suffering but the highest court reversed that decision. It discharged the doctor who prescribed the drugs without penalty or any other measure. Although this case provoked

censure it also provoked a change in guidelines so that “11 of the 15 pending prosecutions (involving non-somatic suffering or patients not in the ‘terminal phase’) were dropped”.⁵⁰ This was seen as a fundamental step away from the approach to euthanasia that took as its basis the Hippocratic ethos, toward a standard that gave primary weight to the wishes of the patient.

The Chabot case is symptomatic of several cases highlighted by opponents of a change in law who have made submissions to many of the bodies quoted in this report.⁵¹

These misgivings, and other conflicted evidence, persuaded the UK Supreme court to safeguard a DPP public interest to prosecute in some cases (as affirmed in Nicklinson and another UKSC 38: R (Nicklinson and Lamb) v Ministry of Justice, R (AM) v Director of Public Prosecutions [2014] UKSC 38 (25 June 2014)) to be determined under prosecutorial discretion *ibid*, #39), and has led Somerville to caution that “making euthanasia and assisted suicide part of medical practice is not, as pro-euthanasia advocates claim...a small and incremental change consistent with interventions that we accept as legal and ethical, such as honouring patients’ refusals of life-support treatment that allow them to die”. It is, she argues, “a seismic shift in our fundamental societal values, not just another step on a path we have already taken”.⁵²

In support of this view, The Anscombe Bioethics Centre (Oxford) highlights common patterns in the jurisdictions where assisted suicide has been legalised such that “safeguards such as psychiatric referral have declined in frequency” so that “the practice has become more widespread and more routine”.⁵³ In a more recent article, 66 cases of psychiatric patients were reviewed in relation to euthanasia or assisted suicide (EAS) between 2011 and 2014.⁵⁴

Most had personality disorders and were described as socially isolated or lonely. Depressive disorders were the primary psychiatric issue in 55%...Other conditions represented were psychotic, post-traumatic stress or anxiety, somatoform, neurocognitive and eating disorders, as well as prolonged grief and autism. Comorbidities with functional impairments were common...11% (n=7) had no independent psychiatric input, and 24% (n=16) of cases involved disagreement among consultants. ...Persons receiving EAS...are mostly women and of diverse ages with complex and chronic psychiatric, medical and psychosocial histories.

Some would see this report as confirming their fears and others as indicating no more than a further and perhaps less ‘abandoned’ path (because doctors actually discussed their end-of-life issues with them) for a varied and problematic group of patients, many of whom may well have ended their own lives whatever was done.

The result is seen by some as releasing the profession from an atmosphere of careful respect for life into an atmosphere where we are to be seen as the technical adjutants of patients who have made their own significant health care decisions. Whether this accurately reflects the way in which Dr Chabot and Mrs B⁵⁵ came to their decision, we are in no position to judge. But the worry is that we are being asked to go “naked” out from under the canopy of sanctity of life into a world where what counts as good medicine will sometimes include

acceding to a wish to actively end a patient's life for a group of patients whom we tend to find troubling and distressing, even in the protected environment of a professional ethos slanted towards the sanctity of life. Most of us recognise that the worst equipment, morally speaking, that one could avail oneself of in this situation is a thick skin, and that the most distressing will be an acute sensibility to the intricacies of terminal (or perhaps non-terminal suffering).

Some who have visited relatives in the Netherlands have mentioned that their elderly relatives have deep misgivings about going into hospital because they fear that they may be victims of euthanasia with or without their consent.⁵⁶ It matters little how ill-founded this attitude is in the light of the attitudes and ethics of the medical profession in the Netherlands and elsewhere; it is an attitude not conducive to the kind of atmosphere we need to allay the widespread alienation of the public from the profession. The recent report about psychiatric patients does little to allay the fears involved.

Hippocratic practice is founded on trust and reverence for life. These orientations keep one going in tricky and demanding situations such as when, for instance, one's "intestinal fortitude" fails at 2am with an 18-month-old infant bleeding badly on the operating table who could die from the neurosurgical operation one is performing (even if one's practice would still fall well within the acceptable mortality for operations of that type in such a case). But they can also drive us to *persist* even perhaps when we should *desist* in the name of humanity and a realistic eye to the outcome of what we are doing. Despite these mixed blessings, the Hippocratic commitment to life and the well-being of our patients has delivered to us medicine as we know it and the safeguards that we have bred into us with our training. That is something we should not lightly abandon.

The Dutch experience with euthanasia should at least make us worry about the reality of slippery slopes and the possible climate of change created by legalisation of euthanasia and assisted suicide. But some further recent studies may seem to have allayed that fear somewhat in relation to non-psychiatric patients:

Our studies show no evidence of a slippery slope. The frequency of ending a life without a patient request did not increase over the studied years. Also there is no evidence for a higher frequency of euthanasia among the elderly, people with a low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations.⁵⁷

The authors of this report are fairly sanguine about the positive effect of legal changes on the medical profession:

Most physicians think that the Act has improved their legal certainty and contributes to the care with which euthanasia and physician-assisted suicide are practiced.⁵⁸

It may be that what we see in the Netherlands is a progressive move allowing us to clarify and refine the desirable safeguards and conditions under which decisions at the end of life

can be taken. Some philosophers and lawyers are less optimistic and see genuine reasons for concern in the Dutch practice, although they acknowledge that the issue is far from simple.⁵⁹ Certain other voices have warned of more worrying tendencies but these warnings have not been reinforced by recent studies in the Lowlands.⁶⁰

5.2 Belgium

Belgium legalised euthanasia and physician-assisted suicide in the Act on Euthanasia of 2002 and “after a large increase between 2001 and 2007, the total percentage of deaths preceded by one or more possibly life-shortening end of life practices remained stable at 47.8% in 2013...the rate of euthanasia increased significantly between 2007 and 2013” from 1.9% to 4.6% of deaths.⁶¹ The total percentage of deaths (47.8%) included those preceded by possibly life-shortening end-of-life practices, the most prevalent of which were intensified alleviation of pain where shortening of life may have occurred, or withholding or withdrawing life-prolonging treatment.

Similar findings emerged from studies of the legalisation of euthanasia in Belgium as those in the Netherlands, with the authors of a 2009 report commenting that “The rate at which end-of-life practices were discussed between the physician and competent patients and their relatives was substantially higher”.⁶²

An earlier examination of the changes in Belgium by the same group yielded a more ambivalent conclusion about continuous deep sedation: “this technique has been strongly promoted for patients with refractory symptoms, especially by healthcare professionals strongly opposed to the legalization of euthanasia...in more than half the found cases...the physician had also the intention to hasten the patient’s death, and it is not yet known to what extent this sedation is performed in competent or incompetent patients”.⁶³ In fact the practice is being used more frequently in end-of-life care settings despite an intense debate about its similarity and differences to euthanasia and about its use in patients who are incompetent.⁶⁴

Overall these authors suggest that the legislative change has had the effect of promoting “the tendency to seek consensus more intensely with close relatives of the patients and with other health care professionals whenever a decision to hasten death had to be made”,⁶⁵ a conclusion paralleled by others working in the area.⁶⁶

Recent studies have therefore allayed some of the earlier fears about the effects on elderly and vulnerable patients.

66 cases of life-ending acts without explicit request identified in a large scale survey of physicians certifying a representative sample of deaths (n = 6927)...Most of the cases...did not fit the label of nonvoluntary life-ending for at least 1 of the following reasons: the drugs were administered with a focus on symptom control; a hastened death was highly unlikely; or the act was taken in accordance with the patient’s previously expressed wishes.⁶⁷

It would, however, be fair to say that evaluations of the existing evidence are universally inconclusive and tend to be concluded with remarks in support of the prior convictions of those who write them. So the broader arguments must be carefully considered and the well-researched opinions by such bodies as the UK Supreme Court and the Scottish Parliament deserve special regard.

5.3 United Kingdom

Assisted suicide has featured in United Kingdom debates over the last decade and a half. In a 2002 case, like that of Lecretia Seales, a UK woman suffering from motor neurone disease (who was unsuccessful in obtaining an undertaking by the Director of Public Prosecutions that her husband would not be prosecuted under the UK Suicide Act 1961 if he helped her to die) applied to the court for judicial review of the refusal.⁶⁸ She was unsuccessful in the UK, and her subsequent appeal to the European Court of Human Rights also failed.⁶⁹

In a more recent case, the UK Supreme Court was asked to determine whether the blanket legal prohibition on assisted suicide infringed article 8 of the European convention on Human Rights (the right to respect for private and family life).⁷⁰ Although the majority of the court considered that the court had constitutional authority to make a declaration of incompatibility with the Convention (despite two judges explicitly finding incompatibility), it nevertheless considered that the issue was more appropriately a matter for Parliament. A press release distils the majority's reasoning:⁷¹

... the question turns on issues which Parliament is in principle better qualified to decide, and that under present circumstances the courts should respect Parliament's assessment. The question requires a judgment about the relative importance of the right to commit suicide and the right of the vulnerable, especially the old and sick, to be protected from direct or indirect pressure to do so. It is unlikely that the risk of such pressure can ever be wholly eliminated. Therefore the real question is how much risk to the vulnerable is acceptable in order to facilitate suicide by others who are free of such pressure or more resistant to it. This involves important elements of social policy and a moral value-judgment, which are inherently more suitable for decision by Parliament as the representative organ of the constitution. This is for three reasons: (1) the issue involves a choice between two fundamental but mutually inconsistent moral values, the sanctity of life and the principle of autonomy, which are sensitive to a society's most fundamental collective moral and social values and upon which there is no consensus in our society, (2) Parliament has made the relevant choice on a number of occasions in recent years, and (3) the Parliamentary process is a better way of resolving issues involving controversial and complex questions of fact arising out of moral and social dilemmas in a manner which allows all interests and opinions to be expressed and considered [228-232].⁷²

The Assisted Dying Bill that was before the UK Parliament at the time of the Supreme Court ruling did not proceed due to the 2015 election. However the latest Private Member's Assisted Dying Bill had its first reading in the House of Lords in June 2016. It aims "to enable

competent adults who are terminally ill to be provided at their request with specified assistance to end their own life; and for connected purposes”.⁷³

The BMA has reiterated its stand on these issues, in that the BMA:

- opposes all forms of assisted dying
- supports the current legal framework, which allows compassionate and ethical care for the dying, and
- supports the establishment of a comprehensive, high quality palliative care service available to all, to enable patients to die with dignity.⁷⁴

At a recent BMA annual meeting, two thirds of doctors voted in support of the continued opposition to assisted dying.⁷⁵

5.4 United States

The US discussion is currently led by the five states that have allowed aid in dying to mentally competent, terminally ill adult patients. This has occurred to follow the established practice of according the right to refuse life-prolonging treatment to patients whose prospects of benefiting from that treatment are bleak and recognises that support for aid-in-dying is increasing and “the desire to protect seriously ill people from intolerable suffering” so that, “In most cases, physicians reporting life-ending acts without explicit patient request did not label their acts in terms of life-ending, but rather in terms of symptom treatment”.⁷⁶

The changes have been extensively studied in Oregon where the changing legal climate has meant that “Early EOL discussions are prospectively associated with less aggressive care and greater use of hospice”.⁷⁷ A further study of quality of death and dying after legalisation of physician assisted death (PAD) in Oregon showed that: “those receiving PAD prescriptions had higher quality ratings on items related to preparedness for death (saying goodbye to loved ones, and possession of a means to end life if desired) than those who did not pursue PAD or, in some cases, those who requested but did not receive a lethal prescription”.⁷⁸ A study of psychiatrists in Oregon found a surprising level of support for the legislative change, despite that specialty’s general disapproval of the active ending of life at the patient’s behest.⁷⁹

It is worth noting that, in considering these issues in a meeting of its membership, the AMA resorted to a general statement that “physician delegates attending the meeting, who represent every state and every specialty, publically professed to uphold the values that are the underpinning of the ethical practice of medicine in service to patients and the public”. These values were taken to include compassion, respect for human dignity and rights, respect for the law, and standards of professionalism.⁸⁰ There is, notably, no mention of sanctity of life (perhaps because of a US tendency not to omit life-prolonging measures under any circumstances and beyond the lengths to which UK or NZ doctors would advise).

5.5 Canada

The Supreme Court in Canada struck down laws criminalising physician-assisted suicide because they considered that the law as it stood was inconsistent with the right to liberty and security of the person under s7 of the Charter.⁸¹

It is not yet clear how this decision will be responded to by the various medical bodies that regulate the profession in the Canadian provinces but some response is called for. Somerville (2015) argues that it wrongly frames itself in terms of an erroneous conflation of sanctity of human life with religious arguments, an elision between sanctity or ultimate respect for human life and doctrines of the absolute sanctity of life that prohibit treatment limitation, and an over-emphasis on individual autonomy as trumping societal values particularly in relation to the mystery of life and death.

5.6 South Africa: an about turn against legal assistance in dying

A South African Supreme Court decision⁸² overturned a High Court ruling that purported to allow physician assisted suicide. (It was a five-member court; judgment by Justice Wallis, all concurring and the judgment was treated as reflecting the South African legal position by a court in New Zealand. Justice Collins referred to the SA High Court decision at para 66 of his Seales judgment.)

Justice Wallis, hearing the case, very politely but exquisitely ‘calls out’ Dignity SA (the pro-PAS group led by Sean Davison) as the real people behind the action; to quote from his report: “They have, at times and for reasons of legal tactics, deliberately tried to obscure their role. Dr Davison should be challenged on that at every opportunity as evidence of duplicity and dishonesty.” The judgment refers to “coercion” (paras 185-194) and “Role of healthcare professionals” (paras 195-209).

A number of pertinent points are raised, in particular about the chain of causation (and possible sources of coercion or inciting) leading to a suicide and the significant people who might participate in that chain of events and could legitimately be considered as parties to an act of murder or culpable homicide.⁸³

The delicate issue of over-broad legislation and rights to personal dignity, privacy and protection from suffering were also included in a careful consideration of the situation relevant to the case and were held to rule out any simple answer to the constitutionality or lawfulness of decriminalising aiding and abetting suicide.⁸⁴ This stance is echoed as in the Seales judgment (see below).

On ‘Respect for autonomy’, the court excluded the consent of the patient as determining the legal consequences of bringing about the death of a deceased person.⁸⁵ The Supreme Court decision therefore overturned any conclusion that physician assisted euthanasia or suicide was legally permissible in South Africa and reaffirmed the principle that it was not excluded from criminal provisions regarding murder or assisted suicide.⁸⁶

5.7 The European Association of Palliative care

The EAPC has formulated a position that reflects a wide range of European palliative care opinion and has considered that position in relation to euthanasia, physician assisted suicide and palliative sedation (2015)⁸⁷ and has settled on what it regards as a consensus position. They affirm, as does the present report, “the intrinsic value of each person as an autonomous and unique social individual” (p7) and assert “requests for euthanasia and PAS require respect and careful attention, together with open and sensitive communication in the clinical setting”. (p8)

In the end, they assert that “euthanasia” is not a part of palliative care. And that “the provision of euthanasia and PAS should not be included in the practice of palliative care and that palliative care is...never futile”. (p8)

VI. Lecretia Seales and aid in dying in New Zealand

The recent case of Lecretia Seales (LS),⁸⁸ a 42-year-old Wellington lawyer dying from a malignant brain tumour, provides a useful summary of the current law in New Zealand and a good jurisprudential and ethical guide to the wider legal situation in most jurisdictions where there has been a principled enquiry into the relevant issues.

LS applied for a declaration in the High Court regarding the lawfulness or otherwise of her doctor aiding her death, and by so doing clarified end-of-life (EoL) decisions and the role of a doctor or health care team in VE or PAiD. The arguments brought to the hearing are best examined in the light of the current situation, to be clear what is and is not available in EoL care in New Zealand (the situation is similar throughout Australasia).

A doctor in Australasia is under no obligation to provide care to prolong life if a reasonable body of medical opinion would deem such care futile.⁸⁹ The concept of futility is, however, much disputed by ethicists as being part of an ethos of paternalism in which healthcare professionals decide what is and is not worth doing for their patients.⁹⁰ Concepts such as *substantial benefit*—an outcome that now or in the future the patient would regard as worthwhile—and the *risk of unacceptable badness* (the RUB)—the likelihood that a treatment would result in the patient surviving in a state that that patient would have deemed unacceptable if consulted before the event—between them restore the patient’s role in end-of-life decision-making, and strengthen the case for an extended and responsive discussion that reflects a sense of the spirit and life of the person involved in making the relevant decisions.⁹¹

The importance of medical judgment in relation to appropriate clinical care is supported in UK and Commonwealth law. The positive provision of treatment is not on the same footing as the patient’s absolute right, if in sound mind and properly informed, to refuse treatment⁹² (even life-saving or life-prolonging treatment).⁹³ It is, however, assumed that healthcare professionals will fulfil their duty of care by delivering appropriate treatment with reasonable care and skill, unless it is quite clear that the patient would not consent, given what is known about him or her. Thus, for instance, the existence of an advanced

directive at odds with the clear clinical duty to provide reasonable care must satisfy stringent requirements regarding its applicability, validity, and the patient's actual extant views about what treatments and outcomes are and are not acceptable. A presumption in favour of the sanctity of life frames all such determinations: "The burden of proof is on those who seek to establish the existence and continuing validity and applicability of an advance directive. Where life is at stake the evidence must be scrutinised with special care. Clear and convincing proof is required."⁹⁴

The problem of patients demanding life-prolonging treatment that medical staff do not agree with has been debated in the cases of Burke in the UK (who wanted to compel doctors to treat him beyond the point where normal medical practice would, as he deteriorated from a neurological condition) and Rau Williams in New Zealand.⁹⁵ (Rau Williams' family wanted his right to life-prolonging renal dialysis recognised as a basis for ongoing health services when he did not meet clinical criteria for its ongoing use). It is quite clear that doctors and the health system generally do not have a duty to provide treatment that, in the opinion of clinicians, is not indicated.⁹⁶

These broad ethical and legal considerations indicate what professionals can actually do for patients who are dying in circumstances where their suffering is clear and their prospects for relief from it are poor.

Major concerns in this area are created by the fact that—unlike past medical care that was often powerless to avoid a cascade of mortality—scientific and technological advances in medicine can now extend life even where that might not be welcome or may (i) involve intrusive and burdensome treatments that distort the dying process; (ii) compromise the patient's dignity or ability to have a peaceful or harmonious death (*euthanatos*); or (iii) result in a state the patient would regard as worse than death (*the Risk of Unacceptable Badness*).

These dire possibilities can be worsened by the concern of doctors or institutions to avoid any hint of negligence or a failure to do all they could for a patient. That defensive position is clearly something to be avoided rather than, in any way, promoted. Defensive medicine is not, or should not be, a concern in New Zealand but our tendency to follow bodies of medical opinion and attitudes reflected in the literature from other jurisdictions means that we must carefully underline an ethical stance grounded in New Zealand reality.

In most Commonwealth and European countries, doctors commonly make a careful decision that the patient's journey towards death has started and that it should neither be prolonged nor hastened (the hospice position). Given that, the doctor (or healthcare team) should never abandon the patient to face the terminal events of the illness journey alone and without sensitive and fitting support. With that commitment in place, palliative care and a careful weighing of risks and benefits from the patient's point of view (often with the inclusion of the patient in the discussion when that is possible and compatible with a peaceful or harmonious death) becomes the preferred mode of decision-making.

In making such decisions, healthcare professionals include the patient and, after suitable consultation, a healthcare team may do things that would be contraindicated in other,

non-palliative, settings, such as destructive neurological lesions (eg, for intractable pain), doses of opiates, and other medications that may otherwise raise concerns (often unfounded) about addiction or compromising vital functions. The regimen that follows once a palliative turn has been negotiated are aimed at relief of suffering, and any associated risks are eclipsed by the underlying treatment goal, so that ‘titration’ of treatment (a careful and incremental use of a treatment with attention to its effects on troubling symptoms)—calibrated against the suffering or distress of the patient—is the rule. To that end, terminal sedation (an induced coma that may be maintained until the patient’s death or periodically reversed to assess pain control) is sometimes used.

Lecretia Seales poses a question that confronts the remaining issue: “Should doctors be permitted to go beyond the relief of the patient’s suffering to administer a lethal dose of medication when they and their patient consider it warranted?” With that question clearly before us, we can evaluate the arguments brought in the case.

Lecretia Seales—the arguments⁹⁷

The arguments for a change in law put by the team representing Lecretia Seales included the following, and fairly comprehensively represent the debate as it has been conducted world-wide:

- (i) Doctors are at risk from the New Zealand Crimes Act 1961 (s160 – murder/ manslaughter and/or s179 – aiding suicide) if they offer a patient aid in dying⁹⁸ (The UK Supreme Court has cast some doubt on this contention in its bald form).⁹⁹
- (ii) An absolute prohibition on aid in dying is contrary to rights 8 (not to be deprived of life) and 9 (cruel and inhuman treatment) of the New Zealand Bill of Rights Act 1990¹⁰⁰ (cf *Carter v. Canada*).¹⁰¹
- (iii) The protection of individual dignity is a critical value in end-of-life decisions.¹⁰²
- (iv) Existing care cannot guarantee painless dignified death.¹⁰³
- (v) Patients may be moved to end their own lives earlier than would otherwise occur if their suffering seems to be worsening,¹⁰⁴
- (vi) There is no ethically relevant distinction between aid-in-dying and other end-of-life decisions, and both are compatible with good clinical relationships.¹⁰⁵
- (vii) Aid-in-dying is very different from suicide because of the impulsivity, reversibility, violence and distress to others associated with the latter.¹⁰⁶ Not all people are vulnerable and need to be protected; most can exercise their own autonomy in significant health care decisions.¹⁰⁷

The arguments against a change in law rehearsed traditional objections against euthanasia:

- (viii) Sanctity of life marks a bright line against killing human beings.
- (ix) There may well be a broadening of scope beyond initial limitations if the bright line (sanctity of life) is crossed—ie, a real slippery slope is created.
- (x) Judging the worth of human lives creates a dangerous, subjective, shifting standard, sensitive to law and other social factors.

- (xi) Existential suffering and self-worth is de-humanising and alienating, and most cultures see this kind of suffering as a threat to the person concerned and as a prompt for legislative change (compare with suicide rate and entrenched Māori attitudes against aid in dying).
- (xii) The marginalised and disabled constitute already vulnerable groups affected by wider changes in society and would be particularly affected by a change in practice towards active ending of life when self-worth is affected.
- (xiii) Active assistance in dying can promote the internalisation of oppressive views of a life worth living often formulated by those who crave a sense of control.

These arguments should be analysed in the light of the ethical issues already raised.

(i) Doctors and murder/manslaughter

The judgment in Seales reaffirmed the distinction between physician-administered aid-in-dying and decisions taken to end life-prolonging treatment in accordance with good medical practice. The latter are often triggered by a refusal of consent by the patient to treatment perceived as burdensome and futile, leading to an expressed desire by the patient to follow a different path and discontinue the life-prolonging treatment. The absolute nature of the right to refuse, providing only that the patient is of sound mind, is not fully conveyed by the statement “it is lawful for doctors to withdraw futile medical services to patients in circumstances where it is known the patient will die without those services”.¹⁰⁸

Justice Collins’ appeal to a judgment of futility does not reflect the full force of the patient’s role here, in that a separate judgment of medical futility, often tainted with an echo of medical paternalism now considered inappropriate in the clinical setting, is not required. Apart from weakening the principle of consent for all treatment (no matter how necessary a healthcare team may deem it to be) when the patient is not of sound mind and the wish is in terms of an advance directive or a substituted decision, a medical team has no right to continue in the face of refusal by the patient.

This is highly relevant to the point in dispute in VE and PAiD. It elucidates the distinction between, on the one hand, withdrawing treatment that is refused by the patient or judged not to be in accordance with good or reasonable medical practice and, on the other, assisting a patient to die. Clarifying that distinction in legal terms (it is often concealed behind the language of passive versus active euthanasia) is a welcome move from such an esteemed medical jurisprudential source.

(ii) Aid in dying and human rights

Rights 8 of the NZBORA (the right not to be deprived of life) and 9 (the right not to be subject to cruel and inhuman treatment) are explicitly aligned with provisions under the Canadian charter that were invoked in *Carter v. Canada*. Justice Collins allowed that the first may have a direct bearing on the case and accepted expert evidence that a patient might feel pressure to prematurely take her own life in the face of uncertain terminal deterioration (just such a concern was attested to by Lecretia Seales). He also noted that palliative care

experts could not completely allay her fear of terminal distress and loss of dignity and that fear and uncertainty may affect the possibility of a dignified and peaceful death.

However, given the measures legally available to Australasian doctors (including terminal sedation), that fear seems a little remote. For that reason, Justice Collins resisted the claim that the possibility of such a state of mind was a compelling argument for a change in law. He also distinguished cruel and degrading treatment (from which any person has a right to be spared) from the effects of an illness or condition. He thereby reflected judicial practice as it applies to determinations of the cause of death (it is usually deemed that the disease process bringing about the patient's dire condition is the cause of death unless some notable treatment failing should be regarded as an independent and legally relevant cause; that would encompass negligence or a failure to use due care and skill). Thus a course of treatment aimed at rescue or saving life, or the cessation of such treatment perhaps because it is considered no longer to be providing a patient with any substantial benefit (as in *Bland*), is not on the same legal footing as clearly negligent treatment causing death where otherwise recovery might be expected or a physician actively providing aid in dying.¹⁰⁹

(iii) Dignity and end-of-life decisions

The issue of dignity and a degrading or humiliating process figures prominently in the *Carter v. Canada* decision and in submissions re *Seales*. It is closely relevant to neurological diseases such as motor neurone disease (where the patient loses muscle strength to the point of absolute helplessness but is cognitively intact) or conditions with a similarly relentless and debilitating course.

The close connection between human dignity and the unique value of human life is noted in the decision and the appalling prospect of losing one's dignity is treated with due consideration. But the wider literature often tends to conflate dignity and independence or autonomy, to the point where disability rights campaigners are justifiably alarmed. When that move is made, our radical dependence on one another and our need for support and affirmation by caring others¹¹⁰ are discounted in ways that many cultures and modes of thinking in faith traditions find quite alienating and isolating because they distort the reality of the human condition and what is involved in a caring society.¹¹¹

Māori voices in this debate are sensitive and alert to this danger and it particularly affects our conception of elder care and the celebration of humanity. Constructive responses to infirmity or the various modes of disability try to foster such attitudes in many contexts where human beings are adversely affected by "the slings and arrows of outrageous fortune" and thereby profoundly disadvantaged.¹¹²

Moving towards an inclusive concept of humanity that is intrinsically relational and respectful of the human spirit, especially when a person is affected by illness or adversity, relativises the issue of autonomy and self-determination to the margins of our shared and profound participation in fragile human life that we all share. To make self-standing and individual capacity as the key issue affecting judgments of human worth in difficult clinical

situations therefore seems less useful and compassionate than a sense of valuing and respecting life on the basis that we are all human and mortal in ways that mean our lives are interwoven. The idea of holding each other in being¹¹³ when any one of us can no longer meet his or her own needs becomes a much more compelling ethical framework within which to address life, death, and human tragedy.

(iv) Palliative care and a painless dignified death

Both Justice Collins and those arguing on behalf of Lecretia Seales noted there are no guarantees in palliative care, but the experts ranged on each side conveyed quite different attitudes to the moral significance and implications of that fact.

Those arguing for change regarded it as not only regrettable but also avoidable by a change in law that would allow the foreshortening of the path to death.

Those against such a change “provided extensive evidence of their experiences of treating dying patients, almost all of whom experienced peaceful and dignified deaths”¹¹⁴ and argued that the principle of sanctity of life is too central to medical practice to abandon in the face of the possibility of an occasional rare, distressing and difficult case. They urged “a wholehearted dedication to holistic care and unconditional inclusion for those who are suffering.” That stance seems to be at the heart of the hospice commitment to neither hasten nor prolong the dying process, and receives at least prima facie support from the adage “*hard cases make bad law*”.

(v) Patients moved to early suicide

Evidence was given both in *Carter v. Canada* and in Seales that patients unable to access aid in dying may contemplate and make use of means to early suicide because they fear the ordeal that awaits them. A malignant glioma such as the one that had its grip on Lecretia Seales is clearly a daunting prospect, and its effects unpredictable as it pursues its course. She felt unable to place her trust in any reassurance of a painless death and, contemplating future suffering that, to her, might become unbearable (all of that, in Justice Collins’ words, “an unimpeachable subjective judgment”), envisaged herself driven to bring about her death. She argued that her dying in such a way might be unpleasant and at the very least less than optimal and bereft not only of expert help but also, perhaps, without anyone to support her, because of the fear of being regarded as an accessory to or assisting suicide.

However, where the palliative measures outlined above are available to ease a patient’s dying, it seems debatable whether such fears are realistic. Care in dying does require “appropriate psychosocial, emotional and spiritual support” alluded to in the evidence from those who opposed the appeals, and it would be unthinkable for a person to be forced into a position where they were denied those things. The law is not interpreted by the courts as a barrier to the kind of death we all agree is both humanely to be preferred and the right of any one of us. It does not, therefore, need to be changed on that count. It is not conceivable that, given the current state of law and medical ethics in New Zealand, a patient could end up being burdened by treatment that they do not want and have not consented to in the

service of an over-zealous imposition of a sanctity of life position (as some believe happens in some medical settings. This report should not be read as moving in that (unwanted) direction.

In the event, it proved to be the case that Lecretia Seales' fears were unfounded. It is therefore of vital importance that clinicians understand the ethico-legal situation and the range of medical techniques at their disposal, including the possible use of terminal sedation (almost certainly only required in a rare and unusual case). Along with a developed understanding of the wider needs of a patient on the pathway towards an expected death, the relevant clinical and ethical understanding should be a feature of both teaching and treatment contexts so that patients do not suffer intolerably as they approach death because of misunderstandings and fears by their doctors about what is available for them.

Here the NZMA can play a key role in sponsoring the right kind of educational and professional development opportunities.

(vi) False distinctions between aid-in-dying and other EOL decisions within clinical care

Philosophers and even doctors sometimes question the distinctions made by Justice Collins between euthanasia, aid-in-dying and other EoL measures such as withdrawal of treatment and possibly life-ending treatment intended and primarily to avoid distress. The relevant distinctions in clinical practice do, however, seem very real to many clinicians who feel closely implicated in and often deeply responsible for the death of a patient, even when their role in the cause of death was peripheral. That should encourage us not to increase that burden on a healthcare workforce that already faces considerable stress—and even moral distress—due to the limitations under which they sometimes work and the suffering of patients. The doctrine of double effect is often singled out for focused criticism by those arguing that the distinctions made within that doctrine are artificial but that debate is not simple.

The doctrine of double effect captures the fact that a primary therapeutic intent—to relieve suffering—may involve an intervention that also has acknowledged risks. Some argue that the doses of pain relief and other medications required for effective palliation blur into the range at which death is caused and that it is an ethical and legal fiction to maintain that the cause of death is the underlying disease. The facts are not so clear.¹¹⁵ It seems that adequate palliative intervention accompanied by the holistic care characteristic of many palliative care services, and the holistic treatments available in hospice-based care in particular, usually obviate the need for excessive medication and the edgy toxic-therapeutic ratio calculations often advanced as a reason to jettison this long-standing doctrine.

All these observations about a decision to not hasten death, a refusal to abandon the patient, and a settled professional assurance in using well-developed skills that allow us to stick with and guide a patient on the sometimes lonely path of death are part of a good clinical relationship of whatever kind and may also be found in the care given by those who, in various contexts, assist their patients to die. It therefore may be hard to distinguish the

different experiential journeys, but the double effect doctrine concerns the intentions of a doctor or health care professional.

Given the nature of end-of-life care it is sometimes difficult to be sure exactly what one intends, but a fairly sure philosophical test rests on the definition of success. If the intention is to relieve suffering, then the success of the regimen of care depends on the patient being free of suffering. So, if, despite the patient seeming comfortable and not in distress, the doctor feels that more ought to be done, then the intention is straying towards physician-assisted aid-in-dying. A reflective understanding of what constitutes 'doing what is needed', and ceasing when that is achieved should clarify the issue and allow most practitioners to be clear what they are aiming at. Justice Collins added legal support to that view when he affirmed that:

“if Ms Seales’ doctor were to administer a lethal dose of pain relief such as morphine to Ms Seales, the doctor’s actions may not be an unlawful act within the meaning of s160(2)(a) of the Crimes Act if the doctor’s intention was to provide Ms Seales with palliative relief, and provided that what was done was reasonable and proper for that purpose, even though Ms Seales’ life would be shortened as an indirect but foreseeable consequence.¹¹⁶

This careful and legally longstanding distinction is reaffirmed both by the UK Supreme Court (in *Nicklinson and another*, UKSC 38) and by the Scottish Parliament (2015).¹¹⁷

(vii) Aid in dying and suicide

“Irrational suicide is impulsive, often violent, and causes extreme distress to family and friends...completely different from physician-assisted dying.” This highlighting of the contrast between what they advocate and suicide is widespread among those who argue in favour of voluntary euthanasia or physician assisted suicide (PAS). On that basis, they sharply distinguish both (and rational suicide) from the stereotypical suicide outlined.

Stressing the contrast is persuasive within the setting of debates about the rights of empowered and independent individuals who understand their options, who are used to getting what they want, and feel the need to be in control of situations in which they participate and live. For those in such a position, it is easy to believe that one has no need for the protections that might be required for those who are vulnerable, lacking in self-efficacy, and being held-in-being by others in a precarious position of marginality or a fragile self-conception and sense of self-worth. Those who suffer crises of self-belief and who feel that their lives are beyond the margins of “the light, the enlightened, the capable, and the upright” are not so resilient.

Their experience, sadly, is the lived reality for many who do not succeed in the successful consumer-driven, market-economy-based, autonomous individualism of our increasingly modernist society. Their marginalisation may be because of ethnicity, disability, impoverishment or the effects of a very damaging childhood, and results in being excluded from the structures of privilege on behalf of which our societies regulate themselves. Among

those who suffer like this, suicidality and other impassable ordeals that life brings their way are devastating, not able to be coped with nor planned for, and are not conducive to rational self-determination. The relevant statistics fall out in disturbing ways, eg, the suicide rates among all indigenous groups are way out of proportion to those of colonising groups and similar fears are voiced by those in touch with disability advocates. A leading New Zealand researcher notes:

The international literature yields a generally consistent account of the risk factors and life processes that lead to youth suicide and suicide attempts. Risk factors which may contribute to suicidal behaviour include: social and educational disadvantage; childhood and family adversity; psychopathology; individual and personal vulnerabilities; exposure to stressful life events and circumstances; and social, cultural and contextual factors. Frequently, suicidal behaviours in young people appear to be a consequence of adverse life sequences in which multiple risk factors from these domains combine to increase risk of suicidal behaviour.¹¹⁸

The appalling health statistics—and particularly those concerning suicide—are, some would say, real casualties of a power- and individual autonomy-driven society that is increasingly producing inequality and under-privileged minorities. Society owes the potential victims of this trend that we are fostering more than their expulsion to the margins of the debates shaping our laws. That debt arises because it is within our society that they have become as they are. These characteristics of what once was once egalitarian and community-minded rather than individualistic and increasingly unequal. A caring society must point the way to a more compassionate way of death in which every moment of life is precious, provided only that those moments do not get extended beyond the limits of human wellbeing. Such wellbeing rests on meaningful engagement and participation in a context where suffering is compassionately and skilfully treated. Where that can be confidently predicted, an escalation of palliative care even to the point of terminal sedation may be required and can usually be made available. A possible objection to that course might arise if we put a positive value being on being conscious right up to the moment of death.¹¹⁹

When some of us are made to feel less than worthwhile and cannot trust the institutions that surround us, we cannot be confident that desperate choices will not be made by those who feel they are out of options and that an efficiently managed death is the best they can hope for. That is a sad state of affairs, but many fear that it will become the norm if we functionalise death and dying to minimise the loss and pain that we should always feel when one of us passes.

(viii) Vulnerability and autonomy

Justice Collins acknowledged that Lecretia Seales was not a vulnerable person and that one purpose of the NZBORA and the Canadian Charter was to protect such people. However, he dissociated the intent of legislation protecting potential suicides from an exclusive concern for the vulnerable, and instead linked it more broadly to an affirmation of the sanctity of human life. This underpinning for both medicine and the law is widely recognised and long-standing.¹²⁰ The status of a preference for life as a foundation for medical practice and

jurisprudential reasoning implies that we cannot so easily distance the vulnerability of terminal illness or any serious medical condition from those who are not considered vulnerable and differentially apply the responsive values generated to one group but not the other.

Other forms of human fragility, both temporary and more enduring, fade into normality in the kind of vulnerability felt by patients in many healthcare settings. Interventions that are difficult to specify and evaluate that cause us to erect a barrier against the all-too-common seduction of 'ending it all' may need to be set in place. An important component of that resistance to a cycle of vulnerability might be the healthcare professions retaining their societal role as guardians of the life-affirming barrier. If that is so, then they are not easily able to occasionally don the mantle of those welcoming death onto the scene as their sometime accomplice where a decision or, possibly unstable, consensus has emerged that it is time to bring a dying process, or the last phase of a patient's life, to its end. In such a setting, the normal safeguards and jealous regard we have for patient autonomy might need to be balanced by the *pause* that nudges us to affirm life. That, at least seems to be a definite opinion among experienced workers.¹²¹

Despite these worries, an adverse effect of permissive end-of-life legislation on patients who are from vulnerable minorities has not been observed in studies where empirical trends are monitored.¹²² But we ought to note that the evidence seems not to be independent of the prior commitments of those reporting it.

(ix) The sanctity of human life

The sanctity of life has always been at the heart of Hippocratic practice, perhaps most important when medicine itself was relatively powerless and a whole-hearted determination not to give up kept one to a sometimes thankless and unrewarding task. In fact, this attitude is often misinterpreted as an imperative to prolong all human life as long as possible, even where the patient is ambivalent and compassionate health professionals could be seen to be ambivalent on the basis of the clinical evidence.

Where the patient is a participant in end-of-life discussions, a decision to end life is less problematic because of the patient's absolute right to refuse treatment. But where the patient is incapacitated, the sanctity of life doctrine can produce anomalies. In most countries, the requirement for doctors to work within the bounds of reasonable medical care and the existence of clinical guidelines for best care provide adequate safeguards. However, in some settings, perverse litigation and entrenched clinical praxis can distort good decision-making.¹²³

I have frequently found myself in the position of urging physicians and family members to respect the wishes of patients. The literature...is full of...cases where treatment continues in spite of the wishes of patients...the patient acknowledges and accepts his terminal condition, but aggressive medical treatment continues.¹²⁴

Now that we command powerful methods to arrest the advent of mortality, we have had to learn moderation (and some do not easily learn that lesson). Discussions about the realities of death tend to make reasonable care in dying more likely.¹²⁵ Having what has been called a sense of life—a sense of what makes life worth living, its adventure and its uncertainty, and yet its irreplaceable worth¹²⁶—is perhaps more important in these challenging discussions as they occur in this technological age than a single-minded dedication to the sanctity of life doctrine as traditionally invoked. But a richer sense of the sanctity of life inclines in the same direction as medical judgement about a patient-centred conception of futility in relation to the present issue.

(x) The slippery slope

Arguments against euthanasia often invoke a slippery slope, claiming that euthanasia or aid-in-dying, particularly when linked to subjective assessments of self-worth, tend to erode the value of human life and mitigate against those who might suffer adverse judgments from wider society. It is unclear whether such slopes exist.¹²⁷

The significance of a change in law in terms of societal attitudes to choices about the end of life in medical care is difficult to determine but should not be set aside. None of us is immune to the regard of others and, indeed, some would say that our own self-reflections inevitably do—and, to some extent, should—mirror the ways that others see us. That is probably a sound basis for a sober assessment of oneself but it does leave some people tragically affected by feelings that are inherently destructive and depressing. Such feelings are hard for any normal human being to separate from entirely realistic and appropriately humble judgments about oneself and one's place in the world. When linked to a knowledge of one's own impending death, certain key attitudes must be considered: the need for care, the unconditional affirmation of one's own worth to others and, as mentioned, "holding-in-being"¹²⁸ become paramount.

Even if a slippery slope beckons, digging one's toes in at just the right place requires a healthy sense of life or even a sense of compassion and care that does not easily limit itself in the face of despair and imminent death.¹²⁹ At such a point, deeply life-affirming attitudes closely linked to a nuanced and responsive "sense of life" are likely to help us resist any tendency to adopt and operationalise practices about which we may feel very uncomfortable indeed.

(xi) The worth of human life

Considering the expressive role of judgments about the active ending of human life touches on aspects of the remaining issues raised by those against Lecretia Seale's application:

- (xii) Existential suffering and its effect on self-worth
- (xiii) Marginalisation, disability and contemporary society
- (xiv) Active aid in dying and a sense of control.

Each issue looks at the subjective context in which a decision to hasten death is taken, and all have already been touched upon. Factors influencing a desire to hasten death seem to

include psychological suffering, perceiving oneself to be a burden to others, demoralisation, less confidence in symptom control, a less religious attitude to life, fewer social supports,¹³⁰ hopelessness,¹³¹ and personal psychiatric history.¹³² Some authors remarked that, rather than a fully rational expression of self-determination, “this wish is more appropriately seen as an ambivalent and fluctuating mental ‘solution’ for the future”.¹³³

These considerations cast further doubt on the sharp divide between ‘rational suicide’ and requests for aid-in-dying or any other cases of the desire to bring about one’s own death. The overall message from the debates about subjective factors seems to vindicate Justice Collins’ rejection of the argument, raised in *Carter v Canada*, that an appeal to sanctity of life creates an overbroad or disproportionate prohibition.¹³⁴ A careful consideration of the subjective views of those making decisions to hasten death sees the sense of control that is sought as having less to do with dignity and more to do with fear and anxiety about what lies ahead, particularly if dying is prolonged. A realistic appraisal of practice in New Zealand tends to lessen worries on that score, even though quality of life seems to be enhanced by the feeling that doctors are there to help with a life-ending or treatment limitation decision as part of an ethos of neither hastening death nor unduly prolonging life. If decisions are made in an ethico-legal context of that type, others can be supportive and even actively involved and present with the patient as death approaches and at the moment of death.¹³⁵

Given the disproportionate rate of suicide in marginalised and disempowered groups in contemporary society, the links between decisions to hasten death and attitudes of helplessness, hopelessness, disaffection with life and low self-worth are worrying. Those of us in post-colonial societies, particularly where steps are actively being taken to mitigate the effects of colonisation, should, perhaps, be particularly attentive to indigenous voices in these matters and strive to incorporate a sense of life’s value arising in an indigenous cultural context into our legislative and ethico-legal deliberations about the issue.

Justice Collins concluded his judgment by commenting that this latest chapter in an ongoing saga for those interested in medical law and ethics had precipitated a level of debate in society that was clearly required and should both be fostered and provoke a consideration of a change in law.

“Although Ms Seales has not obtained the outcomes she sought, she has selflessly provided a forum to clarify important aspects of New Zealand law. The complex legal, philosophical, moral and clinical issues raised by Ms Seales’ proceedings can only be addressed by Parliament passing legislation to amend the effect of the Crimes Act.”¹³⁶

The issues are indeed complex and there is no doubt that an empowered and articulate patient such as Lecretia Seales can feel that the laws we live under do not properly respect her autonomy and opinion about how her death ought to be managed. Our legislators, however, must also pay attention to the fact that experienced oncology staff perceived “those patients desiring an early death as having ‘given up’ and lacking in support”.¹³⁷ That point is often raised in palliative care and hospice submissions on the issue. Those drafting legislation ought also, and with careful and inclusive attention, seek Māori advice and a perspective that may differ in important respects from a pakeha focus on autonomy and

personal choices. That voice has shaped, to some extent, our views where wider societal interests and our shared New Zealand ethos should come to the fore. Perhaps in this (and other areas of healthcare) we need to de-emphasise the voice of the self-possessed or privileged and act with a careful regard for those in disadvantaged groups with a less self-assured self regard so that we are required to focus on our duty of care and a powerful professional orientation towards the sanctity of human life, the unique worth of every human being, and the need for dedicated and responsive concern, rather than choice-driven action as one's mode of preparation for resting in peace.

VII. Severely damaged human lives

The last consideration is deeply relevant to those among us who have suffered devastating injury. Joseph Fins recently published a considerable addition to the literature on severe head injury, disorders of consciousness, and the murky area of minimally conscious states.¹³⁸

Fins presents an extended set of testimonies and a neuroethical analysis driven by a series of stories and reflections from patients and families caught up in tragedies of this type. He conveys a pressing ethical challenge, both to clinicians and to healthcare systems, which should be borne in mind by those debating futility and end-of-life choices. We need to get beyond general categorisations in terms of futility and utility, consciousness and the lack thereof, medicine and its values as distinct from institutional, social and legal policy, and scientific versus more humanistic aspects of clinical practice. For a clinician, engaging in clinical management of ongoing care for patients with severe brain injuries and disorders is often a time for highly particularised judgements and emotionally wrenching conversations because they do not fit the boxes that well-organised healthcare systems (and clear-thinking residents) are comfortable dealing with and that come wrapped around by apparently clear-cut guides to dictate ethically sound regimens of care.

Patients with severe brain injury follow paths marked by uncertainty, wee small hours bedside debates and discussions, and searching questions about what we are doing and why for our patients and their families.¹³⁹ The scientific complexity of our knowledge is expanding by the minute, and the personal and political stakes for those who care for patients have never been more delicately balanced. An informed sense of clinical virtue and the need for savvy engagement with an increasingly strained healthcare system buckling under the costs of technology and possibilities for its use both come into play. Clinicians cannot afford to be complacent about this area, as the sometimes wasteful and futile use of expensive clinical resources that are desperately needed elsewhere must be weighed against a respect and care for the individual patient. Inevitably, the issues become entangled with end-of-life decision-making and the legislative context around it.

The uncertainties of the past in end-of-life care and in diagnosis of disordered states of consciousness following brain injury feed into a quasi-scientific language of efficacy and efficiency involving cost-containment, clinical assessments and prognostication, the natural history of disease, and the highs and lows of heroic medicine's love affair with contemporary media. During this, the profession must find a way of accumulating clinical knowledge and experience and making a sound ethical and scientific contribution to a reality that is never

actually cut-and-dried in the ways beloved of policy-makers, but rather probabilistic and evolving, with a factor attributable within it to ‘the human spirit’.¹⁴⁰

Brain injury is a problem because when it devastates and destroys significant aspects of the patient’s humanity, we question everything. The existential challenge of severe brain injury cannot retreat into a value-marginalising world of medical necessity; myths of miraculous recovery, and objective diagnoses (masking significant value judgments) aided by simplifications based on whizz-bang neuro-imaging, all complicate the problem.¹⁴¹

What we do changes the patient and their prognosis—both objectively and from the point of view of the people most concerned with the illness journey and its outcome.¹⁴² But what we do reflects ethical stances as much as advances in medical technology. When you classify a head-injured young person and their condition in ways similar to people with advanced and progressive degenerative brain disease who are on a completely different trajectory and with whom no-one really tries to communicate, diagnostic prophecies (prognoses) can become self-fulfilling: “it is not useful to view them as reified or static diagnoses but rather as *syndromic works potentially in progress*”.¹⁴³ ‘Syndromic’ speaks of a cluster of presentations with resemblances and differences and ‘potentially’ stresses the morally interactive nature of the clinical reality of brain-injured people, which is that their human voices are silenced as much by de-personalisation and marginalisation as much as physical damage to the brain. This reality does not show up easily in statistics about death rates and vulnerable sections of the population.

Marginalisation, demoralisation (in many different senses), neglect and ignorance combine to create a loss of the delicate integrated whole that is a patient approaching a crisis at what seems to them to be the end of their illness journey. Temporary nightmares of utter dependency and vulnerability—which cannot be resolved but which negate who one is or any future prospects—usher in thoughts about actions that will put a definitive end to the diverse negatives. Each of these threatens the loss—through a premature end-of-life decision—of a unique point of view, and often attenuated set of relationships, commitments and networks of being where we would otherwise be held by others.¹⁴⁴

What is or should be our ethical response to human lives, the essence of which seems to have been destroyed? This is not easy and access to life-ending interventions would only sharpen the difficulties.

The need for ongoing relationships, and a reconnection with the patient’s point of view where possible, is transferred from the world of ordinary social intercourse into a medical setting. The moments of reconnection sometimes disclose the life-world that has been destroyed in a dramatic way: “With a simple downward gaze, Maggie spoke volumes. She told us she knew Nancy was her Mom, providing an answer to a mystery that only a parent could fathom”.¹⁴⁵

This moment between mother and daughter, acutely observed by Fins, could be regarded as a “quilting point”¹⁴⁶—a connection between subjective worlds, respectively, of a badly damaged patient and a clinical professional, each full of meaning, which slide past each

other by reason of damage to the capacities underpinning human relatedness and communication. A human connection potentially brings the brain-injured subject who is isolated from the rest of us back into our world.

Stories and critiques of clinical ethical thinking cast our clinical neuroscience in a new light, recalling the need to analyse the functional neuroanatomy underlying a syndrome and to ask ourselves what difficulties are being faced by the human being struggling to find a voice in what can be a dysfunctional wasteland of '*Clinicum*'¹⁴⁷ that is a dependent care facility in a health system geared to efficacy and efficiency. The face of humane neurology and chronic medical care is often eclipsed by objective measurements of medical necessity for designated disorders. In this area within the domain of organised health care and medical expertise, we often find therapeutic nihilism, and premature end-of-life decisions against which Fins understandably protests.

At this contested margin of ethics and clinical neuroscience, Minimally Conscious States (MCSs), a relatively new and difficult phenomenon in this territory, are a focus of contested claims that often obscure clarity and lead to tendentious interpretations of scientific and imaging data. MCS patients fall between the fully cognitively competent set of patients who are locked in but cannot communicate what they fully appreciate (Locked in Syndrome) and patients with devastating and extensive cortical and subcortical disconnection, unable to process what is happening at any meaningful level or potentially engage with normal life and relationships.

Trials of measures such as Deep Brain Stimulation and attempts to do what is required to restore somebody to us are vital here in states where a diagnosis of PVS inadequately or incompletely captures functional capacities, by over-emphasising neuroanatomical features of an evolving "human and complex" picture in which, a patient might, somewhat unexpectedly convey a message such as "Mama, life is good!"¹⁴⁸ There is ample evidence that Locked in Syndrome can result in a life well-lived in the face of what many of us would consider unbearable suffering.¹⁴⁹

A plea for a group of patients facing real injustices and exclusion from rehabilitative care because of severe brain injury must be balanced with a clear eye on medico-legal issues of capacity, competence, best interests, and those who would genuinely face an unacceptable future by the over-zealous application of life-prolonging technology. The group seems real as several court cases and the recent decision referred to by Justice Collins make plain (*Carter V Canada*).¹⁵⁰ We should not, therefore, set aside our inability to know how to answer the existential questions that might arise for a patient facing a "too short and sad life"¹⁵¹ in aiming for an inclusive life-affirming view; but the uncertainties here should be part of our response to contemporary debates about end-of-life decisions in clinical contexts.

Interactions and interpersonality provide not only an important part of our ethical response but also daunting problems for severely brain-injured patients. A network of support with sensitivity to existential questions is clearly vital in this area. Those struggling to do this vital work for loved ones whose lives threaten to be sadly shortened can be hampered at every turn by a sometimes insensitive health care system and clinicians too well schooled in the

diagnostic categories that the science of medicine thrives on. Ongoing research into advance decision-making and actual clinical experiences of patients and professionals dealing with such problems can result in shared experience that is deeply instructive. But this whole domain of quasi-scientific activity is shot through and through with power, politics, economics, and variously informed and interested lobbies that can make it difficult to arrive at sound and inclusive guidance for the profession. Patients caught in the middle of all this can become neglected victims of an insensitive system. Fins speaks out against exclusion and for those who witness relevant events as a constant in our clinical and ethical lives. This aspect of end-of-life care reveals a world of human experience into which many of us, despite our inchoate (and variously directed) pleas to the contrary, may find ourselves plunged and where we should listen to the voices who speak for those who cannot speak for themselves there.

We are now able to return to the idea of futility as a further concept widely appealed to in clinical practice to allow us to reflect on human life and its value.

VIII. Futility

The concept of futility is sometimes regarded as a guise for medical paternalism, in that it rolls together medical and value judgments. Often, despite attempts to disambiguate the concept, the mix of purely medical and ethical intuitions is unavoidable and can be applied in such a way as to marginalise the real interests of a patient. It can be analysed using a conceptual toolkit that includes *physiological futility*, *substantial benefit*, and the *risk of unacceptable badness* (RUB). These are concepts that allow us to articulate what is at stake in diverse end-of-life situations where well-informed judgments are required.

Futility usually appears in decisions by doctors about quality of life and whether treatment is worthwhile in a given situation. Some suggest that it has “no utility”¹⁵² but it can serve to make us think about what we can do for a patient and the reasons why that might or might not be the right thing to do. Kasimov offers a “working definition”: “A treatment should be considered futile if it will not be beneficial to the physiological or psychological health of the patient”.¹⁵³ Others have discussed a failure to achieve goals that have been agreed by the patient and the medical team.¹⁵⁴ Futility and the cessation of life-prolonging treatment can provoke intense conflicts between those involved in end-of-life decisions.¹⁵⁵ This seems to come close to the idea of futility by using two concepts—*substantial benefit* and the *risk of unacceptable badness*—that together help us to apply a patient-centered view of benefit and futility.

Substantial benefit is an outcome that now or in the future the patient would regard as worthwhile or a state likely to lead to such an outcome.¹⁵⁶ The *risk of unacceptable badness* (RUB) is the probability that a patient will end up living in a state that they would regard as intolerable.¹⁵⁷ When we use these concepts in relation to both medical realities, and a sympathetic understanding of the patient’s life story with its emergent values, we can formulate a framework of clinical decision-making that tracks patient-centered assessments of what we should be doing.

8.1 Varieties of futility

From the variations in the use of the term “futility”, three concepts seem to cover the clinical dilemmas likely to present to an ethicist:¹⁵⁸ a) physiological futility; b) contextual futility; c) quantitative futility. Many argue that the medical facts can be ascertained in physiological or purely medical terms and are the proper domain of professionals, whereas value judgments should be made by patients.¹⁵⁹

8.1a Physiological futility

Physiological futility (some call this *medical futility* or *goal futility*) occurs when the intervention cannot possibly have the physiological effect that is desired; it is a clear point at which a relatively certain determination is available.¹⁶⁰ Three examples might be:

- i. giving an antibiotic for a viral illness (absent secondary infection)
- ii. using oral medications during the emetic phase of migraine (because enteric absorption does not happen in that phase)
- iii. external cardiac massage in a person with constrictive heart failure due to pericardial effusion.

In each case, there are physiological reasons why the intervention cannot affect the clinical problem, whereas it might be effective in another situation. Efficacy in this sense is a medical judgment based on clinical experience and existing patho-physiological knowledge.¹⁶¹

8.1b Contextual futility

Contextual futility is non-physiological—it could reverse an identified pathological change—but, in context, that may not be a suitable thing to do or proportionate to the requirements of the total situation.¹⁶² An example might be cardiac resuscitation in an elderly demented person who is unconscious in a residential care setting and who is expected to die of some complication of her severe Alzheimer’s disease. In such a case, restoring a heartbeat seems pointless.

But here we enter the world of ‘greys’ that bedevil ‘black and white’ judgments about futility and benefit and where we can become quite inarticulate. At this point, *substantial benefit* is a useful ethical concept. For instance, in the case mentioned there is no point in administering cardio-pulmonary resuscitation when it would not get us any closer to restoring the patient to a state that, now or in the future, she (or anybody else) would regard as worthwhile. This is closest to what Schneiderman et al¹⁶³ call *qualitative futility* and what Mohindra calls *value futility*.¹⁶⁴

8.1c Quantitative futility

Quantitative futility assessed on the grounds of probabilistic information is also a concept coined to try and meet the challenge of articulacy. It provides a number to be factored into the decision, for example, less than a 1 percent chance of restoring the patient to active function so that s/he could go home.¹⁶⁵ Mohindra prefers to use a probabilistic version of *goal futility* to cash this out in terms of the medical facts¹⁶⁶ but the problem is that most people reason as follows: “A 1 percent chance is better than none at all; go for it!” We can get our thinking past that point by using *substantial benefit* and the RUB to make the problem a little more realistic and able to be grappled with.

8.2 Decisions about futility and benefit

The ethical importance of questions about *substantial benefit* and the *risk of unacceptable badness*, is that they aim to take account of the orientation and values of the patient, insofar as they are known.¹⁶⁷ Where the care team may lack clear guidance as to the wishes of the patient, they can assess something like objective best interests—what any reasonable person would regard as a worthwhile outcome—with these questions in mind.

Questions about *substantial benefit* and the RUB are ethically useful, even though they have fuzzy borders. Most people would regard a poor neurological outcome (eg, dim and fragmented awareness, no coherent notion of self or survival, breakthrough experiences of pain and discomfort on a background of nothingness) as being something they would rather not risk, so that if the probability of ending up in such a state is high compared with any other outcome, arguably most people would not want to take the chance. By contrast, most would regard the genuine possibility of recovering meaningful, even if dependent, interactions with others and perhaps even returning to a family setting as worthwhile, and the chance of things turning out that way as a chance worth taking. These concepts therefore help us in decision-making where the stakes are high.

For patients with severe brain injury, physiological futility is difficult to apply because of the extreme variability and unreliability of current assessments of neurotrauma and the effects of various interventions on its outcome.

Contextual, qualitative or value futility would apply when considering treatments in many such situations, eg, for a patient who is in terminal renal failure due to kidney damage from extensive bodily injuries and multisystem collapse. In such a case, survival is beyond reach, even if the patient can be pulled through the acute events, so that such interventions might be considered (contextually) futile. In a different way, a patient who has had pre-traumatic brain damage (due to a cascade of cerebrovascular disease producing severe physical and mental impairment from that cause alone) might be so impaired that the prospect of *substantial benefit* resulting from a life-saving intervention for the head injury is not a realistic possibility, so that the attempt at rescue is futile.

Probabilistic or quantitative futility is broken down to require an assessment of the likelihood of certain outcome states and the countervailing likelihood of producing a more distressing state for the patient by a given intervention.

Analogous decisions will apply throughout the range of clinical scenarios where futility assessments are called for. But none of the current futility assessments factor into the ethical calculation the serious and thought-provoking possibility that the patient could be made worse by “giving it a go” or “striving for life against the odds”. In reality, that possibility is often with us and poses the ethically challenging *risk of unacceptable badness*: “Aye, there’s the RUB!” At least, when facing the RUB, patients and relatives must be forewarned of the possible need to make further decisions about treatment limitation or removal of life-prolonging measures that are probably going to arise as the treatment and the patient’s response to it unfold.

Discussions of futility are often conducted without the conceptual tools needed to clearly articulate the issues at stake in an acute situation. The concept of futility—whether physiological, medical, goal futility, value futility, qualitative or quantitative—often fails to capture or clearly identify what ethicists most want or need to know to give proper consideration to the case. We need to be prepared for the complex and often intertwined possibilities of lack of clear benefit or, what is worse, an intolerable outcome (given the patient’s values) as a result of rescue. The concepts of physiological futility, *substantial benefit* (an outcome that now or in the future the patient would regard as worthwhile), and the RUB provide tools for the imaginative task that ethicists inevitably face, and stress—lest the clinical team forget it—that it is the patient’s perspective that is all important here.

IX. Other cultures and faith traditions: some tentative thoughts

We should notice that our intuitions are not nearly as clear-cut in relation to life and death as some pronouncements make them out to be. When we ask what is sacred about life, we see that it cannot be mere biological life or what Helmut Thielicke¹⁶⁸ calls “the empty shell of what once was human...which can therefore no longer act as an independent subject” but must rather be someone who can be addressed as “you”. Thielicke, a Protestant theologian, in this claim converges with Pope Pius XII who also focuses on the person as a subject and gives supreme weight to “the presumed will of the unconscious patient” in the provision of life-prolonging measures. Pope John Paul II, in his 1995 encyclical *Evangelium Vitae*, also affirms the value of human life as the setting where we meet God and enter into communion with God and others. Thus “the life of the body in its earthly state is not an absolute good”.¹⁶⁹

Notice that, in this Encyclical roundly rejecting both abortion and euthanasia, John Paul II makes a distinction between biological life and the life of a subject who can have meaningful relationships (with God or other human beings). It is worth noting that we are called—even by these traditionally conservative voices—to consider the sanctity of life as involving a more nuanced principle than the principle of saving purely biological life in all circumstances and with whatever outcome; a view that seems sometimes to be the thrust of an absolute proscription against any medical or ethical complicity in accepting death as a natural end of life. The “gospel of life” seems to regard death as something that, in the words of the hospice movement, should be neither hastened nor unduly delayed so that we can accept a “natural death” in so far as that is possible in our medically technologised world.

Most faith traditions reject the right of human beings to end their lives when they wish to, and see the use of human ingenuity and technology as falling within a more inclusive set of values and understandings. That is often to the fore in the rejection of suicide in almost all faith traditions (on various ethical grounds).

Christian: The Christian view is that lives are owned by the Father God, their creator, and they do not belong to each person to do what they like with. The Christian position, which centres on a caring and compassionate attitude to those who are dying and a sense of the precious fragile gift that is human life, emphasises human fallibility when it comes to decisions.¹⁷⁰

Jewish: From the Jewish viewpoint, the prohibition of suicide does not come from the commandment “Do not kill” (Exodus 20:13 and Deuteronomy 5:17). Suicide and murder are two separate sins in Judaism but fall under a common prohibition. According to rabbinic classifications, homicide is an offense between man and God as well as man and man, while suicide is merely an offense between man and God. Because of this, suicide is considered a very serious sin. Ultimately, it is viewed as an act that denies that human life is a divine gift and is considered a slap in God’s face for shortening the lifespan that God has given him or her. After all, God “created (the world) to be inhabited”. (Isaiah 45:18)¹⁷¹

Islamic: Islamic jurisprudence, based on the holy Koran, does not recognise a person’s right to die voluntarily. According to Islamic teachings, life is a divine trust and cannot be terminated by any form of active or passive voluntary intervention. There are two instances, however, that could be interpreted as passive assistance in allowing a terminally ill patient to die and would be permissible by Islamic law.¹⁷² These concern what has been discussed above under the concept of *futility*—the lack of initiation or withdrawal of treatment that is thought by doctors to be useless—and the *doctrine of double effect*, the administration of relief for severe pain that also has a chance of hastening death.

Buddhist: One of the fundamental principles of Buddhism is not to kill any living being (the first precept of the panchasila). The Buddhist hospice movement has grown over recent years. One reason for this is because death is seen as a particularly valuable opportunity for spiritual development and a hospice can present the best environment for a peaceful death. However, no Buddhist hospice would practice assisted suicide. This is because assisted suicide is equivalent to intentional killing and therefore constitutes a breach of the first precept.

Hindu: There are several Hindu points of view on euthanasia. Most Hindus would say that a doctor should not accept a patient's request for euthanasia since this will cause the soul and body to be separated at an unnatural time. The result will damage the *karma* of both doctor and patient. Other Hindus believe that euthanasia cannot be allowed because it breaches the teaching of *ahimsa* (doing no harm). However, some Hindus say that by helping to end a painful life, a person is performing a good deed and so fulfilling their moral obligations.¹⁷³

The Hindu concept of *karma* and the ability to rise above the turmoil of *samsara*—the troubled conflicts of passion and earthly engagement—tells against any action that is driven

by attending only to our fleshly condition. The spiritual life, which is the ultimate aim of human growth and development, is aligned against violence (whether directed against the self or another) as it always reflects a triumph of desire over enlightenment. An enlightened one seeks a full realisation of his or her destiny as a part of the being of God.

Indigenous perspectives: Sir Mason Durie, the creator of the Whare tapu Wha model of Māori health, has recently written:

Māori concerns recognised that the mauri of an individual does not reside in the brain. Rather it is an expression of the whole person and has a past as well as a present and a future context and connectedness within a wider set of relationships. Organ dysfunction does not negate the significance of the mauri of a living person since the mere existence of older people elevates the standing of whānau and hapū (families and tribes). The presence or absence of 'sound mind' does not reflect the whole person, the significance of a link with an older generation and a symbol of continuity. While the mauri is alive, death should not be accelerated.¹⁷⁴

Indigenous thought recognises the connectedness of all with all. Bishop Desmond Tutu has often spoken of the Ubuntu principle "I am because you are and you are because we are". He has highlighted its difference from Western individualistic modes of thought with their emphases on personal choice and relatively self-determined well-being. The apparent consensus among indigenous views is that adopting an end-of-life practice that makes dying in care easier or more likely for people who are, in every post-colonial context, already disadvantaged, is something they view with suspicion and unease, and as expressing a failure of the ties that should bind us together in life.

In each of these traditional ways of thinking, individual human life and choice is relativised to a wider context of relatedness and connection to others and the untimely taking of one's own life is rejected as a response to suffering or evil. The grief caused by the loss of a human life is prominent in that reasoning and the belief that even in what seem like empty and worthless moments of a given human life there are goods to be discovered by those who touch and are touched by that life.

X. Children: potentiality and human interests

The birth of a severely compromised child with anencephaly or some other lethal congenital condition is a profound tragedy for all involved and must be dealt with in a compassionate and sensitive manner. Nevertheless, there is an important principle:

The potentiality principle: the life due to each and every child is a life in which the child's human potential is given the best chance of being realised.

The case of anencephaly marks one end of a tragic spectrum and therefore puts a symbolic 'peg' in the ethical ground in relation to an extreme effacement of the potential of the human being involved and our duties to save human life. We do have a general interest in saving the lives of our children as it would be self-defeating for us to allow a situation to arise in which we did not value them. But it does not follow (and here most ethicists would

agree with ordinary folk) that we have an obligation to save the life of a child who has no prospects of living and no potential for future growth and development of any meaningful kind. That has been characterised, by Duff and Campbell, as the *capacity to love and be loved*.¹⁷⁵ This is, in fact, a fairly tolerant and widely accepted threshold criterion for saving infant life that gets us away from cognition and its development—an area of human life much focused on by academic elites.

That decision should not be related to a rejection of disabled children or those among us who are vulnerable. Rather it is a recognition that the anencephalic child has no significant interests that can be served by its remaining alive, in much the same way as Tony Bland or other patients at the centre of landmark cases,¹⁷⁶ might be thought not to have such interests. This intuition embeds the principle of *substantial benefit* (already mentioned):

Clinical medicine should undertake only those interventions the outcome of which now or in the future the patient would think to be worthwhile.¹⁷⁷

If that is why we do not strive to keep alive children with anencephaly, then similar considerations might apply to infant death for other severely affected newborns. There is, we might conclude, no obligation to keep alive a child who is destined only to be in a vegetative or near vegetative state.

These cases might, in fact, be even more compelling in that they force us to look beyond the idea of futility and raise the prospect of a barely sentient human being condemned to feeling only some (meaningless) analogue of pain or distress. If that situation could arise, then whatever is important in avoiding the futile rescue of a severely damaged newborn is reinforced by the imperative to alleviate suffering. To these considerations may be added the real cost, both in terms of health resources and emotional resources, of keeping such an infant alive.¹⁷⁸

The (quasi-Aristotelian) *potentiality principle* implies that if the future life of any child is likely to bring that child any chance of a meaningful human form of life among others in which there exists “the capacity to love and be loved”, then we should nurture it. It also suggests a kind of realistic proportionality according to which interventions in the face of certain threats to a certain point might be justified for an impaired newborn. For instance, we might decide to withdraw treatment when a birth injury of some kind is complicated by neonatal events, and even more damage has been sustained so that any remaining potential has been lost. ‘Substantial benefit’ in such cases should be interpreted in terms of realisable potential and our clinical duty of care (which can become other than the duty to save life if the prospects look too bleak. When considerations such as the lack of potential or severe and unrelieved suffering hold sway, the realisation that our duty of care does not always mean extending life as long as we can makes sense of the otherwise strained justification that we are withdrawing treatment, knowing that the child’s life will end, in the child’s best interests.

10.1 The potentiality principle—further thoughts.

The potentiality principle requires that we give each child the best chance we can of fulfilling its inherent potential to grow and develop. Imagine the following case:

Carl is on the 97th percentile for cognitive and sensorimotor development until 18 months old and then becomes unwell. I take him to the doctor who diagnoses an intercurrent viral infection and advises maintaining hydration and observation. During the night I become worried but, reassured by the doctor's advice, only give my increasingly feverish and fractious child some energy drink. By the next morning Carl is seriously unwell and I take him to the Emergency Department of my local hospital. Meningitis is diagnosed and Carl is treated but suffers severe brain damage and falls through the percentile curves and then pursues a trajectory on the 15th percentile. Now clearly Carl has suffered a loss of potential even though much remains to be salvaged.

Cases such as that of Carl reinforce an argument (detailed elsewhere) that the human form develops through ontogeny and can be understood using distinctions made by Aristotle.¹⁷⁹

Aristotle distinguishes *first potential* from *second potential*. *First potential* represents the capacity to develop or show the kinds of properties that a human organism with her or his typical or natural biological form can show. Every human being with adequate neurological development has the first potential to live a characteristically human life. *Second potential* indicates that the human being concerned has developed a property (such as speech, perception, reason, or coordinated motor function) even though he or she is not at present actually showing it (is asleep, unwell, or silent or meditating, for instance).

For Aristotle, human beings are living souls with vegetative, animate and intellectual or cognitive capacities and all three in harmony constitute characteristic human functioning. In fact, they interactively transform one another in a harmony or integrity that is unique to the human soul/psyche. Thus, in relation to vegetative properties, a human being does not eat as an animal eats (so that *haute cuisine*, obesity and anorexia are possible for human beings) nor do humans have sex in the same way (we fall in love, form stable and exclusive relationships with culturally inflected expectations, become jealous, sing silly love songs, find creative other ways to express our sexuality and so on). Neither do we move as animals move (we dance, play sport, affect cultural mannerisms) and our cognitive capacities are focused on complex domains such as law, ethics and art in a way that animal cognition is not.

We should also note that the human soul, seen this way, is compatible with either secular or religious approaches to human life, unlike the Platonic conception—according to which the soul enters the human body at a certain point and departs at death to return to heaven. Aristotle speaks of a unity or harmony of function underpinning the human form so that to treat the facets of the soul reductively and ask whether, conceived in that piecemeal way (and run through the analytic mill of necessary and sufficient conditions), they are present or absent is to miss the point. Given that holism, it becomes clear that the potentiality of a human child is something much broader than just cognitive development—as is captured by Duff and Campbell's phrase "the capacity to love and be loved".

A commonly used phrase ('ten fingers and toes') signifies the expectation that one's child is tolerably within a broad conception of being a living human soul; perhaps not an exemplary instance of such a being, but *our* instance—the one that has been entrusted to us in this place at this time—and for that reason quite irreplaceable. Of course we hope that s/he will not suffer or that any sufferings will somehow be absorbed in a story which adds up to a good enough life—a somewhat vague idea. It is vague because a good life for a human being does not have anything like the stereotypy of most biological specifications because there are many different ways of being human and they defy simplistic prescriptions (which is why there is such an abiding problem in defining enhancement).¹⁸⁰

What is quite clear is that neither a severely affected conjoined twin, who threatens the survival of both conjoined individuals (or even just the life of the other 'host' twin), nor an anencephalic child reach the threshold for truly human potential (or even according to the broad and vague type of human life gestured at by ten fingers and toes). They are not only undeveloped but also lack the *first potential* to develop further and become a fully functioning human being. In fact, a wider range of infants are not significantly different from anencephalic infants in that respect. The list might include babies with severe static encephalopathy, infants with very profound cerebral damage from prematurity or meningitis—any of these tragically affected infants may lack the *first potential* (the basis for developing a holistic set of cerebral and other bodily functions that is recognisably human) to develop characteristically human functions such as those gestured at by "the capacity to love and be loved".¹⁸¹ The Aristotelian conception of a living soul copes well with such cases because it is evident that such babies as anencephalics do not have an inherent potential to develop as a living soul, which means that partial but meaningful inclusion of babies and infants in the moral community (initially as patients but increasingly as agents) is not only justified, but also mandated (and arguably constitutive) of a decent human society.

We can therefore argue that a child lacking the first (or neurobiological) potential to become a living human soul, although s/he lacks personal (or identity grounded) interests, still has solidarity interests (that are part of our existence as a distinct species on the earth). Among those solidarity interests we could plausibly include being a life-giving saviour to other children. If that is the case then we have no interests supporting a duty to keep the child without intrinsic potential alive, and interests in saving the life of others (as a valued contribution to the human world and thus a presumptive argument for favouring organ transplantation). Other arguments, however, do intervene, such as those associated with transplantation from PVS patients, so this can only be a *prima facie* possibility that looks reasonable based on a plausible conception of solidarity interests and the robust (Aristotelian) notion of potential here outlined.

10.2 Severely impaired newborns and transplant decisions

Discussions of the best interests of a child, the ruling principle in our clinical and other dealings with children, often restrict themselves to interests focused on the person themselves. This creates real problems where the human being concerned does not plausibly have such interests (anencephaly, asymmetrically dependent conjoined twins and

PVS patients have already been mentioned). A conception of solidarity interests may license certain decisions in such cases.

1. A human being has two kinds of interests in virtue of the living creature it is: (i) solidarity interests (in the welfare of the human group into which it is born, and (ii) personal interests.
2. 'Best interests' judgments require that these both be weighed and balanced.
3. Where there are no plausible personal interests eg, in one's future survival, the remaining solidarity interests prevail.
4. Solidarity interests include making a contribution to one's human group in line with that group's traditions and points of sensitivity.
5. An anencephalic child has no plausible personal interests.
6. The child's solidarity interests support the view that its best interests are served by contributing in any way it can to the human group into which it is born (eg, by organ donation).

This conclusion is in line with the intuitively plausible potentiality principle that constrains our duties to children and therefore implies that allowing or assisting organ donation by an anencephalic child meets ethical criteria for a permissible act.

10.3 Children and clinical decisions¹⁸²

The application of adult ethical principles to paediatric practice is not always straight forward because of several barriers in terms of cognitive and executive development that make the principle of autonomy difficult to apply. Do children have a moral or legal right to autonomy, and to what extent it should be moderated by adult views about their best interests?

The concepts of autonomy, partnership, truth telling, and the respective roles of parents and children in paediatric decision-making are all important in such clinical decisions and particularly those concerning a child's life and death.¹⁸³

For adults, where autonomy is a key principle, a genuine partnership is becoming the desired mode of clinical engagement.¹⁸⁴ Parents are, however, assumed to be those who decide about their child's medical treatment, even though children are being encouraged to help make such decisions. Decisions about children are typically regarded as conditional upon medical determinations of best interests and the duty of care, along with parental understanding of the clinical situation, and have been legally resolved in favour of medical opinion on numerous occasions.¹⁸⁵ Clearly children do not have full autonomy, although they ought to be helped on towards it, and they have varying abilities to make their own decisions¹⁸⁶ because they are "not yet competent".

There is a growing consensus around the idea of "Gillick competence".¹⁸⁷ A child is deemed competent if "they can demonstrate sufficient maturity and intelligence to understand and appraise the nature and implications of the proposed treatment including the risks and alternative courses of actions".¹⁸⁸ Clinical judgment is required about the maturity and

adequacy of the child's understanding, but the child cannot take part in such decisions unless there is a shared attitude between the family and clinicians that "it takes three to tango" and this seems particularly important in end-of-life care.

Most clinical guidelines give the child's parents a legal right to determine what the child is told about their condition.¹⁸⁹ While health professionals should counsel parents to tell their children about their illness, when that is refused, the doctor is put in a quandary that cannot arise in adult care. Here principles of graded autonomy, supported competence and partnership ought to be respected, given that we have duties both to protect our children and to assist them to develop their potential or capacity and that the parents' *de facto* power should not infringe a child's *de jure* rights.¹⁹⁰ In fact parental authority can be overturned in therapeutic decision making if the child's best interests do not seem to be foremost in the decisions parents are making.

Failure to tell the truth to children is often justified on the grounds of non-maleficence, and a desire not to distress the child—even though non-disclosure to an adult on those grounds is ethically unacceptable (unless a very "carefully circumscribed" therapeutic privilege can be defended).¹⁹¹ Furthermore, the evidence indicates that rather than protecting children, non-disclosure can in fact induce significant anxiety and distress.¹⁹²

We are now emerging from a period in medicine during which, until the 1980s, non-disclosure to terminally ill patients was fairly common and widely regarded as standard clinical practice.¹⁹³ That was even more the case with children. Over time, we have moved towards increased involvement of the child in medical decision making, but these decisions are ultimately dependent on parental agreement in most cases.¹⁹⁴

That stance is based on the thought that children lack established values and life experience, and may not fully understand the long-term implications of their choices, so that it is difficult for them to have the wisdom to make critical life-affecting choices about treatment.¹⁹⁵

While the same is arguably true for many adults, the age of majority is often used as a cut-off point for Gillick competence, depending on the gravity of the decision and the "maturity" of the child.¹⁹⁶ In New Zealand, children 16 and over can make their own decisions about medical care, even though age of majority is 18 under the Care of Children Act 2004. End-of-life care and the decisions it calls for concern mortal choices for which there is no second chance, so a very conservative position is justified in this area.

We should note that different children develop their abilities to deal with life problems at different ages, depending on life experiences and emotional maturity. It also seems that personal experience with disease or illness seems to be quite important (understandable if there has been an ongoing exchange of information between the child and the physicians).¹⁹⁷

Thus, while the age of majority is a guideline, at least some children will be capable of making autonomous decisions before that. These 'mature minors' should consent to treatments as they possess the understanding and maturity required for Gillick competence. However, the level of competence required to consent in different situations varies, and for

that reason, capability for end-of-life choices in adolescents should be considered case by case. A 14 year old or even an 8 or 10 year old may be more than capable of consenting to many procedures, but lack the competence for more challenging decisions, particularly those that would curtail their terminal illness.

Gradual veracity encompasses the idea that as a patient moves towards increased autonomy, so we also have an increased obligation to share information and decision-making in a safe and controlled environment to facilitate the child's participation.¹⁹⁸ The closer the patient is to being autonomous, the more we should ensure that the patient is told the truth; even if their parents would rather they were not fully informed. Clearly, our direct obligations to a 6 year old are less than what we owe to a 12 year old or a 16 year old but, at every age, being a companion to the child and discussing what is happening in terms the child finds comprehensible will satisfy our clinical duty to act in the child's best interests according to good practice. It will also, incidentally, ensure that the parents understand, what is happening, with the added advantage of creating a supportive and caring milieu that parents may not find easy to achieve. That climate of caring honesty is vital to good end-of-life decision-making.¹⁹⁹

If we accept the gradual development of supported autonomy, rather than an all-or-nothing approach to truth telling, consent and decision-making, it follows that for every paediatric patient there will be a point where truth telling becomes a moral imperative. It may be significantly earlier than the age of majority, in accordance with the understanding requirements of Gillick competence and the fact that children may have a wisdom about their illness and the significance of the decision involved beyond their years.²⁰⁰

While we may have only a moral obligation of gradual veracity to paediatric patients and non-disclosure or non-maleficent 'white lies' should be avoided, the duty of care does not end there. We need to be educators for both the child and his or her parents as they struggle through the difficult situations that arise in terminal illness. The evidence is clear that while non-disclosure may be requested out of a desire to protect children, it often has the opposite effect.²⁰¹ It is worth rehearsing the arguments so that aid-in-dying for children can properly be considered.

- (i) Truth-telling satisfies a child's wish to be informed, and even young children display a need to understand themselves within a context (hence the interminable, "Are we there yet?" questions of long drives). In a healthcare setting, parents may not believe their child can understand the information necessary for them to put their experiences in context, but they often see that that is not the case when a child is provided with developmentally appropriate information. In both children and adults, uncertainty can exacerbate the feelings of loss of control that are common in any hospital setting and can be frightening when a child knows that the situation is dire. Studies have shown that most paediatric patients would rather be informed and involved in their treatment.²⁰²
- (ii) Truth-telling aids psychosocial adjustment. Parents may believe that disclosure of medical information will adversely affect their child but, from an early age,

children are aware when their parents are distressed and seek explanations for what is happening.²⁰³ In the absence of clear information, children tend to assume the worst, leading to significant anxiety and depression.²⁰⁴ Young children may even perceive hospital admission and treatment as punishment if not included in conversations, and their fears and fantasies can be allayed through provision of information.²⁰⁵

- (iii) Truth-telling leads to better treatment outcomes. Evidence suggests that informed patients are less anxious during treatment,²⁰⁶ a fact that can only reduce uncertainty and (understandable) distress during end-of-life care.
- (iv) Truth-telling facilitates trust between child, health professional and parent, particularly when the child has a chronic illness. In this situation, the child will eventually come to know their diagnosis and perhaps wish they had been told sooner. The child's ability to prepare for and be realistic about their own impending death can be a great comfort to parents for whom the sadness of grief is often intensified by concerns for their child's state of mind. A recent study of children dying from cancer is very revealing:

In terms of quality of life, most of the children (73%) were perceived by their parents as happy, in a good mood and peaceful.²⁰⁷

The study includes a remark about the need to treat children for anxiety in terminal illness but concludes "fewer children suffered from depression or anxiety than previously reported, nearly half were visited regularly by their friends, and half received psychosocial aid during end-of-life care".²⁰⁸ It is clear that supportive and surround care of a child during terminal illness, in the context of an open and honest palliative pathway, is both achievable and desirable and here as elsewhere seems to mitigate the suffering that is often invoked to justify voluntary euthanasia or physician aid in dying.

- (v) Truth-telling is likely to lead to less psychosocial morbidity, such as anxiety and depression, in the parents because continued deception is difficult to sustain both practically and emotionally, and is particularly damaging to the trust and sense of being cared for that is so important in palliative care.

In end-of life decisions, the need for sensitivity and inclusion is likely to be even higher than in other situations. Nevertheless, the same principles should apply as elsewhere. The refusal of consent by a child deemed able to take an intelligent part in the conversation and with the support, even if tragic and ambivalent, of parents, should trigger a discussion about withdrawal of life-prolonging treatment. Where parents agree with a child, it may be that the twin considerations of *substantial benefit* and an unacceptable prospect of burdensome treatment make treatment withdrawal the only ethical option. Such decisions are, however, never easy.

XI. Ending the narrative in a fitting way

A person can stop living his or her life (in terms of our characteristic human modes of experiencing) through any course of tragic terminal events. Those of us who know and love them need to do our best to try and ensure that the life story is ended in a way that is fitting to that person. For that to be possible, medical ethics and medical law must work closely together.

Tony Bland, injured in the Hillsborough stadium disaster, was such a case. The judges ruled that we should respect the hypothetical wishes of Tony Bland himself (as we might say “considered as a human subject not a biological organism”), and thus that his death should be fitting in the whole context of his life. Their reasoning about the removal of the gastric feeding tube keeping him alive is similar reasoning to that in the cases of Brophy and Quinlan:²⁰⁹

If Anthony Bland were to be momentarily restored to consciousness with full knowledge that he would shortly revert to his PVS, and if he were to instruct those caring for him that he no longer wanted artificially to be kept alive, the doctors and nurses would be obliged to respect his wishes. ...The horror of his situation is such that few would not think it perfectly reasonable for him to decide that, as he has already lost all sense and consciousness, he would prefer to die. ...Anthony Bland is an individual human being and the principle of self-determination says he should be allowed to choose for himself and that, if he is unable to express his choice, we should try our honest best to do what we think he would have chosen. - Hoffman L.J.²¹⁰

Notice the prominent place given to Tony Bland as a subject with a sense of himself that needs to be respected in the decisions we make about life-prolonging treatment and its continuance or cessation. In fact, because it is a basic feature of the life of any person that he or she should live out his or her own life story, it is not just futile to keep an irreversibly comatose body alive in PVS but it is a certain kind of violence to (or disrespects the sanctity of) the subject as a self-determining human being.

A similar line of reasoning led a New Zealand court to decide that the termination of an Auckland patient's life would not be unlawful.²¹¹ Mr L, a man of 59 years, had been totally paralysed by Guillain-Barre Syndrome (which strips the coverings from nerves throughout the body) so that he had a type of Locked in Syndrome. The specialists who saw him agreed there was no hope of recovery and his view was reliably said to be that he did not ever want to be left in such a state.

His wife supported the medical team in their request to terminate his ventilator treatment and the court ruled that it would not be unlawful for the medical team in charge of Mr L to terminate his life support. (After cessation of ventilation Mr L died within 30 minutes. An outcome deemed to be in accordance with his being as *a human subject* whose potential to truly live as one of us had been cruelly destroyed).²¹²

Two further cases support the same conclusion and also hinge on the idea of respect proper to a human subject. An Irish case concerned a woman aged 43 who had been severely brain

injured at the age of 22 during a gynaecological operation. She was, at the time of the judgment:

...spastic, her jaws were clenched, she could not swallow, she was incontinent and bedridden ...For 20 years she received nutrition and hydration through a nasogastric tube. This caused her some distress and she pulled it out on many occasions...[she] was unable to speak and attempts by a speech therapist to establish some form of communication proved unsuccessful. [she] appeared...able to recognise members of her nursing staff, and reacted to strangers by showing distress. She could follow people with her eyes and reacted to noise, although this appeared to be mostly by way of reflex action²¹³

The High Court, per Lynch J, consented to the withdrawal of artificial nutrition and hydration (upheld by the Irish Supreme Court). The main points of the judgment were:

1. that the ward's best interests should prevail over other considerations
2. that the court exercised a *parens patriae* jurisdiction to ensure that those interests were protected
3. that the right to life includes a right to a dignified death
4. that the provision of nourishment through a gastric tube was intrusive
5. that the right to self-determination means that a competent adult has the right to refuse any medical treatment whatsoever
6. that this right should not be denied a person who did not have the mental capacity to exercise it
7. that in this case the ward should be allowed to die a natural death.

A New Zealand case, Mr G, concerned a 69-year-old man who had suffered a severe brain injury in a road accident 16 months previously.²¹⁴ The judge noted:

He is totally immobile, is unable to talk or otherwise communicate in any meaningful way and is incontinent of urine and faeces. His CT scans and EEG show severe brain damage. Every effort has been made to rehabilitate him but to no avail. He has remained in the same state and there is no prospect of recovery. He is kept alive by food and fluids through a gastrostomy tube and is provided with all necessary and appropriate medical and nursing care.²¹⁵

Judge Fraser consented to the removal of gastric food and fluid, taking note of the cases of Mr L, Tony Bland, and the Irish Ward of court already described, and of:

1. Mr G's injuries and his present condition
2. specialist opinions that artificial feeding and fluid be withdrawn
3. the fact that the prospect of meaningful recovery was "virtually nil"
4. the Ethics Committee's unanimous decision that they had no objection to withdrawal of treatment
5. the application for withdrawal by Mr G's family

6. the evidence that Mr G's wishes if they could be ascertained would be to have treatment withdrawn
7. the fact that withdrawal of treatment would not cause pain and suffering.

He ruled that those measures should be used which would allow Mr G “to end his life and die peacefully with the greatest dignity and the least distress” (p17), again implicitly appealing to something like the fuller sense of life that we are currently interrogating.

The reasoning in the Bland case, in re Ward of court, and the New Zealand cases of Mr L and Mr G are clear. The link between a right to life and the right to a dignified death is striking but in deep accord with the present discussion of a sense of life and a framework for ethical decisions informed by what is profoundly worthwhile in a human life. Absent this connection, we can find ourselves using life-prolonging treatments without adequate ethical or juridical constraints (appropriately sensitive to the expressed wishes and values of a patient) on that use. The Irish court invokes a “right to a dignified death” but we could appeal to the idea of *substantial benefit* (as defined) or a sense of what is fitting in the whole context of the person’s life story delivers the same conclusion.

Our respect for and sense of the value of the life of a human being imply to some there is a link between the right to life and the right to a dignified death, which is based on a conception of human life that is something more than a mere biological life and which should not be equated with its biological remnant when meaningful human life has been destroyed.²¹⁶ But whereas we notice that there are conditions in which we can (and should) decide on somebody's behalf that he or she would not want his or her present existence to continue, we may feel hesitant about the further step of taking it into our own and the patient’s hands to end a life that could continue, albeit for a limited time and with severely reduced prospects. We ought to be able to reassure any patient that, if a state eventuated in which he or she was receiving no conceivable benefit from our interventions, then healthcare professionals would not keep him/her alive by intrusive medical means. That in itself might be a kind of reassurance that takes some of the pressure off the possibility of changing the law around death and dying.

A sense of life proper to our conception of the ethical basis for decisions about withdrawal of life-prolonging treatment should respect the dignity and integrity of the patient (as a human subject). Actively ending or assisting to end a human life seems to need further justification and carries with it a range of possibilities and responsibilities that doctors may feel reluctant to take on as part of end-of-life care. Care and respect seem to favour cherishing the time a person has left even if it is a time in which there are both good and bad moments.

A further word is in order at this point about situations where there is a chance of a good outcome, but also a high probability of something quite unwelcome eventuating.

11.1 The RUB: the worst possible end to the story

When the life of a human being is under mortal threat, decisions must be made—usually with partial and probabilistic information and with possible momentous consequences. Consider the decision to withhold or withdraw life-saving treatment if, for instance, a patient is admitted acutely and rescue treatment or cardio-pulmonary resuscitation (CPR) is required. Two alternatives are commonly mentioned: life and death. But there is another significant category: survival in an unacceptably bad state for the patient concerned. Here we confront the RUB (the *risk of unacceptable badness*).

To sleep, perchance to dream, Aye, there's the rub.

Hamlet is contemplating suicide. He has been told by a ghost (claiming to be his father, the recently deceased king of Denmark) that his uncle (who has married his mother) murdered that same beloved father. Should Hamlet take revenge on his uncle or just exit? If his uncle is innocent, killing him is a mortal sin, which Hamlet would commit based on possibly flawed (indeed demonic) information, and for which he will be damned. But if he fails to avenge his father, he could not live with himself and the regretful dreams that might come in the sleep of death. In this quandary (intensified, according to some commentators, by an Oedipal conflict) he is paralysed by the prospect of eternity dead, therefore, impotent, but wracked with the moral torments fueling his suicidal thoughts, an unacceptably bad prospect: “Aye, there's the RUB.”

The RUB has, however, a much more prevalent clinical presentation. Doctors confront it when they work in rescue medicine and find themselves considering the pros and cons of such things as resuscitation in a seriously compromised patient, heroic surgery for a severe brain injury, or rescue when a patient has had a devastating stroke. The dual prospects of life and death do not exhaust the ethical dilemma we face. We often hear “Well, doc, go for it; after all, any chance is better than none.” But is that so? There is a third possibility—the person may be left in an unacceptably bad state, hence the RUB!²¹⁷

This is a stark and taxing choice but one hopes that those making decisions on one's behalf have a proper sense of life and an understanding of the person concerned so that relatives or other surrogate decision makers can work with somebody open to an end-of-life decision-making partnership.

In most jurisdictions, those making the decision ought to try and do what the person at risk would have wanted to happen and not what anybody else thinks should happen or, worse, what is demanded by an inflexible value. We should try and do what would be of *substantial benefit* to the person concerned (*an outcome which now or in the future the patient would consider worthwhile*) and, try and avoid the RUB even though that is not always possible.²¹⁸

Thus the ethical responsibility of a healthcare team is to make the best decision they can in the face of medical uncertainty about the unfolding clinical reality (and the relatives may be an invaluable source of information) about what, for the patient concerned, would constitute *substantial benefit*.

Often the need for the best information—for instance, about the severity of the initial insult and about its response to treatment—favours what we might call a *trial of treatment* rather than absolute withholding. It is important that everybody understands that treatment is being trialed and that the patient’s response is an important indicator of how long the treatment should continue. If the uncertainties are acknowledged, the idea of a trial of treatment clarified, and the need to act in a way consistent with a sense of life as coloured by the patient’s values (as a human subject) is kept in mind, then people tend to cope well with withdrawing treatment (and do not see it as an inexplicable change in clinical management). Most people understand that the withdrawal of potentially life-saving treatment is an issue to be revisited once its likely effect has been gauged, and that any decision (in which the RUB is a factor) should be made in the light of some all-in sense of what makes for a good human life (in terms appropriate to the individual concerned).

The RUB cuts out the simplistic “two options” approach to life-and-death situations and allows a middle way, when the chance of survival might only be bought at the cost of a very high risk of an unacceptably bad outcome. A trial of treatment guided by and responsive to the patient’s condition as events unfold guides us to take stock and face our responsibility to do what is in the best interests of the patient or what s/he would want if s/he choose. By engaging others in the process of decision-making—responsive to unfolding events—the team, through ongoing conversations, can get a sense of the values and interests the patient had before the catastrophe and respect the more-or-less integrated story that is their patient’s life, as a lived experience. Even without an explicit advanced directive, one can, as a result, usually make a judgment about the fittingness of certain possible endings to the patient’s story.

In an entirely analogous way we can, in a discussion of CPR with the patient, convey the reality captured by the RUB so that, the “any chance is better than none” approach becomes much less attractive than it otherwise seems at first blush. Life (valued positively) and death (valued negatively) can then be compared in the light of a sense of life and a third alternative: *life to be valued negatively* can be put into the moral balance along with the other two.

The RUB does not make life and death decision-making easier—and may make it harder—but it does make it more responsive to the hopes and fears of any person faced with the mortal perils that wait behind a hospital door. Thus, it becomes more likely that what we decide on that person’s behalf at the threshold between life and death is in keeping with what that person would have written into the story him or herself; to appreciate that, an ethical participant must be equipped with a sense of life. And that, for many of us, is the best we can do to ensure that a person’s life ends in a fitting way. However, the possibility of physician aid in dying, for some, threatens to take us out of that type of ethical conversation—of care and mitigating suffering—and into quite another one.

XII. Euthanasia broadly speaking: pulling the threads together

The issues here seem simple when raised for public debate:

1. Is euthanasia—killing a patient at their request for a reason validated according to certain criteria—significantly different from decisions to end life-saving treatment?
2. Should a doctor be enabled to make an agreement with a patient to end the patient's life or provide the means to do so?
3. Should we continue to perpetuate the sharp distinction between allowing a patient to die by not prolonging treatment, and causing or aiding death when it is welcome?

The decision we face as a profession is not quite as impersonal and does not allow us to stand back from what is being asked in quite the same way. It is therefore couched in slightly different terms.

1. Should we as healthcare professionals go beyond what we are currently allowed to do in terms of withdrawing unhelpful and burdensome treatment and embrace the further step of ending, or assisting a patient, to end their own life, at their request?
2. Will that further step, with the dire responsibilities it places on doctors and nurses dealing with end-of-life care, significantly benefit our patients?
3. Should our profession, which has always acted out of utter respect for life and our duty to care for patients in life-affirming ways, embrace a different ethos in one area of our practice?

Having taken part in many end-of-life decisions and spoken to colleagues about their own similar experiences it seems that doctors are somewhat reluctant to take on the weight of the burden that here we are asked to assume. **Every time a doctor is closely involved with treatment limitation resulting in the patient's death, even where that is agreed by all to be the inevitable and perhaps best outcome of the treatment regimen, he or she feels the burden of that decision. This sense of burden has been shared with me by a wide range of doctors and is grounded in the same deep place as the *pause*.**

12.1 Professional morality and legal reform

At this point it is important to notice that the law does not merely reflect the moral standards of a society but, in fact, has a profound influence on them and our perception of those to whom the law applies. If the law permits a certain type of action, then we, as a society, are swayed in our attitudes toward that action. This inevitably means that when an act crosses the line from being unlawful to being lawful, it finds a new level of social acceptance and those who are supposed to act on it are seen in a new light.

Some commentators remind us of what we have already seen happen with abortion, which has gone from being a stigmatised, backroom activity (with all the attendant risks to women) to being an acceptable alternative in the face of what might be a terrible moral conflict for a

woman who finds her life and health or her life story as she has composed and crafted it threatened by an unwanted pregnancy. None of us wants to go back to the abject position in which the previous law left such women, but the prevalence of the practice after law change has affected many of us.

It is clear that, as this last possibility indicates, the acceptable reasons for a significant step in the fashioning of legislation can easily be loosened somewhat from the initial very cautious legislation that circumscribes such choices with stringent safeguards. The importance of our attitudes to human lives and the ways in which we form moral opinions about it are a fragile domain of shifting value at the edge of life. Some worry that permissive legislation may, as (some argue) has happened in the Netherlands, allow a loosening of initially sound checks and balances in the practice of various forms of end of life management; the evidence for that happening is mixed.

Legislation allowing active voluntary euthanasia would, at least arguably, affect the whole context of terminal and palliative care. The choice as to whether or not to ask for euthanasia would then be a feature of the clinical and moral background for everyone. We and our patients would all, when a terminal illness is the context, be wondering what is expected of us and which conversations should be had. The realisation that a request is purely voluntary does not make the issue go away; it decidedly falls short of indicating whether or not to accede to that request for a given patient might be the right thing to do.

This report has discussed the many ways in which dying people can be vulnerable, isolated and distressed by what they perceive to be happening. Many of these reactions are, as Kübler Ross has so eloquently shown us, completely natural but they may well lead a person to question the worth of their going on to live out their 'natural span'. The fact that the question of euthanasia is in the background, and the implication that our society regards it as an acceptable thing to do, would plausibly interact—in ways we do not feel comfortable about—with those uncertainties.

As doctors, we would also, by that legislative stroke, be changed. There is a burden in making mortal decisions. It is bad enough when, as the law routinely determines, the disease itself is the cause of death and we are merely companions and carers on a path that tragically tends in that direction. What we can do, in the cases in point, is modify the patient's journey, but our role is not to be the bringers of death. That dramatic role we leave to God or nature, as arguably its burdensome mantra is too much for a mortal to bear.

12.2 A sense of life in the midst of the clinic

One can think of a number of ways in which the sense of life might inform our stance towards death and dying as we encounter it in our clinical lives. We might, as Nussbaum²¹⁹ urges, cultivate and not allow to slip away a sense of life as a sense of the freshness of what life brings, even in the days and hours before death, and the way in which life can refresh and renew us when we are flagging or losing a sense of "what it is all about" or "whether it is all worthwhile". Stories of death and dying can sharply awaken that sense in us. Sharing our

stories of inspiration, worth, serendipity and courage in the face of adversity provide some indications as to how those things might illuminate end-of-life decisions.

Emmanuel Levinas, himself indelibly inscribed by the events of the Holocaust in which he lost most of his family, is perhaps uniquely positioned to speak to us here. Levinas notes that human faces reveal others, each of whom lives in a world that is, in an important sense, unfathomable except for the glimpses of it they share with the rest of us. The world of another is not ours, but he or she shares my world with us and thereby adds strands of worth to our lives that are as varied as they are valuable. We encounter others, all of whom mean something to us, in a distinct way when they call on us or reach out to us for help. They cannot be categorised or described as a type or in general because they always present themselves as individuals. They may surprise and challenge us when they do not fit neatly into our conceptions of the world and other people.

The being-present or 'proximity' of another person with whom one becomes acquainted more and more deeply as one enters into conversation, signals that one's story is not the only one to be heard and that each story has its own value if the people who live those stories and construct the worlds in which they have meaning are gracious enough to accept one and share their realities. Their disclosures and conversations, particularly as they approach death, reveal differently inspir[it]ed worlds which can never be one's own but which enrich each of us in a way that is unique to each. That is why Levinas is moved to say "‘You shall not kill’ is...the principle of discourse itself and of spiritual life". After the enormity of the Holocaust, the power of his remark is unmistakable and we should never seek to evade it.

Some, at this juncture, speak in terms of the world of spirit—the human spirit or the spirit of medicine—as something transcendent of any given human individual, drawing on the fact that for each us the face of the other opens a 'pore' / 'door' from one person's world to a differently inspir(it)ed world. The world of spirit, then, is seen as the finite but inexhaustible set of all the worlds we could share with each other, replete with the diverse stories each human being brings to our shared life just by living and finding meaning in their own lives and deaths, and those of others. The world of spirit is therefore diminished when any of its stories or witnesses are lost or, to put it differently, when the life of any human being is cut off while their story is being written. We are, as this discussion poignantly reminds us, finite or mortal—our stories do have endings, which can be more or less fitting (and are tragically unfitting in cases such as the suicide of a young person), and in those endings we must all, with due humility, play our parts and learn to bear ourselves well.

So we can now begin to see how a sense of life and the human spirit, both of which inform the 'sanctity of life' doctrine, deepen and complement each other. A sense of life gives us a sense of life's value and what it is that makes a life valuable. These are only appreciated as one lives and encounters other human beings whose lives are both distinct from our own and also full of things that make them worth living.

Recall Clint Eastwood's character in *Unforgiven* who observes: "It's a helluva thing you do when you kill a man, you take away everything he has and everything he's gonna have". The

value of life is here seen as incalculable and deserving of deep respect because it is irreplaceable in a way that neatly encapsulates our present dilemma.

Levinas' invocation of "Thou shalt not kill" as the principle of discourse and spiritual life now takes on further substance such that the very idea of ending a human life should always give us pause²²⁰ even where we are fairly sure that a sufficiency of the powerful considerations in favour of ending a life ought to guide our decision. A sense of life would seem an essential qualification for ethicists involved in such decisions and in the formation of policies and procedures relating to them.

12.3 Inspir(it)ed persons with a sense of life

To judge well as healthcare professionals, we need 'a sense of life', a characteristic that has several dimensions not easily defined but that forms a framework within which to lay out our professional role in our patients' lives and deaths.

First, we ought to be finely attuned to others, because in discourse and inter-subjectivity we find the grounding for a sense of what is at stake in matters of life and death. This is the ground on which we encounter human beings as embodied and vulnerable biological beings with a status importantly derived from our inter-connected strands of subjective being, through which we meet and learn to serve, to befriend, and, in diverse ways, to love, each other—even when our encounters are brief and close to the death of one of us. We are all subjective bodies or embodied subjectivities born of women; we live entangled with our environment and with the lives and deaths of others, and we exhibit a being-towards-death with more or less resolve and more or less care. Our sense of life, as doctors and reflective beings, therefore attunes us to whole beings in deep ways.

As subjects attuned to each other we should be deeply open not only to life warmth and the presence of others but also to discourse, not merely in order to catch on to what others are saying "out there," nor merely as expectant listeners for the echoes of our own 'take' on life but as *mortal-beings-in-the-world-with-others* caring (even concerned) about the lives of others and what stories and inspir(it)ations they bring to our shared world.

Attentive or attuned awareness of and responsiveness to others makes us recognise and respond to mortality, perhaps as instanced in "the widow, the cripple, and the orphan" (not as mere exemplars of types but) as embodied particular human beings—each one a unique (and perhaps unquiet) piece of the spirit world in which we all participate.

Our developed, professional 'sense of life' should make us alert to freshness, the unrepeatability of the moment, the fragility of goodness as lived by mortals, the need for action and interaction to be properly informed, and to care as part of our attending to the health of the soul through engagement with others in spirit and in truth.

If these dimensions enter into us as healers, then we are ethical because a sense of life infuses our understanding of life, death and human nature and makes it more, rather than less, adequate to the encounters with mortality that abound in the clinic. Events around human death subject us to strains that test our sense of life and sometimes entangle us in

distressing decisions. But it is important, in the midst of all that, to hold on to everything that makes us what we value being and to set aside that which does not help us to be that way. It is hard to predict what voluntary euthanasia and physician aid in dying will do to us in respect of the value we place on the lives of others, although the lessons from elsewhere do not seem to be as bad as some have feared. But the spirit that is engendered, that is hard to discern and the value of every moment of meaningful human life is something to be jealously guarded.

Thus legislative change creates a changed moral framework for terminal illness. It is a subtle change but, if viewed through the lens of the moral imagination, a real one. The words of *Evangelium Vitae* are sharply relevant here.

[T]he commandment “you shall not kill” establishes only the point of departure of a journey to true freedom, a journey which must lead to the active promotion of life, the development of attitudes and modes of behaviour which serve life. (p730)

These thoughts may seem somewhat remote from the family stress and on-going pain when loved ones live on (for example, after severe traumatic brain injury) needing a great deal of support but with very limited quality of life, so that family members may feel that an assisted death would be a blessed relief and good idea.

Such feelings are only intensified when resource implications and the demands on a health system trying to achieve improvements in the quality of life of many are brought into the conversation. The drive for permissive legislative change reflects a number of factors that weigh into a very fraught societal and ethico-legal debate. The complexity of the issues makes it impossible to outline any simplistic or linear process of reasoning to a clear-cut position that avoids judicial and prosecutorial discretion and removes the need for informed medical judgment to make good and caring decisions.

XIII. Concluding remarks and convergences

There is clearly a difference—but not a complete disconnect—between the arguments that bear on the morality of an individual act of euthanasia and the arguments that are heeded at a social or legislative level. At the personal level, there is a need for a sense of what is fitting in the context of the life that is coming to an end. Many doctors feel secure in the hospice position that sees the journey through to its end and neither hastens nor delays that end. That looks to be in accordance with a developed sense of life, informed by the many texts that the lives of patients offer, the literature of our own two cultures and others, and the experiences hospice and other caregivers share with us. This body of knowledge has served us well down the years and seems to most doctors deeply satisfying and fundamentally sound in its guidance in dealing with dying patients. Remaining within that ethos in end-of-life decisions carries its own burdens but, arguably, makes them able to be borne in a way that is not asking of us more than we can easily give and that leaves us with a sense of personal integrity.

The WMA reflects this tradition in its resolution on the subject.

Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient's own request or at the request of close relatives, is unethical. This does not prevent the physician from respecting the desire of a patient to allow the natural process of death to follow its course in the terminal phase of sickness.

The WMA Statement on Physician-Assisted Suicide, adopted by the 44th World Medical Assembly, Marbella, Spain, September 1992 and editorially revised by the 170th WMA Council Session, Divonne-les-Bains, France, May 2005. That document states:

Physician-assisted suicide, like euthanasia, is unethical and must be condemned by the medical profession. Where the assistance of the physician is intentionally and deliberately directed at enabling an individual to end his or her own life, the physician acts unethically. However the right to decline medical treatment is a basic right of the patient and the physician does not act unethically even if respecting such a wish results in the death of the patient.

A similar stance is taken by the Declaration of Mumbai in relation to paediatric euthanasia.

We believe that all children (neonates, children and young people) have the right to the best quality of life. When they have life-limiting conditions they have the right to high quality palliative care to meet their needs.

We believe that euthanasia is not part of children's palliative care and is not an alternative to palliative care. It is imperative that we work together to improve access to children's palliative care around the world, including ensuring access to appropriate pain and symptom control.

We call on all governments to transform children's lives through the development of children's palliative care, and in particular we urge the Belgian government to reconsider their recent decision to allow euthanasia of children.

This includes:

- (i) Access to children's palliative care within the children's health care system
- (ii) Access to appropriate pain and symptom management (including medications) for all children
- (iii) Supporting children and their families to be able to live their lives to the best of their ability for as long as possible.

These statements, formulated by independent bodies and consistent with the consensus statement of the EAPC, express a position that the NZMA could advisedly align itself with as a professional institution contributing to the ongoing debate in New Zealand.

Clearly those who exhibit the schooled intuitions that are evident in the most experienced carers for the dying among us deserve to be listened to. They, as individuals, exude a kind of calm and peaceful demeanour that makes many of us feel somewhat inept in the face of death and the grief of losing a loved character in the story of one's life. Communicating the

news to a patient that he or she is dying and that we have no more magic answers to wheel out, calls on all our resources of imagination and identification with the living person who is confronting what we are not. That contact and the fearsome thing laid on the table between us, so needing to be transformed, rarely seeks an intervention but always calls for recognition and awareness. A sense of travelling with the person, albeit at increasing distance, as the person prepares to leave us, brings a kind of understanding as the proximity of death becomes more evident. That shared understanding creates a kind of bond that is at once both personal and professional and that is perhaps vulnerable to the intrusion of a repertoire of techniques that bypass the human-ness of the encounter and existential significance of the encounter and make it a routine matter of clinical care.

The need for a companion, someone who will be sad to see me leave and who does not want to hasten that ending seems to be the most profound need of the dying person. Most of us will not, it seems, want our companions to cling too much but also will not want to be released too readily. A negotiated arrangement at a given point in time does not, as a medical professional considering the current issues in this debate, seem to be the kind of release that brings a good death. But then, we are poised at a juncture in our profession and we all know that extrapolation is a dangerous game.

The debate about the legalisation of euthanasia is complex and the medical profession should remain cautious about any change in law that would interfere with principles that have guided medicine and general healthcare to good effect for most people throughout the centuries. The WMA's resolutions on euthanasia and physician-assisted suicide reflect this tradition; its clear opposition—to what would mark a departure and move towards a different ethos in an area where medical practice needs sound guidance and standards—is worthy of support because of the value it puts on human life.

This stance does not prevent a physician from respecting the desire of a patient (or the patient's guardian) to allow the natural process of death to follow its course in the terminal phase of sickness (where that may involve the withdrawal of life-prolonging treatment or treatment limitation because the treatment is properly deemed futile).

XIV. References (Alphabetical)

- Alderson P. *Choosing for Children* Oxford, Oxford University Press, 1990.
- Alderson P. In the genes or in the stars? Children's competence to consent. *J Med Ethics*. 1992 Sep;18(3):119-24.
- Alderson P, Goodwin M. Contradictions within concepts of children's competence. *Int'l J Children's Rts*.1993 1: 303-313.
- Ardagh M. Futility has no utility in resuscitation medicine. *J Med Ethics*. 2000 Oct;26(5): 396-9.
- Aristotle. *De Anima (On the Soul)* tr Lawson-Tancred H, Penguin Classics, 1986. ISBN 978-0140444711.
- Baines P. Medical ethics for children: applying the four principles to paediatric practice. *J Med Ethics*. 2008 Mar;34(3):141-5. doi: 10.1136/jme.2006.018747.
- Beale EA, Baile WF, Aaron J. Silence is not golden: communicating with children dying from cancer. *J Clin Oncol*. 2005 May 20;23(15):3629-31.
- Beautrais AL. 2000. Risk factors for suicide and attempted suicide among young people. *Australian and New Zealand Journal of psychiatry*.34: 420-436
- Bilsen J, Cohen J, et al. Medical end-of life practices in Belgium. *N Engl J Med*. 2009 Sep 10;361(11):1119-21. doi: 10.1056/NEJMc0904292.
- Bilsen J, Vander Stichele R, et al. 2007. Changes in medical end-of-life practices during the legalization process of euthanasia in Belgium. *Soc Sci Med*. 2007 Aug;65(4):803-8. Epub 2007 May 8.
- Bioethics Aaopco. Informed consent, parental permission and assent in paediatric practice. . *Paediatrics* 1995;95:314-17.
- Bloche, M, 2005 Managing Conflict at the End of Life *N Engl J Med* 352:2371-2373. June 9, 2005 DOI: 10.1056/NEJMp058104.
- Block S. Assessing and managing depression in the terminally ill patient. ACP-ASIM End-of-Life Care Consensus Panel. American College of Physicians - American Society of Internal Medicine. *Ann Intern Med*. 2000 Feb 1;132(3):209-18.
- British Medical Association, *Euthanasia: report of the Working Party to review the British Medical Association's guidance on euthanasia*. London: British Medical Association: Professional Division Publications, 1988.
- Boldt M. Defining suicide. In: Diekstra R, Maris R, Platt S, Schmidtke A, Sonnieck G (Eds.) *Suicide and its prevention*. Leiden: Brill. 1989.

- Bowyer L. Autonomy and why you can “Never Let Me Go”. *J Bioeth Inq*. 2014 Jun;11(2):139-49. doi: 10.1007/s11673-014-9533-4.
- Bowyer L, Gillett G. 2015. Suicide: The lonely path. *Advances in Medical Ethics* 2:3. doi:10.12715/ame.2015.2.3. <http://www.ame-journal.com/> accessed 19/10/2015.
- Caflin CJ, Barbarin AO. Does “telling” less protect more? Relationships among age, information disclosure, and what children with cancer see and feel. *J Pediatr Psychol* (1991) 16 (2): 169-191. DOI: <https://doi.org/10.1093/jpepsy/16.2.169>.
- Campbell AV, Gillett G, Jones DG. *Medical ethics* (4th Edition). Melbourne: Oxford University Press. 2005.
- Caring alliance. CIV 2015-485-235 in the High Court of New Zealand, Wellington Registry. 2015.
- Chambaere K, Bernheim JL et al. Characteristics of Belgian “life ending acts without explicit patient request”: a large scale death certificate survey revisited. *CMAJ Open*. 2014 Oct 1;2(4):E262-7. doi: 10.9778/cmajo.20140034.
- Chambaere K, Bilsen J et al. Physician assisted deaths under the euthanasia law in Belgium: a population based survey. *CMAJ*. 2010 Jun 15;182(9):895-901. doi: 10.1503/cmaj.091876.
- Chambaere K, Vander Stichele R et al. Recent trends in Euthanasia and other end-of-life practices in Belgium. *N Engl J Med*. 2015 Mar 19;372(12):1179-81. doi: 10.1056/NEJMc1414527.
- Chambaere K, Cohen J et al. End-of-life decisions in individuals dying with dementia in Belgium. *J Am Geriatr Soc*. 2015 Feb;63(2):290-6. doi: 10.1111/jgs.13255.
- Chisholm N, Gillett G. The patient’s journey: living with Locked in Syndrome. *BMJ*. 2005 Jul 9;331(7508):94-7.
- Churchland P. The neural representation of the social world. In: *Mind and Morals: Essays on ethics and cognitive science* (Eds.) May L, Friedman M, Clark A. Cambridge (Mass.) MIT Press, 91-108, 1996.
- Clemente I. Clinician's routine use of non-disclosure: prioritizing 'protection' over the information needs of adolescents with cancer. *Can J Nurs Res*. 2007 Dec;39(4):19-34.
- Crigger B. Professing the values of medicine: the modernized AMA code of medical ethics. *JAMA*. 2016 Sep 13;316(10):1041-2. doi: 10.1001/jama.2016.9752.
- Davidson D. *Essays on Actions and Events*. Oxford: Clarendon. 1980.
- Douglas G. The Retreat from Gillick. *Mod Law Rev*. 1992 Jul;55(4):569-76.
- Duff RS, Campbell AG. Moral and ethical dilemmas in the special-care nursery. *N Engl J Med*. 1973 Oct 25;289(17):890-4. DOI: 10.1056/NEJM197310252891705.

- Durie M. A Maori perspective of health. *Soc Sci Med*. 1985;20(5):483-6.
- Dyer C. MPs will debate assisted dying bill in September. *BMJ*. 2015 Jun 10;350:h3187. doi: 10.1136/bmj.h3187.
- Elliott C, Attitudes, Souls, and Persons: Children with Severe Neurological Impairment. In: Elliott C, editor. *Slow cures and bad philosophers: Essays on Wittgenstein, medicine and bioethics*. Durham: Duke University Press; 2001.
- Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet*. 1996 Jun 29;347(9018):1805-10.
- Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J. Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe *JAMA*. 2016 Jul 5;316(1):79-90. doi: 10.1001/jama.2016.8499.
- Fins J. *Rights come to mind: brain injury, ethics, and the struggle for consciousness*. New York: Cambridge University press. 2015.
- Frick S, Uehlinger DE, Zuercher Zenklusen RM. Medical futility: predicting outcome of intensive care unit patients by nurses and doctors--a prospective comparative study. *Crit Care Med*. 2003 Feb;31(2):456-61.
- Gabe J, Olumide G, Bury M. 'It takes three to tango': a framework for understanding patient partnership in paediatric clinics. *Soc Sci Med*. 2004 Sep;59(5):1071-9.
- Ganzini L, Fenn DS, Lee MA, Heintz RT, Bloom JD. Attitudes of Oregon psychiatrists toward physician-assisted suicide. *Am J Psychiatry*. 1996 Nov;153(11):1469-75.
- Giacino JT, Ashwal S, et al. The minimally conscious state: definition and diagnostic criteria. *Neurology*. 2002 Feb 12;58(3):349-53.
- Gillam L. Children's bioethics and the zone of parental disclosure. *Monash Bioeth Rev*. 2010 Sep;20(2):09.1-3.
- Gillett G. Euthanasia, letting die and the pause. *J Med Ethics*. 1988 Jun;14(2):61-8.
- Gillett G. Killing, letting die, and moral perception. *Bioethics*. 1994 Oct;8(4):312-28.
- Gillett G. The RUB. Risk of Unacceptable Badness. *N Z Med J*. 2001 Apr 27;114(1130):188-9
- Gillett G. Wittgenstein's startling claim: consciousness and the persistent vegetative state. In Elliott C, editor. *Slow cures and bad philosophers: Essays on Wittgenstein, medicine and bioethics*. Durham: Duke University Press; 2001.
- Gillett G. *Bioethics and the clinic: Hippocratic reflections*. Baltimore MA: Johns Hopkins University Press. 2004.
- Gillett G. Lecretia Seales and aid in dying in New Zealand. *J Law Med*. 2015 Dec;23(2):308-15.

- Gillett G. *Subjectivity and Being somebody: human identity and neuroethics* (St Andrews series on philosophy and Public Affairs). Exeter: Imprint Academic. 2008.
- Gillett G. Vitamin C: ascerbic ethical discussions. *J Law Med*. 2010 Dec;18(2):263-7.
- Gillett G, Amos C. The discourse of clinical ethics and the maladies of the soul. In Sadler JZ, Van Staden CW, Fulford KWM. Editors. *Oxford handbook of psychiatric ethics*. Oxford: University Press. 2015.
- Gillett G, Chamberlain J. The clinician's dilemma: Two dimensions of ethical care. *Int J Law Psychiatry*. 2013 Sep-Dec;36(5-6):454-60. doi: 10.1016/j.ijlp.2013.06.017.
- Gillett G, Goddard L, Webb M. 'The case of Mr L: A legal and ethical response to the court sanctioned withdrawal of life-support' (1995) *Journal of Law and medicine*, 3: 49-59.
- Gillett GR, Honeybul S, Ho KM, Lind CR. Neurotrauma and the RUB: where tragedy meets ethics and science. *J Med Ethics*. 2010 Dec;36(12):727-30. doi: 10.1136/jme.2010.037424.
- Gillett G, McMurdo M, Nie J. 2015. The human spirit and responsive equilibrium: end of life care and uncertainty. *Asian Bioethics Review*. 2015 Sept;7.3; 292-305.
- Gillett G, Walker S. (2013) The Evolution of informed consent. *J Law Med*. 2012 Jun;19(4):673-7.
- Gillon R. Telling the truth and medical ethics. *Br Med J (Clin Res Ed)*. 1985 Nov 30;291(6508):1556-7.
- Gillon R. "Futility"—too ambiguous and pejorative a term. *J Med Ethics*. 1997 Dec;23(6):339-40.
- Glannon W. Neurostimulation and the minimally conscious state. *Bioethics*. 2008 Jul;22(6):337-45. doi: 10.1111/j.1467-8519.2008.00645.x.
- Gomes B. Palliative care: if it makes a difference, why wait? *J Clin Oncol*. 2015 May 1;33(13):1420-1. doi: 10.1200/JCO.2014.60.5386.
- Griffiths J. Assisted suicide in the Netherlands: postscript to Chabot. *Mod Law Rev*. 1995 Nov;58(6):895-7.
- Harrigan M, Gillett G. Hunting good will in the wilderness. In: O'Connor D, Purves B, editors. *Decision making, personhood and dementia: Exploring the interface*. London: Jessica Kingsley. 2009.
- Harris J. Consent and end of life decisions. *J Med Ethics*. 2003 Feb;29(1):10-5.
- Havill J. Physician-assisted dying. *Policy Quarterly*. 2015;11.3; 31.
- Health and Sport Committee. Stage 1 Report on Assisted Suicide (Scotland) Bill. The Scottish Parliament. www.parliament.scot/S4_HealthandSportCommittee/Reports/her15-06w.pdf. 2015.

- Heintz LL. Legislative hazard: keeping patients living, against their wills. *J Med Ethics*. 1988 Jun;14(2):82-6.
- Honeybul S, Gillett GR, Ho KM, et al. Long term survival with an unfavourable outcome: a qualitative and ethical analysis. *J Med Ethics*. 2015 Dec;41(12):963-9. doi: 10.1136/medethics-2013-101960.
- Honeybul S, Gillett GR, Ho K. 2013. Futility in neurosurgery: a patient-centered approach. *Neurosurgery*. 2013 Dec;73(6):917-22. doi: 10.1227/NEU.0000000000000014.
- Johansen S, Hølen JC, Kaasa S, Loge HJ, Materstvedt LJ. Attitudes towards, and wishes for, euthanasia in advanced cancer patients at a palliative medicine unit. *Palliat Med*. 2005 Sep;19(6):454-60.
- John Paul II. Vatican. *Evangelium Vitae*. 25 March 1995.
- Jones DAJ. Assisted suicide and euthanasia: a guide to the evidence. Oxford: Anscombe Bioethics Centre. 2015 (www.bioethics.org.uk/evidenceguide.pdf)
- Jones JM, Huggins MA, Rydall AC, Rodin GM. Symptomatic distress, hopelessness, and the desire for hastened death in hospitalized cancer patients. *J Psychosom Res*. 2003 Nov;55(5):411-8.
- Jox RJ, Schaidler A, Marckmann G, Borasio GD. Medical futility at the end of life: the perspectives of intensive care and palliative care clinicians. *J Med Ethics*. 2012 Sep;38(9):540-5. doi: 10.1136/medethics-2011-100479.
- Kasimow S. A new approach to the issue of medical futility: reframing the debate. *Macalester Journal of Philosophy*. 2005;14 (1): 112–119.
- Kelly B, Burnett P, Pelusi D, Badger S, Varghese F, Robertson M. Terminally ill cancer patients' wish to hasten death. *Palliat Med*. 2002 Jul;16(4):339-45.
- Kelly WD, Friesen SR. Do cancer patients want to be told? *Surgery*. 1950 Jun;27(6):822-6.
- Keown J, Jones D. Surveying the foundations of medical law: a reassessment of Glanville Williams's the sanctity of life and the criminal law. *Med Law Rev*. 2008 Spring;16(1):85-126. doi: 10.1093/medlaw/fwn001.
- Kim SYH, DeVries RG, Peteet JR. Euthanasia and Assisted Suicide of Patients with psychiatric disorders in the Netherlands 2011 to 2014. *JAMA Psychiatry*. 2016 Apr;73(4):362-8. doi: 10.1001/jamapsychiatry.2015.2887.
- Kleinsman J. Euthanasia and assisted suicide: good or bad public policy? *Policy Quarterly*. 2015;11.3; 36.
- Lacan J. *The Seminar of Jacques Lacan: The Psychoses*. Translated Grigg R. *The Seminar of Jacques Lacan: Book 3*. New York (NY): W.W.Norton; p262ff; 1997

- Larcher V. Consent, Competence and Confidentiality. *BMJ*. 2005 Feb 12;330(7487):353-6.
- Leenan HJ. Euthanasia, assistance to suicide and the law; developments in the Netherlands. *Health Policy*. 1987;8(2):197-206.
- Lloyd, G. *Hippocratic Writings* London: Penguin. 1978
- MacIntyre A. *Dependent rational animals: why human beings need the virtues*. Chicago: Open Court. 1999
- McMurdo M, Gillett G. Consent, competence and lies to children: veracity in paediatric care. *J Law Med*. 2013 Dec;21(2):265-72.
- Mack JW, Cronin A, et al, Associations between end-of-life discussion characteristics and care received near death: A prospective cohort study. *J Clin Oncol*. 2012 Dec 10;30(35):4387-95. doi: 10.1200/JCO.2012.43.6055.
- Mohindra RK. Medical futility: a conceptual model. *J Med Ethics*. 2007 Feb;33(2):71-5.
- Mullen PE. Euthanasia: an impoverished construction of life and death. *J Law Med*. 1995 3.2;121-8.
- Nelson HL. What child is this? *The Hastings Center Report*. 2002;32.6: 29-38.
- Nussbaum MC. *Love's knowledge: essays on philosophy and literature*. Oxford: University Press. 1990.
- Orentlicher D, Pope TM, Rich B. The changing legal climate for physician aid in dying *JAMA*. 2014 May 21;311(19):1961-2. doi: 10.1001/jama.2014.4117.
- Owen C, Tennant C, Levis J, Jones M. Cancer patients' attitudes to final events in life: wish for death, attitudes to cessation of treatment, suicide and euthanasia. *Psycho-Oncology* 1994; 3: 1-9.
- Pereira J. Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls. *Curr Oncol*. 2012 Jun;19(3):139-42. doi: 10.3747/co.19.1088.
- Radbruch L, Leget C, Bahr P, Müller-Busch C, Ellershaw J, de Conno F, Vanden Berghe P; Board Members of EAPC. Euthanasia and Physician-assisted suicide: A white paper from the European Association of Palliative Care. *Palliat Med*. 2016 Feb;30(2):104-16. doi: 10.1177/0269216315616524.
- Raus K, Sterckx S, Mortier F. Is continuous sedation at the end of life an ethically preferable alternative to physician-assisted suicide? *Am J Bioeth*. 2011 Jun;11(6):32-40. doi: 10.1080/15265161.2011.577510.
- Regional Euthanasia Review Committees. Annual report 2013. <https://www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2013/nl-en-du-fr/nl-en-du-fr/jaarverslag-2013/annual-report-2013-tcm52-48.pdf>. The Netherlands. 2014.

- Rietjens J, van der Maas PJ, et al. Two decades of research on euthanasia from the Netherlands. What have we learnt and what questions remain. *J Bioeth Inq*. 2009 Sep;6(3):271-283. Epub 2009 Jul 28.
- Ross L. Health care decision making by children. Is it in their best interest? *Hastings Cent Rep*. 1997 Nov-Dec;27(6):41-5.
- Rys S, Mortier F, Deliens L, Bilsen J. The practice of continuous sedation until death in nursing homes in Flanders, Belgium: a nationwide study. *J Am Geriatr Soc*. 2014 Oct;62(10):1869-76. doi: 10.1111/jgs.13073.
- Sachs GA, Ahronheim JC, Rhymes JA, Volicer L, Lynn J. Good care of dying patients: the alternative to physician-assisted suicide and euthanasia. *J Am Geriatr Soc*. 1995 May;43(5):553-62.
- Sartre JP. *Being and Nothingness*. (Tr. H Barnes) London: Methuen & Co. 1958.
- Saunders C. The dying patient. In Gillon & Lloyd (ed) *Principles of health care ethics*. Wiley & Sons. 775-782. 1994.
- Schiff ND, Giacino JT, Fins JJ. Deep brain stimulation, neuroethics, and the minimally conscious state. *Arch Neurol*. 2009 Jun;66(6):697-702. doi: 10.1001/archneurol.2009.79.
- Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: its meaning and ethical implications. *Ann Intern Med*. 1990 Jun 15;112(12):949-54
- Schneiderman LJ. Defining medical futility and improving medical care. *J Bioeth Inq*. 2011 Jun;8(2):123-131.
- Schrode KE. Life in limbo: Revising policies for permanently unconscious patients. *Houston L Rev*. 1995;36:405.
- Sedgwick E. Patients' right to refuse treatment. *Hosp Med*. 2002 Apr;63(4):196-7.
- Sigman GS, Kraut J, La Puma J. Disclosure of a diagnosis to children and adolescents when parents object. A clinical ethical analysis *Am J Dis Child*. 1993 Jul;147(7):764-8.
- Skegg PDG, Paterson R. *Medical law in New Zealand*. Wellington: Thompson, Brookers. 2006.
- Somerville M. *Bird on an ethics wire: battles about values in the culture wars*. Montreal: McGill Queen's University Press. 2015.
- Swanson JW, Macrary SV. Medical futility decisions and physicians' legal defensiveness: the impact of anticipated conflict on thresholds for end-of-life treatment. *Soc Sci Med*. 1996 Jan;42(1):125-32.
- Sykes N, Thorns A. The use of opioids and sedatives at the end of life. *Lancet Oncol*. 2003 May;4(5):312-8.

- Smith KA, Goy ER, Harvath TA, Ganzini L. Quality of death and dying in patients who request physician-assisted death. *J Palliat Med.* 2011 Apr;14(4):445-50. doi: 10.1089/jpm.2010.0425.
- Thielicke H. *The doctor as judge of who shall live and who shall die.* Philadelphia: Fortress Press. 1970.
- van Delden JJ, Pijnenborg L, van der Maas PJ. The Rummelink Study: Two years later *Hastings Cent Rep.* 1993 Nov-Dec;23 (6):24-7.
- van der Maas P, van Delden J, Pijnenborg L. *Medical decisions concerning the end of life* Amsterdam: Elsevier. 1992.
- Walker D, Feldman A, Vohr B, Oh W. Cost-benefit analysis of neonatal intensive care for infants weighing less than 1,000 grams at birth. *Pediatrics.* 1984 Jul;74(1):20-5.
- Wallace, LM. Informed consent to elective surgery: the "therapeutic" value? *Soc Sci Med.* 1986;22(1):29-33.
- Wheeler, R. Gillick or Fraser? A plea for consistency over competence in children. *BMJ.* 2006 Apr 8;332(7545):807.
- Wicks W. The consequences of euthanasia legislation for disabled people. *Policy Quarterly* 2015.11.3; 38-40.
- Wittgenstein L. *Notebooks 1914-1916.* Oxford: Blackwells. 1969.
- Wolfe JFS, Hilden J. Caring for children with advanced cancer: integrating palliative care. *Pediatr Clin North Am* 2002;49:1043-1062.

XV. End notes

- ¹ Lloyd, G. *Hippocratic Writings*. London: Penguin. 1978
- ² Gillett G, 1988 & 1994
- ³ Nicklinson, Lamb and ‘Martin’ [2014] UKSC 38 (hereinafter Nicklinson and another, UKSC 38, #NN)
- ⁴ van Delden et al, 1993
- ⁵ Emmanuel et al, 1996
- ⁶ Keown et al, 2008
- ⁷ Neuberger, in Nicklinson and another, UKSC 38, #74
- ⁸ Mullen, 1995
- ⁹ Nussbaum, 1990, p148
- ¹⁰ Ibid. p171
- ¹¹ Gillett & Amos, 2015
- ¹² Neuberger in Nicklinson and another, UKSC 38 #74 and #171
- ¹³ Churchland, 1996
- ¹⁴ Nicklinson and another, UKSC 38 #199
- ¹⁵ Nicklinson and another, UKSC, 38 #208
- ¹⁶ Caring alliance, 2015, #50 (submission to NZMA, available on request)
- ¹⁷ Campbell, Gillett, & Jones, 2005, p10
- ¹⁸ Gillett, 2001
- ¹⁹ Nicklinson and another UKSC, 38, #209.
- ²⁰ The next section condenses arguments to be found in *Bioethics in the clinic: Hippocratic Reflections* Johns Hopkins University Press (2004).
- ²¹ Chisholm & Gillett 2005
- ²² Health and Sport committee, 2015 p24
- ²³ Sartre, 1985; Davidson, 1982
- ²⁴ Aristotle, 1986; Gillett, 2008. Aristotle through Aquinas and widely held by Christian and non-Christian thinkers
- ²⁵ 1969, 75e
- ²⁶ Nicklinson and another UKSC 38, #46; Saunders, 1994; Seales, 23-4
- ²⁷ 1989
- ²⁸ Block, 2000
- ²⁹ Brown et al, 1986
- ³⁰ BMA, 1988, p12
- ³¹ At least they are in general medical or hospital experience
- ³² Somerville, 2015
- ³³ Saunders, 1994
- ³⁴ Ibid, p777
- ³⁵ Ibid, p778
- ³⁶ Ibid, p782
- ³⁷ Domenica, 1987
- ³⁸ Ibid, p110
- ³⁹ PDG Skegg notes: “where the withdrawal or withholding of life-prolonging treatment is in keeping with ‘good medical practice’, those responsible have a ‘lawful excuse’ for the noncompliance with any prima facie duty to prolong life.” PDG Skegg, *Medical acts hastening death* in PDG Skegg and Ron Paterson (Gen eds) *Health Law in New Zealand* (Thompson Reuters NZ, Wellington, 2015) ch 20 at 673. See also *Airedale NHS Trust v. Bland* [1993] AC 789; *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235 (patient with Guillain-Barre); *Shortland v Northland Health Ltd* (1998) NZLR433.
- ⁴⁰ Regional Euthanasia Review Committees, The Hague, the Netherlands. Annual report 2013. https://www.euthanasiacommissie.nl/Images/Annual%20report%202013_tcm52-41743.pdf. Published 2014 Regional Euthanasia Review Committees, [hereinafter RTE]

-
- ⁴¹ RTE
- ⁴² RTE p4
- ⁴³ RTE
- ⁴⁴ van der Maas, 1992
- ⁴⁵ Leenan, 1987
- ⁴⁶ summarised in van Delden et al , 1993
- ⁴⁷ Keown, 1992
- ⁴⁸ Griffiths, 1995
- ⁴⁹ Ibid, p235
- ⁵⁰ Ibid, p247
- ⁵¹ Groenewald, JH, Van der Maas, et al (1997) Physician assisted death in Psychiatric practice in the Netherlands. *N Engl J Med* 1997; 336:1795-1801.
<http://www.nejm.org/doi/pdf/10.1056/NEJM199706193362506>
- ⁵² Somerville, 2015
- ⁵³ Jones, 2015
- ⁵⁴ Kim et al, 2016
- ⁵⁵ *State v. Chabot - A Euthanasia Case from the Netherlands Casenote* Kaufmann, *Gene* 20 Ohio N.U. L. Rev. 815 1993-1994
- ⁵⁶ Personal communication, DL Mathieson QC; see also *NZ Law Journal* October 2011.
- ⁵⁷ Rietjens et al, 2009
- ⁵⁸ Ibid, p274
- ⁵⁹ de Wachter, 1992
- ⁶⁰ Pereira J. (2011) Legalizing euthanasia or assisted suicide; the illusion of safeguards and controls. *Current oncology* 18.2; e38-e45.; Mathieson DL. Euthanasia; appropriate safeguards *NZ Law Journal* October 2011; 315. Chambaere K, Bernheim JL, Downar J, Deliens L. (2014) Characteristics of Belgian "life-ending acts without explicit patient request": a large-scale death certificate survey revisited. *CMAJ Open* 2, E262-E267.
- ⁶¹ Chambeare et al, 2015.
- ⁶² Bilsen, Cohen et al. 2009
- ⁶³ Bilsen et al, 2007, 807
- ⁶⁴ Raus et al, 2011; Rys et al, 2014
- ⁶⁵ Bilsen et al, 2007, p807
- ⁶⁶ Chambeare, et al, 2015
- ⁶⁷ Chambeare et al, 2014
- ⁶⁸ *R (on the application of Pretty) v. Director of Public Prosecutions* [2002].
- ⁶⁹ *Pretty v United Kingdom* (2002) 35 EHRR1 at [86].
- ⁷⁰ *R (on the application of Nicklinson) v Ministry of Justice* [2014] UKSC 38.
- ⁷¹ Press summary <https://www.supremecourt.uk/cases/docs/uksc-2013-0235-press-summary.pdf>
- ⁷² *Nicklinson and another*, UKSC 38.
- ⁷³ Assisted Dying Bill [HL] 2016-17
- ⁷⁴ BMA website <https://www.bma.org.uk/>
- ⁷⁵ BMA annual meeting: Doctors vote to maintain opposition to assisted dying **BMJ 2016; 353:i3486**
- ⁷⁶ Chambaere et al, 2014, 1961
- ⁷⁷ Mack et al, 2012
- ⁷⁸ Smith et al, 2010
- ⁷⁹ Ganzini et al, 1996; Gillett & Chamberlain, 2013
- ⁸⁰ Crigger, 2016
- ⁸¹ *Carter v Canada (Attorney General)* 2015 SCC 5; (2015) 384 DLR (4th) 14
- ⁸² ZAGPPHC 230: /2015 (4) SA 50 (GP), hereinafter SA Stransham Ford
- ⁸³ Ibid, 53
- ⁸⁴ Ibid, 71, 74
- ⁸⁵ Ibid, 38
- ⁸⁶ Ibid, 40
- ⁸⁷ EAPC, 2015.
- ⁸⁸ CIV-2015-485-00235 [2015] NZHC 1239 – hereinafter “Seales”.

-
- ⁸⁹ *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235 (patient with Guillain-Barre); *Shortland v Northland Health Ltd* (1998) NZLR433.
- ⁹⁰ Schneiderman, 1990; 2011
- ⁹¹ Gillett, McMurdo, & Nie, 2015
- ⁹² This does not extend to a patient's right to demand treatment (as in *R (burke) v General medical Council (Official Solicitor and others intervening)* [2005] EWCA Civ 1003; [2006] QB 273 reversing the judgment of Munby J. in *R (Burke) v The general medical Council* [2004] EWHC 1879.
- ⁹³ Emma Sedgwick (2013) Patients' right to refuse treatment. Sedgwick Emma **Affiliations** The Medical Defence Union , London SE1 8PJ. DOI: <http://dx.doi.org/10.12968/hosp.2002.63.4.2034> Published Online: September 28, 2013
- ⁹⁴ *HE v. A Hospital NHS Trust* [2003] EWHC 1279 (Fam), at p734.
- ⁹⁵ *Shortland v Northland Health Ltd.* (no 2) 6/11/97Salmon J, HC Whangarei M75/97. (The Rau Williams case)
- ⁹⁶ Skegg describes the lack of medical indications as falling under the scope of a lawful excuse not to provide life-prolonging treatment (Skegg Paterson et al, 2006, at 19.4).
- ⁹⁷ This section is drawn largely from a column in the *Journal of Law and Medicine* with some changes for the present document; . Gillett, G. Lecretia Seales and aid in dying in New Zealand. *Journal of Law and medicine* 2015 23; 308-315.
- ⁹⁸ Seales, 2, 3.
- ⁹⁹ See note 32; and Dyer C. *BMJ : British Medical Journal* (Online); London 350 (Jun 10, 2015).
- ¹⁰⁰ Seales, 6, The New Zealand Bill of Rights Act 1990 (NZBORA).
- ¹⁰¹ *Carter v. Canada (Attorney General)*, 2015 SCC 5, [2015] 1 S.C.R. 331 <http://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do> (accessed 15/10/2015); Seales 50-54.
- ¹⁰² Seales 20-22.
- ¹⁰³ Seales 11-12.
- ¹⁰⁴ Seales 15-16; 44-45.
- ¹⁰⁵ Seales 17-18; 38-39.
- ¹⁰⁶ Seales 37
- ¹⁰⁷ Seales 21-22; 46-47.
- ¹⁰⁸ Seales 5.
- ¹⁰⁹ *Airedale NHS Trust v Bland* [1993] AC 789 (HL)
- ¹¹⁰ McIntyre, 1999
- ¹¹¹ Durie, 1985
- ¹¹² Harrigan & Gillett, 2008
- ¹¹³ Lindemann Nelson, 2002; Bowyer, 2014
- ¹¹⁴ Seales 13.
- ¹¹⁵ Gomes B. (2015) Palliative Care: If It Makes a Difference, Why Wait? *Journal of Clinical Oncology*, Vol 33, No 13 (May 1), pp 1420-1421.
- ¹¹⁶ Seales at [106]
- ¹¹⁷ Kleinsman, 2015
- ¹¹⁸ Beautrais, 2000
- ¹¹⁹ Smith et al, 2011
- ¹²⁰ Keown, 2008
- ¹²¹ Sachs et al, 1995
- ¹²² Rietjens et al. 2009; Chambaere et al. 2010
- ¹²³ Mack et al, 2012
- ¹²⁴ Heintz, 1988
- ¹²⁵ Mack et al, 2012
- ¹²⁶ Nussbaum, 1990
- ¹²⁷ Pereira, 2011; Bilsen et al, 2007; Kim et al, 2015; Chambeare et al 2015
- ¹²⁸ Bowyer L, Gillett G (2015) Suicide: The lonely path. *Advances in Medical Ethics* 2:3. doi:10.12715/ame.2015.2.3 <http://www.ame-journal.com/> accessed 19/10/2015.
- ¹²⁹ Gillett, 2004; esp 211ff
- ¹³⁰ Kelly et al, 2002
- ¹³¹ Jones et al, 2003

-
- ¹³² Owens et al, 1994
- ¹³³ Johansen, et al. 2005
- ¹³⁴ Seales 47
- ¹³⁵ Owen et al, 1994 p6
- ¹³⁶ Seales 54.
- ¹³⁷ Owen et al, 1994, 7.
- ¹³⁸ Fins, 2015
- ¹³⁹ Gillett, Honeybul et al, 2010
- ¹⁴⁰ Gillett, McMurdo, Nie, 2015
- ¹⁴¹ Fins, 2015, p5
- ¹⁴² Honeybul et al, 2013
- ¹⁴³ Fins, 2015, 164
- ¹⁴⁴ Hilde Lindemann Nelson coined the phrase “holding in being” as a characteristic of engaged human life especially relevant to those whose autonomy is impaired.
- ¹⁴⁵ Fins, 2015, 255
- ¹⁴⁶ Lacan’s point de capiton (1993)
- ¹⁴⁷ Gillett, 2004
- ¹⁴⁸ Fins, 2015, 246
- ¹⁴⁹ The semi-autobiographical article by Chisholm (2005, BMJ) and the play *An accidental hero*. <http://www.theatreview.org.nz/reviews/review.php?id=6215> vividly convey the clinical dilemma and the patient journey.
- ¹⁵⁰ Carter v. Canada (Attorney General), 2015 SCC 5, [2015] 1 S.C.R. 331.
- ¹⁵¹ Fins, 2015, 247
- ¹⁵² Ardagh 2000
- ¹⁵³ Kasimov 2005, 118
- ¹⁵⁴ Schneiderman, 2011
- ¹⁵⁵ Swanson & MacRary, 1996; Bloche, 2005
- ¹⁵⁶ Campbell, Gillett, Jones, 2005
- ¹⁵⁷ Gillett, 2004
- ¹⁵⁸ Gillon, 1997; Ardagh, 2000; Mohindra, 2007
- ¹⁵⁹ Mohindra, 2007; Gillon, 1997
- ¹⁶⁰ Frick et al, 2003
- ¹⁶¹ Gillett, 2010
- ¹⁶² Jox, et al, 2012
- ¹⁶³ Schneiderman et al, 1990
- ¹⁶⁴ Mohindra, 2007
- ¹⁶⁵ Schneiderman et al, 1990
- ¹⁶⁶ Mohindra, 2007
- ¹⁶⁷ Hence a patient-centered concept of futility
- ¹⁶⁸ Helmut Thielicke (1970, 70)
- ¹⁶⁹ John Paul II, 1995, 706
- ¹⁷⁰ <http://www.interchurchbioethics.org.nz/>
- ¹⁷¹ <http://judaism.about.com/od/jewishhistory/fl/Judaism-View-on-Suicide.htm>
- ¹⁷² https://www.academia.edu/399232/Euthanasia_An_Islamic_Ethical_Perspective
- ¹⁷³ <http://www.bbc.co.uk/religion/religions/hinduism/hinduethics/euthanasia.shtml>
- ¹⁷⁴ Personal communication
- ¹⁷⁵ Duff, Campbell, 1973
- ¹⁷⁶ *Re G* [1997] 2 NZLR 201; *Re Quinlan* 429 US 922 (1976); *Re Guardianship of Schiavo* 851 SO 2d 182 (2003), *Re L* [1996] 1 NZLR 235]
- ¹⁷⁷ Gillett, 2004 p41
- ¹⁷⁸ Walker et al, 1984
- ¹⁷⁹ Gillett, 2008, Chh 1 & 2.
- ¹⁸⁰ The problem of enhancement has generated a huge and expanding bioethics literature in recent years.
- ¹⁸¹ Elliot, 2001
- ¹⁸² This section draws heavily on McMurdo & Gillett, 2013

-
- ¹⁸³ Gabe, et al, 2004
- ¹⁸⁴ Gillett & Walker, 2013
- ¹⁸⁵ Eg, Liam Williams Holloway. Consent, competence and lies to children: veracity in Paediatric care. (co-author with Maeve McMurdo & Nikki Kerruish) *Journal of Law and Med.* (2013) 21 JLM 265-272
- ¹⁸⁶ Baines, 2008
- ¹⁸⁷ *Gillick v West Norfolk and Wisbech Health Authority* [1985] 3 All ER 402; HDC, “Factsheet 3: The Age of Consent and Informed Consent for Children” available at www.HDC.org.nz
- ¹⁸⁸ Wheeler, 2006
- ¹⁸⁹ Sigman & La Puma, 1993
- ¹⁹⁰ Douglas, 1992; Larcher, 2005
- ¹⁹¹ The old teaching was that it was best to withhold the gory details from patients. Kelly W & Friesen S. (1950) Do cancer patients want to be told? *Surgery* 27:822-26.
- ¹⁹² Die Trill, 1997
- ¹⁹³ Gillon, 1985
- ¹⁹⁴ Harris, 2003
- ¹⁹⁵ Gillam, 2010; Ross, 1997
- ¹⁹⁶ Douglas, 1992; Gillett, McMurdo, Kerruish, 2013
- ¹⁹⁷ Gabe et al, 1072 (see note 1).
- ¹⁹⁸ See Right 7(3), Code of Health and Disability Consumers’ Rights which states that “where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence”.
- ¹⁹⁹ McMurdo, Gillett
- ²⁰⁰ Alderson, 1992
- ²⁰¹ Ignasi, 2007
- ²⁰² Wolfe, 2002
- ²⁰³ Caflin, 1991
- ²⁰⁴ Beale, 2005
- ²⁰⁵ Alderson, 1990
- ²⁰⁶ Wallace, 1986
- ²⁰⁷ Von Luzau, et al 2012
- ²⁰⁸ p279
- ²⁰⁹ Schrode, 1995
- ²¹⁰ *Airedale NHS Trust v Bland* [1993] AC 789.
- ²¹¹ [1993] 1NZLR 235.
- ²¹² Gillett, Goddard, & Webb, 1995
- ²¹³ 1995, 2ILRM, p401-2.
- ²¹⁴ *Re G* [1996] NZFLR 362.
- ²¹⁵ Judgment of Fraser J p2 (see note 165)
- ²¹⁶ Thielicke, 1970
- ²¹⁷ Gillett, Honeybul et al, 2010.
- ²¹⁸ Honeybul et al, 2015
- ²¹⁹ Nussbaum, 1990.
- ²²⁰ I have explored “the pause” in several pieces of work (see eg, *Bioethics in the Clinic* above n7, Ch 12)