

# Submission to the Legislative Council Standing Committee on Legal and social issues

## INQUIRY INTO END OF LIFE CHOICES

*The aim of this submission is to show that current Victorian legislation on end of life choices is incapable of providing regulatory oversight and control. Legal principles are at times in conflict with each other, resulting in arbitrary and hypocritical medical practice, and a lack of coherent, just choices for patients in end of life care. Openly allowing doctors to sometimes end a patient's life, at the patient's informed request, will not only accord with liberal principles befitting a contemporary pluralist society such as our own, but will also treat patients more fairly, and provide the means for regulatory oversight and control.*

### 1. Introduction

In July 1996, the *Northern Territory Rights of the Terminally Ill Bill 1995* became operative. In the following nine months four terminally ill patients died under the provisions of the Act with the help of their doctor. The Act was annulled in March 1997, when federal parliamentarians passed the Commonwealth *Euthanasia Laws Bill 1996*. That Act effectively prohibits Australian territories from enacting legislation that permits ***“the form of intentional killing of another called euthanasia ... or the assisting of a person to terminate his or her life”***, but allows the making of laws regarding non-treatment decisions and the provision of palliative care, provided these laws do not sanction euthanasia.

In this paper I will not specifically focus on either *The Northern Territory Rights of the Terminally Ill Act* or the *Euthanasia Laws Act*. Rather, I will challenge a widely held assumption that underpins not only the *Euthanasia Laws Act*, but much of Australian medical law as well. This is the assumption **that a morally relevant and legally workable distinction can be drawn in contemporary medical practice between cases of euthanasia and medically assisted suicide, on the one hand, and the provision of palliative care and the withdrawal or withholding of life-sustaining treatment on the other.**

In accordance with the Terms of Reference of the Inquiry, I will focus solely on contemporaneously competent adults, able to make informed decisions regarding the end of their lives (1). I shall also in general use the term “euthanasia” to cover medically assisted suicide as well. Where necessary, I shall draw a distinction.

## 2. Ethics and Public Policy

Voluntary euthanasia and medically assisted suicide (2) are traditionally thought to offend against the view that the intentional termination of innocent human life is always morally wrong. But is it always morally wrong for a doctor to end a suffering patient’s life, at that patient’s request? Opinion polls on end of life choices show that Australian citizens hold a variety of different views on this matter, with a large majority being in favour of medically assisted dying under certain conditions. In contemporary society, people approach moral issues from different ethical, cultural and religious perspectives and arrive at different answers to ethical questions. Because these answers have their sources in different value systems, they cannot be shown to be true or false, in the ordinary sense of those terms.

This raises the question of an appropriate social and legal response. Given that there is fundamental disagreement about the morality of euthanasia how should liberal and pluralistic societies respond? Should they allow or prohibit the practice, and on what grounds?

It is now widely accepted that liberty or personal autonomy is a very important moral value and that it is inappropriate for the state to either adopt a paternalistic stance towards its mature citizens, or to restrict their freedom through the enforcement of a particular moral point of view. Decriminalization of homosexual acts between consenting adults is one of the best-known examples of relatively recent liberal legal reforms. Even though such acts may be offensive to some members of society, they ought not to be the subject of legal sanctions because they do not harm others in the relevant sense of that term. Only if one person’s action causes harm to others (or restricts their liberty) is it legitimate for the state to step in, and to bring in laws that restrict individual freedom. As John Stuart Mill put it in his famous essay *On Liberty*: “The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. ... Over himself, over his own body and mind, the individual is sovereign.” (3)

The argument from liberty or autonomy suggests that competent patients should not be subjected to unwanted medical treatment, and that those who are terminally or incurably ill and overwhelmed by suffering should be able to enlist the help of willing doctors to end their lives, *unless* it can be shown that allowing the practice will have harmful consequences for patients and society as a whole.

### 3. Refusal of Life-Sustaining Medical Treatment

Today, the moral and legal right of competent patients to decide on how their lives should end is recognised in their right to refuse unwanted medical treatments – including life-sustaining treatment (see, for example, the *Victorian Medical Treatment Act 1988*). This right had not always been granted to patients. Until relatively recently medical paternalism, fuelled by legal uncertainty, was widely believed to be the appropriate way to manage a patient's end of life. Doctors rather than patients decided when it was time to discontinue treatment; and some doctors even believed that they had a professional responsibility to prolong life as long as they could. Even dying patients were, for example, resuscitated against their clearly stated and recorded wishes (4); and, in a prominent 1986 Victorian case, doctors refused to honour a competent quadriplegic man's wishes to be taken off a ventilator. (5)

The following 1988 case also happened before the passing of the *Victorian Medical Treatment Act 1988*. Both cases were important mile stones in the development of moral and legal thinking in Victoria on non-treatment decision.

#### **Mrs N**

When Mrs N (6) was admitted to St. Vincent's Hospital in Melbourne, she had breathing difficulties and was put on a respirator to sustain her life. Nurses reported that Mrs N had repeatedly expressed the wish to have the ventilator withdrawn. Following consultations with a psychiatrist and the hospital's ethicist, Nicholas Tonti-Filippini, it was agreed that Mrs. N's wish should be respected, and she was told that her distress during the dying process would be managed. The ventilator was "gradually turned down while the oxygen level was increased. "Mrs. N. remained conscious for six hours and, in the seventh hour, died from the effects of carbon dioxide retention". (7)

This is a case, where a patient's right to self-determination was respected. The ventilator that had kept Mrs. N alive, was turned down at her request and she died with the assistance of her doctor.

The Roman Catholic Church has traditionally regarded the intentional termination of (innocent) human life as morally wrong. Given that Mrs. N. died in a large Melbourne Catholic Hospital, and with the approval of the hospital's resident ethicist, confirmed to other doctors and other institutions that discontinuation of life support, at a competent patient's request, was in accordance with traditional Catholic moral thinking and therefore not a case of euthanasia. As Nicholas Tonti-Filippini noted in 1994: "No one criticized our actions. No legal challenge was made." (8)

Whilst the *Victorian Medical Treatment Act 1988* has subsequently resolved much of the previous legal uncertainty, some troubling problems persist. I will discuss these problems in Section 4.

## 4. Palliative Treatment

It is now also widely accepted in the medical and general community that patients should receive adequate pain and symptom control even if this might hasten death. The *Victorian Medical Treatment Act 1988* seems to endorse this when it speaks of the desirability of dying patients receiving "maximum relief from pain and suffering".

Palliative care forms an important part of end-of-life care, but moral disagreement and legal uncertainty persists as to whether a moral and legal distinction can always be drawn between accepted palliative care practices and euthanasia. If such a distinction cannot satisfactorily be drawn, one would expect to find inconsistent practices in medical end of life care, inconsistent treatment of patients; and tensions and/or inconsistencies in existing laws that prohibit the intentional termination of life, but support "maximum relief from pain and suffering".

This raises the following question:

**a. What distinguishes "intentional killing of another called euthanasia" from other permissible end of life decisions?**

The distinction between euthanasia and lawful end of life decisions is frequently thought to rest on the distinction between actions and omissions. But, both morally and legally, it has been recognised that killings may not always involve an action – some omissions may also amount to killings, such as a parent deliberately not providing food to a child, thus starving the child to death. On the other hand, some actions do not involve killings. If the distinction between euthanasia and non-treatment were simply to rest on the actions and omissions distinction, then the withdrawal of treatment (an action) would mean that a doctor who, for example, takes a patient off a respirator kills the patient or practises euthanasia, whereas a doctor who does not put a patient on the respirator in the first place, merely allows her or him to die. This would not make good sense, and is not how euthanasia has traditionally been distinguished from other permissible end of life decisions.

Doubts can also be raised with regard to understanding the difference between euthanasia and the foregoing of life sustaining treatment in terms of the distinction between causing and not causing death. On this view, a doctor who administers a non-therapeutic lethal injection is assumed to be causing death and killing the patient, whereas a doctor who discontinues life-support is assumed to merely allow the patient to die by “letting nature take its course”. Again, this view is problematical. It rests on an over-simplistic understanding of causation. One can cause death by killing or by allowing to die. If this were not the case, how could it be that a patient dies when, say, a ventilator is turned off, but stays alive when life-support is continued? (9)

But sophisticated defences of a distinction between permissible and impermissible end of life choices have never relied solely on the distinctions between actions and omissions or causing and not causing death. Rather, such defences have traditionally relied on the Principle of Double Effect.

## **b. The Principle of Double Effect**

The Principle of Double Effect (PDE) has played a central role in traditional Catholic moral thinking. It outlines four conditions, stated in the *New Catholic Encyclopaedia* as follows:

1. The act itself must be good, or at least indifferent.

2. The agent may not positively will the bad effect but may permit it. If he could attain the good effect without the bad effect he should do so. The bad effect is sometimes said to be indirectly voluntary.
3. The good effect must flow from the action at least as immediately (in order of causality, though not necessarily in order of time) as the bad effect. Otherwise the agent would be using a bad means to a good end, which is never allowed.
4. The good effect must be sufficiently desirable to compensate for the allowing of the bad effect. In forming this decision many factors must be weighed and compared, with care and prudence proportionate to the importance of the case ... (10)

The PDE is easy to state, but difficult to explicate fully in the context of a relatively short submission. Suffice it here to note the following:

As the term “Principle of Double Effect” suggests”, one action can have more than one effect. For example, abiding by a patient’s request to discontinue life-support, a doctor is not only respecting the patient’s wishes and abiding by the law, but also plays a role in the subsequent death of the patient. Similarly in palliative care. Adequate palliation may render the patient comfortable (a good outcome), but may at times result in the patient’s death (a bad outcome).

According to the Principle of Double Effect, a potentially life-shortening action is bad or impermissible if it is directly intended to bring about death, but permissible if it is, other things being equal, a foreseen but unintended consequence of providing adequate pain and symptom control to suffering patients.

The role the Principle of Double Effect and the notion of “intention” play in law is not identical to that played in traditional Catholic thinking. But the PDE and the distinction between what a patient and doctor “directly intends” and what she “merely foresees” still occupies an important place in medico/legal thinking on palliative care.

### **c. Terminal Sedation**

In terminal sedation patients are rendered unconscious until death occurs, through the administration of large doses of sedatives. It constitutes what is sometimes described as a last-resort measure to extreme, otherwise

unrelieved suffering. Typically, terminal sedation is coupled with the decision to discontinue life-support, including hydration and nutrition.

The debate about terminal sedation is far from settled. There is uncertainty in the medical community about the very meaning of the term, about whether and if so when terminal sedation is appropriate, and about the conditions under which one measure or another would be morally and legally justified. (11) The reference in the Victorian *Medical Treatment Act 1988* to the desirability of dying patients receiving “maximum relief from pain and sufferings is not helpful here. A central reason is that doctors are prohibited by law to intentionally end a patient’s life. And providing “maximum relief from pain and suffering” may, at least sometimes, amount to just that: the intentional termination of life, or euthanasia. Terminal sedation is a case in point.

Terminal sedation consists of a coming together of two potentially lethal measures – terminal sedation itself, and the decision to forego life-sustaining treatment including hydration and nutrition. The patient is firstly rendered unconscious, and then – unable to eat and drink by herself – is not being provided by doctors with life-support, such as hydration and nutrition. For some doctors and other commentators it means that palliative care has clearly strayed into the territory of euthanasia. The two actions – terminal sedation and the subsequent withholding of nutrition and hydration – are not merely “allowing nature to take its course”. Rather, the act of rendering the patient unable to take food and fluids by herself, and doctors then not providing nutrition and hydration sets in train a causal chain of events that will inexorably lead to the patient’s death. It amounts, in my view and that of others, to the intentional termination of life, or euthanasia. (12)

If this is correct, the practice of providing “maximum relief from pain and suffering”, thought desirable by the Victorian *Medical Treatment Act 1988*, by patients, and doctors is at least sometimes incompatible with existing laws that prohibit doctors from intentionally ending a patient’s life.

To avoid this conclusion, it might be thought that it should be legally incumbent on doctors to at least provide hydration and nourishment to terminally sedated patients; but this would be a rather strange requirement to impose. Once the decision has been made to totally sedate a patient until death occurs, why institute measures that might prolong the patient’s state of unconsciousness? I can see no rational reason for this; a requirement to provide life-sustaining treatment under these circumstances would be

senseless and of no benefit to the patient. It would merely serve to pay lip-service to the principle that it is never permissible for doctors to intentionally hasten death.

#### **d. The agony of agonal respiration**

I want to mention one other area, where the desire of doctors to prevent unnecessary suffering clearly strays into the prohibited area of the intentional termination of life. Some writers thus advocate the use of muscle relaxants when an already totally or terminally sedated patient from whom ventilation has been withdrawn enters “a prolonged gasping phase” to avoid what they call “the agony of agonal respiration”.<sup>(13)</sup> Given that it cannot be ruled out, they say, that “the intense muscle contraction of the prolonged gasps” can still be experienced by the sedated patient, the use of muscle relaxants is defensible under the rules laid down in the Principle of Double Effect. <sup>(14)</sup>

When muscle relaxants are administered, the patient cannot breathe and therefore not gasp and will die as certainly as she would if she were being smothered. <sup>(15)</sup>

Following criticisms of their applying the PDE to this practice, the writers respond that administering a muscle relaxant need not be seen as “killing”; rather it could also be described in terms of, for example, “benefitting the patient (by relieving suffering)”. If the action were described as killing, they say, “this would make it a type of euthanasia or murder”; and if it were thus described, doctors would [have to] “stand by the bedside until their dying patient takes their last gasp. We see no reason why patients or their families should be required to bear this burden once the patient has chosen to withdraw respiratory support and death is imminent.” <sup>(16)</sup>

Many patients, their loved ones and doctors will agree with the conclusion – but not with the way it is being arrived at. Redescribing actions in terms that make them morally or legally acceptable is hiding what is actually being done under the fig leaf of alternative descriptions. <sup>(17)</sup> Using a muscle relaxant to aid a dying patient’s passing, or withholding hydration and nutrition from terminally sedated patients might be good patient-centred medical practices, but it is difficult to argue that they are not also a cases of the intentional termination of life, or euthanasia.

### **e. Non-treatment decisions and palliation**

In the past, the Principle of Double Effect has also played a role in deciding the morality and to some extent the legality of non-treatment decisions. It was thus assumed that it was legitimate for patients to refuse “extraordinary” or “burdensome” life-sustaining treatments, but not “ordinary”, “simple” or “non-burdensome” treatments. When a patient refused an “ordinary” treatment necessary to sustain life, for example, he was – other things being equal - assumed to intend his death, or to commit suicide; and a doctor knowingly assisting him, was assumed to assist a suicide.

The *Victorian Medical Treatment Act 1988* has somewhat clarified the legal situation. Rather than relying on the ambiguous and largely unworkable distinction between ordinary and extraordinary means of treatment in the context of the PDE, it affirms that patients have a right to refuse all unwanted medical treatments. Moreover, and this is important – the *Act* must also assume that doctors who act in accordance with their patients’ request are not assumed to be assisting in a suicide.

In other words, the *Act* has replaced the traditional emphasis on the slippery notion of patients’ and doctors’ intentions, with the substantive notion of the patient’s consent, or the right to refuse life-sustaining treatment.

#### **i. Patients’ refusal of palliative care in general**

However, not all problems have been resolved, particularly in areas where refusal of treatment overlaps with the provision of palliative care. According to the *Medical Treatment Act 1988* patient’s consent or his right to refuse unwanted medical treatments is the key in non-treatment decisions, but the provision of palliative care is excluded in the *Act* from the definition of “medical treatment”. This suggests that patients have no right to refuse palliative care, and that doctors have, according to the *Act*, an obligation to provide “reasonable medical procedures for the relief of pain, suffering and discomfort...” Again, it is difficult to see a valid reason for this. Palliative care is a medical treatment and if a patient competently decides that she does not want it, she should be able to refuse it. Even if others regard such a decision as foolish, those who might want to do it, should have the right to make that choice.

Should patients also have the right to request particular palliative treatments? Whilst cost factors may make particular treatments unavailable as a matter of public policy (in the same way that other untested or very expensive medical treatments are not made available to all patients who might benefit from them), patients should not be denied a choice of treatments on the basis of their doctor's or the treating institution's moral beliefs and values.

But this is where a problem presents itself: Unlike the refusal of medical treatments, palliative care is not based on patients' rights but on the Principle of Double Effect and on the intentions of doctors and patients. The case of Mrs. N will once again serve as an example of this:

Mrs. N was assured that her distress during the dying process would be managed. Mrs. N died in a Catholic Hospital, and at the time even the withdrawal of the ventilator was justified on the traditional PDE grounds that Mrs. N "had no moral obligation to endure treatment which she found *extraordinarily burdensome*" (18) (Condition 4 of the PDE), with her death being merely a foreseen consequence of her refusal (Conditions 1, 2, 3 of the PDE). Given that the refusal was thus deemed permissible under the Principle of Double Effect, it was also deemed appropriate to provide palliation. But what *kind* of palliation?

Patients may not share the values and beliefs of their doctors. Some doctors do not, for example, believe that terminal sedation is a morally acceptable practice. This means that certain patients – those who would want it and benefit from it – will not have access to it. I do not know the answer, but wonder whether Mrs. N., for example, was asked whether she would want to stay conscious for as long as possible when the ventilator was withdrawn, or whether she would prefer terminal sedation? Regardless of whether or not Mrs. N was or was not asked, some dying patients will undoubtedly be palliated in ways that are not of their choosing, and that they may be regarded as undignified. No doctor should be required to act in ways that she or he regards as morally reprehensible; by the same token, however, no patient should die in ways that will impose indignity and suffering on him, for the sake of upholding the moral beliefs of doctors. Doctors and institution, unwilling to provide accepted palliative measures, should therefore be legally obliged to make their position clear, prior to admitting patients.

## ii. Patients' refusal of food and water

The *Medical Treatment Act 1988* also classifies the “reasonable provision of food and water” as “palliative care”. This suggests that patients who deliberately stop eating and drinking to hasten their death are embarking on a course of suicide, and that doctors who assist them through the provision of palliative care, for example, are assisting in the suicide. (19)

Patients are free to reject life-sustaining treatments on the grounds that they derive no benefit from them, without being regarded as suicidal. Why not apply the same reasoning to the refusal of food and fluids: whilst eating and drinking would prolong life, seriously ill patients can at times see no value in prolonging a life that offers only prolonged pain and suffering.

Honouring a patient's decision to stop eating and drinking requires cooperation from doctors and other members of the health care team. The effects of dehydration and lack of nourishment can be distressing; and dying can take several days, to a few weeks, depending on the patient's medical condition, metabolic functioning, and so on. (20)

As it stands, the Victorian *Medical Treatment Act 1988* would not seem to permit this. Doctors who provide palliation to a patient who deliberately stops eating and drinking, would on a plausible reading of the *Act* be providing assisted suicide.

## 5. From Doctors' Intent to Patients' Consent

The above discussion has shown, I think, that there is an inconsistency between the principles that govern contemporary palliative care practices and the legal prohibition of medically and euthanasia. It has also shown that the Principle of Double Effect and the distinction between what patients and doctors “directly intend” and what they “merely foresee” is not an appropriate basis for public policy and the law.

Roger Hunt, a medical practitioner who has pioneered hospice and palliative care in South Australia, comes to somewhat similar conclusions, arriving at them from the perspective of a practising palliative care physician. He argues that the Principle of Double Effect rests on an implausibly narrow notion of intention and fails to recognise the philosophical and psychological complexity of clinical intentions. Those involved in the care of dying patients can, and

often do, act with a wide range of intentions. Palliative care and euthanasia are not, he suggests, distinct practices; rather they lie on a continuum of end-of-life decisions, where some forms of palliative care might be described as cases of “slow active euthanasia”. There is not, Hunt continues, a clear dividing line separating permissible end of life decisions from impermissible ones; the continuing belief in the existence in such a line does, however, stand in the way of good patient care. It will foster and reinforce self-deception, secrecy and isolation, undercut professional responsibility, and may lead to the abandonment of patients when patients are most in need. (21)

These comments by Roger Hunt, and others need to be taken seriously. It would be wrong in my view for legislators to allow the divisions and confusion that result from appeal to the Principle of Double Effect in palliative care to continue. Rather, as in the case of non-treatment decisions clarified in the Victorian *Medical Treatment Act 1988*, the legal focus should shift from the doctor’s intent to the patient’s right to competently decide what kind of palliative care is appropriate for him or her. Whether we describe such decisions as medically assisted suicide, euthanasia, or palliation is of but secondary importance. What matters is that medical end of life decisions meet the patient’s need of patients, accord with the different moral values and beliefs of patients.

### **a. Public opinion and what practising doctors think and do**

Opinion polls have shown that there is increasing public support for euthanasia. It currently stands at around 80%.

A number of Australian surveys have shown that a considerable number of doctors support and practise both voluntary and non-voluntary euthanasia, and medically assisted suicide. A 2008 survey of Victorian doctors, for example, showed that 35% of those surveyed have administered drugs with the intention of hastening death, at the request of patients. (22)

### **b. Patients**

Patients sometimes take matters into their own hands. Rather than face to prospect of a prolonged dying process they will buy drugs, such as Nembutal, on-line or whilst overseas. These drugs will provide a quick and peaceful death, in some ways akin to terminal sedation. Other desperately ill people will take

less reliable prescription drugs in large and what they hope are lethal doses; or they inhale a lethal gas, such as Helium (from cylinders usually sold for filling party balloons), and nitrogen. Yet others will travel to Switzerland, where they can, under certain conditions, receive lawful aid in dying.

In short, empirical evidence makes it clear that existing prohibitive laws are not being observed and that but scant attempts are being made to persecute doctors who provide a dignified death to seriously ill and suffering patients, or members of the public who take matters into their own hands.

Would it not be better to allow patients to openly and lawfully request aid in dying from doctors willing to provide it - aid that does not rely on the unworkable distinction between the intentional and merely incidental termination of life, but focuses on the patient's needs and his or her consent?

### **c. Other countries**

An increasing number of countries and American states have recognised that the time for law reform has come. They have laid down frameworks that will, under clearly defined circumstances, allow doctors to provide assisted suicide and/or euthanasia to patients:

Belgium, Colombia, Luxembourg, Montana, The Netherlands, Oregon, Vermont, and Washington State. The next country to legalise direct medical assistance in dying is likely to be Canada.

Would it even be possible for the State of Victoria to enforce laws that prohibit doctors who take the right to self-determination of suffering patients seriously? I cannot see how this could successfully be done without such laws detrimentally affecting end of life care.

## **6. Conclusion**

For the purposes of public policies and laws governing palliative care decisions for competent and informed patients, we should stop asking whether a doctor or patient “intends” death or “merely allows it” to occur, whether death comes

as a result of one measure, or the omission of another; a slow-acting therapeutic drug, or a fast-acting non-therapeutic one. While some of these distinctions have moral relevance in the context of some religious or moral views, they are not a proper basis for end of life decisions for competent patients. What is needed is a framework that does not rely on the largely unworkable notion of intention, but on the substantive notion of respect for the autonomous choices of patients, which finds expression in the procedural requirement of consent.

Under such a framework, patients and doctors would be free to jointly and openly decide on a mode of dying that best meets the needs of particular patient. For many patients this would involve foregoing life-sustaining treatment and acceptance of palliative care. But for some patients this would also involve the open and intentional termination of life, in acts euthanasia and medically assisted suicide.

Even if the *Northern Territory Rights of the Terminally Ill Act* was not a perfect legal instrument, the *Commonwealth Euthanasia Law Act* is wrongheaded in forbidding Territories to enact laws that allow “the form of intentional killing of another called euthanasia...or the assisting of a person to terminate his or her life.” The moral distinctions that the *Commonwealth Euthanasia Act* is seeking to enforce are, as I have tried to show, not only impossibly hard to codify in public policies and laws, but are also expressive of a non-liberal approach. It seeks to enforce one particular moral vision on even those who do not share it. While the Commonwealth Euthanasia Act has no bearing on Victorian state law, Victorian law shares with the Act the erroneous presupposition that a clear and legally unproblematic line can be drawn between “euthanasia” and palliative care.

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## References:

(1) This means that I will not discuss advance directives by patients executed whilst competent, to govern medical decision-making at a future time when they may no longer be able to decide for themselves. Advance directives pose very serious and different moral and legal issues in their own right. These issues have not satisfactorily been resolved in existing Victorian legislation. I would strongly recommend that they be the subject of a new, separate Parliamentary Inquiry, subsequent to the present one.

(2) Voluntary euthanasia is understood here as the deliberate and intentional ending of an incurably or terminally ill informed and competent patient's life, by a doctor, at that patient's request. Medically assisted suicide is understood as palliative and other assistance rendered by a doctor, when a patient has decided to bring about his death by refusing treatment, or by refusing food and drink.

(3) John Stuart Mill's essay "On Liberty" is reprinted in many different anthologies.

(4) See the case described in Helga Kuhse: "Active and Passive Euthanasia", *Social Development Committees First Report on Inquiry into Options for Dying with Dignity – Incorporating a Discussion Paper: A Range of Views on Options for Dying with Dignity*, March 1986, Government Printer Melbourne, pp. 94-95.

(5) For a description of the case, see Nicholas Tonti-Filippini: "Withdrawing Ventilation at a Patient's request", in Helga Kuhse (ed): *Willing to Listen – Wanting to Die*, Penguin Books, 1994, pp. 172 ff.

(6) *ibid*, pp. 176 ff.

(7) *ibid*, p. 180.

(8) *loc.cit*

(9) A more sophisticated way of attempting to distinguish killing from allowing to die is to distinguish between an agent initiating a causal process that will lead to death (such as administering a lethal injection) and not intervening in a "natural" causal chain that also leads to death, *unless* the agent intervenes – as would be the case if a doctor does not put a patient on life support, or takes him off.

I have argued elsewhere that this distinction does not work, and have decided against including these lengthy and intricate arguments here. See Helga Kuhse: *The Sanctity of Life Doctrine in Medicine – A Critique*, Oxford University Press, 1987, Chapter 2.

(10) Catholic University of America, New Catholic Encyclopaedia, Vol. 4, New York: McGraw Hill, 1976, pp. 1120-22.

(11) See Torbjørn Taennsjo (ed.): *Terminal Sedation: Euthanasia in Disguise?*, Kluwer Academic Publishers, 2004; Molly S. Olsen et al. "Ethical Decision Making with End-of-Life Care: Palliative Sedation and Withholding and Withdrawing Life Sustaining Treatments", *Mayo Clinic Proceedings*, 2010 October; 85(10): 949-954. Johannes J.M. van Delden: "Terminal Sedation: source of a restless ethical debate", *Journal of Medical Ethics*, 2007, April, 33

(12) See Helga Kuhse: "Why Terminal Sedation is no Solution to the Voluntary Euthanasia Debate", in Torbjørn Taennsjo (ed): *Terminal Sedation: Euthanasia in Disguise?*, ibid, pp. 57 – 70. Johannes J.M. van Delden: "Terminal sedation: Sources of a restless ethical debate", op. cit., and other contributors to Tjorboern Taennsjo's above collection.

(13) R.M. Perkin and D.B. Resnik: "The agony of agonal respiration: is the last gasp necessary", *Journal of Medical Ethics*, 1992, vol. 28, pp. 168-9.

(14) R.M. Perkin and D.B. Resnik: "Response to Kuhse", *Journal of Medical Ethics*, 2002, Vol. 28, pp. 273-4, at p. 273.

(15) Helga Kuhse: "Response to R.M. Perkin and D.B. Resnik: "The agony of trying to match sanctity of life and patient-centered medical care". *Journal of Medical Ethics*, 2002, Vol. 28, pp. 270-272. See also L. Hawryluck "Neuromuscular blockers – a means to palliation?", *Journal of Medical Ethics*, 2002, Vol. 28. Pp. 170-2.

(16) R.M. Perkin and D.B. Resnik: Response to Kuhse", op. cit, p. 273.

(17) The descriptions of actions are flexible and it is often not clear where the line between an action and its consequences are to be drawn. An example by the British philosopher Jonathan Glover will illustrate the point:

"when we are on a desert journey and I knowingly use all the drinking water for washing my shirts, my act may be described as one of 'washing shirts', or 'keeping up standards even in the desert', and our being out of water may be thought of as a [merely] foreseen [but not directly intended] consequence. But it is at least equally acceptable to include the consequence in the description of the act, which may then be described as one of 'using up the last of the water' or of 'putting our lives at risk'." Jonathan Glover: *Causing Death and Saving Lives*, Harmondsworth, Penguin Books, 1977, p. 90.

The flexibility of descriptions is of obvious relevance to the palliative care/euthanasia debate.

(18) See Nicholas Tonti-Filippini, op. cit, pp. 183-85.

(19) Timothy E. Quill, MD, and Ira R. Byock, MD, for the ACP-ASIM End-of-Life Care Consensus Panel: "Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids", *Annals of Internal Medicine*, Vol. 132, No. 5, 7 March, 2000, p. 410.

(20) loc.cit.

(21) Roger Hunt: "Palliative Care – the Rhetoric Reality Gap", in Helga Kuhse: *Willing to Listen – Wanting to Die*, op.cit., pp. 115-117. See also Johannes J.M. van Delden, "Terminal sedation: source of restless ethical debate", op. cit. , pp. 187-188.

(22) David A. Neill, C.A.J. (Tony Coady) et al: *End of Life Decisions in Medical Practice: A Survey of Victorian Doctors*", *Journal of Medical Ethics*, 2007, Vol. 33, pp. 721-725.

See also Helga Kuhse, Peter Singer, Peter Baume et al: "End of Life Decisions in Australian Medical Practice", *Medical Journal of Australia* 166 (17 February 1997: pp. 191-196. Peter Baume and Emma O'Malley: *Euthanasia: attitude and practices of medical practitioners*", *The Medical Journal of Australia*, Vol. 161, 18 July, 1994, pp. 137-144.

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