WHY DO I HAVE TO KEEP WAKING UP?

TERMINAL SEDATION AND THE LAW IN AUSTRALIA

Kieran Tapsell*

Abstract

Terminal sedation is a medically induced coma from which the patient does not recover. Professional guidelines for palliative care restrict its use to within a few days of death. The law relating to its use in Australia is governed by the law of homicide, assisted suicide and the law of trespass. In this article, I argue that the law in Australia does not justify the restrictions on its use imposed by the professional guidelines, and that, ethically and legally, it can be made available to patients with a terminal disease, those who are likely to suffer serious physical or existential pain by remaining conscious, and for those who refuse food and water. Its use should be regulated to ensure that those asking for it are competent to do so, and that they are suffering from a medical condition that makes life for them intolerable.

Keywords: terminal sedation, palliative care, palliative sedation therapy, continuing deep sedation, euthanasia, homicide, assisting a suicide, trespass, autonomy.

Background

In 1991, a friend was dying from pancreatic cancer. He wanted to die at home, and as I was shortly going overseas I went to say goodbye to him. On his chest, he had a morphine box whose button he could press to give himself more, but not enough to overdose. He said to me: 'I am dying, but I keep waking up. What wakes me up is the pain. Why do I have to keep waking up?' Over the years, I have heard of similar experiences from others who watched family and friends dying. Doctors are regularly using drugs to put patients into induced comas for head injuries and burns for better medical management. It also has the other effect of saving them from the suffering that they would otherwise endure.¹

Terminal sedation is a specific form of an induced coma at the end of life. It is sometimes called palliative sedation therapy ('PST') or continuous deep sedation ('CDS'). These terms appear in some citations below, and, for the purposes of this article, are interchangeable.² The increasing public support for some form of assisted dying is an indication that many do not want to go through the drawn out suffering that they have observed in their loved ones in the last stages of a terminal disease.³

---

¹ Maryam M Shanechi et al, (2013) 'A Brain-Machine Interface for Control of Medically-Induced Coma', PLOS Computational Biology, 10.

² According to one study, there are 50 different terms to describe the medical intervention with some differences between them: Robert Twycross, 'Reflections on palliative sedation', (2019) Palliative Care, Research and Treatment, 1. Terminal sedation for the purposes of this article means Palliative Sedation Therapy as defined below by the Australian and New Zealand Society of Palliative Medicine.


* LL.B (Hons) (Syd), Solicitor and Barrister of the Supreme Court of New South Wales (1973-2013). An edited version of this article has been published in the Journal of Law and Medicine (2019) 27 JLM 178.

An edited version of this article has been published in the Journal of Law and Medicine (2019) 27 JLM 178.
The limitations on the use of terminal sedation in the various palliative care guidelines discussed below are difficult to understand legally and ethically. An advance care directive cannot force doctors to do something with which they do not feel comfortable, or that they believe might lead them to front a medical disciplinary board. If those guidelines are based on a misunderstanding of the law and unconvincing ethical arguments, they need to be reconsidered and rewritten.

Professional Restrictions on the Use of Terminal Sedation

The Australian and New Zealand Society of Palliative Medicine (‘ANZSPM’) defines PST as: ‘Palliative Sedation Therapy (PST) is the monitored use of medications to lower a patient’s awareness in order to provide relief of symptoms that are refractory to usual measures, are distressing and result in considerable suffering if unrelieved.’ It considers that ‘PST should be an important and necessary approach in selected patients with life limiting illness with refractory symptoms, and this is aligned with the European Association for Palliative Care (EAPC) framework and recommendations.’

According to the EAPC, terminal sedation, described by it as ‘continuous deep sedation’ (CDS) is said to be an 'extraordinary' measure: 'Continuous deep sedation should only be considered if the patient is in the very terminal stages of their illness with an expected prognosis of hours or days at most.’ The Joint Select Committee on End of Life Choices of the Western Australian Parliament, (‘My Life, My Choices’), accepted expert evidence that it was only used in order to relieve otherwise intractable suffering within the last 24 to 48 hours of life.

The EAPC framework further says: 'Although there are data indicating that palliative sedation does not hasten the death of patients overall, a small risk of hastened death for individual patients exists (through respiratory depression, aspiration or haemodynamic compromise). The EAPC gives no explanation as to why terminal sedation should be considered 'extraordinary' even in the cases where there is no such risk.

A Visit to a Palliative Care Team

In 2017, a friend in her late fifties was diagnosed with motor neurone disease (‘MND’). Her speech had become slurred, and she could no longer give classes at a university. Eventually, she could not talk, and further down the track, she could not swallow. A tube was put into her stomach so that she

---


5 ANZSPM, n 4, [1]. The EAPC recommendation prior to terminal sedation is on 'titrating doses proportionately against symptoms, maintaining awareness if possible': Twycross, n 2, 2.

6 The Board of the European Association for Palliative Care, (2009) European Association for Palliative Care (EAPC) recommended framework and recommendations for the use of sedation in palliative care, 584. <https://issuu.com/antea.associazione/docs/eapc_2009_sedazione_palliativa>.


8 EAPC, n 6, 582. Rodney Syme in 'Necessity to palliate pain and suffering as a defence to medical homicide' (2009) Journal of Law and Medicine, 443, 439, does not consider the risk to be 'small', because cardiovascular and respiratory collapse are likely to occur unless preventative measures are taken, as is the practice with induced comas for better medical management; Twycross, n 2, 8 agrees; Riisfeldt criticises the studies for the claim of non-shortening of life and is 'agnostic' about their results: 'Weakening the ethical distinction between euthanasia, palliative opioid use and palliative sedation' (2018) BMJ Medical Ethics, 1.
did not die of starvation. Then the disease affected her respiration. Her mind was very clear at all times, right to the end.

My friend accepted her fate, but expressed fear about dying by slow asphyxiation. She asked me to go along with her to see some palliative care specialists to see whether they were prepared to put her into terminal sedation at the time of her choice.

As my friend could not talk, she communicated her wishes in writing through the use of a tablet. She was aware that palliative care workers were unable to give her a lethal drug because that would amount to the crime of homicide or assisted suicide. She repeated a number of times in writing that she wanted terminal sedation at a time when she found her situation intolerable.

The four medical staff were very sympathetic, but they explained that they could only treat 'refractory symptoms.' They could provide oxygen for lack of breath and morphine and other drugs for pain, the amounts being increased ('titrated') according to her response. She could only be given terminal sedation very close to death. These views reflected the ANZSPM guidelines. 9

Any reluctance to use terminal sedation except within hours or days of death seems to derive from confusion over the line between homicide and assisting a suicide on the one hand and legally and ethically permissible palliative care on the other. 10 This confusion is apparent from the evidence given to the Joint Select Committee on End of Life Choices of the Western Australian Parliament, ('My Life, My Choices'), and it recommended clear guidelines. 11

The Western Australia branch of the Australian Medical Association ('WAAMA') explained the reluctance to use terminal sedation at an earlier time in the disease's progress: 'It is not a choice available to patients who do not need it, because then it would not be terminal sedation or palliative sedation anymore; it would be, actually, euthanasia. 12

Actually, it cannot be euthanasia understood as homicide if the treatment does not advance death. It might advance the time of death if it was given without assisted nutrition and hydration ('ANH') and in those patients at risk of complications arising from the process. However, even if it did advance death whether because of the patient's wish for no ANH or complications that might arise from the process, it is justifiable under the doctrine of double effect and the law of trespass.

Further, if terminal sedation is euthanasia, that is, homicide, then it continues to be homicide whether it is given within hours or days of death or a week or a month before it. 13 The relevant issues are whether an action advances the moment of death, and whether in refusing to eat or drink

---

9 At common law, there is no requirement to follow reasonable medical practice, but failure to do so may be seen as evidence of an intention to relieve pain by ending life which may result in criminal or disciplinary action. In Queensland and Western Australia, statutes provide that palliative care must be reasonable in the context of good medical practice: Benjamin White, Lindy Willmott and Michael Ashby, 'Palliative care, double effect and the law in Australia' (2011) 41(6) Internal Medicine Journal, , 485-492.

10 An example of differences of opinion amongst practitioners is dealt with in L Anquinet et al, 'Similarities and differences between continuous sedation until death and euthanasia - professional caregivers' attitudes and experiences: a focus group study.' (2013) Journal of Palliative Medicine, 553-561.

11 My Life, My Choices, n 7, 130.

12 My Life, My Choices, n 7, 125 [4.62];

or to be given ANH, the patient is committing suicide and in that case, the palliative care worker could be seen as assisting suicide.

The Law in Australia on the Treatment of Terminal Illnesses

The law of homicide, assisted suicide and the law of trespass to the person govern the treatment of terminal illnesses in Australia. The legal principles involve a mixture of statute and the common law, and they have been described as 'ambiguous and inconsistent'. Recent decisions of the Supreme Courts of South Australia and Western Australia have taken some of the ambiguity out of the legal situation, but the professional guidelines have lagged behind when it comes to the use of terminal sedation.

Homicide

Criminal responsibility involves both mens rea and actus reus: The actus reus in the case of homicide is advancing the time of death, and any action which does so is prima facie homicide. The mens rea is the state of mind fixed by the law that must be proved to hold the accused liable. So far as relevant to the present discussion, to be guilty of murder a person must intend to advance the time of death or know that this is the probable consequence. There are limits to what a doctor can do at the patient's request. Giving a lethal injection even with the consent of the patient is still homicide.

Assisting a Suicide

Anyone who assists a person to commit suicide, whether by providing them with a lethal dose or any other means, commits the crime of assisting a suicide.

The Doctrine of Double Effect

The doctrine is the invention of the 12th century philosopher, St Thomas Aquinas. It provides that if an action has two effects, one good (relief of pain) and one bad (death), so long as the intention is to achieve the good effect, then it is morally permissible because the bad effect is 'not intended' and is 'accidental'.

Deliberate killing was justified by Aquinas in the case of self-defence, just wars and capital punishment, but the doctrine of double effect does not work in those cases. The execution of a criminal is not an 'accidental' effect of defending the state. It is a deliberate act of killing for the purposes of protecting the state.
There is nothing unusual with dubious logic to draw lines in the legal sand. Fictions are used all the time in law: a horse is a motor vehicle for the purposes of some Motor Traffic Acts; the age of consent is based on the assumption that young people are emotionally incapable of consenting to sex before they turn 16, but become capable on their 16th birthday and thereafter. For practical reasons, a line is drawn in the legal sand at 16 years. The doctrine of double effect used in the law of homicide is another example of that kind of device. Let me explain.

Laws generally draw a distinction between an intention to kill and recklessness as to the consequences of one’s actions. Sometimes recklessness is included in the definition of intention, and sometimes not. Recklessness as to the consequences of one’s actions is not the same as intention under the Queensland Criminal Code.\(^\text{21}\) Intention includes recklessness in the Commonwealth of Australia Criminal Code which provides: ‘A person has intention with respect to a result if he or she means to bring it about or is aware that it will occur in the ordinary course of events.’\(^\text{22}\) At common law, a person is guilty of murder if he or she intends to cause death or is aware that it will probably follow from their actions.\(^\text{23}\)

If medical treatment cannot restore the health of terminally ill patients, relieving them of pain and suffering is permissible even if the effect is to hasten death, because the law deems there to be no mens rea, an intention to kill or recklessness, and the death is an accidental result of relieving the pain.\(^\text{24}\) Several expert witnesses at the My Life, My Choices hearing expressed the view that the doctrine of double effect has no relevance to terminal sedation because it does not hasten death.\(^\text{25}\) If there is no causation, there is no actus reus. This has to be correct where terminal sedation does not advance the time of death. The doctrine of double effect only comes into play in those cases where terminal sedation creates a risk of hastened death, and the risk occurs. Death then becomes an unintended or accidental effect under the doctrine of double effect in the same way as when the patient is given increasing doses of pain killing drugs.\(^\text{26}\)

A doctor who gives a lethal dose to a patient can also have the primary intention of relieving the patient of pain.\(^\text{27}\) A stark example can be found in R v Cox, where Dr Cox prescribed potassium cyanide (which rapidly causes death) for a patient with chronic pain who refused any further heroin

\(^{21}\) Zaburoni v The Queen (2016) HCA 12 (6 April 2016). In that case, the High Court held that under the Criminal Code 1899 (Qld) recklessness regarding the transmission of the HIV virus by unprotected sex was not to be understood as intended. ‘The (Queensland) Code is distinguished from its Commonwealth counterpart, which allows that a person has intention with respect to a result if the person is aware that the result will occur in the ordinary course of events.’ (Keifel CJ, Bell and Keane JJ) 14.

\(^{22}\) Criminal Code Act 1995 – Schedule The Criminal Code s 5.2(3). The Code also has a definition of 'recklessness': where there is a 'substantial risk' of something and taking the risk is not justified: s 5.4.

\(^{23}\) R v Crabbe (1985) 156 CLR 464.

\(^{24}\) R v Adams [1957] Crim LR 365. Legislation in Queensland, Western Australia and South Australia create defences which are generally more limited than the common law principle: White, Willmott and Ashby n 9, 485-492.

\(^{25}\) My Life, My Choices, n 7, 134. This view is supported by Alexander de Graeff and Mervyn Dean 'Palliative sedation therapy in the last weeks of life: a literature review and recommendations for standards,' Journal of Palliative Medicine (2007) 10:67-85.

\(^{26}\) Lars Johan Materstvedt, Intention, procedure, outcome and personhood in palliative sedation and euthanasia, (2012) 2 BMJ Supportive & Palliative Care, 9.

\(^{27}\) Niklas Juth et al 'European Association for Palliative Care (EAPC) framework for palliative sedation: an ethical discussion', (2010) 9 Biomedical Central Palliative Care, 49, 3; Tur, n 13, 228; Syme, n 8, 446-448; Materstvedt argues that there is an ethical difference because euthanasia and terminal sedation, because in the former, the intention is to stop the suffering by death and in the latter to relieve it by unconsciousness. Any foreseeable complications leading to death by terminal sedation are covered by the doctrine of double effect: Materstvedt n 26, 9.
treatment for pain. He was convicted of attempted murder.\textsuperscript{28} His crime could be seen as providing his patient with the wrong drug that worked too quickly. If he had given her increasing doses of heroin leading up to an injection that caused her death, he would not have been convicted.\textsuperscript{29}

That is where the whole area becomes conceptually slippery, because the higher the probability of death with titrated pain medications or with terminal sedation, the harder it is to say that there is no intention to cause death or at least recklessness about that result, either of which is sufficient for a charge of homicide under any statutory or common law formulation.

The doctrine of double effect makes sense where death is a possible or even probable result of an action, but it is highly artificial when the death is certain to occur. If doctors know that the next dose of pain killing medications will be lethal, even though their intention is also to relieve pain, it is artificial to suggest that they do not intend the death or were not at least reckless as to its happening. Indeed, leaving aside the doctrine of double effect, an act done, knowing that the death is certain or highly likely to occur, is enough for a charge of homicide whether under the formulations in the Queensland Code, the Commonwealth Code or at common law. The doctrine of double effect creates an exception to that general rule by means of a fiction that there is no intention to kill and no recklessness. It is a fiction that gives some comfort to doctors by providing ‘moral distance’ from the result which they know will occur.\textsuperscript{30}

The artificiality of the doctrine was recognized by the Medical Board of Australia in ‘Syme’s case’.\textsuperscript{31} The Medical Board described the doctrine of double effect as: ‘a concept which conceptually and practically raises acute difficulties within the medical profession.’\textsuperscript{32}

Juth et al say that the controversies over terminal sedation cast doubt on whether the doctrine of double effect is a ‘plausible principle at all.’\textsuperscript{33} Others have described it as ‘a piece of complete sophistry’, and as being ‘artificial and indeed Jesuitical’.\textsuperscript{34} It is artificial when death is certain to occur, but so is calling a horse a motor vehicle and deeming all young people capable of consenting to sex only on their 16th birthday.

Despite the artificiality, the doctrine of double effect is the line in the legal sand, and it is reflected in the \textit{ANZPMS}'s Position Statement on Euthanasia: ‘Treatment that is appropriately titrated to relieve symptoms and has a secondary and unintended consequence of hastening death, is not euthanasia.’\textsuperscript{35} It is also reflected in the \textit{AMA} Position Statement on Euthanasia and Physician

\textsuperscript{28} \textit{R v Cox}, (1992) 12 BMLR 92. Cox was only charged with attempted murder because his patient had been cremated and there was no direct evidence that the potassium cyanide actually caused her death which might have satisfied the criterion of proof beyond reasonable doubt: Syme, n 8, 439.

\textsuperscript{29} Syme, n 8, 447.


\textsuperscript{31} \textit{Syme v Medical Board of Australia (Review and Regulation) [2016] VCAT 2150, 40 [147(e)]} (‘Syme’s case’).

\textsuperscript{32} ‘Syme's case’, n 31, 27 [85]. The conceptual difficulties are explained by Riisfeldt, n 8.

\textsuperscript{33} Juth et al, n 27, 4; Syme, n 8, 449, also states that the use of a subjective intention as the basis of criminal liability in the case of end of life matters is fundamentally flawed because it cannot be objectively measured or verified. In addition, the intentions of palliative care workers are likely to be multiple and varied, because death is often the only real way to prevent continued suffering.


\textsuperscript{35} Australian and New Zealand Society of Palliative Medicine (2017), \textit{Position Statement: The Practice of Euthanasia and Physician Assisted Suicide}, 2 [6].
Assisted Suicide: ‘All patients have a right to receive relief from pain and suffering, even where that may shorten their life.’

The doctrine is also reflected in the EAPC recommended framework for the use of sedation in palliative care:

Abuse of sedation occurs when clinician’s sedate patients approaching the end of life with the primary goal of hastening the patient’s death. This has been called ‘slow euthanasia’. Indeed, some physicians administer doses of medication, ostensibly to relieve symptoms, but with a covert intention to hasten death.

The fuzziness of the line in the sand is obvious when hastening death is permissible under the doctrine so long as the subjective intention of the doctor is not to do so. The practical problem with its application is that doctors cannot safely give an increased dose of pain killers which are likely to cause death unless they are satisfied that a lesser dose will not eliminate the pain. This means that the patient has to ask for more pain killers or show continuing distress under the previous dose, so the doctor can feel safe from the law or a disciplinary tribunal in giving the final injection. As Syme points out: “the slower the death is hastened, the more protection there is for the doctor.”

The Law of Trespass to the Person

The law of trespass to the person has existed since the 12th century. It forms the basis for consents being required or implied for all medical treatment and for the prohibition on force feeding. Any physical dealing with a person without their consent, express or implied, constitutes an assault. The law of trespass is particularly relevant to whether starving oneself to death is to be regarded as suicide, and providing palliative care either by terminal sedation or by any other means amounts to assisting a suicide.

In 1914 in *Schloendorff v New York Hospital*, Cardozo J said: ‘every human being of adult years and sound mind has a right to determine what shall be done with his own body.’ This principle has been followed in the Anglo/American legal system, including Australia. A doctor who ignores the directions of a patient not to provide treatment is guilty of assault, even if it has the effect of preserving life.
The law is clear that everyone is entitled to refuse any form of medical treatment, including ANH, even though the result is death.43 A competent individual’s right to self-determination prevails over the state’s interest in preserving life.44

The Right to Reject Food and Water

The right of terminally ill patients to starve themselves to death has been recognised for some time.45 In Nicklinson’s case, Tony Nicklinson suffered a stroke and was ‘locked in’. He was not dying and his illness was not fatal in itself. He asked the Court to declare that he had the right to have someone assist him to die. The Supreme Court of the United Kingdom rejected the application. He subsequently refused to eat, contracted pneumonia and died.46

The Court rejected the idea that anyone could help him die more quickly than by starvation. Nevertheless the principle that no one can be force fed has survived Nicklinson’s attempt to have the English court approve assisted dying.47 Decisions of the Supreme Court of Canada have also confirmed the right of anyone to refuse to eat and drink, without interference, even though that might cause death.48

Further, a number of decisions have absolved those involved in hospice and aged care centres from any liability where a patient of sound mind refuses food and drink.49 The obligations to provide care in such facilities do not entirely rely on the common law because there are also statutory provisions in different states of Australia. Despite those differences, the general principles from the cases show that ‘respecting a competent refusal will not give rise to liability’.50

In another case, H Ltd v J, J had suffered polio as a child and was a diabetic kept alive with regular doses of insulin. She informed her carers that she intended to stop eating and drinking and taking insulin. She was found to be mentally competent, and she was not being artificially fed. The carers sought a declaration as to their legal situation. The South Australian Supreme Court concluded that refusing medical treatment, food and water was an act of personal autonomy and should not be considered suicide for the purposes of the law prohibiting assistance to a suicide.51 Kourakis J said:

45 Benjamin White, Lindy Willmott and Julian Savulescu ‘Voluntary palliated starvation : A lawful and ethical way to die?’ (2014) Journal of Law and Medicine, 22, 376-386; Downie, n 40, 48-58.
48 Downie, n 40, 50.
50 White, n 45, 4.
51 H Ltd v J (2010) 107 SARS 352, [47]-[59]; ‘The legal concept of suicide, being the intentional taking of one’s own life, is not engaged in a case where medical assistance is refused, even in the knowledge of certain death,’ X v Sydney Children’s Hospitals Network [2013] NSWCA,320, [59] (Basten JA). Margaret Otlowski describes the traditional common law definition of suicide as ‘the intentional, voluntary taking of one’s own life by a person
I acknowledge that there is a difference between food and medicine. There is also a difference between the taking of food by natural means and the medical administration of nutrition. However, those differences do not appear to me to be sufficient to sustain a distinction between suicide and the exercise of the right to self-determination. Similarly, if a competent adult is entitled to refuse life sustaining products, including nutrition, and it is not unlawful to respect that wish when he or she is in a vegetative state or has a terminal illness, there is no legal principle which could allow a distinction to be made between the refusal of a person who has those conditions and a person who does not. 52

Kourakis J rejected the idea that providing palliative care would involve aiding or abetting a suicide.

Respecting the right of personal autonomy recognised by the law cannot constitute that offence. Moreover, a person who is not under a duty to prevent the commission of an offence does not aid and abet it by failing to prevent it [...] or by communicating that he or she will not act to prevent it, unless by so doing he or she, as a matter of fact, encourages the commission of the offence.

Likewise, in Brightwater Care Group v Rossiter, Martin CJ said that palliative care to alleviate distress can be provided even though the distress comes about by the patient’s own decision:

> There are a number of general principles which can be confidently stated in relation to this issue. The first is that the legal rights and obligations relating to the provision of palliative care are unaffected by the circumstance that the occasion for the provision of that care comes about as a consequence of Mr Rossiter’s withdrawal of consent to the continuing provision of other medical treatment, namely, the provision of nutrition and hydration. Put another way, Dr Benstead’s rights and obligations with respect to the provision of palliative care to Mr Rossiter if and when he directs Brightwater to discontinue the provision of nutrition and hydration are no different to the obligations which attend the treatment of any other patient who may be approaching death. 53

White et al argue that there should be no difference in principle where Jehovah’s Witnesses’ legally accepted right to refuse a blood transfusion will also cause death. They are entitled under the law to be provided with palliative care: ‘The fact of the suffering is relevant, not its origin.’ 54 Although the cases did not discuss the form of palliative care, the same principle should apply to terminal sedation, as it is an accepted form of palliative care, albeit with restrictions in the guidelines. The International Association of Hospice and Palliative Care (‘IAHPC’) accepts that palliative care should be given to patients who choose not to eat and drink:

> IAHPC recognizes that voluntary cessation of hydration and nutrition hastens death. Respecting the patient’s wishes, as we recommend, means not providing artificial hydration and/or nutrition and providing appropriate control of symptoms that may occur under such circumstances. Without food, patients may live several weeks. Without fluids, death usually occurs within a week. 55

Jox et al regard the refusal of food and drink by persons who can eat normally as suicide, and providing palliative care for them is assisting a suicide unless they are determined to continue with their fast irrespective of the unpleasant symptoms that come with it. 56 The authors are correct in saying that such persons are committing suicide in the normal meaning of that term, but in most jurisdictions, the law either creates another fiction that it is not suicide for those who have serious physical or existential pain, or if it is suicide, providing palliative care to make the process more


52 H Ltd v J (2010) 107 SASR 352, [64], and a similar decision in Re E (Medical Treatment: Anorexia) [2012] EWHC 1639, [7].

53 [2009] WASC 229, [52].

54 White n 45, 9.


56 Jox et al ‘Voluntary stopping of eating and drinking: is medical support ethically justified?’, (2017) BMC Medicine, 15, 186. It seems that the authors would regard any causal connection between the palliative assistance and the death as broken if the patient insisted on continuing with the fast. The authors seem to exclude the Brightwater situation from their definition of suicide because ‘withdrawing artificial nutrition, hydration, or ventilation, it is not a physiological everyday behaviour that is stopped but a medical treatment that technically replaces a pathologically lost organ function.’ This was a distinction rejected by Kourakis J in H Ltd v J.
comfortable does not breach the law against assisting a suicide. Andrew McGee and Franklin Miller point out that palliative care in these circumstances is not assisting a suicide because death is brought about by starvation or dehydration, and not from any palliative drug that makes that process more comfortable. 57 This jurisprudence is based on some 800 years of the law of trespass: do not touch me unless I give you permission.

The current position in Australian law is reasonably clear: those with serious medical conditions are entitled to refuse food and drink as a way of hastening death, and palliative care given to them does not involve assisting a suicide.

**Criticism of the EAPC Guidelines**

Juth et al have argued that the EAPC guidelines (which the ANZSPM has adopted) are insufficiently precise in defining what are 'refractory symptoms,' justifying terminal sedation and in defining what is or is not euthanasia. 58 In the absence of refractory symptoms, the EAPC guidelines regard the use of terminal sedation as an 'abuse'. They do not explain why. The guidelines define refractory symptoms as: 'intolerable distress due to physical symptoms, when there is a lack of other methods for palliation within an acceptable time frame and without unacceptable adverse effects.' 59

Juth et al criticise the guidelines for being unclear:

> What seems to be lacking in the EAPC framework is the very thing you expect from a guideline, namely a more thorough analysis of intolerable suffering, refractory symptoms and the relation between them: what are necessary and sufficient criteria for palliative sedation at the end of life, and why? 60

As Juth et al point out, it is difficult to see why the doctor is in a better position than the patient to decide if something is refractory, and the guidelines are not clear as to who should determine it. Further, according to the guidelines, the patient has to suffer before terminal sedation can be considered — the view put to me by the palliative care doctors in the case of my friend with MND.

> As regards physical or somatic symptoms, the most common refractory symptoms are explicitly identified: 'agitated delirium, dyspnoea, pain and convulsions. Emergency situations may include massive haemorrhage, asphyxiation, severe terminal dyspnoea or overwhelming pain crisis.' (p. 584) [4]. However, refractory existential and psychological distress as an indication for palliative sedation therapy in the end of life is considered to be so controversial as to merit 'special guidelines' (p. 588) [4], including repeated trials of intermittent therapy before continuous therapy can even be considered. 61

In other words, the patient may be required to suffer through trial and error, even with physical pain. The authors also criticize the distinction made by the EAPC guidelines between existential and physical suffering. 62 My friend with motor neurone disease was not in pain, but was unable to talk, then could not swallow and had to pour liquid food into a tube in her stomach. She was unable to share a meal with her family, had to use a vacuum pump continuously to remove saliva from her mouth, and the distances she could walk progressively decreased. She was uncomfortable with anyone other than family and very close friends visiting her. The Australian cases of Bridgewater and H Ltd v J did not draw any distinction between physical and existential suffering, and in both cases, the patient's suffering was predominantly existential.

---

57 Andrew McGee and Franklin G Miller, 'Advice and care for patients who die by voluntarily stopping eating and drinking is not assisted suicide', (2017) 15 Biomedical Central Medicine, 222.
58 Juth et al, n 27, 3.
59 Juth et al, n 27, 1
60 Juth et al, n 27, 3.
61 Juth et al, n 27, 2.
62 Juth et al, n 27, 3.
As artificial as the doctrine of double effect might be, the law has determined it as the convenient place to draw a fuzzy line between compassion and criminality. The decisions of the Supreme Courts of Western Australia in Bridgewater and of South Australia in H Ltd v J have improved the clarity of that line by determining that doctors are not assisting a suicide by providing palliative care to patients who refuse food and drink, whether consumed naturally or through ANH. Palliative care by terminal sedation for such people does not carry a risk of prosecution, but while the guidelines have a time limit on its delivery, doctors run the risk of a complaint for professional misconduct if they provide it outside those time limits.

Religion and the Guidelines

The position of religion in life and death matters has always been fundamental. Ian Maddocks, the first Australian Professor of Palliative Medicine, stated on ABC Radio RN that:

‘The roots of modern palliative care are of course to be found in religious orders concerned with the care of the dying’, and that ‘palliative care usually has adopted a confrontational position against voluntary euthanasia, partly because of the historical association with Christian (Catholic) concern to preserve life’. 63

Catholic Health Australia operates 52% of all palliative care hospital beds in Australia, with other faith based communities also providing palliative care services. 64 Ellen McGee has written: ‘Since its inception, the hospice has seen itself as a moral enterprise; it shares a vision of what constitutes “good dying”. This moral vision is unique in the secular health care field.’ 65

Alex Broom carried out a six month study in a Catholic hospice, interviewing doctors, nurses and patients. He found that virtually all patients supported assisted dying, but a desire for a hastened death was seen by the hospice as a call for help. The patient ‘just needed more time’ to adjust. In his opinion, the hospice had an ideological model of dying, based on religion. 66

In 1995, Pope John Paul II stated: ‘Euthanasia in the strict sense is understood to be an action or omission which of itself and by intention causes death, with the purpose of eliminating all suffering.’ 67 Starving or dehydrating oneself to death to hasten death to avoid suffering comes within that definition. Speaking in 2004, the same pope said that ANH is not a ‘medical act’, but a ‘natural means of preserving life’, even though it is artificial. 68 In 2007, the Church’s Congregation for the

Personal autonomy is now entrenched in the law: Review of Politics

According to the Catholic Archbishop of Sydney, Anthony Fisher, Catholic moral theology says there is a moral obligation to continue life by eating and drinking, and refusing to do so in 'ordinary' circumstances is suicide. Rather than being an assertion of self (Schopenhauer), suicide for Fisher is 'hardly the kind of gentle acceptance of God's will that opens up heaven to us.'

Catholic teaching does not require 'extraordinary' or 'heroic' measures to prolong life especially when death is imminent. Modern medicine has ensured that what was extraordinary in the past is now ordinary, and, according to the Church's teaching, one example is ANH. For Fisher, failing to provide or withdrawing ANH is murder or suicide, unless it has become 'excessively burdensome' and has 'very limited ability to prolong life or provide comfort.' When dealing with the cruelty that may arise from this, Fisher says that suffering calls forth '...much that is noble in the human spirit: patient endurance, perseverance, fortitude, even heroism, on the part of patients, doctors, families and communities...impatience (with a slow dying) can be at the heart of a decision to stop feeding.' Emphasising the religious aspect of this doctrine, Fisher quotes Cardinal Ratzinger: "The world is redeemed by the patience of God. It is destroyed by the impatience of man.'

The palliative care guidelines on terminal sedation in the context of ANH seem to be an attempt to find a compromise between two irreconcilable philosophies: the absolute prohibition of Catholic religious doctrine on suicide by starvation, and the notion of personal autonomy in the law of trespass to the person, whose origins, ironically, are in the writings of the Church's 12th century canon lawyers. Fisher accepts that personal autonomy is 'a powerful strand in contemporary culture.'

The attempted marriage between the two philosophies is not a happy one, because the EAPC and ANZSPM guidelines for terminal sedation do not accept the Catholic doctrine on ANH. Under the guidelines, a patient is always entitled to refuse ANH. At the same time the guidelines

---

70 Anthony Fisher, Catholic Bioethics for a New Millenium, (Cambridge University Press 2012), 226. Fisher relies on the 12th century canonist, Gratian who said that refusing to give food to a starving man is killing him, the corollary being that deliberately starving oneself to death is suicide. The Church has an absolute prohibition on taking human life before birth (abortion), and during the dying process (euthanasia). In between those two periods, it allows deliberate killing in self-defence, just wars and capital punishment. For reasons mentioned above (nn 19 and 20), none of these can be justified by the doctrine of double effect. The conditions the Church imposes on these three forms of deliberate killing seem to be based on consequentialist principle of the lesser of two evils – which it is unwilling to apply in the cases of abortion and euthanasia. Risfeldt argues that the same conceptual difficulties apply to the ethical distinction, based on the doctrine of double effect, between palliative care (with opioids or terminal sedation) and euthanasia. The difficulties can only be overcome by abandoning the idea that human life is intrinsically sacred: n 8, 6.
71 Fisher, n 70, 243.
72 Fisher, n 70, 231.
73 Fisher, n 70, 226.
74 Fisher, n 70, 226.
76 Fisher, n 70, 215.
preserve the worst features of the Church's doctrine by requiring a patient to suffer because of time limitations on the use of terminal sedation.

The influence of religion on palliative care is not confined to Western or predominantly Christian countries. Turkish law not only prohibits any form of euthanasia, but also lowering consciousness unless it is temporary and for curative purposes. This prohibition is based on the teachings of Sunni Islam that terminal sedation would eliminate the opportunity to worship, as well as the chance to repent of sin prior to death. An objection to terminal sedation from a Catholic perspective only arises when it is believed to be 'slow euthanasia' by the withdrawal of ANH, and not because the loss of consciousness is intrinsically evil. Terminal sedation from the Catholic perspective is an acceptable form of palliative care in cases of extreme distress so long as the disease is allowed to kill the patient.

All religious faiths are entitled to lobby for civil laws and professional standards that align with their beliefs, but in multicultural societies it is to be expected that those beliefs will not always be reflected in the laws of the land and professional guidelines.

**Non-Religious Ethical Objections to Earlier Terminal Sedation**

The limitations on the use of terminal sedation in the case of terminally ill patients to shortly before death, and as a last resort, do not seem to have any legal basis in Australia. However, some academics argue that there is an ethical basis for such restrictions.

Robert Twycross argues that terminal sedation is still ethically controversial because it ends a person's 'biographical (social) life', the ability to interact meaningfully with other people. It is for that reason, he says, 'an exceptional last resort measure and should not be considered routine or the default option'. It is hard to see how this can be an ethical objection for patients of clear mind who request terminal sedation to avoid continuous suffering. They have always had the right to opt out of interacting meaningfully with others by refusing to communicate with anyone. Contemplative nuns and monks make a lifestyle choice out of silence, and no one has ever seriously suggested that they are acting unethically. Deciding to sleep rather than going to a party is an appropriate ethical choice. Unconsciousness is ethically acceptable if done for a good reason. We practice it every night by going to sleep, we take sleeping pills to avoid sleeplessness from pain and agree to it for surgery for similar reasons.

Twycross acknowledges that 'doctors have a fundamental ethical responsibility to ease suffering.' That means that persons in pain have a right to be relieved of it where the means are available and appropriate. Any arguments about a lack of meaningful interaction with other people by being rendered unconscious are dwarfed by that fundamental right not to have to suffer, particularly when the suffering is serious.

---


79 Twycross, n 2, 3.

80 Twycross, n 2, 3.

Twycross also says that 'one purpose of the time limit is to emphasize that the intention underlying terminal sedation is the relief of suffering and not to cause death.' That gets back to the point made by Syme, that the time limit is not for the benefit of patients, but to create appearances for the protection of doctors. The EAPC guidelines may disapprove of earlier terminal sedation as 'slow euthanasia,' but from the patient's point of view, the system of titration in the guidelines could be seen as 'slow torture' because of pain killers wearing off, the need for complaints or signs of distress, and increasing doses because of more severe pain. There has to be a better way to protect doctors from criminal and disciplinary complaints than by exposing their patients to the suffering inherent in a trial and error process.

The unsatisfactory nature of the EAPC and ANZSPM guidelines is evident from the increasing public support for medically assisted dying. Twycross laments the increasing use of terminal sedation in cases which are not 'exceptional', the 'dissonance between guidelines and practice,' and the involvement of family doctors and non-palliative care specialists in treating the dying, where 'dose titration is often not the norm.' These developments are understandable given the potential for suffering imposed by the guidelines.

The Norwegian guidelines are more flexible, allowing terminal sedation for patients who are not 'dying', but have treatment-refractory symptoms. Where the patient has already stopped drinking, ANH will not be provided. There is no time limit on the time the sedation will be provided, and the guidelines can be departed from where 'necessary' after discussions at a managerial level.

My Life, My Choices

The My Life, My Choices Report of the Western Australian Parliament stated the law as found by Kourakis J in H Ltd and Martin CJ in Bridgewater. As indicated above, WAAMA's submission to the Western Australian Parliamentary Inquiry said that terminal sedation is not available to 'those who do not need it', because otherwise it would amount to 'euthanasia.' Where terminal sedation does not advance death, it cannot be euthanasia in the sense of homicide. Giving patients increasing amounts of pain killing drugs which will eventually kill them by suppressing their respiration is much closer to homicide than terminal sedation in cases where there is no or little risk of it advancing the time of death.

The key element in WAAMA's statement is deciding who is a patient 'who does not need' terminal sedation. One can understand such an objection to terminal sedation for someone who is simply depressed and wants to die. The objection falls away when the patient is suffering from a fatal illness and is going to die soon anyway. It also falls away for cases like Rossiter in Bridgewater where he was not dying of a terminal disease but found life intolerable as a quadriplegic kept alive by ANH, or like J in H Ltd v J who had multiple health problems and was kept alive on insulin, and for someone like Tony Nicklinson who is 'locked in' and finds it intolerable for the same reason.

---

82 Twycross, n 2, 5.
83 Syme, n 8, 444.
84 Twycross, n 2, 11.
86 My Life, My Choices, n 7, 116.
87 Zylicz and Krajnik, n 7, 50: 'Hospital protocols where morphine is administered (usually intravenously) in increasing doses until a patient's death... has little in common with terminal sedation and may be correctly seen as an attempt at euthanasia.'
The Committee expressed concern about the lack of knowledge of the availability of terminal sedation, particularly for those in intractable pain.

In discussing terminal sedation, the Committee noted:

In the case of terminal sedation, some people contend that there is little difference between it and voluntary assisted dying, and that the process is simply slower. Some practitioners and commentators describe terminal sedation as a slow form of euthanasia. There is therefore no ‘bright line’ that separates this practice from assisted dying. This form of sedation simply offers a slow dying process where the individual is unconscious throughout. In addition, the practice remains unrecorded and unregulated.88

The ‘bright line’, in my opinion, is that there has to be a good medical reason for providing terminal sedation. A terminal illness, quadriplegia like Rossiter’s, or multiple health problems like J’s or being ‘locked in’, are conditions where Australian law permits it. The practice needs to be regulated for a number of reasons. The most obvious is that those who request terminal sedation must have the mental capacity to do so, bearing in mind that there is no turning back on the decision. Another is that medical practitioners need to have certainty over what they can and cannot do, thus avoiding the stress of ending up in court on a criminal charge or before a medical tribunal for malpractice. The current guidelines only encourage an overconservative and risk averse attitude which is leading to needless suffering among patients.

*My Life, My Choices* ultimately recommended a system of regulated assisted dying.89 As current legislation both actual and proposed is limited to those suffering terminal illnesses, terminal sedation is still an option for those outside those limits, and for that reason it needs to be regulated even if such assisted dying laws are passed.90

**Conclusion**

Where terminal sedation does not advance the time of death, it cannot be homicide. Nor can terminal sedation be homicide where it does hasten death but is used to reduce suffering. The doctrine of double effect applies.

Where terminal sedation is given to someone who has serious suffering and has rejected any further medical treatment, food and water, the palliative physician is not assisting a suicide in Australian law. Further, even if the rejection is regarded as suicide there is no causal link between the palliative care and the death from dehydration.

There are no justifications in Australian law for the restrictions in the EAPC guidelines that require terminal sedation to be only given just before death. The ethical arguments for them are unconvincing and are dwarfed by the fundamental ethical obligation of doctors to alleviate suffering. The EAPC guidelines are inherently cruel because they require the terminally ill patient to be the subject of a trial and error process to make sure that no other form of palliative care works before terminal sedation is used.

Terminally ill patients and those suffering from serious existential pain in the case of quadriplegics kept alive by ANH, those with 'locked in' syndrome and those with multiple health problems should have the right to avoid suffering by the use of terminal sedation at a time of their choosing. That right should be regulated, as recommended by the *My Life, My Choices* Report.

88 *My Life, My Choices*, n 7, 148.
89 *My Life, My Choices*, n 7, 225-229.
The medical profession through AMA opposes both voluntary euthanasia and physician assisted suicide.\textsuperscript{91} Surveys in Western Australia indicate that 86\% of those surveyed supported the assisted dying legislation proposed for that State.\textsuperscript{92} The irony is that the restrictions on the use of terminal sedation can only have the effect of increasing political support for physician assisted dying as more people watch their loved ones suffer under the trial and error process required by the current Australian and European palliative care guidelines.

**Disclosure:** I have no financial or other interest, including appearing as counsel or as solicitor in any legal proceedings which arise from the issues discussed in this article. I retired from legal practice in 2013, and have never been involved in a case that dealt with these issues.

\textsuperscript{91} Gannon, n 34.
\textsuperscript{92} Adshead, n 3.