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A PERSONAL EXPERIENCE WITH SUFFERING PATIENTS: BRINGING HOME THE ASSISTED DYING DEBATE

RODNEY SYME*

This manuscript details the author's experiences with the assisted dying debate in Australia. As a practiced physician and end-of-life counsellor, Dr Rodney Syme speaks about his commitment to respecting the dignity and autonomy of his patients. He advocates for the de-criminalisation of assisted dying, arguing that existing Australian legislation is based upon outdated perspectives, not adequately informed by the voices of suffering patients. Ultimately, this manuscript speaks to our universal humanity, requesting that we privilege a patient's right to control their death over our blind preference for the preservation of a painful life.

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I Introduction

Since the time Marshall Perron's Rights of the Terminally Ill Bill was proposed in 1995, there has been a vigorous "debate" about euthanasia in Australia. Just what has been in debate has never been entirely clear, due to differing interpretations of language. Even the understanding of the classical word "euthanasia" has been subjective and vague. What might be a "good death" for one person might be a "bad death" for another, which is one reason why the eminent bio-ethicist Margaret Pabst-Battin coined the term 'least

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worst death'.¹ In the Netherlands, where the birth of modern assistance of dying developed, the Government's Remmelink Commission adopted a very strict definition in order to carefully study practices and outcomes.² They made it clear that the term 'euthanasia' was only applicable to ending of life with the explicit request of a person, and that it was a medical action with the specific intention of ending life. If ending of life occurred without consent, it was defined as non-voluntary euthanasia. These definitions did not include the reason for the action (the relief of suffering), nor the circumstance (unbearable suffering). It was a useful definition for statistical purposes, but did not tell the whole story, and allowed 'euthanasia' to be described as intentional killing.

The Remmelink Commission clearly differentiated the provision of medication for the person to end their own life as "assisted suicide". Euthanasia has come to be understood in practice as the delivery of a lethal injection which quickly terminates life. From the outset, an anaesthetic model of intravenous sedation followed by muscle relaxants to stop breathing was adopted, and assisted suicide was actually very uncommon. After some years of covert practice, the Dutch Government, in consultation with the Dutch Medical Association, agreed in 1984 not to prosecute doctors, provided certain criteria of good practice were adhered to. In 2002, a formal law was passed to give statutory protection to doctors who, with due care, responded to explicit requests from persons with unbearable and enduring suffering. Suffering was the issue, not any specific illness or stage of illness. The person did not have to be terminally ill.

This step was based on a belief that law should be guided by reality, rather than perpetuate legal fictions. Medical practitioners were already practicing these behaviours in an effort to uphold their patients' autonomy. Decriminalisation and regulation allowed for safe, consistent procedures to be followed. This inevitably increased the control suffering people had over the quality of their deaths, and allowed doctors to act without fear of prosecution. In Australia, the law has not developed in this way at all.³ Suicide was decriminalised in the 1960s, but aiding and abetting suicide remained a crime. Exactly what this phrase means in a medical context has never been

¹ Margaret Pabst Battin, 'The Least Worst Death' (1996), 22(3) *Journal of Medical Ethics* 183.

² Paul J Van der Maas et al, 'Euthanasia and Other Medical Decisions Concerning the End of Life' (1991) 338(8768) *The Lancet* 669.

³ The law does vary to some extent across jurisdictions, but although my reflections are based primarily off my experiences as a physician in Victoria, I believe my insights apply to the Australian context generally.

clear, since to my knowledge only one doctor has ever been charged with this offence (Daryl Stephens in Western Australia), and that was for concocted reasons.⁴ A jury took less than 10 minutes to find him not guilty. Australian law does nothing to protect doctors who are involved on a day-to-day basis with end-of-life decisions, and thus participate in actions which may (or actually do) hasten death. I am not aware of any special defence for doctors if they deliberately hasten death, even by a few minutes. If they can foresee that their actions could cause death, they could technically be engaging in murder.

Such actions are theoretically criminal were it not for the assumed relevance of the British Court decision of Justice Devlin in 1957 in *R v Adams*.⁵ Dr Adams had given morphine injections to his stroke patient and the police alleged that he had deliberately intended to cause her death. Justice Devlin famously stated 'the giving of drugs to an elderly patient to alleviate pain was lawful even if incidentally it shortened the patient's life'. It has been accepted in the broader sense that if a doctor's intention is to relieve pain and suffering, the incidental and even foreseen consequence of hastening death is excused. This judicial decision, although from a British court, has been generally accepted to apply to Australian jurisdictions. A form of legal "double effect" (based on the doctor's expressed intention to relieve suffering), has allowed Australian doctors to "ease dying" with relative impunity.

No Australian doctor has been charged with murder or attempted murder in the last 60 years. Published surveys of medical practice reveal that doctors do assist patients to die, largely on a "wink wink, nod nod" basis, using large doses of narcotics like Adams. Much of this happens in the security of the home, though specialists may oblige in hospitals. Nevertheless, all it takes for trouble to ensue is one complaint from a disgruntled relative or a morally challenged colleague or nurse for referral to the Medical Board, or possibly investigation by police and prosecution, to occur. It is no wonder that doctors are extremely cautious in talking openly about such matters, and that evidence for practices that hasten death are rarely reported.

⁴For more information on the circumstances, see Robin Bowles, *What Happened to Freeda Hayes?* (Pan Macmillan Sydney, 2002).

⁵ *R v Adams* [1957] Crim L R 365.

⁶ See, eg, Charles D Douglas et al, 'The Intention to Hasten Death: A Survey of Attitudes and Practices of Surgeons in Australia' (2001) 175(10) *Medical Journal of Australia* 511.

In the UK, in 2000, Dr Harold Shipman was prosecuted and found guilty of murdering 15 elderly patients. The police alleged that he had killed over 300 people, mostly elderly women living alone, and it was intimated that he acted for profit. Regrettably, Shipman died without ever uttering a single word of explanation for his actions, so it is unknown whether he was acting out of compassion or from greed, or whether his patients made requests to him for assistance. Shipman's activities over a long period of time were only investigated when a relative made a complaint, in this case fully justified, but that is all it takes, one complaint from a concerned relative, nurse or doctor for an investigation to occur.

Now many UK GPs are wary of giving dying patients terminal doses to relieve their suffering. Geriatrician Min Stacpole says 'Shipman has had a negative effect on the quality of dying'. If doctors are in fear of prosecution for providing compassionate and humane assistance to their dying patient, they will not do so. Who suffers? — not the doctor. Does the fact that only one doctor has been prosecuted in Australia in 60 years give comfort? Hardly, if the protection rests on a single judicial statement in another country and on subjective notions of intention. Dr Stephens suffered two years of anxiety, damage to his practice, his finances and his marriage. It is remarkable that some Australian doctors do take these risks on behalf of their patients — they do so with a legal vulture perched on their shoulder.

II GRIM STATISTICS, GRIM DEATHS

What do we know of doctors' practices around assistance in dying in Australia? Very little, beyond the anonymous information published by bio-ethics researchers.⁸ This reveals that a small number of doctors acknowledged practicing 'euthanasia' and 'assisted suicide'. Most surveys show that a majority of doctors support legalisation of assistance in dying (which includes both the above practices). But how these doctors assist their patients is actually a mystery. It is certainly not comparable to euthanasia in the Netherlands (intravenous sedation for deep sleep, followed by muscle relaxant to stop breathing) or assisted suicide (quick-acting oral barbiturate after anti-emetic

⁷ Maggie Ferguson, 'How to Have a Good Death', *The Economist: 1843* (online), January/February 2016 https://www.1843magazine.com/features/how-to-have-a-good-death.

⁸ See, eg, David A Neil et al, 'End-of-Life Decisions in Medical Practice: A Survey of Doctors in Victoria (Australia)' (2007) 33 *Journal of Medical Ethics* 721.

preparation). I think it is highly unlikely that a Dutch style euthanasia has ever occurred in Australia. Given that quick-acting barbiturates cannot be prescribed in Australia, the use of such medication by physicians is also likely to be uncommon. However, such drugs can be obtained from overseas countries and brought into Australia for medicinal use, probably more commonly without medical supervision than with it.

Unfortunately, assistance in dying in Australia, covert as it is, is not uncommonly attempted using combinations of drugs which are quite unsuitable. Roger Magnussen's book Angels of Death,9 surveys a number of assisted deaths in the HIV/AIDS communities of Australia and the west coast of USA, and reports a number of badlybotched attempts, but ultimately ugly deaths, due to the use of indiscriminate cocktails of drugs, which were quite unsuited to a dignified and secure end-of-life procedure. Compassionate intent was no compensation for ignorance and lack of the proper drugs. It is constantly reported that people die tragically from overdoses of narcotics, sedatives, and anti-depressants, though whether by accident or intent is not always evident. The doses ingested are rarely known and the manner of their dying is also obscure, as they usually die alone. Suffice to say that the use of such drugs to end life is fraught with uncertainty, much depending on the tolerance that develops when these drugs have been in long-term use. This is particularly so with opioids. In the absence of the ability to prescribe quick-acting barbiturates, assisted dying by oral means is highly precarious. As a consequence of the above, it should be clear that euthanasia or assisted suicide as practiced in the Netherlands is probably rare in Australia.

And can we rely on the Coroner's statistics for enlightenment? Certainly not, because when a person who is close to death takes an overdose of barbiturate, there will be no overt indication that this has happened, and thus no reason for referral of the death to the Coroner. I am convinced that, on many occasions like this, when the certifying doctor may have some suspicion of suicide, no referral is made — the matter is "let go through to the keeper". Most doctors will make no judgment about the action, will not want to embarrass the distressed family with a police interview, see no reason to delay funeral proceedings, and would regard the real cause of the death as the disease causing the intolerable suffering. I am aware of a number of circumstances where local doctors

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 $^{^9}$ Roger S Magnusson, *Angels of Death: Exploring the Euthanasia Underground* (Melbourne University Press, $1^{\rm st}$ ed, 2002).

have been aware that an overdose was planned, and turned a blind eye to the actual cause of death.

This of course raises the intriguing question as to whether such hastened deaths should be described as "suicide". There is a world of difference between a dying person ending their life after careful thought, and discussion with their family and doctor, in order to relieve their suffering, and a violent suicide of a healthy person without any discussion and in circumstances where appropriate assistance might have avoided such a death. It is cruel and unnecessary to subject the former to society's stigma regarding suicide (itself unfortunate) — the concept of rational suicide should be recognised and an exception made in its description and aftermath. The Coroner is in a cleft stick in these matters. The law mandates an investigation if the death is reported (no death certificate signed) and toxicology reveals the presence of *Nembutal* in the blood. 10 Even though the dying person was at death's door, a Coroner's investigation must take place, with the police involved to interview anyone who might have been present when death occurred or might have knowledge of the matter. Experienced police officers are effectively going through the motions, collecting information rather than pursuing prosecution.

The South Australian Coroner confirmed his experience with tragic suicides of ill elderly persons in a letter to Marshall Perron. He wrote:

[T]his is a subject for politicians who are quite capable of ascertaining the facts and publishing them in the Parliaments if they wish to do so ... Any politician who cared to inquire of any coroner could quickly become acquainted with at least an anecdotal idea of the extent of the issue.¹¹

Despite what I believe is significant inaccuracy in the Coroner's statistics on suicide in the elderly and terminally ill, Victorian Coroner John Olle nevertheless described to the Victorian Parliamentary Committee of Inquiry into End of Life that between 2009 and 2013, 240 cases of suicide were reported in which there was evidence that the deceased had experienced an irreversible deterioration in physical health due to disease or

¹⁰ Nembutal is a brand of pentobarbitone, a form of quick-acting barbiturate discussed earlier in the

¹¹ Dying with Dignity Victoria, Submission No 623 to Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices*, July 2015, 16.

injury.¹² Most of these deceased were suffering from multiple diseases — 50 per cent had cancer, 10 per cent had diabetes, 10 per cent had arthritis, 8 per cent had cardiovascular diseases, 5 per cent had Parkinson's disease, and 4 per cent had Huntington's disease. 74 died of poison, 64 by hanging, 34 by firearms, 19 by a threat to breathing, 13 by a motor vehicle accident, and 8 by a rail accident.¹³ Grim statistics, grim deaths, and note that up to 50 per cent may not have had a terminal illness. Intolerable suffering is not confined to terminal illness. Advanced incurable illnesses may have intolerable suffering that can last far longer than that of a terminal illness.

III MY EXPERIENCE WITH SUFFERING PATIENTS

I have had a particular interest in end-of-life matters for over 40 years. I have made an intense study of the bio-ethical literature around end-of-life, and the palliative care literature since 1996 when I became aware of terminal sedation. I have counselled well over 1500 people about their end-of-life concerns. I have attended seven World Right to Die conferences which involve meeting and talking with ethicists, legislators, and doctors who function in the jurisdictions of Belgium, the Netherlands, Switzerland, and Oregon, where assistance in dying is practised, and also Canadians who have so resoundingly argued the case for reform in their Supreme Court, and in ethics bodies, with the Canadian Medical Association and in their Parliament. This research and experience in counselling has convinced me of three important, self-evident truths first, that dying may be associated with intolerable and unrelievable suffering that may escalate towards the end; second, that some suffering will only end with death; and third, that doctors have an ethical duty to relieve suffering and respect their patient's autonomy. This leads me to the conclusion that a doctor may sometimes be faced with the necessity to hasten death, if requested by his patient, in order to relieve suffering and to uphold a patient's human dignity.

Unfortunately, the current legal environment in Australia, somewhat hypocritically, does not reflect the same commitment to patient autonomy when it comes to assisted dying. Whilst a strong focus is placed on a patient's right to life, including a firm stance

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¹² Coroners Court of Victoria, Submission No 1037 to Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices*, 20 May 2016.

¹³ Ibid 3.

against forceful treatment or refusal of treatment, a patient's control over the end of their life is not respected under law. This inconsistency violates a patient's autonomy at a point where it will never feel so important — when taking control over death means taking control over their life. In part, this may stem from a failure to prioritise the experiences and insights of patients making end-of-life decisions. My experience talking with, and assisting, a number of persons has lead me to question the credentials of many who commentate in the Australian "euthanasia" debate, and that includes the debates in our Parliaments. I would venture to suggest that the vast majority of commentators have no idea of what takes place in an assisted dying by oral medication. They have never seen it and probably never talked to anyone who has. They usually speak from the personal experience of only one, occasionally more, dying relatives or friends. They speak from emotion (which may be good) but also from ignorance (which is bad). They have usually not taken the trouble to study the large amount of empirical research evidence about assisted dying. They almost always introduce the subject with a comment such as "this is a very difficult and controversial matter".

I can only say that the difficulty exists in the mind of the commentator, for by the time a suffering person has had a sensitive dialogue with their family and their willing doctor, and they have reached a decision that they can go no further, there is no difficulty, only an extraordinary calmness which has to be seen to be believed. It is true that determining when is the time to say goodbye is the most difficult part of that decision, but once that decision is made, a relaxed calmness ensues, provided they have control. I have always believed that it is critically important that family and/or friends should be aware of such discussions, brought into an understanding of why such a serious decision is being made, helped to an acceptance of that necessity, and given the opportunity to share in the experience of a loved one dying. It is a profound experience, one that most people will treasure and never forget. It has a power to transcend grief. I do this because of the importance of saying goodbye and so that no-one will have to die alone, even though it opens up the possibility that a grieving relative may make a complaint. Suffice to say that has never happened.

There is no more powerful demonstration that a suffering person can go no further than that they take their own action to end that suffering, by ending their own life. They take that responsibility upon themselves, and do not pass it on to their doctor. It is ultimately

their responsibility, unless they are physically incapable of implementing their wishes; in that case, and in my opinion, only that case, the doctor has a responsibility to more actively assist by an injection. Placing the control directly in the hands of the suffering person is the greatest safeguard that an unwanted death will not occur.

IV SHORT REFLECTIONS ON THE VICTORIAN PARLIAMENTARY INQUIRY

A good debate should be an informed debate when sound argument based on fact is presented. This took place at the recent Victorian Parliamentary Inquiry. It was notable that the only institutional voices raised in opposition to change were those of the Australian Christian Lobby, the Catholic Archdiocese of Melbourne, the Australian Catholic Bishops Conference, the Australian Family Association, and Palliative Care Australia. Cardinal George Pell has proudly stated that 55 per cent of palliative care in Australia is provided by the Catholic Church. I believe palliative care's foundational philosophy of not hastening death condemns some of its patients to prolonged, unwanted suffering. Law Professor Margaret Otlowski gave evidence to the Parliamentary Inquiry. She has indicated that it is absolutely clear from the outcomes in lay mercy-killing cases that the prosecutorial process treats these cases differently to other killings. Sometimes juries do not convict despite the overwhelming evidence and judges bring down non-custodial sentences.

Retired Supreme Court Justice John Coldrey gave further evidence that the law needed to be changed. He said 'these cases don't sit comfortably in a court setting. The person goes out into society labelled a murderer when their motive has been compassion and love. I'd like to see a regime where people who act in this way are not put at risk of criminal charges'. I'd like to see a system where laypersons are not put at risk, because they can obtain advice and if necessary assistance from their protected doctor. Most of the Inquiry members travelled to the Netherlands, Switzerland, Canada, and Oregon to obtain first-hand evidence of the function of assisted dying legislation in those

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¹⁴ Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices Final Report* (2016) 213.

¹⁵ See, eg, Jane Cadzow, 'Our Man in Rome', Sydney Morning Herald (online), 16 June 2012

http://www.smh.com.au/lifestyle/our-man-in-rome-20120610-204wh.html.

¹⁶ Margaret Otlowski, Submission No 841 to Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices*, July 2015, 175.

¹⁷ Above n 14, 175–6.

countries. The Inquiry found, as did the Supreme Court of Canada, ¹⁸ that the arguments put against assisted dying lacked substance, and determined that the status quo in Victoria was not sustainable. They recommended that the government legislate for assisted dying with clear safeguards — the manner of assistance was for oral administration by the suffering person, with a lethal injection only allowed if that person was not capable of self-administration. My only criticism of the recommendations in the Victorian Parliamentary Inquiry is that it confined assistance to people with weeks or months to live. By so doing, it ignored the very compelling evidence of the Victorian Coroner that intolerable suffering driving people to end their own lives was not confined to the terminally ill. The recommendation is discriminatory against people with advanced incurable illness.

IV CONCLUSIONS: A BENIGN CONSPIRACY?

In 1968 in Victoria, Justice Menhennitt ruled that an abortion was not illegal if it was performed to protect the life or health of a pregnant woman. ¹⁹ This judicial decision changed the practice of law without changing the statute (this did not happen for another 40 years) by protecting doctors from prosecution. I have argued that providing medication which gives a person with intolerable and unrelievable suffering control over the end of their life is a very significant palliative act which relieves psychological and existential suffering. I have openly admitted to providing *Nembutal* to such a patient, hoping to provoke a similar judicial outcome around assisted dying as occurred with Menhennitt and abortion. I did so because Parliaments have for years dismissed attempts to address this issue. My efforts to have this issue tested in Court have been in vain, leading me to suggest there is a "benign conspiracy" on the part of the prosecutorial authorities to also avoid this issue.

Hopefully, at last, the Victorian Parliament, faced with a comprehensive, thorough, well-researched and penetrating report from its Upper House Committee of Inquiry will pass legislation that is already so strongly supported by the community. I believe this legislation could provide patients with the means to exercise control over their suffering, and to ultimately live their final days on their own terms.

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¹⁸ Carter v Canada (Attorney General) [2015] 1 SCR 331.

¹⁹ R v Davidson [1969] VR 667.

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