The Case for Voluntary Assisted Dying (VAD)

Tabled at the WA Joint Select Committee on End of Life Choices on 26 February 2018, by Dr Peter Beahan

Throughout the whole of history, there has always been a proportion of the population that has suffered a dying process that was slow, painful and undignified. Some have taken their own lives in lonely, often violent circumstances. That is the background against which we discuss the present day. It is really only in the past 50 years that attention has been focused on this neglected area of medical care.

In 1969, the Swiss psychiatrist Elisabeth Kübler-Ross introduced the five stages of grief in her book entitled: On Death and Dying. In 1977, the English Anglican nurse and physician Cicely Saunders, at the invitation of the late Professor David Allbrook, gave a pivotal lecture on the same subject, at Royal Perth Hospital. The stage was set for a new era of hospice and palliative care services.

In 1980, the first palliative care service in WA was set up by the Rev. Dr Douglas MacAdam. His model was a domiciliary-based service staffed by General Practitioners and Nurses employed by the Silver Chain. In 1987, the Cottage Hospice at Shenton Park, supported by the Cancer Council WA, was the first purpose-built, freestanding hospice in the country.

It is clear from the names mentioned, that many drawn to this work had a religious affiliation or motivation.

Much skill was devoted to making the dying process more dignified and more comfortable, both physically and spiritually. Nevertheless, it remains today that not all patients can be helped to the same degree, and that some still suffer a bad death. It has been estimated that more than 5% of palliative care patients fall into this category[1].

Strategy for these most difficult patients has included the avoidance of futile intervention and the withdrawal of life-supporting treatment. In addition, the liberal use of sedative, pain-relieving and anti-emetic medications has become widely recognized as a modern application of the doctrine of double effect, i.e. treatment that while relieving suffering may hasten death. Such strategies are now considered acceptable and mainstream, within the medical profession. That has not always been the case.

Assisted dying, sometimes loosely referred to as assisted suicide, has historically been a taboo subject, and its condemnation was implied within the Hippocratic Oath. Nevertheless, it is clear that there has been a reappraisal of this position, based on changed circumstances and changed attitudes of our times.

1. The original Hippocratic Oath included the statement: "I will give no deadly medicine to anyone ... nor suggest any such counsel". This statement addressed *all* encounters of doctors with patients. It was not specifically directed at the dying patient. The original intent of that tenet remains as valid today as it was when first formulated. What is not valid is to apply that tenet to circumstances that were never contemplated in those early times.

2. Before the modern era, the inevitability of death in the circumstance of disease was not clear-cut or obvious. By contrast, modern medicine provides diagnostic and prognostic certainty of a high degree. Those who request assisted dying know exactly the nature of the affliction they have and the outcome they can expect.

3. When the tenet referred to was first formulated, and for all but the most recent of generations that followed, the management options we have today, both to prolong life, and to manage a life in the process of ending, simply did not exist.

4. It is also apparent that attitudes in more civilised societies have moved toward a more kindly, more understanding, less judgmental, less patronising and less authoritarian direction.

While voluntary euthanasia for the terminally ill had been condoned in the Netherlands and in the US State of Oregon, the first legislative assembly to pass a law explicitly legalising voluntary euthanasia for the terminally ill was in Australia's Northern Territory. This was in operation from July 1996 to March 1997 when it was overridden by the Federal Parliament, on a private member's bill, introduced by Kevin Andrews.

Since that time, some 7 countries and 9 states, one (Victoria) in Australia and the rest in the USA, have enacted voluntary assisted dying laws. There are several other states in the pipeline.

Resurgence of interest in this subject has been provided by television personality Andrew Denton, who has produced podcasts, television documentaries and books on the subject. Anyone who doubts that VAD is reasonable and necessary should read his collection of 72 actual cases, entitled The Damage Done – referred to by Denton as the tip of the iceberg. A copy can be obtained from the Go Gentle site for $20, or it can be downloaded at no cost.

VAD has the advantage of efficacy and certainty. The case for VAD is based on the recognition of the right of individuals to autonomy and dignity with

respect to their personal lives. The World Medical Association's Declaration of Geneva (otherwise known as the Physician's Pledge) was recently updated to include the clause: I WILL RESPECT the autonomy and dignity of my patient.

The same Declaration includes the older clause: I WILL MAINTAIN the utmost respect for human life. Confusingly, some cite this clause in support of their opposition to any treatment that is intended to bring to a close intolerable suffering, by bringing forward inevitable death, at the specific request of the patient.

There are two problems with this position:

1. It makes these two clauses mutually incompatible.

2. In principle, the difference between treatment based on the double effect and VAD is contrived rather than real. The former could be described as a cop-out.

The fine line between intention to relieve suffering, and intention to end life is so fine as to be apparent only in the mind of the individual attending physician. It is not measurable, it is not transparent, and it is not accountable.

Contrary to common assumption, it should be noted that terminal sedation, an application of the double effect, is a form of assisted dying, and is not exempt from a charge of murder in the Criminal Code. Once commenced, the death of the patient is certain, and intended.

Although the same thing in principle, there are differences in practice, between treatment based on the double effect, and VAD. We think they are important:

1. With terminal sedation the outcome is prolonged and uncertain. The patient may linger in an anguished or comatose state, dehydrated and deteriorating, a spectre far from any conventional notion of care. This is not a criticism of the physician, rather of the limitations imposed by the law.

   With VAD the outcome is quick and certain. The patient chooses an earlier time in the dying process, when dignity and purpose are intact. This can be, and is, both a rational and a mentally healthy choice.

2. With treatment based on the double effect, documentation is cryptic and statistical information impossible to collect. There is no regulatory framework or oversight.

   With VAD documentation is clear, frank and open to scrutiny.

3. With treatment based on the double effect, the decision is made by the physician.

   With VAD the decision is made by the patient.

There is one area of similarity between double effect and VAD. With treatment based on the double effect, the primary objective is not that of ending life. It is that of relieving overwhelming suffering.

With VAD, the primary objective is *also* not that of ending a life. It is that of *putting an end* to suffering, as specifically requested by a terminally ill patient. In both cases, the end result is the same.

The fact is that the most effective treatment for unrelenting, terminal suffering, refractory to palliative measures, or simply preferred by the patient, is one that painlessly ends both suffering and life. The two cannot be separated.

Dying patients are not a different category of patient. All patients deserve to be offered the most effective treatment available for their condition. This is medicine at its best, at its most compassionate and at its most efficacious. There is nothing in it for shame or criticism.

Most of the opposition to VAD stems from faith-based beliefs, where only God has the right to end life. Such beliefs are often subliminal, not disclosed and not acknowledged. They may explain why the double effect doctrine rests uncomfortably with some, and is not always followed.

Australia has a mixture of people, some religious and some more secular in outlook. If we have learned anything in recent years it is that the bulk of the population prefers government to follow a path based, not on dogma, but on reason, evidence, science and fairness. Support for these principles can be found in religious, as well as non-religious groups. Over 70% of those who identify either as Catholic, or as Anglican, support assisted dying.[2]

Assisted dying can be seen as a medical treatment aimed at cutting short intolerable pain, suffering and indignity, where specifically requested by the patient. The word suffering suffices to cover the whole gamut of what

motivates a dying patient to seek VAD, including existential considerations other than pain. Pain, in fact, is not to be found at the top of the list of motivating factors[3].

More common concerns are those of losing independence and autonomy, of losing dignity, of being unable to do the things one has enjoyed doing, and of being a burden on others.

It should be noted that it is the disease process that is the cause of the suffering, and the inevitable death. Assistance with the dying process is a treatment, in this context. Ending suffering is the primary intention. Ending suffering and ending life cannot be separated. The same applies to terminal sedation.

The word suicide is not appropriate to use, in either case. In this regard, it is unfortunate that some have chosen to use such terminology. Imposition of this term represents a value judgment that is very hurtful to the patient and the patient's loved ones. Our patients deserve much better than this. It is important that the law should not follow such terminology.

While some favour has been expressed for oral pentobarbitone (Nembutal) as the agent of choice for assisted dying, most patients, where given the choice, prefer a physician administered, or supervised, intravenous injection. This can be arranged for the patient to self-administer.

As a medical treatment, we recommend that the method chosen to assist dying should be in the hands of attending physicians and any protocols drawn up from time to time by professional bodies. Legislation with respect to such medical care should not be overly prescriptive.

There are some benefits of VAD that may not be obvious:

1. Giving a patient the ready option of VAD can greatly relieve anxiety. It can have the effect of the patient postponing the decision and better enjoying any remaining life. This is why over a third of patients granted access to Nembutal never get to use it[4]. The dying fear the process of dying, far more than death itself.

2. Giving patients control over the timing of their death can make their parting with loved ones easier to cope with, and much happier. Close family and friends can visit in a planned way and be present if desired, at the time of death.

> One of our problems as human beings is the difficulty we have in letting go. The opportunity provided through VAD, of close contact and heart to heart discussion, can have a great easing effect on this process.

Why then, is there opposition to VAD?

Here we can only address, at face value, the counter-arguments put forward.

1. One assertion is that all that is necessary is to put more funding into palliative care. But, even in the best-funded and best-run centres, there remains a residual proportion of deaths that amount to bad deaths. Extra funding may well help, but cannot be expected to reduce this residual proportion.

Palliative care services in Australia are amongst the best in the world, coming second only to those in the UK[5]. In some regards, they are at the top of the league. That is not to disregard problems with access.[3] Funding could certainly help that – and we would support it.

We see VAD not as an alternative to palliative care. Rather, it is a natural, fitting and complementary part of the spectrum of service that should be available to the dying patient.

2. Another argument is that control of symptoms is now so good that there is simply no need for VAD. Some physicians even suggest there is no patient whose symptoms cannot be controlled. This argument is unconvincing on two counts.

1. There is effectively nothing in medicine that is as perfect as that. Such assertions are simply not believable. They more likely reflect a tenacious attachment to a faith-based philosophy.

2. This judgment is made by the doctor, not by the patient.

3. A more plausible concern is that of pressure being applied by family members or other interests. In his studies in Belgium, the Netherlands and Oregon, Andrew Denton came to the conclusion that this was a near impossibility with the safeguards that existed. However, there is a need to apply systems of monitoring, and case review, as occur in overseas jurisdictions.

In fact, VAD legislation brings with it the opportunity for a greater

transparency than is present under current arrangements.

4. Finally, there is an argument that is referred to as "the slippery slope", which of course, is applied to all reforms when first considered. In the case of VAD, it fails to recognize that the Victorian legislation, as the closest example, is considered the most conservative in the world, with many safeguards. It is based largely on the Oregon model that has remained unchanged for some 20 years.

That is not to say that any law can be or should be cast in stone. It is unlikely that any assisted dying legislation will be perfect. But, any proposal for change will not bypass the scrutiny that is being applied to current proposals. Democracy and debate will be just as much in evidence.

In reality, fear of change equates to a fear of public opinion. Furthermore, there is no moral justification for denying dying patients a benefit (VAD) on the grounds that a future generation may wish to extend the criteria for that benefit. One generation should not seek to control what another generation may wish to do.

In WA, popular support for VAD runs at 89% according to a November 2017 Roy Morgan opinion poll[6]; it runs at 87% nationally. Such support appears to be less than that amongst AMA members, with a 2016 AMA survey showing 38% support, with 50% against[7].

It should be said that this AMA survey has been has been the subject of comprehensive critical review.[8] Furthermore, it is not in line with another 2016 survey reported by Paul Smith in the Australian Doctor. This found a 65% support for VAD[9].

As well as this, there are sympathetic statements from the Royal Australian College of General Practitioners[10] and the Australian Nursing Federation[11]. These groups are significant because they have members working at the coalface. The Australian and New Zealand College of Anaesthetists has a submission before the Committee that is even-handed and non-judgmental on the issue.

To some extent, the results of a survey depend on the questions asked. For example, in the AMA survey referred to, 52% believed euthanasia could form a legitimate part of medical care. Also, the survey concluded that if VAD becomes legal, a majority of doctors want the medical profession to be involved in delivering any treatments.

Finally, as the uptake of VAD by those patients and doctors who wish to avail themselves of it, does not affect any patients or doctors who do not wish to do so, there should be no reason for the AMA to take one side or the other, in this debate. It should simply not take sides.

A large minority, if indeed it is a minority in this case, should be respected and accommodated, in its own right.

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1 Personal communication
2 2007 Newspoll survey
3 ABC News 3 Dec, 2017 Euthanasia: it's not just about unbearable pain, it's about self-determination, expert says
4 K. Callinan The Hill 25 Dec 2017 Allow Modern Medicine to Relieve Agonizing End-of-Life Experiences
5 The 2015 Economist Intelligence Unit, Quality of Death Index
6 Roy Morgan Survey 10 Nov 2017, Finding No 7373
7 The Sydney Morning Herald 24 Nov 2016
8 Neil Francis 2017 DyingForChoice.com
9 P. Smith Australian Doctor 15 Oct 2016 Half of Doctors back assisted suicide
10 RACGP media release 20 Oct 2017
11 ANF position statement May 2012