AMA Tasmania submission to the Enquiry into the Dying with Dignity Bill 2009

August 2009

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AMA Tasmania does not support physician assisted suicide or voluntary euthanasia.

AMA Tasmania contends that “dying with dignity” is not synonymous with euthanasia although this phrase has now almost become a euphemism for premature death intentionally brought about by medical means.

In 1997, AMA Tasmania made a submission to the Parliament of Tasmania on the need for legislation on voluntary euthanasia. The Community Development Committee reported its findings in 1998.

This previous AMA submission remains relevant as little of real substance has altered in the 11 years since the report was published and the views of the AMA are unchanged since then. The 1997 submission is included as appendix 1.

In April 2008 the Federal AMA made a submission to the Senate Legal and Constitutional Affairs Committee’s Inquiry into the *Rights of the Terminally Ill (Euthanasia Repeal) Bill 2008*. AMA Tasmania fully supports the views expressed in the Federal body's submission. This is included as appendix 2.

AMA Tasmania does not believe that the enquiry into the Dying with Dignity Bill 2009 is sufficiently at variance with previous enquiries into the question of euthanasia to require a complete re-examination of all of the well rehearsed arguments for and against this contentious issue.

The aim of this submission is to provide an update since the initial AMA Tasmania submission made in 1997 and to reiterate the Association's opposition to euthanasia and the currently proposed Bill.

CHANGES SINCE PREVIOUS AMA SUBMISSION OF 1997.

A. 1998 Tasmanian Parliamentary report.

The Tasmanian House of Assembly Community Development Committee Report on the need for legislation on voluntary euthanasia was published in 1998. The executive summary lists the findings of the committee:

1. The Committee found that whilst many of the moral arguments put by both sides of the debate were persuasive, a determination of the need for legalisation on voluntary euthanasia cannot be made on the basis of a subjective moral choice.

2. The Committee found that the polarised character of the moral debate for and against voluntary euthanasia limited its utility as a determinant for legal reform. Euthanasia legislation would have to be based on a general principle that treated all individuals equally.

3. Anecdotal evidence presented to the Committee identified a need for patients' rights to be affirmed. The committee found that in some cases patients had difficulty ensuring that their wishes would be respected in regard to their medical treatment when they became incompetent.

4. The Committee found that whilst individual cases may present a strong case for reform the obligation of the state to protect the right to life of all individuals equally could not be delivered by legislation that is based on subjective principles.

5. The Committee found that there is evidence to suggest that abuses of the current prohibition on active voluntary euthanasia do occur and Tasmania may not be immune to such abuses.

6. The Committee does not consider the legalisation of voluntary euthanasia as an appropriate solution to abuses that may be occurring in the current system.

7. The Committee found that the codification of voluntary euthanasia legislation could not adequately provide the necessary safeguards against abuse.

8. The Committee found that common law rights exist for a competent patient to refuse any medical treatment, including life-sustaining treatment. Likewise legal recognition is given to a competent patient's anticipatory consent in the form of an advance directive or through an advocate in the event of becoming incompetent.

9. The Committee found that a doctor was not legally culpable for manslaughter or murder if his intent in withholding or withdrawing medical treatment from a patient who subsequently died was to relieve the patient of the burden of futile treatment in accordance with prudent medical treatment. Likewise the administration of sedative and analgesic drugs to terminally ill patients for the relief of pain and suffering even when it is foreseeable that such action will shorten life is not illegal whilst the intent is to provide palliation and not to deliberately kill the patient.

10. The Committee found that the legalisation of voluntary euthanasia would pose a serious threat to the more vulnerable members of society and that the obligation of the state to protect all its members equally outweighs the individual's freedom to choose voluntary euthanasia.

11. From the evidence presented the Committee found that in the majority of cases palliative care was able to provide optimum care for suffering patients.

12. The Committee recognises that in a small percentage of cases palliative care is ineffective in relieving all pain, however whilst regrettable this is not sufficient cause to legalise voluntary euthanasia.

13. The Committee found that there is a need for greater resources to expand and improve the quality of palliative care services.

14. There was a demonstrated need for increased education on several levels to improve the delivery and efficacy of palliative care.

    - To provide for greater public awareness of the services available and their benefits;
    - To familiarise general practitioners with the availability of specialist palliative care and encourage them to access it for their patients; and
    - To provide greater palliative care training for health care workers in under-graduate and postgraduate settings.

The Committee received 1162 submissions and its comprehensive and thoughtful report, some 60 pages in length, is essential reading for anyone seriously contemplating a change in the current Tasmanian legislation.

AMA Tasmania would submit that the only change of any note since the report was released is that palliative measures to support end of life care have continued to improve.

B. Changes in other jurisdictions.

Active voluntary euthanasia and physician assisted suicide are no longer illegal throughout the world.

In the Netherlands, the practice of euthanasia has been overt and tolerated since the early 1980s and fully legal since 2002. In Belgium, a law modelled on that of the Netherlands was passed in 2002. Physician assisted death has been legal for a decade in Oregon and the state of Washington passed a measure that was modelled on Oregon's *Death with Dignity Act* in the 2008 general election.

The Netherlands permits both physician-performed active euthanasia and physician assisted suicide, the Dutch law requires that the patient be facing intolerable suffering but not that the patient be terminally ill, nor even that the suffering be physical. In contrast, the Oregon and Washington statutes permit only the writing of a prescription for a lethal drug but not active euthanasia, they require that the patient be terminally ill and they make no mention of suffering.

Studies have shown that only 1 in 1000 Oregonians choose physician assisted suicide (Okie S. Physician-assisted suicide. New England Journal of Medicine 2005; 352:16.), indicating that there really is minimal need for such legislation. This brings to mind the legal dictum that exceptional cases make bad law.

Furthermore, for the majority of Oregonian patients the Dying with Dignity Act was used for reasons of autonomy or out of fear of possible future suffering rather than for present pain or unrelieved physical suffering (Ganzini L, Goy ER, Dobscha SK. Oregonians' reasons for requesting physician aid in dying. Arch Intern Med. 2009;169 :489-92.

Of further interest, a recent study of those Oregonians who had made use of the Act found that “Although most terminally ill Oregonians who receive aid in dying do not have depressive disorders, the current practice of the Death with Dignity Act may fail to protect some patients whose choices are influenced by depression from receiving a prescription for a lethal drug”. (Ganzini L, Goy ER, Dobscha SK. Prevalence of depression and anxiety in patients requesting physicians’ aid in dying: cross sectional survey. British Medical Journal 2008;337:a1682 doi:10.1136/bmj.a1682).

The legalisation of physician assisted suicide in Switzerland has led to “suicide tourism”, particularly attracting the British. However a recent review of the first 115 Britons who committed suicide at the Dignitas facility in Zurich found that 20% did not have a terminal condition; their diagnoses included Crohn’s disease (a treatable inflammatory bowel condition), rheumatoid arthritis, and kidney disease. These and other revelations have led the Zurich authorities to consider tightening the Act that governs the Dignitas facility and others like it.

A number of studies have been published of the practice of euthanasia during the brief period when it was legal in the Northern Territory (1996-97), Seven patients made use of the Rights of the Terminally Ill Act and four died under it. According to the most detailed report, published in the international medical journal The Lancet, three of the patients were socially isolated and four had symptoms of depression. The authors, who included the general practitioner who was most prominent in facilitating use of the Act, cautioned that "…the assessment of depression is difficult in the terminally ill, and accurate prediction of prognosis is subject to disagreement. There are clear limitations of the gatekeeping roles of the medical specialist and psychiatrist in the ROTI legislation." (KIssane DW, Street A, Nitschke P. Seven deaths in Darwin: case studies under the Rights of the Terminally III Act, Northern Territory, Australia. The Lancet 1998; 352; 1097-1102.)

More recently, the *Rights of the Terminally Ill (Euthanasia Repeal) Bill 2008* has been tabled in the Senate and is awaiting debate. This Bill seeks to overturn the 1997 Federal legislation which invalidated the Northern Territory's euthanasia law. The AMA has made a submission to the Senate Enquiry and this is included as Appendix 2.

C. All Major National and International Medical Associations remain opposed

World Medical Association.

The WMA has recently revised and reaffirmed its position. The World Medical Association Declaration on Terminal Illness, adopted by the 35th World Medical Assembly Venice, Italy, October 1983 and Revised by the WMA General Assembly, Pilanesberg, South Africa, October 2006 makes the following statements:

> When addressing the ethical issues associated with end-of-life care, questions regarding euthanasia and physician-assisted suicide inevitably arise. The World Medical Association condemns as unethical both euthanasia and physician-assisted suicide.
>
> The patient's right to autonomy in decision-making must be respected with regard to decisions in the terminal phase of life. This includes the right to refuse treatment and to request palliative measures to relieve suffering but which may have the additional effect of accelerating the dying process. However, physicians are ethically prohibited from actively assisting patients in suicide. This includes administering any treatments whose palliative benefits, in the opinion of the physician, do not justify the additional effects.

British Medical Association

At the BMA's annual conference in Belfast on 29 June 2006, doctors voted by an overwhelming majority against legalising physician assisted suicide and euthanasia.

The current policy is that the BMA:

- believes that the ongoing improvement in palliative care allows patients to die with dignity;
- insists that physician-assisted suicide should not be made legal in the UK;
- insists that voluntary euthanasia should not be made legal in the UK;
- insists that non-voluntary euthanasia should not be made legal in the UK; and,
- insists that if euthanasia were legalised, there should be a clear demarcation between those doctors who would be involved in it and those who would not.

The American Medical Association is opposed as described in its Code of Medical Ethics:

> “It is understandable, though tragic, that some patients in extreme duress such as those suffering from a terminal, painful, debilitating illness may come to decide that death is preferable to life. However, allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.
>
> Instead of participating in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life. Patients should not be abandoned once it is determined that cure is impossible. Multidisciplinary interventions should be sought including specialty consultation, hospice care, pastoral support, family counseling, and other modalities. Patients near the end of life must continue to receive emotional support, comfort care, adequate pain control, respect for patient autonomy, and good communication.”

The position of the **American College of Physicians-American Society of Internal Medicine** (ACP-ASIM) is as follows:

> “[the College] does not support the legalization of physician-assisted suicide. The routine practice of physician-assisted suicide raises serious ethical and other concerns. Legalization would undermine the patient-physician relationship and the trust necessary to sustain it; alter the medical profession’s role in society; and endanger the value our society places on life, especially on the lives of disabled, incompetent, and vulnerable individuals. The ACP-ASIM remains thoroughly committed to improving care for patients at the end of life.”

Australian Medical Association

From the *Position Statement on the Role of the Medical Practitioner in End of Life Care 2007*:

> 10.1 The AMA believes that while medical practitioners have an ethical obligation to preserve life, death should be allowed to occur with dignity and comfort when death is inevitable and when treatment that might prolong life will not offer a reasonable hope of benefit or will impose an unacceptable burden on the patient.
>
> 10.2 Medical practitioners are not obliged to give, nor patients to accept, futile or burdensome treatments or those treatments that will not offer a reasonable hope of benefit or enhance quality of life.
>
> 10.3 All patients have a right to receive relief from pain and suffering, even where that may shorten their life.
>
> 10.4 While for most patients in the terminal stage of an illness, pain and other causes of suffering can be alleviated, there are some instances when satisfactory relief of suffering cannot be achieved.
>
> 10.5 The AMA recognises that there are divergent views regarding euthanasia and physician assisted suicide. The AMA believes that medical practitioners should not be involved in interventions that have as their primary intention the ending of a person's life. This does not include the discontinuation of futile treatment.

10.6 Patient requests for euthanasia or physician-assisted suicide should be fully explored by the medical practitioner in order to determine the basis for such a request. Such requests may be associated with conditions such as a depressive or other mental disorder, dementia, reduced decision-making capacity, and/or poorly controlled clinical symptoms such as pain. Understanding and addressing the reasons for such a request will allow the medical practitioner to adjust the patient's clinical management accordingly or seek specialist assistance.

10.7 If a medical practitioner acts in accordance with good medical practice, the following forms of management at the end of life do not constitute euthanasia or physician assisted suicide:

- not initiating life-prolonging measures;
- not continuing life-prolonging measures;
- the administration of treatment or other action intended to relieve symptoms which may have a secondary consequence of hastening death.

10.8 Medical practitioners are advised to act within the law to help their patients achieve a dignified and comfortable death.

In summary, the Tasmanian Branch of the AMA is fully in step with its national organisation and with all major international physician associations in opposing the legalisation of active euthanasia (the killing of dying patients by their physicians) and of physician assisted suicide. We believe such legislation is not needed and is potentially dangerous. To equate the emotive term 'dying with dignity' with medically-assisted death is disingenuous.

Dying with dignity can best be achieved when physical symptoms are relieved, depression is recognised and treated, and existential suffering is addressed. To the extent that these ideals are not achieved now in Tasmania, improvements could be brought about by better education of the general public and health professionals, and by addressing the additional needs of the already excellent palliative care services in our state.

This submission was prepared on behalf of AMA Tasmania by

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APPENDICES

1. AMA TASMANIA 1997 SUBMISSION

2. AMA 2008 SUBMISSION TO THE SENATE

[Australian Medical Association Submission to the Senate Legal and Constitutional Affairs Committee's Inquiry into the *Rights of the Terminally Ill (Euthanasia Repeal) Bill 2008*.]

3. AMA POSITION STATEMENT ON THE ROLE OF THE MEDICAL PRACTITIONER IN END OF LIFE CARE 2007

SUBMISSION BY THE TASMANIAN BRANCH OF THE AUSTRALIAN MEDICAL ASSOCIATION TO THE COMMITTEE OF ENQUIRY OF THE TASMANIAN HOUSE OF ASSEMBLY INTO THE NEED FOR EUTHANASIA LEGISLATION

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30 June 1997

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SUMMARY

The Tasmanian Branch of the Australian Medical Association, which represents the majority of doctors in clinical practice in this state, respectfully submits the following views for the consideration of the members of the Committee of Enquiry:

- The meaning of the word ‘euthanasia’ is frequently misunderstood but in the context of this enquiry is taken to mean the deliberate and abrupt putting to death of a terminally ill patient at his or her request, by a medical practitioner.

- Euthanasia legislation is unnecessary since excellent palliative care is available in this state and is able to control severe pain and other symptoms in almost all dying patients.

- Euthanasia contravenes national and international codes of physician conduct and ethical standards.

- Active voluntary euthanasia and physician-assisted suicide are illegal throughout the world. If euthanasia legislation were enacted here, Tasmania would become the world focus of a radical social experiment.

- Legalisation of euthanasia would threaten the weak and vulnerable members of our community. Law makers and the medical profession share a common duty to protect those not able to fend for themselves.

- In response to claims made by those in favour of euthanasia, the AMA asserts that clandestine euthanasia (the administration of a lethal injection) is not practised to any extent in Australia. Furthermore, claims that euthanasia is a ‘right’ cannot be sustained, and the killing of one person by another is never a private matter.

- We should care for the dying, not kill them.

WHAT IS EUTHANASIA?

The original, literal meaning of the Greek word ‘euthanasia’ is ‘good death’, a concept with which everyone agrees. However in the current context and in the context of the recently annulled Northern Territory legislation, the word ‘euthanasia’ refers to the administration of a lethal injection by a medical practitioner, to bring about the abrupt and immediate death of a terminally ill patient. Alternatively, it may refer to the medical provision of lethal drugs which are then self-administered (‘doctor-assisted suicide’).

The general public is said, as a result of surveys, to be in favour of the legalisation of euthanasia. Much of this comes from surveys that use emotive expressions such as ‘mercy killing’. Furthermore, despite much discussion and publicity over the past 2-3 years, there is still considerable confusion amongst the general public as to the meaning of the word ‘euthanasia’. Evidence of this comes, amongst other sources, from a poll of public opinion conducted in the Northern Territory in 1995, a time when the NT Rights of the Terminally Ill Act was a matter of intense local interest (Appendix 1). For example, in that survey

- 60% mistakenly agreed with the statement that ‘euthanasia is the withdrawal of medicines and machines to support life’

- 37% mistakenly agreed with the statement that ‘euthanasia is the administration of increasing doses of medicine over a period of time with the motive of relieving suffering, but having the side effect of shortening life’

Forgoing futile treatment to allow a terminally ill person to die peacefully is not euthanasia, rather it is proper and good medical practice, and it is what happens now. Another widely-held mistaken belief is that euthanasia-type legislation is needed to stop doctors treating patients against their wishes; but this is not so. A patient’s right to refuse all or any treatment is supreme. Any doctor who treated a patient against his or her wishes would be guilty of assault in common law. Furthermore, there have been no cases brought to the notice of the Tasmanian branch of the Australian Medical Association in recent times which have involved a charge that a doctor had treated a patient against the patient’s wishes.

It’s vital, therefore, before discussing the AMA’s attitude to it, that the meaning of the word ‘euthanasia’ is absolutely clear. In the present context **euthanasia means**

> **the abrupt and immediate putting to death of an ill person by medical means, either by the direct administration of a lethal injection or by provision of an easy means for self-administration of a lethal dose (‘physician-assisted suicide’).** [Note the *Macquarie Dictionary* definition is ‘the putting of a person to death painlessly…’.]

Euthanasia does NOT mean

- **the withdrawal of futile or any treatment, at the request of a dying patient, thus allowing nature to take its course**

- **the provision of adequate and appropriate palliative care, including the use of opiate and other drugs in doses necessary to relieve pain**

- **turning off a respirator or other life-support system in a person who can no longer benefit from such treatment**

EUTHANASIA IS UNNECESSARY

Palliative care is one of medicine's great recent successes. It has become a recognised specialty with its own corpus of knowledge and its own experts. Through the expertise developed by palliative care specialists, no-one today need die with severe unrelieved pain, despite popular contrary views based, perhaps, on over-dramatic and misleading portrayals in the media. Perhaps it has been a failure on the part of the profession that the public believes and fears that agonising unrelieved pain is a feature of dying, but this is quite false.

The Australian Association for Hospice and Palliative Care defines **Hospice and Palliative Care** to mean

> 'a concept of care which provides co-ordinated medical, nursing and allied services for people who are terminally ill, delivered where possible in the environment of the person's choice, and which provides physical, psychological, emotional and spiritual support for patients, and support for patients' families and friends. The provision of Hospice and Palliative Care services includes grief and bereavement support for the family and other carers during the life of the patient and continuing after death.'

State and Federal governments in Australia have accepted a measure of responsibility for providing funding for hospice and palliative care services. The Tasmanian model follows that generally regarded as desirable in that it integrates home care, hospital consultation and in-patient care in a hospice setting, where appropriate for each individual patient. The nursing and medical staff who operate Tasmania's Palliative Care Services have been widely praised for their ability to deliver effective palliative care in a wide variety of settings in both urban and rural areas of the state. However more funding is desperately needed to fill gaps in the provision of 24-hour cover, and to provide education for general practitioners, other medical practitioners and general nursing staff.

People value life differently when they are well and when they are facing death: then, every day is precious. Even though, according to opinion polls, the public in general supports the concept of euthanasia, studies that have focussed on dying patients have shown that their desire for euthanasia decreases as they approach death[1]. A number of treatable factors also influence patients' attitudes including lack of pain control, depression, loss of control (feelings of helplessness), pre-existing psychiatric illness, prior suicide attempts and fear of dependency[2] [3] [4] [5]. As long as the symptoms are tolerable, every extra moment with family and friends is a bonus.

EUTHANASIA CONTRAVENES NATIONAL AND INTERNATIONAL CODES OF PHYSICIAN CONDUCT AND ETHICAL STANDARDS

The following resolutions of the World Medical Association, the Australian Medical Association and the Tasmanian Branch of the Australian Medical Association show the consistent views of the medical profession.

World Medical Association Declaration on Euthanasia, 1987:

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

World Medical Association Statement on Physician-Assisted Suicide, 1992:

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

Australian Medical Association Position Statement, 1996:

> 'The AMA believes that doctors should not be involved in interventions that have, as their primary goal, the ending of a person's life. … [E]uthanasia and doctor assisted suicide are

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[1] Owen C et al. Suicide and euthanasia: patient attitudes in the context of cancer. *Psycho-oncology* 1992; 1: 79-88

[2] Jacobson JA et al. Decedents' reported preferences for physician-assisted death: a survey of informants listed on death certificates in Utah. *Journal of Clinical Ethics* 1995; 6: 149-157.

[3] Breitbart W et al. Interest in physician-assisted suicide among ambulatory HIV-infected patients. *American Journal of Psychiatry* 1996; 153: 238-242.

[4] Layson RT et al. Discussion about the use of life-sustaining treatments: a literature review of physician and patient attitudes and practice. *Journal of Clinical Ethics* 1994; 5: 195-203.

[5] Layde PM et al. Surrogate prediction of seriously ill patients' resuscitation preferences. *Archives of Family Medicine* 1995; 4: 518-524.

> unethical …. While doctors have an ethical obligation to preserve health, death should be allowed to occur with dignity and comfort when death is inevitable and when treatment which might prolong life appears futile. Under such circumstances, the AMA believes withholding or withdrawing treatment, or refraining from resuscitation procedures, may well be in the patient's best interests… . Council continues to support the WMA [World Medical Association] Declaration on Euthanasia, 1987 and the WMA Statement on Physician-Assisted Suicide, 1992. The AMA endorses the right of patients to refuse treatment and the right of severely and terminally ill patients to have relief of pain and suffering, even when such therapy may shorten the patient's life.'

Tasmanian Branch Council, 13 June 1997 (passed unanimously)

> 'Council reaffirms its opposition to the legalisation of active voluntary euthanasia.'

Full copies of these resolutions are provided in Appendix 2.

The medical profession is large, and a minority do not share the general view espoused above. It is of interest though that within the profession the groups most strongly opposed to the legalisation of euthanasia are cancer and palliative care specialists. This is because, firstly, that they know how effective good palliative care can be; and secondly, because they deal daily with seriously ill and dying patients, recognise their vulnerability and understand their need for protection.

Doctors are trained to treat patients and their illnesses, to cure sometimes, to care always. For doctors to use their training deliberately to cause death would be a gross misuse of the trust given them by their patients. It would turn on its head the very basis of medical ethics.

ACTIVE VOLUNTARY EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE ARE ILLEGAL THROUGHOUT THE WORLD

Despite much interest and despite a number of legislative enquiries, active voluntary euthanasia and physician-assisted suicide remain illegal in all jurisdictions. The attention of the Committee of Enquiry is drawn to the papers published by the Select Committee of the House of Lords. This was probably the most detailed enquiry ever held by a body of legislators and it came to the unanimous conclusion that legalisation of euthanasia would potentially be dangerous and wrong. The members of the Select Committee were especially influenced by the 'slippery slope' argument, and wrote[6]:

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[6] Walton J. The House of Lords on issues of life and death. *Journal of the Royal College of Physicians of London* 1994; 28: 235-236.

> ‘We do not think it is possible to set secure limits on voluntary euthanasia … We took account of the present situation in the Netherlands; indeed some of us visited that country and talked to doctors, lawyers and others. We returned feeling uncomfortable, especially in the light of evidence indicating that non-voluntary euthanasia … was commonly performed … ‘

Furthermore

> ‘We concluded that, if legalized, it would be virtually impossible to ensure that all acts of euthanasia were truly voluntary and hence that any liberalization of the law in the UK could not be abused. We also felt that vulnerable people—the elderly, lonely, sick or distressed—might feel pressure, whether real or imagined, to request early death. Our decision was also influenced by the outstanding achievements of the palliative care movement in the UK.’[7]

Several states of the USA have conducted enquiries. Most recently (27th June, 1997) the Supreme Court of the USA, in a rare unanimous decision, ruled that patients did not have a ‘right’ to euthanasia or physician-assisted suicide, and the Court validated laws in 35 states which made such acts illegal.

The Northern Territory law which was valid for a short period during 1996-97 was passed by a single vote (13 to 12) in one of the world’s smallest legislatures. In the Northern Territory there is no Upper House (ie, no house of review). The NT law was brought in at a time when there was virtually no Palliative Care Service available, so that the benefits of such a service were not evident to the NT public or the members of parliament. Subsequent publicity (eg on an ABC Four Corners program shown after the law was overturned) has starkly illustrated the problems with control of pain and other symptoms that can arise when palliative care experts are not consulted. As is well known, the NT law was overturned by the Federal parliament after an exhaustive enquiry in which it received a record number of submissions.

The situation in the Netherlands is a special one. Euthanasia there is not legal, but has been permitted by the equivalent of case law. The extent to which it is practised, the extent to which the guidelines of the courts are obeyed, and the extent to which the quasi-legalisation of voluntary euthanasia has led to involuntary euthanasia are widely debated. Even though the extent may be debated, the fact that the guidelines are often disobeyed and the fact that involuntary euthanasia takes place are not disputed.[8] It’s also worthy of note that some recent cases of ‘voluntary’ euthanasia have involved patients with severe depression with no physical illness. These facts highlight the danger of allowing voluntary euthanasia. Once it is permitted at all, any restrictions almost certainly will be abused. Another point of note is that palliative care services have been poorly developed in the Netherlands until now. In this way the attitude in the Netherlands is similar to that which prevailed for a time in the Northern Territory, in that, in the absence of palliative care services, euthanasia may be seen as the preferred method of ‘treating’ dying

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[7] Lord Walton of Detchant. Dilemmas of life and death: part two. *Journal of the Royal Society of Medicine* 1995; 88: 372-376.

[8] Twycross RG. Euthanasia: going Dutch? *Journal of the Royal Society of Medicine* 1996; 89: 61-63.

patients. The Netherlands has now recognised this deficiency, and is in the process of actively setting up UK-style palliative care services.

If Tasmania were to pass euthanasia legislation it would be the only jurisdiction anywhere in the world where the practice was legal. What would that say about our community's attitude to the value of life? What would it say about our concern for the aged and infirm, the handicapped, the seriously ill? In Tasmania in particular, with our recent history, rather than legislate to facilitate killing, we should legislate to ensure that all dying patients have access to the highest quality palliative care services and that sufficient resources are available to meet their needs.

LEGALISATION OF EUTHANASIA WOULD THREATEN THE WEAK AND VULNERABLE MEMBERS OF OUR COMMUNITY

It is concern for the weak and vulnerable that is at the heart of the profession's opposition to euthanasia legislation. While the strong, such as certain society leaders including a previous governor-general, express support for euthanasia, it is the disempowered, the frail, the infirm, the extreme aged, and the severely handicapped, who are vulnerable. They are vulnerable to pressure from relatives to sign, perhaps to relieve real or perceived suffering in loved ones. In such circumstances could an agreement to allow oneself to be killed be truly voluntary? For the dependent and powerless, the pressure may overwhelm. (In parenthesis we note that not all relatives are selfless.)

The frail and the handicapped are the most vulnerable to abuse of voluntary euthanasia legislation — the risk that the next step will be involuntary euthanasia. And even if that abuse were not to happen, or to happen only rarely, the *perception* that it might can poison the atmosphere between medical practitioners and their patients, as indeed happened in the Northern Territory. When the NT law was in place, Aboriginal leaders advised members of their communities not to enter NT hospitals, so fearful were they of its potential for abuse. Similarly in Holland, where euthanasia is quasi-legal, many elderly patients fear its use without their consent and ask for large signs to go on their bedhead 'Not For Euthanasia'.

The answer to a patient who is suffering from improperly controlled symptoms is not to end the patient but to end the symptoms. The goal of the medical profession is to ensure that everyone in need has access to palliative care of the highest standard. The genuine concerns of all for the sick and dying should be used to improve medical care, not to withdraw it.

When prominent people, economic rationalists, and powerful media organisations support medical killing, it's time for those of us who act as advocates for the weak, the vulnerable, the frail, the handicapped, and the dying, to speak out. If we cross the dividing line between caring for our patients and deliberately killing them we change one of society's most fundamental values, the respect for human life and dignity.

RESPONSES TO ARGUMENTS IN FAVOUR OF EUTHANASIA

1. ‘It happens all the time anyway so why not legalise and control it’

In a recent paper in the Medical Journal of Australia[9], it was alleged that 1.8% of all Australian deaths were brought about by clandestine euthanasia and that in up to 30% of deaths a ‘medical end-of-life decision’ hastened or influenced death. This paper has generated enormous controversy with strong contradictory views expressed both in the medical[10] and lay[11] press. To anyone involved in the care of the dying, the suggestion that nearly one in 50 Australian deaths is brought about by a physician injecting the patient with poison (for that is what euthanasia means in the current debate) is completely preposterous. Of crucial relevance, all the authors of this paper were known advocates of euthanasia legislation. Furthermore, the authors were unable to distinguish between the intention of ‘not prolonging life’ and that of ‘hastening death’, whereas to a practising doctor this is the most fundamental difference imaginable. The key to understanding the paper’s astounding claims is to realise that the answers to the questionnaire used have been distorted. Almost certainly the explanation for the claim that 1.8% of patients were killed by euthanasia is that the figure refers to the proportion of patients who, on being given appropriate medication to relieve their pain and suffering, slipped into a coma and died through natural processes perhaps a little faster than might otherwise have been the case. As for the 30% of deaths where there was a ‘medical end-of-life decision’, this refers to instances where treatment was adjusted appropriately in dying patients. For instance, if a patient is in the process of dying, it would be common and correct practice to stop unnecessary medication such as cholesterol lowering drugs, antihypertensive medication and antibiotics. It is a distortion to suggest that proper ethical clinical practice, in limiting medication to that which is necessary for the patient’s comfort and well-being, in some way equates to practising euthanasia.

Much of the misunderstanding in this area comes from a failure to appreciate the effect of morphine and other opiate drugs. Far from being a common cause of death, or hastening death, the aim of morphine administration is to enhance quality of life, which it does by relieving pain without causing drowsiness or coma when given in appropriate doses. When given correctly the administration of opiates, like the general aim of palliative care ‘neither hastens nor postpones death’. Indeed it would be quite difficult to kill a patient using morphine unless one were to give an enormous overdose. Contrary to some popular views, the picture of a doctor faced with the choice of increasing the dose of morphine and thus killing the patient, or failing to control pain is another ‘morphine myth’. In this situation the doctor would either

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[9] Kuhse H et al. End-of-life decisions in Australian medical practice. *Medical Journal of Australia* 1997; 166: 191-196.

[10] Ashby M. The fallacies of death causation in palliative care. *Medical Journal of Australia* 1997; 166: 176-177.

[11] Manne R. How data on death became a numbers game. *The Australian* , 1997 Feb 17, p11.

increase the dose as needed to control the patient's pain, almost certainly without any effect on the patient's life expectancy, or he/she would use some non-morphine method of pain control. (Much pain is morphine non-responsive, and palliative care specialists have a range of alternative pain-relieving medication available as well as physical methods of pain relief such as nerve blocks.)

Unfortunately the euthanasia debate threatens to undo much of the success of the last decade in abolishing myths about morphine, in encouraging patients to use this highly effective drug early in their disease for appropriate pain relief and not to regard it as something kept for the final few days or to bring on death.

Euthanasia is medical murder. Far from euthanasia being a form of mercy killing, it is in fact medical killing.

2. 'There is a right to euthanasia and it is a private matter'

One of arguments put most strongly in favour of active voluntary euthanasia is the consumerist view, that it is a private matter of no consequence to the rest of society, and that it is a person's right to choose the date, time and manner of one's death. However these arguments are specious. The concept of a 'right' to choose the manner and time of one's death is not accepted anywhere and has recently been rejected by the US Supreme Court. After all, one does not choose the manner and time of one's entry into the world, so from where comes the 'right' to choose the manner and time of leaving it?

The idea that the killing of one person by another, even with the victim's consent, is a private matter is false. The community, for its own protection and for the protection of its weaker members, must take and always has taken an interest in all deaths. Otherwise we would be a lawless society with no respect for life. No one has an unfettered right to do what they choose with their own body. If someone was prepared to do it, would I have the right to have my arm cut off? Do I have the right to sell myself into slavery? If a dying person has the right to be killed with consent, why not a sick person who is not dying? Why not someone who is depressed but not physically ill? Why not anyone? It is for the protection of the weak, the handicapped and the vulnerable in our society that society makes laws against all these things.

Professor J Norelle Lickiss, one of Australia's leading palliative care specialists (formerly of Tasmania) has written[12]

> 'There will always be differences of opinion on profound matters in a free society, but being put to death with one's consent is not a private matter, for it strikes at the foundations of what we are, and affects not only the one put to death, but the one who carries it out. Our acts shape us, and the act of putting another person to death must change us. If we are doctors, it strikes at the core of what we should be in society: bringers of life, of hope, of healing, of comfort, sometimes bringers of bad news, companions on the way. But no bringers of death.'

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[12] Lickiss N. *In*: Chapman S, Leeder S, editors. *The last right? Australians take sides on the right to die.* Melbourne: Mandarin, 1995: 98.

WHAT PALLIATIVE CARE CAN ACHIEVE

The Directory of Hospice and Palliative Care Services in Australia, issued May 1997, lists 16 institutions and organisations involved in palliative care in Tasmania. Despite constant funding difficulties (which must be addressed) all patients referred to the service receive assistance, either directly or through advice given to each patient’s general practitioner. Palliative Care Services in Tasmania provide comprehensive assistance, ranging from pharmaceutical advice to supply of physical devices such as beds and mattresses to arranging 24 hour nursing cover and visits by hospice volunteers. Where possible and where it accords with the desires of the patient and his or her relatives, services are provided in patients’ homes; in other circumstances patients are admitted to general hospital wards or to dedicated hospice wards which are available in several hospitals. The continued provision of such a service, and its further improvement, are the answer to the calls for euthanasia legislation.

We need to send a signal to the weak and the dying that this community cares for them. The AMA calls on the members of the Committee of Enquiry to reject calls for euthanasia legislation and instead to back moves to improve and extend Tasmania’s palliative care services.

ENCLOSURES

1. Final Report of the Poll of Public Opinion in the Northern Territory, May 1995

2. Resolutions of the Australian Medical Association

include letter by Paul Dunne & myself to Mercury Jan 97

Australian Medical Association Submission to the Senate Legal and Constitutional Affairs Committee's Inquiry into the *Rights of the Terminally Ill (Euthanasia Repeal) Bill 2008*.

The AMA recognises the divergence of views regarding voluntary euthanasia and physician-assisted suicide in Australia. Indeed, the range of views, from those who fully support voluntary euthanasia to those who totally oppose it, is reflected within the medical profession itself.

AMA position on euthanasia and physician-assisted suicide

The AMA believes that medical practitioners should not be involved in interventions that have as their primary intention the ending of a person's life (this does not include the discontinuation of futile treatment).

This position was recently reaffirmed in the AMA's *Position Statement on the Role of the Medical Practitioner in End of Life Care 2007* (see attached). This position statement resulted from a long consultation process. As recognised above, we received the full range of views on euthanasia and physician-assisted suicide from our members and others. The majority of opinion, however, was to reaffirm our policy opposing medical practitioners' involvement in euthanasia and physician-assisted suicide.

The AMA feels very strongly that medical practitioners participating in euthanasia or physician-assisted suicide undermines the trust that is the cornerstone of the doctor-patient partnership. The public trusts medical practitioners to care for patients (and their families and carers) throughout the course of their disease or condition and to advocate for their health and well-being.

We cannot confuse the role of the medical practitioner as someone who supports life with someone who takes life.

In consultation with the patient (or their advocate), medical practitioners apply the most appropriate therapeutic means to treat their patients. Where death is inevitable and when treatment that might prolong life will not offer reasonable hope of benefit or will impose an unacceptable burden on the patient, death should be allowed to occur with dignity and comfort. For medical practitioners, this means using their skills to care for the patient by making them as comfortable as possible, free from unnecessary suffering. It does not mean deliberately taking the life of the patient.

The AMA absolutely recognises that for most patients in the terminal stage of illness, pain and suffering can be alleviated by therapeutic and comfort care; however, there are still currently instances where the satisfactory relief of suffering cannot be achieved.

We must, therefore, ensure that all patients have access to appropriate palliative care and advocate that greater research must go into palliative care so that no patient endures such suffering. No one should feel that their only option for satisfactory relief of pain and suffering is to end their own life.

Definitions

It is important for any discussions on euthanasia and physician-assisted suicide to clarify the terminology.

The AMA defines euthanasia as:

> *the act of deliberately ending the life of a patient for the purpose of ending intolerable pain and/or suffering (from AMA Position Statement on the Role of the Medical Practitioner in End of Life Care 2007).*

The AMA believes that if a medical practitioner acts in accordance with good medical practice, the following forms of management at the end of life **do not** constitute euthanasia or physician assisted suicide:

- not initiating life-prolonging measures;
- not continuing life-prolonging measures;
- the administration of treatment or other action intended to relieve symptoms which may have a secondary consequence of hastening death.

The AMA defines physician-assisted suicide as:

> *where the assistance of the medical practitioner is intentionally directed at enabling an individual to end his or her own life (from AMA Position Statement on the Role of the Medical Practitioner in End of Life Care 2007).*
>
> .

We advocate that patient requests for euthanasia or physician-assisted suicide should be fully explored in order for the medical practitioner to adjust the patient's clinical management or seek specialist assistance.

Again, we advocate that quality palliative care services must be available to everyone in need of such services. A patient should never feel that death is their only option for relief of pain and suffering because appropriate palliative care is not at available.

Advance care planning

The AMA endorses advance care planning as a means for supporting patients' wishes in their end of life care (see *AMA Position Statement on the Role of the Medical Practitioner in Advance Care Planning 2006*). Advance care plans provide (competent) patients with the opportunity to express their goals and values in relation to their future health care should they lose decision-making capacity.

Some patients may fear that when they lose decision-making capacity, their goals and values in relation to their end of life care will be unknown or even disregarded by their families and/or the health care team since the patient can no longer actively participate in their own health care decisions. As such, this fear may lead some patients to consider undergoing euthanasia or physician-assisted suicide before they lose decision-making capacity.

An advance care plan, which may include an advance directive and/or an enduring power of attorney, provides patients with the reassurance that they can participate in future decisions regarding their health care by articulating their wishes and goals of care in their plan.

Concluding remarks

The AMA does not support the provisions of the *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008.*

Whilst acknowledging the range of societal views on euthanasia and physician-assisted suicide, the AMA strongly reiterates that medical practitioners should not be involved in interventions that have as their primary intention the ending of a person’s life.

Position Statement on the Role of the Medical Practitioner in End of Life Care

2007

1 Preamble

1.1 The AMA believes that the primary role of the medical practitioner in end of life care is to facilitate the provision of good quality patient-centred care that emphasises continuous, open, informed communication and collaboration between the patient, the health care team, and, where appropriate, the patient's carers, family members, and/or surrogate decision-maker.

1.2 Further, the AMA believes that good quality end of life care should:

1.2.1 ensure the patient is always treated with respect, dignity, and compassion;

1.2.2 ensure that the patient is free from unnecessary suffering;

1.2.3 endeavour to facilitate care in the patient's environment of choice;

1.2.4 ensure that the patient's goals and values for end of life care are respected;

1.2.5 respect the patient's privacy and confidentiality, even after death;

1.2.6 support not only the physical needs of the patient but also the psychological, emotional, religious, and spiritual needs of the patient and their family members and carers;

1.2.7 empower patients and, where appropriate, their family members and carers to participate in managing their treatment;

1.2.8 provide counselling and other support to patients, their family members and carers throughout the patient's condition, including support for family members and carers beyond the patient's death.

1.3 The AMA recognises and respects the intimacy of death. Death, dying, and bereavement are all an integral part of life; however, reflecting on and discussing death can be profoundly confronting and difficult. The AMA encourages open and frank discussion of death, dying, and bereavement within the profession and in the wider community.

1.4 The AMA supports a guidance framework rather than a legislative system to oversee end of life care. Where legislation does exist, the AMA supports uniform, flexible legislation that protects medical practitioners and allows them to undertake their clinical duties in line with good medical practice.

2. Terminology Used in This Document

Advance care planning (ACP) – A process that allows a competent individual to express their views in relation to future health care decisions when the capacity to express those views is lost. The outcome of an ACP process is an advance care plan that may include:
(a) an Advance (Health or Care) Directive (AD) (or other similar instruments);
(b) a Medical Enduring Power of Attorney (EPA) (or other similar instruments);
(c) a letter to the person who will be responsible for this decision-making;
(d) an entry in the patient medical record;
(e) a verbal instruction or other communication which clearly enunciates a patient's view; or
(f) any combination of the above.

Advance directive - A statement that allows patients who understand the implications of their choices to state in advance how they wish to be treated when they are no longer capable, as a consequence of physical or cognitive incapacity, of making such health care decisions in a particular circumstance.

Carers – This refers to family carers who provide unpaid, informal care to the patient. Whilst some family carers may be eligible for government benefits, this definition excludes those that are actually employed as carers.

Euthanasia – The act of deliberately ending the life of a patient for the purpose of ending intolerable pain and/or suffering.

The AMA acknowledges that some people prefer to categorise euthanasia in specific ways; for example, voluntary, non-voluntary, or involuntary euthanasia **and/or** active or passive euthanasia. These are generally defined as[1]:

- voluntary euthanasia – ending the life of a competent, informed patient at their request;
- non-voluntary euthanasia – ending the life of a patient with impaired decision-making capacity who cannot provide truly informed consent (this does not include murder);
- involuntary euthanasia – ending the life a patient against their will or consent (this may include murder or manslaughter);
- active euthanasia – giving a patient a treatment or action that directly and deliberately results in their death;
- passive euthanasia– not initiating or no longer continuing life-sustaining treatment that results in death as a direct consequence of the underlying disease.

The AMA believes, however, that if a medical practitioner acts in accordance with good medical practice, the following forms of management at the end of life **do not** constitute euthanasia or physician assisted suicide:

- not initiating life-prolonging measures;
- not continuing life-prolonging measures;
- the administration of treatment or other action intended to relieve symptoms which may have a secondary consequence of hastening death.

Futile treatment – Treatment is futile when it is no longer providing a benefit to a patient, or the burdens of providing the treatment outweigh the benefits[2].

Good medical practice – Good medical practice is practice that is consistent with:

- the current recognised medical standards, practices and procedures of the medical profession in Australia; and
- the current recognised ethical standards of the medical profession in Australia.

Life-limiting illness – An illness where it is expected that death will be a direct consequence of the specified illness. A life-limiting illness may be expected to shorten an individual's life.

Life-sustaining treatment - Medical treatment that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation. This includes assisted ventilation, artificial nutrition and hydration and cardiopulmonary resuscitation but excludes measures of palliative care.

Medical Enduring Power of Attorney (EPA) – A legal document that gives another person authority to make health care decisions on behalf of a person who has lost capacity. In relation to ACP, this attorney may have an important role in assisting in health care decisions that need to be made with the treatment team. It is important for both patients and practitioners to understand that relevant to State or Territory legislation, a person may appoint a single (or joint) attorney for all matters or different attorneys for different matters (eg., one for personal matters, one for financial matters, one for health matters).

Palliative care – Care provided for people of all ages who have a life-limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life[3]. Palliative care integrates physical, psychological, emotional, and spiritual care for patients, their families, and other carers.

Physician-assisted suicide – Physician-assisted suicide is where the assistance of the medical practitioner is intentionally directed at enabling an individual to end his or her own life[4].

Surrogate decision-maker or 'person responsible' – The person legally responsible for giving valid consent to medical treatment, including its limitations on behalf of a patient who lacks decision-making capacity. The designation of such a person should be undertaken in accordance with legislation relevant to one's jurisdiction (eg., state Guardianship Acts).

Terminal illness - An illness which is inevitably progressive, the effects of which cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily) and which will inevitably result in death within a few months at most. Terminal phase of a terminal illness is defined as the phase of the illness reached when there is no real prospect of recovery, or remission of symptoms (on either a temporary or permanent basis).

3 Cultural and Religious Influences on Decision-making

3.1 In recognising the diversity of cultural and religious perspectives relevant to end of life care, the AMA advocates a culturally sensitive approach, acknowledging that culture-based and religious-based responses may vary, even within the same cultural and/or religious 'group'.

3.2 Views may vary between cultures and religions on issues such as[5]:

- the preferred place of treatment;
- communication of diagnosis and prognosis. For example, in certain cultures it is not appropriate to inform the patient of a 'terminal' diagnosis;
- the role of family/relative/friends in caring for the patient. For example, the designation of a decision-maker for medical treatment. In certain cultures, it is not appropriate for a competent patient to make his/her own treatment decisions, particularly regarding life-sustaining treatment;
- the role of health professionals and volunteers, for example, whether or not they may be welcome in the home;
- attitudes to pain relief, whether certain medicines are taboo;
- attitudes to euthanasia;
- 'taboo' words. For example, in certain cultures it is inappropriate to use 'cancer' or 'death';
- handling of the body. For example, in certain cultures, only family members of the same sex as the deceased may handle the body;
- the expression of grief and bereavement.

3.3 Medical practitioners should be provided with education and support in cultural awareness to enable them to care for all their patients and family members in a sensitive and culturally appropriate manner. This includes timely access to support personnel such as trained translators, indigenous community members, and religious advisers.

3.4 Indigenous Australians have their own perspectives regarding death and dying. In addition, they may feel a lack of trust in government services, including health care services that may become even more apparent in relation to end of life care[3].

3.5 Medical practitioners caring for Indigenous Australians at the end of life may benefit by working in partnership with the Aboriginal controlled health organisations, where they exist[3].

4 Conscientious Objection

4.1 The AMA recognises that the diversity of cultural and religious views and practices regarding end of life care are reflected within the medical profession itself.

4.2 Medical practitioners caring for patients at the end of the patient's life should be under no obligation to recommend or participate in treatment to which they hold a conscientious objection related to the end of life management. In such a circumstance, the medical practitioner should explain to the health care team involved as well as the patient or the surrogate decision-maker, why they are not willing to recommend or participate in the treatment. Where possible, the practitioner may remove themselves from that aspect of care but continue to provide other necessary care.

5 Equity of access to end of life care and other support services

5.1 The AMA strongly advocates for equity of access across Australia to intensive care, respite care, palliative care, bereavement support, carers' support, and other relevant services to patients undergoing end of life care and their families and carers.

5.2 Equity of access means that care must be available regardless of gender, age, ethnicity, race citizenship status, language, religion, mental health, medical condition, disability, location, place of residence, or ability to pay.

5.3 Different patient groups including neonates, children and young people, older persons, and persons with mental health problems may have specific care requirements.

5.4 Regardless of where a patient lives, appropriate support services for family members and carers should be available, including respite care and grief and bereavement support.

6 Resource allocation

6.1 The AMA advocates that medical practitioners, governments, independent, and voluntary agencies must work together to ensure that limited resources are utilised in the most effective way in order to provide patients and families with physical, psychological, social, domestic, financial and spiritual support[6].

7 The role of good communication within end of life care

7.1 The AMA promotes the patient-practitioner relationship as a partnership, where patients and practitioners work together to achieve informed and mutually agreed goals of health care. An essential component of this partnership is good communication between the patient, their family members and carers as appropriate, and the practitioner and health care team. Good communication in end of life care is timely, open, informative, provides opportunities for questions, and where possible and relevant, allows patients and/or their family members and carers time to come to terms with the patient's condition.

7.2 Good communication between the patient, their family members and carers, and the health care team may help alleviate fear, confusion, and guilt over the patient's condition, assist decision-making, and reduce the potential for conflict over the patient's care.

7.3 Good communication within the health care team itself is important in reducing any confusion, stress and anxiety that may be experienced by team members over the patient's condition and/or treatment.

7.4 It is important that the process for decision-making along with the outcomes should be made clear to all participants involved and documented accurately.

8 Competent patients and decision-making

8.1 The AMA supports the right of a competent patient to make fully informed health care decisions, including the right to refuse treatment. The AMA recognises that this may include life-sustaining treatment as well as palliative care.

8.2 The AMA strongly promotes advance care planning as a process of supporting patient self-determination, including the development of advance directives and the identification of surrogate decision-makers such as Enduring Powers of Attorney (EPA) (or similar), as a means to ensure that the patient's values and goals of care are known. ACPs are prepared by the competent patient to assist in decision-making if he/she loses the capacity to make treatment decisions in the future.

9 Patients who have impaired decision-making capacity

9.1 The AMA recognises that patients with impaired decision-making capacity may include:

- those who were competent before losing decision-making capacity and had previously expressed their goals, values, and/or wishes around end of life care;
- those who were competent before losing decision-making capacity and did not express their goals, values, and/or wishes around end of life care;
- those who never had decision-making capacity;
- patients with a mental illness resulting in permanent or fluctuating impairment of decision-making ability;
- patients with decision-making capacity for some, but not all, decisions.

9.2 For many patients, the loss of decision-making capacity is progressive rather than immediate and may fluctuate over time. Such patients should be encouraged to participate in treatment decisions consistent with their level of capacity at the time a decision needs to be made.

9.3 Situations may arise where a patient has impaired decision-making capacity and a surrogate decision-maker must make health care decisions on behalf of the patient, including decisions to no longer continue or not to commence life-sustaining treatment. This should be undertaken in collaboration with the practitioner.

9.4 Where a known and valid advance directive exists, it should be used in decision-making.

9.5 Where a surrogate decision-maker is required, the patient's known values and goals regarding end of life care should be used to guide a care plan and treatment decisions.

9.6 The surrogate decision-maker, or 'person responsible', for a patient lacking decision-making capacity should be identified in accordance with relevant legislation (eg., guardianship acts). Ideally, a surrogate decision-maker should be familiar with the patient and able to represent the patient's values and goals regarding end of life care.

9.7 Children and young people

9.7.1 Children and young people may be considered to have limited rather than impaired (unless otherwise relevant) decision-making capacity.

9.7.2 The continuing physical, emotional and cognitive development of children and young people sets them apart from adults and influences all aspects of their care.

9.7.3 Children and young people experiencing end of life care should be involved as much as possible in clinical decision-making as appropriate to their mental and emotional maturity as determined by a medical practitioner.

9.7.4 Developmental influences through infancy, childhood, and adolescence may impact upon[3]:

- the experience of illness;
- the understanding, reporting, and management of symptoms;
- psychological/emotional distress; and
- the understanding of death and dying.

9.7.4 Guidance should be offered to parents about how to communicate with their child and their siblings, where appropriate, regarding the child's condition.

10 Good medical practice and the relief of pain and suffering

10.1 The AMA believes that while medical practitioners have an ethical obligation to preserve life, death should be allowed to occur with dignity and comfort when death is inevitable and when treatment that might prolong life will not offer a reasonable hope of benefit or will impose an unacceptable burden on the patient.

10.2 Medical practitioners are not obliged to give, nor patients to accept, futile or burdensome treatments or those treatments that will not offer a reasonable hope of benefit or enhance quality of life.

10.3 All patients have a right to receive relief from pain and suffering, even where that may shorten their life.

10.4 While for most patients in the terminal stage of an illness, pain and other causes of suffering can be alleviated, there are some instances when satisfactory relief of suffering cannot be achieved.

10.5 The AMA recognises that there are divergent views regarding euthanasia and physician-assisted suicide. The AMA believes that medical practitioners should not be involved in interventions that have as their primary intention the ending of a person's life. This does not include the discontinuation of futile treatment.

10.6 Patient requests for euthanasia or physician-assisted suicide should be fully explored by the medical practitioner in order to determine the basis for such a request. Such requests may be associated with conditions such as a depressive or other mental disorder, dementia, reduced decision-making capacity, and/or poorly controlled clinical symptoms such as pain. Understanding and addressing the reasons for such a request will allow the medical practitioner to adjust the patient's clinical management accordingly or seek specialist assistance[7].

10.7 If a medical practitioner acts in accordance with good medical practice, the following forms of management at the end of life **do not** constitute euthanasia or physician assisted suicide:

- not initiating life-prolonging measures;
- not continuing life-prolonging measures;
- the administration of treatment or other action intended to relieve symptoms which may have a secondary consequence of hastening death.

10.8 Medical practitioners are advised to act within the law to help their patients achieve a dignified and comfortable death.

11 Artificial nutrition and hydration

11.1 The AMA recognises that in Australia, artificial nutrition and hydration, or medically administered nutrition and hydration, may legally be considered 'medical treatment'. Like all treatment limitation decisions, decisions to not offer or no longer continue artificial nutrition and hydration must be undertaken in accordance with good medical practice.

12 Resuscitation orders

12.1 The AMA recognises that limitations on resuscitation orders constitute treatment limitation decisions that must be undertaken in accordance with good medical practice. Good medical practice may include, as well as override limitations on resuscitation orders.

13 Grief and bereavement

13.1 The AMA affirms that grief and bereavement are a natural part of the dying process, experienced by the patient, family members, and the health care team. The expression of grief and course of bereavement is unique to each individual.

13.2 The morbidity associated with grief and bereavement is a major cost to healthcare[3].

13.3 The health care team can play a vital role in reducing the impact of grief and bereavement on family members and carers by attempting to alleviate the burden and guilt associated with having to make treatment-limiting decisions.

13.4 Counselling can help an individual to accommodate their loss and grief and assist in reducing the associated morbidity for the patient, their family members and carers. Counselling should be available to the patient throughout their end of life care and to their family members and carers, as well as the health care team, before and after the patient's death.

14 Carers

14.1 The AMA recognises that carers play an important and integral role in working with the health care team to support the patient's health care.

14.2 All carers are entitled to the same rights, choices, and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education[8].

14.3 There are a diverse range of carers including young carers, aged carers, culturally and linguistically diverse carers, gay men and lesbian carers, rural and remote carers and others. Some carers may have special requirements to assist them in their care situation.

14.4 Carers experience associated physical and emotional stress, anxiety, social isolation, financial stress, and other difficulties that may adversely affect their own health and well-being.

14.5 The health and well-being of carers is linked to the availability, quality, responsiveness and cost of support from health and community services[8,9].

14.6 Appropriate respite care and other support services should be accessible for patients and carers.

14.7 Carers should be offered appropriate training to support the management of the patient, including 'hands on' skills development for their carer role.

15 Workforce

15.1 The AMA advocates that medical practitioners should have appropriate ongoing training in end of life care, including palliative care and grief and bereavement counselling, to support both patients and their family members.

15.2 Medical practitioners should also have reasonable access to relevant end of life care specialists for advice, including advice regarding ethical dilemmas.

15.3 Whilst caring for patients at the end of life, junior doctors should be:

- appropriately trained in communication with patients and their families;
- supervised and supported by senior practitioners within the health care team; and
- made aware of their legal and ethical obligations to the patient and the patient's family members.

16 Clinical settings

16.1 Some patients may be treated in more than one clinical setting through the course of their illness including intensive care (including neonatal intensive care), inpatient hospital care, aged care facilities, palliative care facilities, and at home. Support should be given to the development of services that will meet the changing requirements in patient care and streamline movement between clinical settings.

16.2 Where possible, the patient should be cared for in the environment of their choice.

17 Palliative care

17.1 Palliative care provides not only physical support but also psychological, social, emotional and spiritual support for patients, their families and friends[3,9]. This includes grief and bereavement support.

17.2 Quality palliative care services should be available to everyone in need of such services.

17.3 Adequate funding for quality palliative care services should be provided.

17.4 Adequate funding for appropriate palliative care research and projects should be provided.

See also:

AMA Code of Ethics 2004. Editorially Revised 2006.

AMA Position Statement on the Role of the Medical Practitioner in Advance Care Planning 2006.

*Please note that the Position Statement on Care of Severely and Terminally Ill Patients - 1997 has been revised and is now the Position Statement on the Role of the Medical Practitioner in End of Life Care - 2007

Reference:

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[1] Kerridge I, Lowe M, McPhee M. *Ethics and law for the health professions. 2nd edition.* The Federation Press, Australia, 2005.

[2] Adapted from White B and Willmott L. *Rethinking Life-Sustaining Measures: Questions for Queensland*. QUT, February 2005.

[3] Palliative Care Australia. *Standards for Providing Quality Palliative Care for All Australians.* 4th edition. PCA, Canberra, May 2005.

[4] *World Medical Association Statement on Physician-Assisted Suicide*. Adopted by the 44th World Medical Assembly, Marbella, Spain, September 1992 and editorially revised at the 170th Council Session, Divonne-les-Bains, France, May 2005.

[5] Taylor A and Box M. *Multicultural Palliative Care Guidelines.* Palliative Care Australia, 1999.

[6] Australian Medical Association (Queensland). *Options for Dying With Dignity.* AMAQ, February 1994.

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