

PLANNING FOR THE END OF LIFE FOR PEOPLE WITH DEMENTIA

**A REPORT FOR
ALZHEIMER'S AUSTRALIA**

PAPER 23 PART TWO

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TABLE OF CONTENTS

PREAMBLE	5
FOREWORD BY A FAMILY CARER	6
SECTION 1: OVERVIEW	7
SECTION 2: WHAT IS DOCTOR-ASSISTED DYING?	8
THREE DEFINITIONS OF EUTHANASIA	8
DEFINITION OF PHYSICIAN-ASSISTED SUICIDE	8
WHAT EUTHANASIA IS NOT	8
NONE OF THESE IS EUTHANASIA, AS EXPLAINED BELOW	9
SECTION 3: ARGUMENTS FOR AND AGAINST AVE	10
3.1 ARGUMENTS IN FAVOUR OF AVE AND RESPONSES TO THOSE ARGUMENTS	10
COMPASSION AND RELIEF FROM SUFFERING	10
DEATH WITH DIGNITY	10
PATIENT AUTONOMY, SELF-DETERMINATION AND CONTROL	10
THE NEED FOR OPENNESS, HONESTY AND ACCOUNTABILITY	11
SOCIAL JUSTICE	11
WE LIVE IN A DEMOCRACY AND THE MAJORITY WANT IT	11
IF AVE IS LEGALISED PATIENTS WON'T NEED TO END THEIR LIVES PREMATURELY	12
3.2 ARGUMENTS AGAINST AVE LEGISLATION (NOT AGAINST AVE) AND RESPONSES TO THOSE ARGUMENTS	12
FEAR OF ABUSE/COERCION	12
THE SLIPPERY SLOPE ARGUMENT	12
PALLIATIVE CARE CAN CONTROL PAIN AND OTHER SUFFERING AND SHOULD BE BETTER RESOURCED	13
3.3 ARGUMENTS AGAINST AVE AND RESPONSES TO THOSE ARGUMENTS	13
RELIGIOUS CONVICTIONS AND A BELIEF IN THE SANCTITY OF LIFE	13
THE PROBLEM OF KNOWING WHEN REQUESTS ARE TRULY INFORMED AND AUTONOMOUS	13
EUTHANASIA WOULD DESTROY TRUST BETWEEN DOCTORS AND PATIENTS, AND BETWEEN DOCTORS AND THE COMMUNITY	13
AVE WOULD INCREASE MEDICALISATION OF THE END OF LIFE	14

3.4 ADDITIONAL ISSUES RELATED TO THE CHALLENGES OF A FEDERAL LEGISLATIVE SYSTEM	14
SECTION 4: SPECIFIC AVE ISSUES FOR PEOPLE WITH DEMENTIA	15
4.1 MAJOR ISSUES	15
DISTRESS AT BEING DIAGNOSED COULD TRIGGER A REQUEST FOR AVE	15
HIGHER LEVELS OF SUPPORT MAY BE REQUIRED FOR PEOPLE WITH DEMENTIA	15
POSSIBLE EFFECT OF RECENT MEDIA COVERAGE OF DEMENTIA RATES	15
SHOULD A PREVIOUSLY EXPRESSED WISH FOR AVE BY A PERSON WITH DEMENTIA BE RESPECTED?	16
SHOULD OTHERS BE ABLE TO REQUEST AVE FOR PEOPLE WITH ADVANCED DEMENTIA?	16
SHOULD A REQUEST FOR AVE MADE WHILE THIS IS ILLEGAL BE HONOURED IF AVE IS LEGAL AT A LATER TIME?	17
4.2 OTHER ISSUES	17
ADEQUATE PAIN MANAGEMENT	17
WITHHOLDING ARTIFICIAL NUTRITION AND HYDRATION (FOOD OR FLUIDS)	18
REFUSAL OF ANTIBIOTICS	18
SUMMARY	19
REFERENCES	20
ALZHEIMER'S AUSTRALIA PUBLICATIONS	22

PREAMBLE

The general reluctance in our society to discuss end-of-life issues translates into a failure by many to prepare properly for the end of life. This includes not making wills, expressing wishes about funeral arrangements, considering the need to make powers of attorney or give directions for care through advance directives.

The consequence is that the failure to think in advance about end-of-life issues will impact not only on the quality of life of the individual in their final years and months, but also on those around them. End-of-life issues are, by their nature, complex, personal and sensitive, but they are made all the harder if the wishes of the person concerned are not properly understood or set out.

The first part of this publication, which was released on 4 April 2011, explained the legal options that people can exercise now in respect of planning for the end of life. These include advance care planning, preferred place to die, refusal of treatment and withdrawal of treatment.

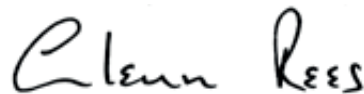
This second publication considers what additional options might become available in the future that people with dementia could access towards the end of their lives. These could include euthanasia and assisted suicide.

We take the view that the debate on euthanasia is clouded in confusion, particularly in relation to the terminology used.

The intention of this publication is not to tell people what view they should take, but rather to explore issues for and against more active approaches to the termination of life.

We are clear that the debate about end-of-life issues should not be one about states' rights, but one by people about the lives of the people themselves.

We are deeply grateful to Professor Colleen Cartwright for undertaking this task and for working with the National Consumer Advisory Committee. This publication simply would not have been possible without the commitment and experience of Professor Cartwright in this difficult and complex area. Many thanks to Jenny Laraman for her editing expertise.



Glenn Rees
Chief Executive Officer
Alzheimer's Australia

FOREWORD BY A FAMILY CARER

The Alzheimer's Australia National Consumer Advisory Committee commissioned work on dementia and end-of-life issues for two reasons.

First, because of a general concern that people with dementia and their family carers do not understand their rights and options in relation to financial and medical decisions at the end of life. These difficulties are compounded by a poor level of understanding in the community about dementia and also by the lack of appropriate counselling and advice about the currently available legal options.

Our belief is that this results in people living with dementia making less use than they should of currently available legal options, thereby depriving themselves of the peace of mind that can come from knowing their rights and that these will be respected.

Some will take the view that increased resources, including better information and counselling, could make the current system work much better for people with dementia and their family carers. Others will take the view that more active approaches to termination of life, including euthanasia or assisted suicide, should be available.

The second reason for commissioning work on end-of-life issues is to assist Australians, and in particular those living with dementia, to better understand the additional end-of-life options which are under discussion. That is the purpose of this publication. We have not sought to argue for a particular position but rather we seek to assist people living with dementia, and their carers/families, to be better positioned to take part in what we anticipate will be a vigorous national debate over the coming years.

Many of the issues discussed are of general

relevance to all Australians but there are particular issues that need consideration in respect of those with dementia. These are discussed in the last section of this publication.

I should like again, on behalf of the Ethics Subcommittee of the Alzheimer's Australia National Consumer Advisory Committee, to thank Professor Colleen Cartwright for being so willing to undertake the writing of this publication. We are even more grateful for her openness and willingness to take on board the many different comments from different quarters that she has received from the Subcommittee.

We hope that this publication will assist Australians generally, and people living with dementia in particular, to discuss issues that, if we are honest, we all seek to avoid to our own disadvantage.

Elizabeth Fenwick
Chairperson
Ethics Subcommittee
National Consumer Advisory Committee

SECTION 1:

OVERVIEW

Part 1 of this publication explained what dementia is and what receiving such a diagnosis means. It then discussed options for Advance Planning – both for financial matters and for personal care and medical treatment that might be wanted or not wanted at the end stage of life. The issue of capacity to make choices relating to such planning was then explored, including who has the legal authority to make such decisions if the person with dementia cannot do so.

Part 1 then outlined the options that the law currently allows, including such things as refusal of food or medical treatment, adequate pain control, resuscitation, terminal sedation and palliative care. Issues for carers, funeral arrangements and bereavement care were also considered in Part 1 and a list of resources and helpful contacts was provided (Part 1 is available at www.alzheimers.org.au).

Part 2 of the publication is a discussion about additional end-of-life options which may become legally available at some time in the future, i.e., assisted death (usually called euthanasia or assisted suicide). Alzheimer's Australia is not advocating that such options become available and takes a neutral position about them. However, there is a need for an informed debate on the issues, given that well-conducted research indicates that a significant proportion of the community supports making such options available.^{1 2 3 4}

Some people believe that they should have the right to make decisions about their own bodies and about the way they die; in other cases people see the current legal and medical options as inadequate. While Australia was the first place in the world to pass legislation allowing both euthanasia and physician-assisted suicide (i.e. the Northern Territory Rights of the Terminally Ill Act (1995)), that legislation was overturned by the

Commonwealth's Euthanasia Laws Act (1997) and at present these options are illegal throughout Australia. However, given that assisted dying Bills are regularly presented to state/territory parliaments in Australia (e.g. the recent: Western Australian Voluntary Euthanasia Bill 2010, introduced to the Parliament by the Hon Robin Chapple on 20 May 2010; the South Australian Voluntary Euthanasia Bill 2010, introduced to the Parliament by the Hon Bob Such MP on 24 June 2010; and the Restoring Territory Rights (Euthanasia Laws Bill) introduced into Federal Parliament on 29 September 2010 by the Hon Bob Brown, leader of the Greens Party), it is possible that, at some time in the future, legislation will be passed that allows such options. It is therefore important for the arguments for and against assisted dying to be understood and for open debate to be encouraged. We hope that the information provided in this document will contribute to that debate.

Section 2 of Part 2 asks: What is doctor-assisted dying*? and identifies what is and what is not euthanasia. In Section 3, arguments for and against doctor-assisted dying are provided and in Section 4 some issues which relate specifically to assisted dying for people with dementia are considered.

*(Note: while it is possible in some countries, such as Switzerland, for people to be assisted to die by someone other than a medical practitioner, in most countries – including Australia – legislation which has been enacted or proposed limits the carrying out of such actions to medical practitioners and therefore the term “doctor-assisted dying” will be used in this publication).

SECTION 2:

WHAT IS DOCTOR-ASSISTED DYING?

The terminology most often used when referring to doctor-assisted dying is euthanasia and physician-assisted suicide.

Three definitions of euthanasia

The European Association for Palliative Care defines euthanasia as "A doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request".⁵

In Australia, the Senate Standing Committee on Legal and Constitutional Affairs, in its report on the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008 defined active euthanasia as "where medical intervention takes place, at a patient's request, in order to end the patient's life".⁶

The definition used in studies by Steinberg et al, 1996a & b and Cartwright et al, 1998, 2002 is:

Euthanasia is a deliberate act intended to cause the death of the patient, at that patient's request, for what he or she sees as being in his/her best interests.

That is, it is active (involving a deliberate act); it is voluntary (at the request of a competent patient); it is euthanasia in its original meaning of a good or peaceful death; and the primary intention of the act is to cause the death of the patient.

Definition of physician-assisted suicide: A final definition is the distinction between active voluntary euthanasia (AVE) and physician-assisted suicide (PAS). Physician-assisted suicide relates to:

the doctor giving a person advice about how to commit suicide, giving the person a prescription for medication to use for suicide, preparing a mixture for the person to take to commit suicide and/or setting up equipment

for the person to use to commit suicide. It does not include performing the action, such as giving the person an injection of the drugs.⁷
8 9 10

What euthanasia is not: There is a great deal of fear in the general community about the end stage of life. Many problems stem from confusion over what is, or is not, euthanasia. Some commonly held beliefs are that euthanasia includes:

- (a) giving increasing amounts of needed pain relief which may also have the effect of shortening the person's life; or
- (b) respecting a patient's right to refuse further treatment where such refusal will result in the patient's death; or
- (c) withholding or withdrawing life support systems that have ceased to be effective or that will provide no real benefit to the patient; or
- (d) terminal sedation.

None of these is euthanasia, as explained below.

(a) Giving pain relief which may also shorten life is often referred to as “the doctrine of double effect” – the primary intention is to relieve pain; a secondary, unintentional effect may be the hastening of the person’s death by a few hours or days. In Australia, the UK and many other countries “double effect” is accepted by most religious and medical groups, including those who strongly oppose euthanasia, such as the Catholic Church. Conversely, not giving adequate pain treatment when it is needed may actually shorten life: the patient may suffer complications such as life-threatening cramps or severe respiratory problems if severe pain is left untreated. Leaving someone in pain is abuse and there have been several successful legal cases in the US where doctors and/or hospitals have been sued for inadequate treatment of pain.^{11 12 13 14} In addition, some Australian legislation (e.g. South Australia’s Consent to Medical Treatment and Palliative Care Act 1995) offers specific protection to doctors who provide medical treatment with the intention of relieving a patient’s pain or other symptoms and the doctor will not be liable for civil or criminal action even if the treatment hastens the patient’s death.

(b) Respecting a patient’s right to refuse treatment was fully explained in Part 1; in brief it is a legal and moral right of every competent person, through a current refusal, and is also the right of a person who is no longer competent but who expressed such a refusal in an Advance Directive or requested a substitute decision-maker to refuse on their behalf, even if such refusal will result in the patient’s death.

(c) Withholding/withdrawing futile life-support systems, also explained in Part 1, used to be called “passive euthanasia” but that term is not only inaccurate – and therefore unhelpful – but it can lead to the inappropriate continued use of invasive technology that often is not prolonging life, but is merely prolonging the dying process. Removal of futile treatment is good medical practice. Futility is generally considered to be when burden outweighs benefits – but “burden” and “benefit” should usually be from the patient’s viewpoint.

(d) Terminal Sedation, as noted in Part 1, is a recent, controversial addition to the discussion about what is legally allowed in relation to end-of-life care. It refers to the use of sedative drugs to induce unconsciousness in terminally ill patients in order to relieve suffering, including anxiety, when other attempts at relief have failed. It includes withholding or withdrawing artificial nutrition and hydration and is used extensively in the UK.¹⁵ Some doctors have described terminal sedation as “slow euthanasia” and claim that it is ethically inferior to euthanasia because it takes patients longer to die, with the potential for further suffering. Others disagree and argue that the major concern is patient care and comfort. Some palliative care clinicians prefer the term “palliative sedation”, since calling it “terminal sedation” may suggest that it is euthanasia, with the result that treatment for intractable terminal suffering may be under-prescribed.

Cellarius¹⁶ notes that:

Although terminal sedation has received widespread legal and ethical justification, the practice remains ethically contentious ... [I]t is clear that providing terminal sedation in combination with the withholding or withdrawing of life-prolonging treatments such as fluid and nutrition can foreseeably hasten death significantly—what is here called early terminal sedation (ETS). There are ethical justifications for the use of sedation in palliative care and thus it would seem that ETS is an ethically and legally acceptable practice.

In Summary: giving pain relief which may also shorten life, accepting a person’s right to refuse medical treatment or to have treatment withheld/withdrawn (whether that refusal/request is given in the immediate present by a person who still has capacity, or through an advance directive or substitute decision-maker by a person who has lost capacity, such as someone with advanced dementia) is not euthanasia; they are actions which allow the person to die naturally from their underlying disease (for the purposes of this publication, that disease is dementia). From this point on, AVE will be used to apply to both euthanasia and physician-assisted suicide.

SECTION 3:

ARGUMENTS FOR AND AGAINST AVE

Few issues have the power to incite such strong emotions and heated debate as that of AVE, and whether or not the law should allow it as an option for terminally ill patients. In most cases, both proponents and opponents of AVE are people of good will grappling with how to achieve what they see as the best options at the end of life.

Examples of the most common arguments for and against AVE and whether or not it should be legalised – and responses to those arguments – are presented in Sections 3.1 – 3.3 but it is acknowledged that there are many more ethical, philosophical, religious and practical arguments on this topic than can be included here. The arguments are complex and it is unlikely that universal consensus on this issue will ever be reached.

3.1 Arguments in Favour of AVE and Responses to those Arguments:

The most common arguments in favour of AVE (and legislation allowing AVE) relate to: compassion for suffering at the end of life; death with dignity; autonomy, self-determination and control; the need for openness, honesty and accountability; social justice issues; majority rule in a democracy; and that if AVE is legalised, patients won't need to end their lives prematurely.

- **Compassion and relief from suffering:** those who support euthanasia argue that the current law lacks compassion and mercy, forcing patients to continue to suffer and denying doctors the option of ending the patient's agony, which can sometimes only be achieved by rendering the patient unconscious or assisting them to die. Patients may wish to not only relieve their own suffering but also the suffering of the people they love. Proponents

of the compassion argument also claim that because AVE is illegal, some patients resort to suicide, often by more painful methods, such as gunshots or hanging.

Responses to these arguments include that palliative care can provide adequate comfort for pain and suffering and that distress is labelled 'unrelievable' when the real problem is that

health care providers are inexperienced in palliative care.

- **Death with dignity:** the argument here is that patients have a right to preserve their dignity and that death (especially in a hospital setting) can be very undignified, especially if the person is incontinent and/or connected to machines. Many people fear that the last memories their loved ones have of them will not be how they wish to be remembered.

The main response to this argument is that preserving a person's dignity depends more on the attitudes of those around them – families and staff – and on the courtesy and respect afforded to them than it does on the treatment they are receiving.

- **Patient autonomy, self-determination and control:** Arguments here include: respect for individual autonomy and self-determination are fundamental principles in Western medical ethics and decision-making, often expressed as a desire for control over the timing and manner of death. A competent, terminally ill patient, who has judged that their suffering makes continued life an unwelcome burden, should be able to request a medical practitioner to bring about their death. Prohibiting AVE is a restriction on liberty and autonomy. Given that the right to refuse treatment, even if that refusal will result in death, is both a legal and a moral right (as

explained in Part 1), there should be the same moral right to AVE. For people who are physically unable to bring about their own death, this should include the right to be assisted to die.

Responses to these arguments include that, because AVE requires the assistance of a second person, it is not just one person's autonomy or self-determination that is at issue and a right to die does not equate to a right to be killed. Autonomy is never absolute; the legitimate competing rights of other people or of society must also be taken into account - the potential bad consequences may outweigh the good. There is a risk that physicians who do not know how to adequately relieve a patient's suffering may agree to end that patient's life. Patient autonomy is an illusion when the choice becomes continued agony or a hastened death.

- **The need for openness, honesty and accountability:** Both anecdotal and research evidence demonstrates that the practice of AVE already occurs; providing that they are sure that their responses are confidential, doctors and nurses acknowledge that they assist patients to die, including where it is not legal to do so. However, because it is currently illegal, there cannot be open discussion about it and grieving families/loved ones have to pretend that something different occurred from what they know to be the case. If AVE were legalised it could be discussed openly, allowing relatives and friends to also grieve openly. Because of the illegality, and/or the social stigma attached to AVE, there can be traumatic psychological consequences for family members and others involved, including feelings of guilt and fear of detection. To protect loved ones from this, some patients who desperately want to die feel forced to go on living.

Decriminalisation would also allow the development of better practices, including doctors working with pharmacists to develop a documented regimen of drug use producing least sideeffects. When AVE is practiced in secret, problems can, and do, occur, e.g. patients do not die after being given all available medication, leading in some cases to a family member having to take actions to end the person's life. The resulting trauma is obvious and long-lasting.

Response: Even where assisted death is legal, technical difficulties and other complications are still sometimes experienced, resulting in diminished, not enhanced, quality of end-of-life care.

- **Social justice:** Many people who are well-educated and in the higher socio-economic groups, who know who to ask and how to ask, have access to AVE while the rest of the community does not. Also, patients whose diseases make them dependent on machines or other technology can control their time of dying by requesting that treatment be withheld or withdrawn while patients who are not technology-dependent do not have the same right. This is discriminatory and proponents argue that, given that there is no moral difference between withholding or withdrawing life support and providing AVE, those who are not technology-dependent should be provided with assistance to die if they request it.

Other arguments in this group include that: there is no intrinsic moral difference between killing and letting die because both intention and outcome are the same; it is morally worse to prolong someone's suffering rather than kill them; and it is unjust to prolong someone's life by a range of interventions but then refuse them assistance to die at the end.

Response: There is indeed a moral distinction between taking life and withdrawing inappropriate treatment to allow death to occur, and between making a person die and letting a person die. Intention to relieve pain, even if death is thereby hastened, is morally different to intention to end the patient's life.

- **We live in a democracy and the majority want it:** The majority of the general community support the legalisation or the practice of assisting terminally ill patients to die if that is what they want. This is evidenced by both opinion polls and academic research. If such a law has majority support, the minority may choose not to have anything to do with it but should not deny the option to those who want it.

Response: Many surveys are flawed because questions are ambiguous or "leading," and the general public hold misperceptions about medical practices; some people say they support euthanasia when they actually support

giving adequate pain relief, something which is already legally available.

- **If AVE is legalised, patients won't need to end their lives prematurely:** An additional argument in favour of legalising AVE is that if patients know AVE is available, they may delay taking action or not take up the option at all. Some terminally ill people kill themselves before they really want to, for fear of losing the ability to do so through hospitalisation or disability. Legalising AVE would give patients peace of mind and reassurance that they could control their own dying, should they need to.

Response: If patients and their carers receive adequate support and counselling, including high-quality palliative care, and are encouraged to focus on life rather than death, they may not want to end their lives at all.

3.2 Arguments against AVE Legislation (not against AVE) and Responses to those Arguments:

Another group of arguments is proposed by those who are not opposed to AVE but who do not believe that it should be legalised. These arguments include: fear of abuse/coercion; concern about "the slippery slope"; and the claim that palliative care can adequately control suffering if properly resourced.

- **Fear of abuse/coercion:** If AVE were legally available, some people might be directly or indirectly pressured into requesting it by families who are no longer able or willing to carry the burden of care, or by health professionals who feel helpless to provide further medical treatment, or by a health system that wants to save money. Others would request it in order to remove the burden of their care from their families. Vulnerable patients, such as these who are old, poor or mentally ill could also be coerced into requesting it. The right to AVE could become the duty to accept AVE or having to justify not asking for AVE.

Response: Patients can already be coerced into refusing treatment or requesting that treatment be withdrawn, both actions intended to bring about their death, yet that is legally available. Many people feel forced to go on living when they would rather die.

- **The slippery slope argument:** The majority of slippery slope arguments contain all or some of the following claims: that abuse of legalised AVE cannot be prevented; once it is allowed for competent, terminally ill people numbers requesting it will increase dramatically and it will then be extended to terminally ill people who are no longer competent, then perhaps to non-terminally ill people who may never have been competent and finally to those vulnerable patients who may be competent but whose lives are judged by others to be "not worth living" (e.g. those who have a severe physical disability or advanced dementia or who are simply "too old"). The abuses of Nazi Germany are seen as evidence of such a "slippery slope"; in the Australian context it was argued that the Northern Territory's Rights of the Terminally Ill Act risked indigenous people's lives being ended prematurely, with the history of white-on-black racial discrimination being seen as cause for concern.

Responses: If the slippery slope is a probable consequence of legalising AVE, why has it not been a result of allowing treatment refusal or withdrawal? Why should allowing AVE weaken society's general abhorrence of killing, if killing in war and/or self-defence has not already done so? The reasons that justify AVE - mercy and respect for autonomy - cannot logically also justify killings that are neither merciful nor show respect for autonomy. Carefully tested safeguards can include: AVE only being available to competent adults who give fully informed consent; and psychiatrists ensuring that those with serious mental illness cannot access AVE in a crisis. What the Nazis did had nothing to do with euthanasia, (i.e. a good or peaceful death), it was murder. Use of qualified interpreters and procedural safeguards could deal with communication issues in indigenous populations; such patients would be more likely to experience barriers to obtaining AVE than risk having it when they do not want it. Evidence from the Netherlands indicates that the percentage of very old people who receive AVE is very small compared to other age groups and people who cannot request AVE are more likely to receive terminal sedation than AVE.

- **Palliative care can control pain and other suffering and should be better resourced:**

Requests for AVE are calls for help because end-of-life care needs are not being met. With an ageing population and limited health-care resources, governments would see AVE as a less-costly alternative to good palliative care*, requiring fewer resources. Until all patients have equal access to palliative care, AVE should not be an option.

Responses: Patients still ask for AVE, even when they are pain-free and exemplary palliative care is provided. Palliative care may control most pain but cannot always control non-physical suffering, nor some physical symptoms such as nausea, breathlessness, inability to swallow and extreme weakness. What counts as intolerable suffering is a subjective matter. Dying, including when and how to die, is a personal and social problem, not just a medical issue. Since only a small percentage of terminally ill people request assistance to die, even where it is a legal option, the needs of the majority will still have to be met, so palliative care must be well-resourced, but this will not remove all requests for AVE.

(*Note: The enactment of The Rights of the Terminally Ill Act in the NT actually saw an increase in government funding for palliative care in that state, perhaps to ensure that the government did not see AVE as a less-costly alternative to palliative care).

3.3 Arguments Against AVE and Responses to those Arguments:

The final group of arguments is made by those who strongly oppose AVE. Such arguments relate to: religious convictions/sanctity of life; knowing when requests are truly informed and autonomous; the possibility that AVE could destroy trust between patients and doctors; and the medicalisation of the end of life that AVE would bring about.

- **Religious convictions and a belief in the sanctity of life:** Only God has the right to control life and death. The principle of sanctity of life means that it is never acceptable to intentionally kill an innocent human being. To terminate a patient's life, even at his or her request, would violate divine law in a crime

against life itself.

Responses: Sanctity of life is not an absolute nor is AVE explicitly forbidden in the Bible. What appears in some texts as "thou shall not kill" is actually "thou shall do no murder". In a democratic society, it is unacceptable for some people to impose their religious beliefs on others or to compel those who have different values to die painful or protracted deaths. Patients or doctors who have religious objections do not have to take any part in AVE. Medicine has conflated sanctity of life with the increasing scope of technological advances to prolong life, thus making acceptance of death morally suspect.

- **The problem of knowing when requests are truly informed and autonomous:** There are so many factors that may propel a person to request AVE (some of them possibly not even recognised by the patient themselves) that it is doubtful that such requests could ever be said to be truly voluntary. If people feel useless and a burden, or are otherwise vulnerable, the choice for AVE may not really be a free choice but may be coerced by socially limiting options.

Responses: A competent person whose condition is unlikely to improve (and perhaps may become worse) and who has decided that their present state is intolerable is making a legitimate request, even though they made their decision while suffering. If the person is no longer competent but they made their decision in a legal advance directive while they were free of distress and had a clear mind, their wishes should be accepted as autonomous and voluntary.

- **Euthanasia would destroy trust between doctors and patients, and between doctors and the community:** AVE is fundamentally inconsistent with the physician's role of healer. Legalisation will undermine the public's trust in the medical profession and dramatically change the nature of the doctor-patient relationship.

Responses: Legal cases, even those involving refusal of life-sustaining treatment, have rejected the notion that the ethical integrity of the medical profession might, at times, over-ride patient self-determination. Trust between patients and their doctors could be increased, not eroded, by knowing that the doctor will assist the patient to die under some

circumstances. AVE is entirely consistent with one of the highest ideals of medicine, i.e., to do everything possible to promote patients' well-being while completely respecting patients' autonomy.

- **AVE would increase the medicalisation of the end of life:** a medical intervention would bring about the person's death.

Response: Having to continue living with medical technological support, against one's will, increases the medicalisation of the end of life more than would legalising assistance in dying.

3.4 Additional Issue Related to the Challenges of a Federal Legislative System*:

Australia is a federation of states and territories, which constitutionally all make their own health law, resulting in different legislative provisions, documentation and terminology. This is already providing a significant challenge for a National Working Party¹⁷ in trying to achieve national consistency in relation to Advance Care Planning and use of Advance Directives. It is reasonable to assume that this problem would increase significantly if any state or territory passes legislation allowing AVE.

"AVE tourism" is already a reality in Europe, with people travelling to Switzerland from other countries, including Australia, to access the assisted-suicide provisions which exist in that country. In Australia, when the NT Rights of the Terminally Ill Act was in place, one of the first people to attempt to use the legislation was a man from Broken Hill in NSW, who travelled to Darwin expecting to be assisted to end his life by Dr Philip Nitschke. Although this did not happen because all certification required under the legislation could not be obtained, it is reasonable to assume that terminally ill people, or those with dementia, would travel to any state or territory in which AVE was legally available.

Response: Any legislation would require carefully thought-out regulations to deal with "AVE shopping". These could include residency requirements and/or established relationships with medical practitioners in the state/territory.

* Note: A National approach would be ideal but is probably unlikely.

In summary, as previously identified, there are many complex arguments on all sides of this debate and it is unlikely that consensus on this issue will be ever be reached.

SECTION 4:

SPECIFIC AVE ISSUES FOR PEOPLE WITH DEMENTIA

All of the issues and arguments discussed above take on an additional level of complexity when they are applied to people with dementia. Some people with dementia live for many years with good – or at least acceptable – quality of life, even when they have lost the capacity to make many or most of their own decisions (see Part 1 of this publication for a discussion of Capacity). Some issues are presented below, followed, where appropriate, by responses to the statements. However, some issues will require much more discussion, debate and community-wide research to ensure that all the salient points have been considered.

4.1 Major Issues

- **Distress at being diagnosed with dementia could trigger a request for AVE:**

The trauma of a diagnosis of dementia, especially when that is combined with limited understanding of what that will mean and fear for their quality of life, or concern for the burden that loved ones will bear, may make AVE seem like the best option for some people with dementia. The stigma attached to dementia may also prompt such a request.

Response*: Most legislation proposed in Australia and overseas requires a “cooling off” period after the first request and also a discussion with a palliative care specialist to ensure that the person and their family/carer understand the help that is available.

*Note: while the responses to this issue, outlined above, may help to reduce the risk associated with distress associated with a diagnosis of dementia, it is acknowledged that this risk would nevertheless remain and that it is a serious issue which would require vigilance on the part of the family/carer and

service providers in order to protect the person with dementia.

- **Higher levels of support may be required for people with dementia:** If legislation is passed allowing AVE, people with dementia would require an even higher level of counselling and support than is the case for the general population; this would need to be provided early in the disease process by counsellors skilled in working with people with impaired capacity and these resources are simply not in place.

Response: Continued lobbying of governments at all levels must be undertaken by both specialist medical and consumer groups to try to achieve adequate resources to provide the best counselling and support possible. However, in a country such as Australia with both geographical and multicultural challenges, “adequate resources” will be difficult to achieve. Nevertheless, if such legislation is passed, care will be needed to ensure that people with dementia are not denied access to it on the basis that adequate counselling is not in place, as this would constitute double discrimination.

- **Possible effect of recent media coverage of increasing numbers of people with dementia:**

The stigma that attaches to dementia in our current society is too great to risk AVE for people with dementia. At its extreme, this attitude is reflected in a statement reported by the UK Daily Telegraph on 18 Sep 2008, where Baroness Warnock, a UK Government advisor on ethics during the 1980s, said that people suffering dementia may have “a duty to die” because they are a burden on their families and the National Health Service¹⁸.

Response: One of the biggest challenges for people working in this sector is to alert the

community and policy-makers to the undoubted large and rapid increase ahead in the number of people with dementia but at the same time to not cause so much alarm and fear that it results in a backlash against people with dementia. It is also important that media coverage does not make everyone in the community who is becoming older think that it is inevitable that they will develop dementia. While numbers of people with dementia will certainly increase, because of the increasing longevity of the population, the percentage of people in each age group who have dementia is not increasing.

Approximately 12% of people in their early 80s have dementia and this increases to approximately 25% for those aged 85 and above – which means that 88% of 80-84-year-olds and 75% of those aged 85 and above do not have dementia! Communicating a balanced message will demand great skill.

- **Should a previously expressed wish for AVE by a person with dementia be respected?** A person who may previously have expressed a wish for AVE when their condition reached a particular level would no longer be able to competently request that when the time came, even if it was legally available by then. If previously expressed wishes are to be actioned, there would need to be very careful regulations about how such wishes are recorded. Options for people with dementia could include writing their wishes in an Advance Directive when they were in the early stages of the disease and still had capacity and/or they could ask their legally-appointed substitute decision-maker to organise AVE for them at a particular point in their disease process.

Opponents of AVE claim that advance requests for AVE are not uncommon in places such as the Netherlands and Belgium. However, Hertogh¹⁹ in an "evaluation of the practice of euthanasia" in the Netherlands, found an "absence of euthanasia cases concerning patients with dementia and a written advance euthanasia directive". He suggests two principal reasons for this absence: one is that it is not possible to be certain that the patient is truly experiencing the suffering they feared; the second is that advanced dementia prevents the opportunity for shared decision-making between the patient and

doctor that euthanasia should entail. This finding is supported by a broadcast by Radio Netherlands Worldwide on 24 November 2010 (downloaded 12/1/11) which indicated that most doctors in the Netherlands would not proceed with a request for AVE in an Advance Directive, particularly if it was completed some years before, because they require the person to confirm, at the time that AVE is to be administered, that this is still what they want.

It is also difficult to see how asking for AVE in an Advance Directive or through a substitute decision-maker is different to asking in an Advance Directive or through a substitute decisionmaker for life-sustaining treatments to be withheld or withdrawn at a given stage of illness – options that are currently legally available – given that both actions (AVE and withdrawing/withholding treatment) will result in death.

There could be a degree of difference if the person completed the Advance Directive or gave their instructions many years previously, based on what they thought their life might be like if they had advanced dementia, if once they actually reached that stage they appeared to be comfortable and not in distress. This could raise doubts about the validity of respecting the Directive or the instructions of a substitute decision-maker. In such cases a treating medical practitioner who might be prepared to provide AVE should seek advice from their hospital ethics committee or from the Public Guardian (or equivalent) in their particular state/territory before proceeding.

- **Should others be able to request AVE for people with advanced dementia?**

Response: We understand too little about how a person with dementia feels to be confident about taking such decisions on their behalf. If AVE becomes legally available and a person with dementia has not specifically requested that they are to receive it, they should not receive it. There would be no evidence that this is what the person would choose for themselves, were they competent to speak. Many people working in this field strongly advocate that the term "euthanasia" should only ever be used in relation to a specific request from a competent person. If the person with dementia who has not requested AVE was obviously in pain or otherwise distressed, medical procedures should be

utilised to provide the best comfort care and symptom relief for them, even if this subsequently hastened their death, but such actions should not be called euthanasia.

It would also be a very big burden for a substitute decision-maker to carry (whether that person was appointed by the patient themselves or was the legally authorised "next in line" to make substitute decisions) if they had to make such a decision.

- **Should a request for AVE made while this is illegal be honoured if AVE is legal at a later time?** A person who receives a diagnosis of dementia now, while AVE is illegal in this country, may request in their Advance Directive that they be provided with AVE when/if they reach a specific set of conditions in their illnesses trajectory "provided legislation is then in place which would allow for such an action".

Response: It is difficult to predict what a court would decide in such a case, given that what the person requested was illegal when the request was made but was posited against the action becoming legal when it was required to be provided.

4.2 Other Issues

Three other issues of particular relevance to end-of-life care of people with dementia, which are frequently misrepresented as AVE, are: adequate pain management; withholding artificial nutrition and hydration; and treatment of pneumonia or other infections with antibiotics. These issues were discussed at length in Part 1 in relation to people with dementia. A summary of the issues is repeated here because these actions are frequently misconstrued as AVE when they are absolutely not – they are legally sanctioned actions which are an essential part of good end-of-life care.

Adequate pain management: Every person (competent or not) has the right to adequate control of pain and other symptoms; to leave someone in pain or distress is abuse, yet research shows that people with dementia often die with inadequate pain control.²⁰ The Nuffield Council on Bioethics²¹ notes that:

[T]here is evidence that people with dementia experience poor care at the end of their lives,

with badly controlled pain ... (and that) ... recent research in the UK has suggested that amongst older people who die in hospital, those who have dementia are less likely to receive palliative medication ... than people who do not have dementia.

With good palliative care, almost all dying patients can be kept comfortable but still "awake" enough to communicate with family and friends. Proper assessment of pain in people with dementia is a skill which many health care providers lack; if someone no longer has capacity they may lack the ability to tell someone that they are in pain. However, good assessment tools, such as the Abbey Pain Scale²², are available and every health care professional who works with people with dementia or terminally ill people should be trained to use these tools. Giving adequate pain relief, even if it subsequently hastens the person's death by a few hours or days, is **not** AVE, it is good medical care. In fact, leaving someone in severe pain can hasten their death as they can suffer cramping or respiratory distress because of the pain.

Sometimes a patient's pain relief is compromised because families fear the use of morphine and object to its use, thinking that giving it equates to AVE. This is not the case but the treating health care professionals may need to give the family sufficient information for them to understand that morphine – or any other drugs – will only be given in the doses needed to control the person's pain or other symptoms. While death may be hastened, the intention is to relieve the patient's pain and other symptoms and their death will be a result of their illness, not of the medication. AVE should never be a substitute for adequate pain relief.

(Note: While seldom confused with AVE, an important issue related to adequate management of pain and other symptoms is access to good palliative care. The quality and availability of palliative care varies tremendously, especially for people in rural and regional communities. This problem is exacerbated for people with dementia because many palliative care practitioners have little or no training in providing palliative care to people with dementia. See Section 3 in Part 1 of this publication for a thorough discussion of the issue of palliative care for people with

dementia).

Withholding artificial nutrition and hydration (food or fluids): For a person with dementia, loss of the swallowing reflex is a normal part of advanced dementia, and a sign that death is approaching. To continue artificial nutrition and hydration** when the person has reached this stage of their illness can actually increase their suffering²³ and even deprive them of a peaceful death.^{24 25} (See Part 1 of this publication for more information about this).

(**Artificial nutrition and hydration: food or fluid provided through a tube down the person's nose or a tube inserted directly into the stomach).

It can be very challenging for carers and other family members to understand and accept that the person with dementia no longer wants or needs food or fluids. Carers or family members may feel helpless and think that providing food for the person they love is at least "doing something". Unfortunately, what they may be doing is causing the person distress and discomfort – or even actual suffering. Withholding artificial nutrition and hydration from a person with advanced dementia is **not** AVE, it is good medical care.

Refusal of antibiotics: "Pneumonia is common among patients with advanced dementia, especially towards the end of life."²⁶ Unless they have been specifically refused, antibiotics are often used to treat pneumonia, even in terminally ill people with dementia, based on the assumption that this will both prolong life and improve comfort. However, in a 6-year study conducted by Givens et al (2010) of over 320 nursing home residents with advanced dementia, the researchers found that while such treatment was associated with prolonged survival it did not improve the comfort levels of the patients with advanced dementia. This raises the question, "Is it ethical to prolong the life of a person in such a condition?" Again, not giving antibiotics to such patients is **not** AVE – while the research did show prolonged survival, in reality it is not prolonging their life, it is merely prolonging their dying.

SUMMARY

The issues outlined above, and in Part 1 of this publication, illustrate just how complex the issue of end-of-life care is for people with dementia. The rights and needs of many stakeholders have to be taken into account:

- patients have a right to the best quality of life possible; to have their wishes respected within the limits of the law; and at the end of life they need – and have a right to receive – exemplary care, especially in relation to pain and symptom management;
- carers have a right to be supported so the burden does not become too great; they have a need for good information about medical, legal, financial, social and ethical issues and, where possible, training to help them undertake the demanding work that they do;
- doctors have a need for better training to understand how to care for people with dementia and their families, as well as better training in pain management and palliative care; they also need information about the legal rights of the patients and of themselves;
- nurses also require better information and training and they also need to be acknowledged for the excellent work that many of them do to support their patients and their families, often beyond the call of duty.

If AVE ever becomes legally available the main challenge will be to support those who clearly want it to record their wishes and work with their carers to achieve the patient's desired outcomes while at the same time strongly protecting those who do not want it. In the meantime, a much bigger investment is needed to promote awareness and understanding of dementia.

For a thorough understanding of all of the issues around end-of-life care for people with dementia and their families, we recommend that Part 1 and Part 2 of this publication be read as one document.

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