

SUBMISSION

on the

MEDICAL TREATMENT ACT

On behalf of the

VOLUNTARY EUTHANASIA SOCIETY OF
VICTORIA INC.

70 Greville Street, Prahran

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1. EXECUTIVE SUMMARY

The Victorian *Medical Treatment Act* is little known (and therefore little used) and presents significant administrative and interpretive problems. Whilst it recognises the great importance of patient autonomy, it does not ensure this to its greatest and natural extent.

Of much greater importance is its failure to ensure maximum relief of pain and suffering which legalisation of medically assisted dying would allow.

2. INTRODUCTION

The Victorian *Medical Treatment Act (MTA)* was developed following the Parliamentary Committee of Enquiry (1986) into dying with dignity.

Its aims were threefold:

- (1) To legislate the established common law right to refuse treatment (a clear recognition of a person's autonomy);
- (2) To allow for the appointment of a medical enduring power of attorney (medical agent) to act if the person was incompetent (a clear recognition of a person's autonomy extending into incompetence) and establishing an extremely limited form of advance directive;
- (3) To recognize the need to ensure the maximum relief of pain and suffering for terminally ill persons.

These aims are entirely appropriate, and supported by medical (palliative care) opinion about autonomy and the necessity to relieve pain and suffering. (All the following quotations are from leading palliative care experts from the referred medical literature.)

3. AUTONOMY

The principle of autonomy is the dominant ethic of health care in North America and Western Europe.¹

The modern palliative care practice model is based firmly on the acknowledgment of the centrality of the patient's autonomy in all decision making.²

4. THE NECESSITY TO RELIEVE PAIN AND SUFFERING

It is morally reprehensible to leave a patient to suffer intolerably.³

A peaceful death must be acknowledged as a legitimate goal of medicine, and as an integral part of the physician's responsibilities.⁴

A doctor who leaves a patient to suffer intolerably is morally more reprehensible than one who performs euthanasia.⁵

(See Attachment 1 for a Synopsis of Disease and Symptoms which are at best difficult, at worst impossible to control with modern palliative care).

5. OBSERVED OUTCOMES

An Act of Parliament is only effective if the people it is meant to assist are aware of its existence and value, and there is an administrative structure to ensure that it functions as intended; but in the case of the *MTA* this has not happened. The *MTA* places total reliance on palliative care to ensure maximum (i.e. complete) relief of pain and suffering, yet Palliative Care Australia acknowledges that even the best palliative care cannot achieve this.

In addition, the Act must be sufficiently clear legally to allow implementation without fear of prosecution. Concerns over refusal of tube feeding indicate that this is not so.

6. SPECIFIC CRITICISM OF THE ACT

(1) The Act is Little Known or Used

There is no requirement under the *MTA* to record the appointment of agents. The Office of the Public Advocate has no idea how many agents exist as there is no register. During the 14 years that the Act has been in operation, only 76 Refusal of Treatment Certificates have been completed. A Monash University study found that 44% of nearly 1,000 doctors had little or no understanding of the legal effects of the Act.⁶ VESV's research, through counselling, end-of-life workshops, and communications with health care institutions, leaves us in little doubt that the *MTA* and its rights are very poorly understood, or little used in situations where it would have been of great benefit, by the Victorian community. This has been accepted by the Victorian Government.

(2) Health Care Institutions Do Not Record Agents

VESV's research into health care institutions shows that, although these institutions go through the motions of explaining that patients may refuse treatment, most have no formal process for recording the existence of an agent, despite the fact that an agent has superior legal status to the next of kin (unless they are the same person). However the next of kin is always recorded.

(3) There Is No Legal Status For Formal Advance Directives

The *MTA* does not specifically mention advance directives (living wills), which are a written and witnessed statement of the wishes of a person created when they are of sound mind regarding end-of-life care. In fact it clearly excludes advance directives by referring only to a "current condition", which is not defined. They stand as clear expressions of the person's wishes in clearly defined circumstances. In contrast the *MTA* essentially allows an agent to act on the basis of a perhaps distant oral communication, which may or may not be well remembered. The British Medical Association recently stated that: *A valid advance refusal of treatment has the same legal authority as a contemporaneous refusal, and legal action could be taken against a doctor who provides treatment in the face of a valid refusal.* An advance directive has the same common law status as did refusal of treatment before the *MTA* created a statutory right; the analogous statutory right should be created for advance directives.

What does a "current condition" mean? Is it simply that disease state that currently exists, or does it also include a consequence or complication of that condition? The current acceptance of "not for resuscitation"

certificates suggest the latter, but the matter is unclear, yet of considerable importance.

Advance directives, such as the living will and durable power of attorney for health care, have been endorsed by virtually every medical organization and State and Federal policy as a tool for this purpose.⁷

(4) Some Hospitals Do Not Provide Refusal Of Treatment Certificates

Recently a VESV member, presenting to a hospital run by a religious organization, was refused access to a refusal of treatment certificate, and told that the hospital's solicitors advised that such forms should not be made available. In 2002, an agent's express refusal of treatment was ignored in a public teaching hospital, and the agent was refused any co-operation in completing a refusal of treatment certificate (see Case Studies). Such instances may be uncommon, but it does illustrate that in certain places there is philosophical opposition to the proper observance of the *MTA*.

(5) Reasonable Provision of Food and Fluids

There is confusion in the medical and legal communities regarding the meaning of "reasonable provision of food and fluids". It is generally accepted by medical authorities that a competent person can refuse artificial hydration (by intravenous means, or by NG or PEG tube).

Common law supports the principle that forced feeding is an assault and contrary to human rights.

Artificial administration of nutrition by enteral or parenteral routes are medical interventions with the potential for associated morbidity.⁸

Artificial feeding cannot be readily distinguished from other forms of medical treatment ... Accordingly the liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual's deeply personal decision to reject medical treatment including artificial delivery of food and water.⁹

There is no disagreement that physicians are morally and legally prohibited from overruling the rational refusal of therapy by a competent patient, even when they know that death will result.¹⁰

It should therefore follow that a legally appointed agent should also be able to refuse these treatments.

There is no disagreement that physicians are allowed to provide appropriate treatment for pain and suffering that may accompany such refusals.¹¹

Despite this, patients and their agents are having great difficulty having their wishes respected, even by the Public Advocate. 'Reasonable' is not defined in the Act, and therefore various views exist in practice; nor is there any indication as to whose view of 'reasonable' is referred to, i.e. the patient/agent or the doctor. The Office of the Public Advocate is of the view that artificial feeding is medical treatment and can be refused, a view recently confirmed by the Victorian Civil and Administrative Tribunal. The recent decision of the Supreme Court (BWW) has clarified

these issues somewhat, yet unless the medical profession and the public are aware of this decision, nothing will change.

(6) It Does Not Fully Recognize Patient Autonomy

Some in palliative care are antagonistic to full patient autonomy.

*Autonomy of the individual cannot be the ultimate guide to action. I would contend that the interests of the individual are best served by refraining from euthanasia.*¹²

Such a philosophy of palliative care does not allow the full expression of patient autonomy. Speaking of withdrawal of treatment, Faber-Langendorn said: *This variation (of inter-institutional practices) raises the question of whether these practice differences reflect physician or institutional values that ignore patient preference*¹³.

Gert et al stated: *When patients have terminal diseases, however, it is generally the case that when they want to die, it is rational for them to choose death.*¹⁴

Despite this, Seale and Addington found that: *Respondents for hospice patients are significantly more likely to feel that an earlier death would have been better.*¹⁵

Patient autonomy, then, is not being fully realized in some palliative care institutions; more importantly, the *Crimes Act* prohibits medical assistance in suicide, specifically where the request for assistance is a rational request from a terminally or hopelessly ill person for the relief of

suffering. We would argue that this should be a valid part of medical treatment (particularly palliative care) in legally defined circumstances.

(7) Palliative Care Cannot Provide Maximum Relief Of Pain And Suffering

Palliative Care Australia's Position Statement on Euthanasia (1999) states in Section 5 that it: *acknowledges that while pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care.* The following statements confirm this fact.

Professor Michael Ashby (Monash University) states that: *The idea that modern palliative care can relieve all the suffering associated with death is a flawed approach.*¹⁶

Professor Robert Twycross, the doyen of British palliative care experts, writing of care in his own institution, said that after four weeks of care: *23% of patients still had unacceptable severe pain*¹⁷ on their last pain assessment.

M.M. Cohen stated: *Dyspnoea (shortness of breath) however is probably an even more distressing symptom than severe pain.*¹⁸

D.B. Reuben reported that: *Data derived from patient interviews, at the last interview, on average seven days prior to death, 11% had moderate dyspnoea, 15% had severe dyspnoea and 8% had horrible dyspnoea.*¹⁹

Neil MacDonald (Canada) says: *Weight loss, asthenia (loss of energy) and anorexia (loss of appetite), often associated with chronic nausea, are*

*among the most common symptoms afflicting patients with advanced cancer. Family studies demonstrate that this complex ranks at the top of physical causes of suffering and contributes to psycho-social distress.*²⁰

Professor Michael Ashby said: *For many people who are dying it is not just a question of comfort or absence of physical suffering (framed in the negative) but a loss of function, independence and role which are hardest to bear. It is not the role of any health-care team to suggest that its ministrations can give meaning, purpose and dignity to a dying person's remaining life if that person feels that these are irretrievably lost.*²¹

N.I. Cherny et al: *The period leading to death is characterized by increasing prevalence and severity of a multitude of physical, psychological, existential and social problems.*²²

Clearly, palliative care alone cannot provide complete relief of pain and suffering, yet it acknowledges the ethical necessity and responsibility to do so.

*There is an ethical imperative to offer care and to provide adequate relief of suffering, and there is an overwhelming obligation to optimize comfort until death ensues.*²³

*The risk of undesirable outcome (shortening of life) is acceptable only because of the more compelling need to act to relieve suffering.*²⁴

Chater was speaking of terminal sedation, but may just as well have been referring to assisted suicide.

7. CONSEQUENCES OF THE DEFICIENCIES OF THE ACT

(1) The Prolongation Of Life Without Dignity

In the absence of an appointed agent, or a specific advance directive, life prolonging measures are often undertaken from caution and fear of legal consequences, and medication which would relieve suffering but would also hasten death is not given. (See Case Studies)

C.S. Cleeland stated in an editorial in the *Journal of the American Medical Association: The optimal treatment of pain and adverse effects of analgesics requires aggressive use of controlled substances, potentially raising fears of regulatory scrutiny, or the disapproval of professional colleagues.*²⁵

Paul Kempen states that: *The medical profession's reluctance to provide narcotics on demand to cancer patients is multifactorial and clearly includes physicians fears to 'assist suicides' or become otherwise liable for malpractice or drug abuse offences.*²⁶

South Australia's *Consent to Medical Treatment and Palliative Care Act 1995* (Clause 17) removes the medical anxiety by specifically indicating that a doctor "incurs no civil or criminal liability by administering medical treatment with the intention of relieving pain or distress even though an incidental effect of the treatment is to hasten the death of the patient provided it occurs with the consent of the patient or their agent, is in good faith and in accordance with proper professional standards of palliative care.

Clear documentation of the degree of life-prolonging treatment without request or in the absence of a clear statement of refusal is difficult to document. C. Seale and J. Addington-Hall surveyed relatives and others who knew 3,696 people who were dying or had died. Regarding those in hospice, 28% of respondents reported death would have been better earlier; 26% of the deceased had stated they wanted an earlier death, whilst 7.9% of the deceased had wanted euthanasia. VESV has compiled numerous reports of prolonged and inadequate deaths due to lack of agents and advance directives. (See Case Studies)

(2) Hastening Of Death By Terminal Sedation

Instead of allowing intolerable suffering to continue (v.s.), it is common palliative practice to use deep sedation to unconsciousness for relief, which inevitably hastens death.

Prof. Erich Loewy concludes: *Terminal sedation, we would claim, differs from some form of voluntary active euthanasia mainly in that it has not been and is unlikely to be legally challenged.*²⁷

Janet Hardy stated: *Death is commonly heralded by agitation, mental anguish and general unease, generally referred to as terminal restlessness. A common management approach is sedation. The stated justification is that there is no other means of relieving intractable distress in a dying patient, and that it is morally reprehensible to leave a patient to suffer intolerably.*²⁸ (Such sedation is also used for dyspnoea, uncontrollable pain, and existential distress.)

N.I. Cherny et al said: *In this situation, death can be reasonably anticipated in a short period of time, whether due to the underlying disease, dehydration, the sedative agent or a combination of these factors.*²⁹

Alan Fleischman stated: *Terminal sedation is used explicitly to relieve severe pain with the knowledge that the debilitated condition of the patient along with the suppressive effects of the medication will likely result in respiratory or cardiac depression and death in a relatively short period of time. Terminal sedation is justified to alleviate pain and suffering whilst acknowledging that death is not only a risk but a likelihood.*³⁰

As John Luce and Judith Luce said: *Opioids and benzodiazepines may depress ventilation significantly when given in high doses.*³¹

It is clear that the provision of maximum relief of pain and suffering currently may require the deliberate induction of deep unconsciousness, maintained until a hastened death occurs. This is a process that can mean the deliberate hastening of death in pursuit of the doctor's intention to relieve suffering. It so closely mimics euthanasia that it has been dubbed 'slow euthanasia', the principal distinction being the prolonged time of unconsciousness preceding death.

Terminal sedation is used in palliative care in exactly the same situations where the choice of voluntary euthanasia or physician assisted suicide is advocated.

8. THE PROBLEM WITH THE STATUS QUO

The study by Kuhse et al³² sponsored by the National Health and Medical Research Council into end-of-life medical practice clearly showed that the incidence of euthanasia and assisted suicide in Australia (where it was illegal) was greater than in the Netherlands (where it was tolerated under guidelines). Thus, despite the law, both voluntary and non-voluntary euthanasia occur in Australia in a covert, uncontrolled and unscrutinised manner.

The recent book *Angels of Death* by Roger Magnussen (Lecturer in Law, Sydney University) has detailed the most unsatisfactory covert practice of “euthanasia” in the Australian HIV/AIDS community.

Moreover, deliberate, quasilegal hastening of death by terminal sedation is not uncommon; but *patients may continue for days in this state before dying*.³³

The status quo does not prevent assisted, hastened deaths, but does allow them to occur in an entirely arbitrary manner. What happens depends on:

- (1) The location of the patient, i.e. home, hospital, hospice or nursing home. Ventafridda found that over 50% of terminally ill patients, given home palliative care, received sleep-inducing sedation³⁴;
- (2) The courage of the doctor, the nature of the patient-doctor relationship, and the religious and philosophical position of the doctor;
- (3) The illness suffered by the patient, and its stage of development;

- (4) The intellectual and economic status of the patient.

9. EVIDENCE OF SUPPORT FOR CHANGE

Studies of Australian doctors have shown significant support for legislation for voluntary euthanasia:

Victoria (1988)	59%
South Australia (1993)	57%
N.S.W. (1994)	59%
South Australia (1994)	45%
Queensland(1997)	33%
N.T. (Doctors, nurses)	59%
Royal Australian College of General Practitioners (1997)	45% (law inadequate)
Royal Australian College of Surgeons (2000)	45%

The Doctors Reform Society supports change to the law; the RANZCP (Psychiatrists), the RACS (Surgeons), the RACP (Physicians), and the RACGP (General Practitioners) all take a neutral position on the issue. The AMA holds a position of opposition to euthanasia, yet its Federal Council in 2002 passed the following motion: *that the AMA supports doctors whose primary intent is to relieve the suffering and distress of terminally ill patients, in accordance with the patients' wishes and interests, even though a foreseen secondary consequence is the hastening of death.*

Surveys of Australian nurses show even greater support:

Australian nurses (1992)	78%
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Australian nurses (1994)	62%
Palliative care/oncology nurses (1995)	50%
NSW nurses (1997)	80%

10. OVERSEAS PRACTICE

(1) The Netherlands

The Netherlands is the best example of a carefully controlled change of end-of-life medical care, extending over more than 20 years, and culminating in definitive law in 2001, allowing voluntary euthanasia and medically assisted suicide in specific circumstances. This process has led to overwhelming support (90%) by the Dutch public, and no evidence in carefully conducted studies of a ‘slippery slope’.

(2) Switzerland

Swiss law since the early 1950s has allowed assistance in suicide provided it is not done for selfish motives. 2% of Swiss deaths occur this way with the assistance of the Swiss ‘Right to Die’ Society. In October, 1999, 71% of the Swiss voted for the legalization of voluntary euthanasia in a referendum.

(3) Belgium

The Government introduced a Bill for a liberal voluntary euthanasia practice (similar to the Netherlands) which was passed by the Senate in 2001 and the lower house in 2002.

(4) Oregon, USA

Following the success of two citizens initiative referenda, Oregon has legislation allowing medically assisted suicide. Five official annual reports have been published, showing limited and responsible use of the legislation, without abuse or of duress, and no evidence of a ‘slippery

slope'. It has been notable that 78% of the 1999 assisted deaths were patients receiving hospice care. Oregon has the highest use in the United States of opioids in palliative care, and of hospice care, together with the highest incidence of death at home.

The results of these five years of practice of physician assisted suicide in Oregon shows an extremely safe, effective, abuse-free situation, associated with increased use and effectiveness of palliative care.³⁵

11. PUBLIC OPINION

Regular opinion polls by ethical pollsters have shown a steadily rising level of support for medical assistance in dying from 53% in the early sixties to nearly 80% in the nineties. In 2002 a Morgan Research Poll of Victorians showed 76% support for voluntary euthanasia (Catholics recorded 72% support) and 71% for physician-assisted suicide (Catholics recorded 61%).

12. SUMMARY AND CONCLUSION

The *Medical Treatment Act* is little known (and therefore little used) and presents significant administrative problems. Whilst it recognizes the great importance of patient autonomy, it does not ensure this to its greatest and natural extent. Of much greater importance is its failure to ensure maximum relief of pain and suffering, which legalisation of medically assisted dying would allow. This leads to:

- Abuse of current law, which doctors find inadequate;

- Arbitrary medical practice which allows a few to achieve assistance under uncontrolled conditions, but not the majority; and
- Condone the hypocritical and futile practice of terminal sedation as a quasi-legal substitute for effective, patient controlled practice, and which protects the legal and moral interests of the doctor rather than the best interests of the patient.

13. RECOMMENDATIONS

Given the current shortcomings of the Victorian *Medical Treatment Act* VESV recommends that the Victorian Parliament enacts legislation that will include the following:

- (1) The enactment of legislation with strict safeguards to allow full respect for autonomy and maximum relief from pain and suffering, including hastening of death, that is, for choice of palliation in dying.
- (2) The amendment of the *Crimes Act* to allow for medical assistance in suicide when the decision to suicide is rational (i.e. a person is hopelessly ill and has unrelievable suffering), and the doctor does not act from selfish motives.
- (3) The creation of a computer register of agents and a process for ensuring that there is widespread knowledge of the register and its purpose.
- (4) The creation of statute recognition for advance directives that are a written and witnessed statement of the wishes of a person regarding end-of-life care.

CASE STUDIES

Case Study 1

This case illustrates confusion about the application of the *MTA* and abuse of the instructions of an agent.

A 92 year old woman, previously living independently, had a massive stroke rendering her incompetent and unable to take fluids orally. She had appointed her grandson as her agent and had specifically advised that she did not want artificial feeding if such a situation arose. The teaching hospital placed a naso-gastric tube for feeding purposes, and after consultation with the woman's immediate family, the grandson requested that the tube be removed. The tube had been placed with physical restraint, and the woman's attempts to remove the tube were frustrated by restraining her functioning hand. The grandson/agent requested the tube be removed, but was told that the hospital was legally obliged to provide food and fluids.

Despite frequent approaches to the treating doctors including the consultant, the hospital administration, the Public Advocate, and ultimately through his solicitors, the tube remained in place for three weeks, until sufficient oral fluids could be administered. Further, the hospital refused to assist in witnessing a Refusal of Treatment Certificate. The woman was discharged to a nursing home where she languished, paralysed and unable to communicate, for 18 weeks.

This story reveals deliberate frustration of the rights of the patient, as expressed through her agent, in defiance of the intention of the *MTA*.

Case Study 2

This case illustrates the cruel results of not having an agent, the difficulty people have in obtaining help and advice, and the obstruction that is placed in the way of the operation of the *MTA*.

A 68 year old woman suffers from a progressive dementia (Pick's disease). Whilst she is living at home, mobile but incompetent, her nurses advise that they cannot maintain adequate oral nutrition, and her husband gives permission for a PEG feeding tube to be placed. He is not her agent. Three years ago, no longer able to be nursed at home, she is moved to a nursing home. There, she progresses to a 'vegetative state', curled into a completely immobile foetal position. She has no awareness of any physical, emotional or spiritual contact. The husband and his family all believe that she had expressed views at earlier times that she would not want to be kept alive in this situation, and the husband makes many requests to have the tube feeding ceased. The local doctor and the nursing home refuse, indicating that, although they are sympathetic to the request, they believe the law does not allow this. Despite approaches to the Public Advocate and the Health Services Commissioner, no help is forthcoming. Finally, an approach to the Guardianship Board results in the Victorian Civil and Administrative Tribunal considering a decision to appoint a guardian for the purpose of ceasing the feeding. This appeal takes two months to achieve a sitting and a further two months

deliberation before reaching a decision that artificial feeding is medical treatment that can be refused by an agent or guardian.

Case Study 3

This case illustrates poor hospital administration and education of its staff when dealing with relatives who wish to assert the rights of the patient to be treated in a manner which they have already foreseen and have thought about and have indicated their clear wishes.

A 72 year old woman who had suffered from intermittent congestive cardiac failure in discussion with her cardiologist she said that she did not wish to continue treatment. He warned her that her death would be slow and painful.

In the final two years before her death she had seven admissions to hospital for emergency treatment. She finally decided that she no longer wished to be treated but given pain relief medication and allowed to die. It was at this time she had a further cardiac failure and was resuscitated once again.

This was in spite of the fact that her GP and the hospital had certified copies of a Medical Enduring Power of Attorney, naming a proper agent and clear instructions of the patient that she not be resuscitated.

Case Study 4

This case illustrates some of the problems which may arise when the following facts are present.

Where there is no power invested in an agent such as one possessing a valid Enduring Power of Attorney and Enduring Power of Attorney Medical Treatment.

All the difficulties in dealing with hospital authorities will be exacerbated by differences of opinion occurring between relatives.

An 89 year old woman was admitted to hospital with a massive CVA. Previously she had been very healthy, active and totally rational.

Prior to this episode she had told her four children that, should she suffer a medical problem from which she would not recover her mobility or become substantially dependent on nursing, she did not wish to be resuscitated.

She had not appointed an agent with an Enduring Power of Attorney Medical Treatment and when she had her stroke her children could not agree to no intervention when she was admitted to hospital

The woman lived another six weeks in hospital in circumstances everyone described as 'nightmarish'.

Case Study 5

This case illustrates the fact that some palliative care workers can have a judgemental attitude about the way in which a patient endures and responds to pain.

A 62 year old man with advanced oesophageal cancer had received effective treatment. Seven years later, secondary cancer of the spine developed and he received further radiation treatment and pain relief. From this stage on for the next two years he was never without pain and nausea.

In the final months he was attended by palliative care workers but he felt that they treated him as if he was neurotic and unreasonable with his complaints.

It was only at the very end that the palliative care team decided to increase pain relief drugs to a sufficient level to make any difference to his suffering.

His family reports that his death at home was horribly painful for him. Cruelly prolonged and deeply distressing to all of his family.

Note

There have been reports of relatives who have been well satisfied with the service given by palliative care providers but this appears to have mainly occurred when one of the following situations exist:

Oncologists have actively participated in the planning of pain control.

General practitioners have been available to advise and work with palliative care providers and are willing to consult with relatives of the dying person.

When there are family members who have worked in the hospital system and have found ways to help staff have more understanding or involvement in the wishes of the dying person and their family.

There are many illustration of substantial disagreement between palliative care staff, the patient and their family about what constitutes ‘reasonable pain relief’.

Case Study 6

This case study illustrates how the effective application of the *MTA* can prevent prolonged suffering but could easily be thwarted by uninformed doctors.

An 84 year old married man was suffering from very severe chronic respiratory disease, together with significant blindness and early dementia. During his rational moments, he found his life to be futile and full of intolerable suffering, despite the loving care of his wife and daughter. He had suicide, but failed once and was resuscitated on a second occasion. When he developed a severe, life-threatening chest infection, he was treated with antibiotics and survived. As a result he was severely weakened, was unable to return home, and was placed in a nursing home. He detested this circumstance and repeatedly asked his family to obtain assistance so that he could end his life. A second episode of chest infection was again treated in hospital and he again survived.

At this point, his daughter sought advice, and learnt about the *MTA* and refusal of treatment. She approached VCAT and was appointed guardian to her father. A sympathetic doctor then took over his medical care. It

was clear that he did not want treatment for the next chest infection. After consultation with the whole family, a Refusal of Treatment Certificate was completed, requesting that antibiotics not be administered in that event, but that maximum relief of pain and suffering be provided.

Three months later, severe dyspnoea occurred due to a chest infection. Despite the RTC he was taken to casualty at a local hospital, and planned antibiotic administration was only averted by the intervention of his doctor. On return to the nursing home, treatment with rapidly increasing doses of opioids and sedatives led to coma and his death 30 hours later.

His family was sad at his death, but gratified that his suffering was over, and that they had been able to help him achieve that end.

ATTACHMENT 1

A Synopsis Of Disease And Symptoms Which Are At Best Difficult, At Worst Impossible To Control With Modern Palliative Care

(This list was prepared for Marshall Perron, former Chief Minister of the Northern Territory. It was updated by a South Australian palliative care expert in 2001).

Even with state-of-the-art palliative care many terminally ill patients will experience substantial physical suffering.

Hopelessness, futility, meaninglessness, disappointment, remorse, and a disruption of personal identity are frequently experienced. The hospice ideal, therefore, to provide a pain-free, comfortable death with dignity is usually unobtainable and should not be promised. It is a rhetorical myth that hospice and palliative care can relieve all the suffering associated with the advance of diseases like cancer, AIDS, and motor neurone disease.

Over 90% of people with terminal illness will endure their situation, but around 5% find it intolerable and request euthanasia.

1. Difficult/Impossible to Control Pain Situations

Pain, particularly that due to infiltration by cancer of extremely sensitive nerve rich areas such as the head and neck, pelvis and spine, is commonly episodic and excruciating aggravated by movement, and may be likened to a dental drill on an unanaesthetised tooth nerve.

Pain is not always adequately controlled by palliative medicine, 5-10% of cancer pain may be of this type and in some cases can only be "palliated" by producing a prolonged unconsciousness, coma or "pharmacological oblivion". This may last for days until death occurs by dehydration and circulatory collapse or retention of bronchial secretions ("the death rattle") pneumonia and pulmonary collapse. This is not a dignified process.

1.1 Raised intracranial pressure due to inoperable brain tumour

Severe head pain due to pressure on sensitive nerve structures by tumour expansion in a confined space, may be accompanied by loss of function, e.g. blindness, paralysis, incontinence

- 1.2 Infiltrating head and neck cancers with/without ulceration
Some tumours fungate, hideously distort the face and produce foul odours.
- 1.3 Lung Cancer infiltrating the root of the neck or chest wall and damaging sensitive nerves.
- 1.4 Mesothelioma (associated with asbestosis - utterly incurable)
Producing severe chest pain with each breath, made far worse on coughing which may be chronic and persistent - associated difficulty breathing and feelings of suffocation.
- 1.5 Recurrent bowel obstruction due to widespread abdominal cancer
Diffuse deposits of cancer obstruct the bowel, causing pain, nausea and vomiting and abdominal distension - surgery may be advised which may be either futile or of only very short-term benefit. Vomiting and malnutrition lead to a kind of starvation until death.
- 1.6 Pelvic cancer (bowel, bladder, prostate, uterus, ovary) may infiltrate major nerve plexuses affecting the legs or genitalia and cause severe neuropathic pain (+/- paralysis of sphincters/legs). Incontinence of urine and faeces can occur.
- 1.7 Severe chronic poly arthritis with joint disintegration, which renders most movements excruciating and severely limits mobility.
- 1.8 Spinal cancer with nerve root pain; vertebral collapse +/- paraplegia. One of the worst situations possible, confined to bed with - episodic excruciating neuritic pain with simple movement.
- 1.9 Inoperable bladder cancer with very frequent and painful urination, often with bleeding, blockage to flow and incontinence (hence the old medical saying "Please God, do not take me through my bladder").
- 1.10 Severe chronic spinal osteoporosis with vertebral collapse produces severe and unremitting pain, particularly in elderly women, which

because of its chronic and non-life threatening nature is commonly ignored or badly under-treated by the medical profession.

2. Non-Pain Syndromes Causing Extreme Suffering

- 2.1. Cachexia - commonly associated with advanced cancer, involves severe loss of appetite and weight, loss of energy in extreme degree and severe psychological "pain" (distress) due to this gross debilitation and loss of independence. Malnourished bed-bound patients are prone to develop ulcerating bedsores over bony prominences.
- 2.2. Loss of appetite with intractable nausea and vomiting due to either cancer itself or drug/other therapy including chemotherapy and radiotherapy.
- 2.3. Obstructing oesophageal cancer with inability to eat or even swallow saliva. Anything swallowed is vomited back.
- 2.4. Chronic progressive difficulty in breathing. Possibly with severe cough, perhaps with blood. +/- severe pain with each breath or cough. Fear of suffocation causes enormous anxiety.
- 2.5. Incontinence of bowel and bladder due to communication of these structures with the vagina, secondary to surgery/radiotherapy for cancer of the cervix or due to confusion and immobility. Producing gross indignity to some people.
- 2.6. Chronic inexorably progressive neuropathic syndromes leading to paralysis of all limbs, loss of speech, blindness, loss of control of bowel and bladder, and perhaps inability to breathe or swallow .as in multiple sclerosis, motor neurone disease. The person's body functions disintegrate, yet trapped within that shell may be a perfectly lucid mind.
- 2.7. AIDS - A potentially fatal disease, often of young persons, with an horrific dying process of cachexia, immobility, incontinence and progressive loss of mental faculties.
- 2.8. Total Dependence Syndrome. The loss of dignity due to loss of independence and control in the terminal decaying phase,

particularly in hospital. This is a major reason for euthanasia request.

2.9 Blockage of lymphatic or venous drainage of tissue fluid causes swelling of limbs, genitalia and face. In severe cases fluid seeps through the skin which breaks down.

2.10 Severe stroke (such as brain stem stroke or profound dense hemiplegia) can result in permanent paralysis, inability to communicate, inability to swallow (resulting in the necessity for tube feeding), commonly followed by muscle contractures, incontinence, and bedsores, and a state of total dependence which can last for years.

3. Pen Pictures

3.1 Cancer in the spine with nerve root pressure and spinal collapse

Pain will be lancinating around the body, and also possibly into the legs (as in sciatica). The pain will be provoked by simple movements such as turning in bed, coughing, urinating, using bowels. Its intensity and unpredictability make routine analgesic measures inadequate. Bedsores are a common risk. Incontinence or inability to urinate is highly likely. Every physical action, washing for example, is dreaded. Such a situation can last for months until the ravages of further cancer spread occur.

3.2 Multiple sclerosis

Progressive loss of motor/sensory function in a haphazard way over many years leads to virtually total loss of movement. Initially wheel-chair life, later bed-bound. Total dependence, incontinence and if speech and sight are impaired, loss of even the ability to communicate. The intellect may remain unimpaired, the person is a prisoner in a body which cannot move or function in any real way.

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