NOTE: The following submission makes numerous references to euthanasia. While the committee has decided that, in this instance, the entirety of the submission will be accepted, those aspects of the submission that relate to euthanasia will not be considered by the committee in its deliberations. Euthanasia does not fall within the committee's terms of reference for its inquiry into Palliative Care.

Submission

from

Dying With Dignity ACT

to

Inquiry by Community Affairs Committee of the Australian Senate on

Palliative Care in Australia

Re submission on 3 May 2012

Palliative Care in Australia

Terms of reference

The provision of palliative care in Australia, including

a) ***the factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including***
    - ***people living in rural and regional areas***
    - ***indigenous people***
    - ***people from culturally and linguistically diverse backgrounds***
    - ***people with disabilities, and***
    - ***children and adolescents***

Response: A significant factor that affects palliative care in Australia is the definition of what palliative care is. Palliative Care includes the care of people at all times in their lives including dying and in Australia in relation to dying is defined as neither hastening nor slowing death. In Belgium palliative care the definition is the same, but includes the provision of assistance to die.

The fact that palliative care can be different in different countries must have an outcome on what happens for the end of life care for individuals in those countries. For Dying with Dignity ACT a definition of palliative care that does not include assisted dying means a significantly worse outcome for **all** Australians who are dying wherever they live because their deaths are not managed by them but by what the medical professional is allowed to do by state and territory laws in order to support them. Death is slow, perhaps taking many years and perhaps being cruelly subjected to intense pain, manageable only by the provision of symptom relief. Australians who wish to have access to the appropriate palliative care of their needs when they are dying that would be available to them in Belgium have **no access to it and no choice**.

The fact that the Federal Government has no law against the provision of assisted dying but will not even allow for its discussion in a senate committee on palliative care is of grave concern in a liberal democratic country. **This is a seriously difficult factor in influencing access to and choice of appropriate palliative care that meets the needs of the population.**

f) the adequacy of standards that apply to the provision of palliative care and the Standards for Providing Quality Care to All Australians

Response: To address the issue of standards of palliative care in Australia we provide the following literature study by Doctor Rodney Syme. It includes references to commentators on palliative care by doctors and practitioners from other equivalent modern nations as well as Australia. It covers a wide range of issues to do with the capacity of palliative care to deal adequately with people who are dying. In our opinion it reveals the **innate** inadequacy of palliative care in ***Providing Quality Care to All Australians***.

PALLIATIVE CARE AND THE CARE OF THE DYING

A LITERATURE STUDY BY DR RODNEY SYME

The study covers literature from the late 90s to 2008

EFFECTIVENESS OF PALIATIVE CARE

1. Zimmerman

2. Salisbury

3. Wilkinson

4. Parker

5. Peruselli

1. C. Zimmerman et al JAMA, *Effectiveness of specialized care,* 2008:299;1698

"Fourteen studies [out of 396] specifically assessed symptoms, some using an over-all symptom distress or severity measure and others using scales for symptoms such as pain, nausea, constipation, dyspnoea, sleep, anxiety, and depression and morale. **Only one trial demonstrated benefit from the palliative care intervention for any of the individual symptoms measured."**

"Patients' satisfaction with care was assessed in 10 studies, which were conducted in home, hospital and outpatient settings in the UK and USA. Four studies showed significantly increased satisfaction in the intervention groups compared with the control groups."

"There is scant evidence to support the effectiveness of specialized palliative care for patients with terminal illness in terms of quality of life, patient and care giver satisfaction, or economic cost. Of these outcomes there is consistent evidence only for better caregiver satisfaction."

"Some of the results that are of borderline significance might have occurred by chance."

"In addition, the studies did not assess the large personal costs that may be incurred by patients and their family members, including expenses for medications, transportation, homemaking, personal care and lost income. Caregivers can also experience substantial physical and psychological morbidity as a consequence of caregiver burden."

2. C. Salisbury et al, *The impact of different models of specialist palliative care on patients' quality of life,* Palliative Medicine 1999: 13; 3-17

Conducted a systematic review of research evidence. "We found few comparative trials of reasonable quality."

"Research on palliative home care teams and co-ordinated nurses has demonstrated limited impact on quality of life over conventional care for patients dying at home."

"The concept of quality of life is hard to define, which makes its use as an outcome measure problematic."

"It is generally accepted that quality of multi dimensional and instruments need to assess a number of constructs; symptom control, psychological well-being, social support, functional status, economic well-being, spiritual well-being, control over life, meeting life-goals and sexuality."

"The concept of quality of life is also subjective, and one individual may have values and priorities which are different from those of the group. **This is particularly important in the context of palliative care, which places respect for individual autonomy and choices as a core value."**

"The evidence overall suggests that studies which rely on care-givers or staff assessment of patient's quality of life should be interpreted cautiously and possibly accorded less weight than those that used patients own assessments."

"There was no evidence from the National Hospice study that patients quality of life was affected by care in a hospital based hospice, a home-based hospice or a conventional care site. Hospital based hospice patients had slightly better pain control and greater use of analgesics."

"In his study of an advisory domiciliary service, Parkes (St.Christopher's) was unable to detect any differences in perceived symptom control or quality of life between patients receiving and not receiving home care service."

Quality of life declined slowly, with an accelerated deterioration in the last three weeks of life. A substantial minority of terminal patients retained a good quality of life almost until death."

"Some studies have shown that neither care-givers nor staff are reliable proxies for quality of life experienced by patients."

"The overall conclusion must be that there is little robust evidence that any form of organization of specialized palliative care offers significant advantages in terms of impact on patients' quality of life. This finding may be interpreted as disappointing. However specialist palliative care may be justified on other grounds."

3. E. Wilkinson et al, *Patient and care preference for, and satisfaction with, specialist models of palliative care,* Palliative Medicine 1999: 13; 197-216

"The great challenge of attributing change in outcomes to the quality of care within a palliative care environment has been well documented. **Indeed, it is difficult to rule out the possibility that other factors such as personal characteristics of a patient or the course of a disease have had an effect on the outcome."**

4. M. Parker et al, *Impact Of Speciality on Attitudes of Australian Medical Practitioners To End-Of-Life Decisions*, MJA 2008:188;450

"Fifty-four percent of respondents stated that their belief/philosophy was very important in their professional attitude towards end-of-life decision-making."

"Patients with a 2 week life expectancy and poorly controlled pain received least support for terminal sedation at their own request from geriatricians, and somewhat low levels of support from palliative care specialists and oncologists; conversely, most support for terminal sedation, *when initiated by the medical practitioner,* came from palliative care specialists and oncologists."

"The results suggest that these specialties (palliative care, oncology, geriatrics) are less responsive to patient requests for procedures that will lead to death, but more prepared than others to initiate such procedures without patient consultation."

"While actions traditionally perceived as direct hastening of death are avoided by these groups for all patients, other actions with the same result but purportedly with different intentions (eg terminal sedation) would sometimes be taken without reference to competent patients."

"Our results indicate that perceptions concerning the causation of death as well as aspects of medical culture influence attitudes towards medical decisions at the end of life."

5. Carlo Peruselli et al - *Outcome Evaluation in a Home Palliative Care Service, Journal of Pain and Symptom Management* - 1997:13-158

"The complexity of assessing the impact of palliative care is much greater than in other fields of medicine due to the short comings of traditional outcome measures."

COMMENTARY

There is clearly little evidence as to the effectiveness of Palliative Care, and its lack of scrutiny reflects its 'untouchable' position (Doyle p61), but it has now become the lynch-pin of government policy. Undoubtedly, much of this difficulty in demonstrating effect is due to the 'shifting sands' under the research base (Peruselli), and the difficulties of measurement. Parker's comments reveal the tendency for Palliative Care to want to control the agenda.

PALLIATIVE CARE – COMMENTS ON SYMPTOM RELIEF

1. Hunt

2. Ashby

3. Meier

4. Addington-Hall

5. Tamburini

6. Morris

7. Peruselli

8. Vachon

9. Quill

10. Lickiss

11. Zalcberg

12. Barbato

13. Cherny

1. Roger Hunt, *Willing to Listen, Wanting to Die* (Edited by H. Kuhse), Penguin 1994

"Even with state of the art palliative care, many patients experience substantial physical suffering before they die. Many others experience psychological and other non-physical suffering. **The hospice ideal of providing a pain-free comfortable and dignified death is usually unachievable and should not be promised.**"

2. M. Ashby (Professor of Palliative Care, Monash University), Journal of Law & Medicine 1995: p3

"If we can all acknowledge that there are 'hard cases', where dying persons cannot obtain acceptable relief of suffering, regardless of our views on active voluntary euthanasia, this would be a first constructive step in obtaining community consensus on how to proceed."

"**However, the idea that modern palliative care can relieve <u>all</u> the suffering associated with death and dying is a flawed approach.**"

3. D. E. Meier et al - *Improving Palliative Care, Annual of Internal Medicine* - 1997:127-225

"Symptomatic, terminally ill patients receive frequent adjustments in pain medication and often require careful management of dyspnoea, delirium or agitation. Such patients may take as long as several weeks to die in a highly labor-intensive demanding clinical setting."

4. Julia Addington-Hall and M. McCarthy - ***Dying From Cancer: Results Of A National Population-Based Investigation*****, Palliative Medicine - 1995:9-295**

"At some stage in the last year of life 88% were reported to have been in pain, 66% were said to have found it 'very distressing', and 61% to have experienced it in their last week. Treatment that only partially controlled the pain, if at all, was said to have been received by 47% of those treated for pain by their GPs and by 35% of hospital patients. Other common symptoms experienced by more than half the sample in their last year of life were loss of appetite, constipation, dry mouth or thirst, vomiting or nausea, breathlessness, low mood and sleeplessness."

5. Tamburini et al, ***Journal of Pain and Symptom Management*** **- 1996:11-32**

"Quality of life assessment by the physician or nurse, as done with the quality of life index, showed that median values worsened during the last days of life."

6. John Morris et al, ***Journal of Chronic Diseases,*** **1986:39-47**

Last Days: A study of the quality of life of terminally ill cancer patients.

A collected sample from 28 hospices in U.S. and Canada.

"**The general finding, as expected, is one of increasing deterioration in quality of life, with accelerated deterioration between 3 and 1 week of death.** Pain follows a somewhat different pattern than other measures. More patients are in either of the extreme categories at an earlier point in time than found for other measures, and there are fewer changes as death is approached. Finally about 20% of the patients do not fall into extremely low quality of life categories, even in the week prior to death."

7. Carlo Peruselli et al, ***Journal of Pain and Symptom Management -*** **1997:13-158**

"Assessing the quality-of-life pattern over time, we observed that palliative care was effective in **mitigating** pain, and at least in part, in stimulating appetite, curbing nausea and controlling psychological aspects. The subscales referring to social and functional aspects steadily worsened."

8. M.L.S. Vachon et al, ***Journal of Pain and Symptom Management -*** **1995:10-142**

"It has been shown that physical symptoms in the person in the terminal phase of disease are associated with increasing distress, as well as major depression and anxiety, severe pain, which was inadequately controlled and poorly tolerated has been associated with suicide in cancer patients. In addition the burden of illness is borne by family members who may also experience distress and poor health, financial problems, and disruption to their work lives.

9. T. E. Quill et al ***Palliative Options of Last Resort,*** **Journal of the American Medical Association - 1997:278-2099, -**

"Patients request a hastened death not simply because of unrelieved pain, but because of a wide variety of unrelieved physical symptoms, in combination with loss of meaning, dignity and independence."

10. Professor Norelle Lickiss, AMA Meeting 11/8/94

"Most symptoms in most patients (but not all) are relievable by contemporary palliative therapy, without undue side effect".

11. J. R. Zalcberg and J. D. Buchanan, *Medical Journal of Australia* 1997: 166-150

"Although it is possible with modern palliative care, to relieve physical pain in <u>most</u> of these patients**, it is more difficult to overcome <u>frequent</u> problems that cause distress and suffering, such as lethargy and dependency on others**. **Thus it must be acknowledged that good palliative care is not always good enough."**

12. Michael P. Barbato, *Medical Journal of Australia* - 1998:168-296

"He prepared for his death; he died in his own bed after saying good-bye to his wife and family. It was one of those deaths that we in palliative care hope to see <u>but rarely do</u>."

"I have learnt that we do not necessarily fail if we do not cure, but we do fail if, in our attempts to cure, we cause our patients **<u>to sacrifice their healing journey</u>**."

"It can be very difficult to withdraw active treatment or to call an end to interventions, particularly for people we have treated for some considerable time. But this is **<u>our journey</u>**, and our failure to partake of it can be as harmful to us as it is to those we treat."

"the point where spiritual care takes precedence over 'curative' treatment is not one that we can define, but we can perceive it if we really listen to our patients."

"While it may sound controversial, part of our work as doctors (and a large part of my work as a palliative care physician) is to help people die. In saying this I am not referring to euthanasia (whether by active or by passive means) but, rather, to the help that dying people need to undertake their journey, face the inevitability of their death and prepare **<u>in whatever way they choose</u>**."

13. N.I. Cherny, N. Coyle, K. Foley, *Guidelines in the care of the dying cancer patient,* Haematology –Oncology, 1996: 10; 261

"The period leading to death is characterized by increasing prevalence and severity of a multitude of physical, psychological, existential and social problems."

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

COMMENTARY

It is abundantly, and not surprisingly, clear that there is a significant gap between the palliative care rhetoric and reality. Physical suffering accelerates as death approaches, problems become frequent

(Zalcberg), and it is associated with increasing psychological and existential suffering. Many problems are frequent and unrelievable. Michael Barbato's comment is particularly telling.

PALLIATIVE CARE – COMMENTS ON TERMINAL SEDATION

1. Saunders
2. de Sousa
3. Burke
4. Ventafridda
5. Bottomley
6. Council J/E
7. Twycross
8. Cherny
9. Hammes
10. Dunlop
11. Hunt
12. Lickiss
13. Ashby
14. Ashby
15. Zalcberg
16. Cherny
17. Turner
18. Morita
19. Ravenscroft
20. Corner
21. McGee
22. Fainsinger
23. Chater
24. Quill
25. Emanuel
26. Asch
27. Wilson
28. Fleischman
29. Cherny
30. Hardy
31. Lawlor
32. Faber-Langenden
33. Krakouer
34. Fainsinger
35. Loewy
36. Luce
37. Chin
38. Kaldjian
39. Reitjens
40. Lundstrom
41. Navigante
42. Miccinesi
43. Verkerk
44. Reitjens
45. Harrison
46. US Supreme Court

1. Dame Cicely Saunders, The Lancet - 2/9/1961

"We are now always able to control pain in terminal cancer in the patients sent to us and only very rarely indeed do we have to make them continually asleep in so doing."

2. Emile de Sousa, Bridget Jepson - *Midazolam in Terminal Care*, The Lancet - 2/7/1988

"Of 157 patients who died at this hospice between July and October, 1987, 99 (65.6%) received subcutaneous infusions of Diamorphine in the terminal phase of their disease" ... "Several such patients require sedation" ... "we found Midazolam in combination with Diamorphine (and when necessary Hyoscine) to be an effective sedative for continuous subcutaneous infusion administration".

3. A. L. Burke et al - *Terminal Restlessness - Its Management and The Role of Midazolam,* Medical Journal of Australia - 1991:155-485

"The management of terminal restlessness is an important aspect of palliative care, **often present a most difficult clinical problem for the practitioner**."

"In the 10-month period September, 1989 to June, 1990, Midazolam was used, that is, in 86 patients in the Hospice Unit of Bethlehem Hospital."

"Initially the use of the drug was infrequent. Fourteen patients received the drug in the first four months. in the following six months, the drug was used for 72 patients."

"Midazolam was found to be an effective drug in every case except one. **It provided a readily available means of controlling symptoms and overcoming patient distress where no feasible alternative existed previously."**

"During the last six months, almost 20% of in-patients received Midazolam, compared with 2% of home care patients."

"Morphine alone, even in increasing doses, does not relieve the symptoms of terminal restlessness."

“Although intravenous and intra-muscular administration of Midazolam have been reported to cause respiratory and cardiovascular depression, in the terminal care setting subcutaneous Midazolam does not appear to cause problems with respiratory depression.”

“The use of Midazolam is not recommended for patients who do not exhibit terminal restlessness because the degree of sedation induced by the drug is usually regarded as inappropriate for patients who are not near death.”

“The serenity the drug provides to these patients and the sense of relief felt by the relatives and staff are measures of the effectiveness of treatment.”

4. V. Ventafridda et al, ***Palliative Care*** **- 1990, 6.7**

“The lack of control of physical suffering among cancer patients in the last days or hours of life **is a common medical problem, but is rarely discussed in an open fashion**.”

“52.5%” of terminal cancer patients treated at home by palliative care teams, had physical symptoms unendurable to the patient and controllable only by sedation-inducing sleep on average two days before death. The most common symptoms included breathlessness (50%), pain (50%), delirium (20%) and vomiting (8%). **More than 50% of these patients die with physical suffering that is controllable only by means of sedation**.”

5. D. M. Bottomley and G. W. Hanks, ***Journal of Pain and Symptom Management*** **- 1990:5-259**

“Restlessness and agitation are common problems in advanced cancer patients in the final days of life. Restlessness and agitation in a patient who is dying may cause considerable distress, not only to the patient, but also to the family, and active intervention is indicated. Such patients are usually unable to take medication by mouth, either because of their agitated state, or fluctuating levels of consciousness, or general level of debility.”

Authors recommend subcutaneous Midazolam infusion. **“Respiratory depression is more likely when Midazolam is used together with opioid analgesics.”**

6. Council of Judicial and Ethical Affairs, American Medical Association, ***Journal of the American Medical Association*** **- 1992:267-2229**

“The ethical distinction between providing palliative care that may have fatal side effects and providing euthanasia is subtle because in both cases the action that caused death is performed with the purpose of relieving suffering”.

7. R. G. Twycross, I. Lichter - ***The Terminal Phase,*** **Oxford Textbook of Palliative Medicine - 1993, p.651-661**

Advised deep sedation for the management of terminal anguish. They commented that **nothing short of deep unconsciousness could provide relief and that inadequate sedation makes matters worse**.

8. **N. I. Cherny et al -** ***The Treatment of Suffering when Patients Request Elective Death, Journal of Palliative Care*** **- 1994: 10-71**

"For some patients with advanced disease, adequate relief of physical symptoms may only be achieved at the cost of profound sedation. The prevalence of this situation is controversial and has been variably estimated at between 5% and 52%."

"Refractory delirium may be associated with severe agitation, refractory depression, anxiety or existential distress Persistent patient distress of this kind places great stress upon the resources of family, friends and professional health care providers. **Indeed the combination of distress fatigue and perceived therapeutic destitution may be such that death is seen as the preferred option."**

"Infrequently psychiatric or existential distress is refractory to the routine interventions.

Given that suffering is, ultimately, a perceptual experience that requires consciousness, for some patients sedation may be an appropriate intervention."

"Patients with persisting distress, despite an initial respite, and those for whom death is imminent, may elect to be deeply sedated until death ensues."

"This offer of sedation as a therapeutic option is often perceived as an emphatic acknowledgment of the severity of the degree of patient suffering. The **advanced patient trust in the commitment of the professional care-givers to the relief of suffering may, in itself, provide enough relief or patient and family distress to render sedation unnecessary**."

9. **B. Hammes and J. Cain -** ***The Ethics Of Pain Management For Cancer Patients,*** **Journal of Pain and Symptom Management - 1994:9-166**

"In many treatment choices, the risk of death is real and clearly understood."

"In the clinical setting, the ability to determine the relation between respiratory depression and carefully administered opiates with secondary sedation in a dying patient is at best difficult. Assuming that the primary goal is comfort and that the opiates have been administered to this goal, efforts to improve respiratory rate may interfere with that goal, and therefore are not an obligation of a health professional."

"As with many treatment plans, the risk of earlier death may be real. **If the death of a patient is expected, the risk need not be considered a serious burden, especially when compared with the value of comfort."**

"Comfort care requires that the health professional addresses as much of the suffering of the patient, and family and friends as is possible within the restraints of professional responsibility. **The physical pain of the patient is often a big part of this suffering and should be relieved. Suffering can and does include much more."**

10. **R.J.Dunlop et al, J.Med.Ethics 1995; 21: 141-145**

Terminal agitation must be treated aggressively, otherwise the distress of the patient will become extreme. Even when incremental doses of sedative are given, **it is rarely possible to achieve a balance between relief of agitation and alertness."**

11. R. Hunt, *Willing to Listen, Wanting to Die* (Edited by H. Kuhse), Penguin, 1994

"When analgesics and sedatives are infused, the patient enters a kind of 'pharmacological oblivion' and appears at peace - it is usually assumed that in this state there is freedom from pain and distress. The patient cannot eat or drink, has a dampened cough reflex, develops retained airway secretions which 'rattle' and become infected, all of which hasten death. **This is 'also true in a subjective sense, permanent unconsciousness is, in the patient's view, similar to being dead."**

12. Professor Norelle Lickiss, AMA 11/8/94

"Sedation (with due safeguard) is occasionally necessary to reduce suffering associated with intractable symptoms, normally after careful discussion with the patient. But morphine is not appropriately used in sedating doses and should not be increased close to death; other drugs are far more appropriate to assist patients sleep gently in their last days, and the knowledge concerning the most appropriate medical care of patients who are actually dying needs rapid dissemination."

13. M. Ashby - *Hard Cases, Causation and Care of the Dying, Journal of Law and Medicine* - 1995: 3-152

"Heavy sedation may be used to induce a state of impaired consciousness to control so-called terminal restlessness, or when symptoms and suffering cannot be controlled by other palliative treatments."

"This practice has been termed 'pharmacological oblivion'; the Canadian Senate calls it 'total sedation' or the 'practice of rendering a person totally unconscious through the administration of drugs without potentially shortening life'. Such treatment is argued to be within accepted palliative care practice, as the death is not intended, and the doctrine of double effect applies, although **it is surely impossible to state that such treatment does not have the potential to shorten life."**

"Hunt also disputes this, believing that there are occasions on which it is appropriate to intentionally hasten death, and that this is often the case with so-called pharmacological oblivion. The interpretation is that sometimes practitioners are hiding behind a false application of the doctrine of double effect as the unstated intention and the outcome is to hasten the patient's death, and this should be openly acknowledged."

14. Professor M. Ashby (Professor of Palliative Care, Monash Medical Centre), *Medical Journal of Australia* - 1995:162-596

"I would reassure her that nothing would be done to prolong her life and that if a time came when she did not wish to be aware, this could be achieved by pharmacological means. It is sometimes argued that intentional shortening of life may be justified if requested by a terminally ill patient, and that so-called "pharmacological oblivion" (using sedation to make a person drowsy or unconscious while they are dying) is merely a rationalization of what the medical practitioner is really doing.

However intentional ending of life is not part of palliative care practice and it is different in kind from all other clinical interventions."

15. J. Zalcberg, *Medical Observer* - 19/1/1996

"It is true that when people are within days or weeks of the ends of their lives, the introduction of morphine can lead to an alteration of their conscious state. We accept this is an inevitable effect of treating pain at the end of people's lives, their length of life being determined by their disease. If the pain is well controlled the dose of Morphine is kept constant. We aim to have patients awake and alert, but if the patient is not awake at the time their pain is controlled, we accept that as an inevitable consequence. Is that euthanasia? I think some doctors would say it is. I believe it is symptom control. But if it is euthanasia then, **yes**, we practice euthanasia."

16. N.I. Cherny, N. Coyle, K. Foley, *Guidelines in the care of the cancer patient,* Haematology-Oncology Clinics of North America, 1996; 10: 261

"Situations in which the patient is confused or unconscious owing to advanced disease, or when symptom control can be achieved only with therapies that induce sedation or cognitive impairment, can be particularly difficult for patients."

"Induced sedation is a strategy of last resort in the management of dying patients who have refractory symptoms. In deciding if a symptom is refractory, the clinician must perceive that further invasive and non-invasive interventions are (1) incapable of providing adequate relief (2) associated with excessive or intolerable acute or chronic morbidity or (3) is unlikely to provide relief within a tolerable time frame."

"This approach recognizes the right of dying patients to adequate relief of unendurable symptoms and the right of all patients to choose among appropriate therapeutic options" This approach has "**unavoidable untoward consequences (the likely diminution of interactional function and the potential for hastening death)"**

17. K. Turner et al - *Dignity In Dying: A Preliminary Study Of Patients In The Last Three Days Of Life*, Journal of Palliative Care - 1996:12:7

44/50 patients had sedation; 43/50 had morphine; 4/50 patients were unconscious for the duration of the last 3 days. "Recognition is made of the occasional patient for whom death precipitates severe anguish that is not amenable to the best symptom control or counselling efforts; in these patients sedation may be preferable in the last phase of life." "Indications for the use of anxiolytic or sedating drugs included suboptimal relief of major symptoms in 20 patients and a sudden terminal event in 16 patients."

18. T. Morita et al - *Sedation For Symptom Control In Japan,* Journal of Pain and Symptom Management - 1996:1232

69/143 (48.3%) received sedation and died an average 3.9 days after sedation was begun. Symptoms requiring sedation included dyspnoea, pain, general malaise, agitation and nausea. In 83% of cases symptoms were escalating as death approached.

"In 10% of cases death was not imminent".

In only 7% were both family and patient informed of the possibility of life shortening. In 93%, patients were not informed of the possibility of life shortening.

“We regard psychological or existential suffering as an indication for sedation.”

“It may be safely said that escalation of symptoms related to cancer is common and frequently requires sedation.”

“When it is impossible to confirm the patient’s wishes, it is permissible for the physician to follow the patient’s previous statements, or information from close family members instead of the patient’s requests.”

19. Peter Ravenscroft (Professor of Palliative Care), *The Australian Magazine* - 15-16/2/1997

He says he has no hesitation in acceding to requests for sleep, even deep sleep, when patients cannot be helped in any other way. “Some people feel the suffering is so great they feel they can’t stand it any more**. Much of that is psychological, and we don’t have any difficulty - if that’s the overwhelming problem - sedating them so they don’t feel it (their suffering in all its aspects).”**

He says this involves putting them in a deep sleep so “they can’t wake up, or one they would wake from if stimulated”. He gives an example of a motor neurone disease sufferer who felt great anxiety as her respiratory muscles became weaker. “She asked for sleep, and her husband agreed she was terrified.” “So we did put her to sleep and she died two or three days later” says Ravenscroft. “To my mind, this is not euthanasia.”

20. Jessica Corner (Director and Deputy Dean (Nursing), Centre for Cancer and Palliative Care Studies, Royal Marsden Hospital), *British Medical Journal* - 1997:315-1242

“The easing of death, as an intentional double effect, is common place in palliative care and general practice.”

“At a time when all clinical decisions are to be made in the light of research evidence, maintaining a climate of fear and secrecy and somewhat paradoxically shrouding practice with grey ethical principles is counter-productive. **Palliative care needs to take the lead by making clear the strategies it employs for managing difficult situations at the end of life, and, when double effect is used with a view that death is a likely and welcome secondary consequence, to be open about this**.”

21. Ellen McGee - *Can Suicide Intervention In Hospice Be Ethical?*, Journal of Palliative Care - 1997:13-27

“A recent study of the usefulness of the WHO Standards for the relief of cancer pain showed that 3% of 401 dying patients had severe pain. For those patients with unrelieved pain, hospices may resort to the suppression of consciousness i.e. terminal sedation. When other means have failed, physicians can initiate an infusion of barbiturates which induces deep sedation, a procedure which is basically akin to general anaesthesia, and which requires skilled professional administration. **The response of hospice indicates that for hospice there is value to the biological life of the patient as well as the biographical life; hospice recognises and honours the body in human existence**.”

22. R. Fainsinger et al - *Sedation For Uncontrolled Symptoms In A South African Hospice*, Journal of Pain and Symptom Management - 1998:16:145

30% (23/76) consecutive patients (retrospective study) received terminal sedation on average 2.5 days before death. None of the patients received parenteral hydration. The mean equivalent daily dose of parenteral morphine in the last week of life showed a significantly higher mean for the sedated group.

"There was a trend for the patients receiving sedative treatment to be more drowsy and unresponsive in the last days of life, although this was statistically significant only on day 3 prior to death. The perceived adequacy of symptom control in the sedated group was worse in the last 3 days of life."

"The intention of treating staff to sedate patients could not be assessed."

"The relatively short period of time between onset of sedation and death is consistently reported. Comfort has often been taken that this brief period indicates that the need for sedation is an indicator of impending death rather than a cause of premature death."

23. S. Chater et al - *Sedation For Intractable Distress In The Dying,* Palliative Medicine - 1998:12:255

In a survey of 61 specially selected palliative care experts "89% believed terminal sedation was sometimes necessary in the management of terminally ill patients".

"Over 60% of these patients had either pain or respiratory distress as the major symptom requiring terminal sedation." **1/3rd were for psychological reasons (including fear, panic, terror, anxiety).**

"One correspondent with 17 years experience in palliative care, commented that the decision became easier as the appropriateness of providing sedation increased."

"While Twycross is firmly opposed to euthanasia, he commented that 'a doctor who leaves a patient to suffer intolerably is morally more reprehensible than the doctor who performs euthanasia."

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

Reasons for using terminal sedation in 100 patients reported by 39 respondents

Symptom	**No.**	**%**
Pain	32	20%
Anguish	22	14%
Respiratory distress	19	12%
Agitation/delirium	19	12%
Fear/anxiety/terror	16	10%
Emotional/psychological/ Spiritual distress	16	10%
Restlessness	17	10%
Seizures/twitching	7	4%
N and V	4	2%

24. Timothy Quill, *A Midwife Through the Dying Process*

"The difference between terminal sedation and euthanasia (when a lethal overdose is given at the terminally ill patient's request) is paper thin, requiring highly intellectualized analysis and presentation of the physician's intentions. In both circumstances the patient inevitably dies as a result of the treatment. With terminal sedation, the wished for death must be foreseen but not intended if it is to remain under the protective umbrella of "the double effect". **The potential for self-deception in such justifications is substantial."**

25. L. Emanuel, *Facing requests for assisted suicide*, J.A.M.A. 1998: 280;643

"The term terminal coma is avoided here because of the confusion in the literature about how it can be used with intent to euthanize. Anaesthetic coma is taken to mean induction and maintenance of coma for patients with pain that can be controlled in no other acceptable fashion. Following coma induction there should be no further actions to hasten dying, and there should be suitable monitoring to maintain the level of coma, preventing either anaesthesia induced death, or unwanted return to consciousness. While **patients may continue for days in this state before dying**, the patient is not suffering."

"Aggressive pain management may ultimately result in anaesthetic coma and offer thereby a similar degree of relief from physical suffering as induced death, but **without the higher degree of moral questioning associated with physician assisted suicide."**

26. D.A.Asch, *Tensions between theory and practice in palliative care,* J.P.S.M. 1998;16: 135-6

"A patient in the advanced stages of terminal illness, who has already expressed clear goals to be kept pain-free, comfortable and off mechanical ventilation, receives morphine and other sedatives to manage air hunger. Many clinicians who care for patients like this are probably gratified about the **increasing acceptance of terminal sedation as a therapeutic approach in these situations."**

"At an abstract level, intent often discriminates well between what are viewed as moral or immoral actions. **In practice, however, terminal sedation is often used not only with the intent of providing comfort, but also with the unstated – and 'winked at' – intent of hastening death**. In these situations, the doctrine of double effect is just a precious euphemism. Because intent is so important to understanding the moral implications of an action, but intent cannot be directly observed, examining the process of clinical care does not unambiguously reveal its moral appropriateness."

"There are no easy solutions to these tensions. They result, in part, from those who stress subtle theoretical distinctions between permissible and impermissible activities near the end of life – distinctions that may not reflect how clinicians feel about real bedside decisions they must make."

27. K.M.Wilson, J.J.Schneider, P.J.Ravenscrof, *Stability of midazolam and fentanyl in infusion solutions,* J.P.S.M. 1998;15:138-39

"The combination of an opioid and a short acting benzodiazepine is **frequently required."**

28. Alan R.Fleischman, *Ethical issues in pediatric pain management and terminal sedation,* J.P.S.M. 1998;15: 260-261

"Sedation at the end of life to alleviate severe and unremitting pain has been called 'terminal sedation', **because of its inevitable association with the death of the patient.** Unlike aggressive pain management, which may, although rare, result in respiratory compromise, 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."**

"To justify the risk of death due to pain medication associated with continued treatment, clinicians often invoke the principle of 'double effect'. This doctrine, prominent in Catholic teaching, is designed to provide guidance when an action can have at least one possible bad effect at the same time it has at least one intended good effect."

"Terminal sedation is justified to alleviate pain and suffering **whilst acknowledging that death is not only a risk but a likelihood**."

29. N.I.Cherny, *Ethics Rounds. Terminal sedation and existential distress,* J.P.S.M. 1998; 16: 403

"In general there is an increasing awareness and acceptance of the use of sedation in the management of refractory symptoms"

"Particular concern has been raised regarding the issue of sedation accompanied by continued withholding of artificial hydration. 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."**

In this context, sedation is a medically indicated and therapeutic response to refractory symptoms which cannot be otherwise relieved."

"It is neither desirable to subject patients with refractory psychological or existential suffering to protracted trials of therapies that provide inadequate relief, nor to sedate patients when viable alternatives remain unexplored."

30. Janet Hardy, *Sedation in terminally ill patients,* Lancet 2000;356: 1866-1867

"Death from malignant disease is rarely the calm, dignified process so often portrayed on stage and screen. It is commonly heralded by agitation, mental anguish and general unease and results in a well-recognised state, generally referred to as terminally restlessness.

In many cases the cause is irreversible and it is usually inappropriate or impossible to determine all contributory factors. **A common management approach is sedation.**

Sedation is also used as a means of relieving specific symptoms (e.g. dyspnoea) in patients with advanced disease. Similarly, in the minority of patients in whom pain cannot be fully controlled by standard techniques and analgesics, sedation is occasionally used as the only means of relieving overwhelming distress.

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.

The concept of sedation causes considerable unease in many palliative care workers, most of whom are ardently opposed to any form of euthanasia or patient-assisted suicide.

There is concern that sedation as the best means of symptom control in the dying patient may be underused because of fear of employing "terminal sedation".

31. P.G.Lawlor, R.Fainsinger, E.Bruer, *Delirium at the end of life,* J.A.M.A. 2000; 284: 2427

Induction of deeper levels of sedation (e.g. with higher doses of neuroleptic medications or continuous infusions of midazolam) can compromise a patient's ability to protect their airway.

32. K.Faber-Langenden, P.N.Lanken, *Dying patients in the Intensive care unit,* Ann. Int. Med, 2000: 138; 886

"Patient comfort must be assessed frequently, and signs of discomfort should be treated with adequate doses of sedatives and opioids**." "Terminal weaning that lasts for many hours only prolongs the dying process and should be avoided."**

"Dyspnoea and anxiety should be anticipated when ventilator support is withdrawn by any method. Intravenous opioids and benzodiazepines are the drugs of choice to treat dyspnoea and anxiety or agitation respectively. These drugs may also be given before ventilator withdrawal to prevent anticipated symptoms from occurring."

"When several interventions are in use, a somewhat predictable pattern of withdrawal; occurs…….the reasons for this 'step-wise retreat' are complex, and in some cases may be related to the symbolic importance of an intervention (such as artificial feeding) or to how immediately withdrawal of intervention (such as ventilator) leads to death. **However, many of these rationales do not reflect patient values, and may not be ethically justified."**

33. Eric Krakauer et al, *Sedation for intractable distress of a dying patient*, J.P.S.M.2000;5:5 3

Describes the terminal care of a 20 year old man with a high grade epithelioid haemangioendothelioma. "He had a large mass on the right side of his neck that was compressing his trachea and he had moderate to severe dyspnoea. He was only able to speak a couple of words at a time because of his dyspnoea. I asked him if he would prefer to be sedated and comfortable, if it came to a choice, or be more awake and tolerate some discomfort. He very clearly went for option A.

We started IV diazepam. Initially I think there was some improvement. I don't think his symptoms were under excellent control but I think he was a little improved."

"Quite quickly things really got worse and he developed very severe dyspnoea and stridor……..we increased the opioid and diazepam dose rapidly. He would nod off to sleep for 30-45 minutes after bolus doses, and his respiratory rate would fall from the 40s to the 20s. For a few minutes ha would seem comfortable, but within 30-40 minutes he would wake up and immediately become severely dyspneic and distressed with a respiratory rate in the forties. He was then given IV Propofol. For the last 6 hours of his life, he was sedated and comfortable. His symptoms that we hadn't been able to control any other way were under control."

“I knew that the use of an anaesthetic induction such as propofol risked unintended but clearly foreseeable side effects including death.”

34. R.I.Fainsinger et al, *A multicentre international study of sedation for uncontrolled symptoms in terminally ill patients,* Palliative Medicine 2000: 14;257-65

A study of 387 patients from 4 centres – Israel, Spain, South Africa (2)

“More than 90% of patients required medical management for a major symptom issue in the final week of life. There was a striking consistency among the four sites in the need for medical management of pain, nausea and vomiting. There was a wide variation in the need to manage the agitated symptoms of delirious patients as well as dyspnoea.”

“The intent varied from 15% (Israel) to 36% (Cape Town).”

“The management of delirium was the most common problem requiring sedation.”

“Assessments of level of consciousness and adequacy of symptom control are extremely subjective and were open to interpretation by the participating physician.”

Good symptom control was present in only 53-75% of patients 6 days before death, and only 53-73% of patients 3 days before death.

35 Erich H. Loewy, *Terminal Sedation, Self Starvation and Orchestrating the End of Life,* Arch. Int. Med. 2001; 161: 329-332

“At least in law, and I would reasonably hold the same true for ethics, one is responsible not only for what one has clearly intended, but also for what one could reasonably foresee. In terminal sedation, not only is the patient’s death clearly foreseen, it is in fact the end point of what is being done. Clearly (and however it may be cloaked by the use of language), the intent here is more than just the clear goal of relieving pain and suffering. Because the goal of relieving pain and suffering adequately can be attained only by obtunding the patient until death ensues, the patient’s death becomes the end point and, therefore, one of the intended goals. **These goals do not differ from those of physician assisted suicide, or, for that matter, voluntary euthanasia. Most patients are, in fact, sedated and given analgesics at the end of life.** Thus the term ‘terminal sedation’ is, at the very least, misleading and euphemistic. **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**. When patients ask for and seem to require sedation sufficient to render them unconscious at the end of their life, there can, in selected cases , be little ethical objection. Patients injected with overdoses of a drug with the intention of causing their deaths or patients kept unconscious with the intent of keeping them unconscious until death ensues are in the end both very much dead. To say that in the former case (the injecting of a drug to directly cause death) death was the intended consequence but in the latter to deny that death was the intended consequence seems, at the very least, disingenuous. The difference is maintained for two reasons. **The first reason is to escape legal difficulties; the second is a form of self-delusion aimed at giving comfort to the physician and the medical team**. There is basically nothing wrong with accommodating the law when doing so does not conflict with ethical values or trying to minimize the anguish of the medical team. But self-delusion, because of its tendency to produce a form of unrecognized dishonesty, is not something to be encouraged.

I want to be clear. Although such a practice may shorten life, I do not in any way oppose maximal sedation and analgesia for patients at this stage of life. Indeed I can see no rational or humane argument against such a practice. But I do oppose the idea that we should engage in this practice for our own or the court's sake. Ethics, if it must be anything, must be honest. Twisting things or calling them by a different and more benign set of names merely obfuscates instead of addresses the problem."

36. John Luce, Judith Luce, *Management of dyspnoea in patients with far advanced lung disease.* J.A.M.A. 2001; 285 :1331

"The long term administration of sustained release morphine (for COAD) has not been shown to be superior to placebo in reducing breathlessness in such patients, most of whom reported drowsiness, nausea constipation and other adverse effects."

"Hospitalized terminal patients may be treated with intravenous opioids by either constant infusion or patient controlled systems."

"Benzodiazepines have been shown to reduce dyspnoea in some patients with COAD because they blunt respiratory drive and the perception of breathlessness. Yet these agents may cause drowsiness, unco-ordination and dysphoria."

"**Opioids and benzodiazepines may depress ventilation significantly when given high doses.** Nevertheless, clinicians should be aware that administration of these drugs, even to the point of terminal sedation is both ethically and legally sanctioned under the principle of double effect."

37. Tai-yuan Chin et al, *Sedation for refractory symptoms of terminal cancer patients in Taiwan,* JPSM 2001:21;463

Study from Taiwan of 251 patients. **27.9% received sedation** – some oral, some intermittent, not necessarily terminal. It was provided for agitated delirium (57%), dyspnoea (23%), severe pain (10%) and insomnia (7%).

In fewer than half was with consent of both patient and family.

"Unfortunately the majority of cancer patients suffer physically, psychologically and spiritually in their terminal stages."

"A study conducted at memorial Sloan-Kettering showed that 17% of 185 patients thought about committing suicide."

"Although there is total suffering in terminal cancer patients, physical symptoms such as pain, weakness, nausea, delirium, constipation, dysphasia and oedema often demand the most attention. These symptoms are often aggravated in the last days. There are some symptoms that cannot be adequately relieved. Sedation is usually considered to relieve these refractory symptoms."

38. C.Kaldjian et al, *Internists attitudes towards terminal sedation in end of life care,* J.Med.Ethics 2004;30:499

Surveyed 677 ACP members re attitude to terminal sedation (definition excluded simultaneous withholding of food and fluids).

- 96% supported the use of analgesics even at the risk of a hastened death
- 73% supported the practice of terminal sedation
- **33% supported PAS and TS**

Those with more experience with dying patients fell into Gp 11. Those frequent religious observers were more likely in Gp 1 or 11.

The physicians we surveyed were widely supportive of aggressive palliative care in terminal illness. It appears that most of the physicians we surveyed make a distinction between treatments that intend comfort and *risk* a hastened death and treatments that intend a hastened death.

39. J.Rietjens, *Physician reports of terminal sedation without hydration and nutrition for patients nearing death in the Netherlands,* Ann Int Med 2004:141;178

"Patients nearing death frequently have symptoms such as dyspnoea, agitation, pain, and anxiety. If treatment with analgesics and anxiolytic agents are not effective, sedatives are sometimes used as an alternative to render patients unconscious and then oblivious of their symptoms. Subsequently, if artificial nutrition and hydration are not given, death will follow soon."

"Terminal sedation preceded an estimated 10% of all deaths in the Netherlands."

"Physicians partly had the intention to hasten death in47%, and had the explicit intention to hasten death in 17%." Terminal sedation was more often practiced in hospital.

"the major reasons for using terminal sedation were to alleviate severe pain, agitation, dyspnoea and anxiety." Terminal sedation was almost always discussed with relatives, but not always with the patient, who was often no longer communicative.

Reasons given for choosing TS rather than VE were (1) patient preference, less intrusive (2) patient unable to request and possibly (3) no need to have a request for TS, no need for special reporting requirements as for VE.

40. S.Lundstrom et al, *When nothing helps: Propofol as sedative and anti-emetic in palliative cancer care* JPSM 2005:30;570

"There are still a number of patients in whom symptoms of pain, agitation, delirium, dyspnoea, and nausea cannot be satisfactorily controlled. In such treatment refractory situations, the use of palliative sedation may be the only way to achieve symptom control and relieve suffering."

"A recent review of the literature on palliative sedation suggested that it was used in 15-30% of the terminally ill."

“The most common indicators were agitation, restlessness and pain.” Propofol “is associated with the risk of causing hypotension and respiratory depression.”

41. A, Navigante et al, *Midazolam as an adjunct to morphine in the alleviation of severe dyspnoea perception in patients with advanced cancer*, J.P.S.M. 2006:31;38

“Dyspnoea remains one of the most challenging symptoms to manage in the setting of advanced cancer patients. The prevalence and severity of dyspnoea increase in the last weeks of life, and it is the main symptom in more than 20% of patients in the last 48 hours of life.”

“Studies suggest that in the last weeks of life, current management strategies, although helpful, are not adequate for symptom control, resulting in more frequent need for hospitalization and heavy sedation.”

“Many patients report anxiety concurrent with the feeling of breathlessness. Dyspnoea can lead to anxiety and anxiety can exacerbate dyspnoea.’

“The mainstay of dyspnoea palliation remains altering its central perception. Morphine is the main drug and anxiolytics have a less established role.”

“Many physicians are still reluctant to use this combination [morphine and midazolam] because of the fear of respiratory depression.”

42. Guido Miccinesi et al, Continuous deep sedation: physicians’ experiences in six European countries, JPSM 2006:31;122

“Previous studies reported indications for the use of sedation in patients nearing death are intractable pain, dyspnoea, delirium, agitation, **severe psychological symptoms such as anxiety and existential distress.”**

“continuous deep sedation may be the only way to control symptoms.”

In 35-64% of all CDS cases, the patient did not receive artificial nutrition or hydration

(ANH). Italy and Belgium had the highest reported incidence of CDS (8.5% and 8.2% of all deaths). CDS is clinically indicated for imminently dying patients with severe symptoms refractory to conventional palliative treatments.

43. A NATIONAL GUIDELINE FOR PALLIATIVE SEDATION.\, Verkerk et al, JPSM 2007:34;666

Dutch government sponsored committee designed guidelines.

Palliative sedation is “the deliberate lowering of consciousness of a patient in the last phase of his or her life.”

“The objective of palliative sedation is to relieve suffering (caused by refractory, i.e. untreatable symptoms), and lowering of consciousness is a means to achieve this. It is very important that palliative sedation is given for the right indication, proportionately and adequately. Proportionally means that consciousness is lowered only to the level necessary and sufficient to achieve the desired level of symptom alleviation. The level of reduction of consciousness to achieve this end may vary from superficial to deep. The assessment and decision-making processes must focus on adequate relief of the patient's suffering, so that a peaceful and acceptable situation is created. Palliative sedation is given in the last phase of life, in the imminently dying patient."

Palliative sedation is indicated "in the presence of one or more refractory symptoms, which leads to unbearable suffering for the patient." "A symptom is or becomes refractory if none of the conventional treatments are effective (within a reasonable time frame) and/or these treatments are accompanied by unacceptable side effects. Pain, dyspnoea and delirium are the most common refractory symptoms that in clinical practice lead to use of palliative sedation."

"The administration or dose increasing of opioids or other non-primarily sedative medications with the implicit or explicit objective of producing sedation is regarded as improper use of these medications."

"When palliative sedation is started, usually a stepwise approach is taken."

The guideline expresses the view that palliative sedation is normal medical practice.

44. CONTINUOUS DEEP SEDATION FOR PATIENTS NEARING DEATH IN THE NETHERLANDS : DESCRIPTIVE STUDY, JRietjens et al BMJ 2008:336;

This study compared the incidence and characteristics of continuous deep sedation in 2001 and 2005.

The use of continuous deep sedation increased from 5.6% in 2001 to 8.2% in 2005 (7.1% such sedation was provided in conjunction with decisions that potentially hastened death). For 47% of all patients who received continuous deep sedation, the sedation was started in the last 24 hours before death. 42-55% were reported as experiencing pain, fatigue, dyspnoea and unclear consciousness in the last 24 hours of life and 23% and 21% had confusion and anxiety.

Palliative consultation in the month before death was quite rare (9%). For almost all the patients for whom sedation was used, general practitioners and nursing home physicians withheld artificial nutrition and hydration. In 6% of cases patients were sedated for more than one week (11% among clinical specialists).

In 9% of cases the decision to use deep sedation was preceded by an explicit request for euthanasia, which was not granted (due to insufficient time, 'lack of unbearable suffering', and withdrawal of request).

45. LETTER TO EDITOR – BMJ re CONTINUOUS DEEP SEDATION, PJ Harrison, BMJ 2008:336;1085

This doctor's father, 92 year old with incurable colon cancer, had his life ended by CDS without any consultation with patient or family.

"Neither he or any of his close relatives was consulted before such a decision"

"No drip, heavy sedation, increasingly confused. Protocol successful; patient died quietly with his family. No goodbyes." "He had never consented to terminal sedation".

COMMENTARY

These comments make it absolutely clear that terminal sedation/pharmacological oblivion is an integral and common part of modern palliative care in dealing with the more severe symptoms of terminal disease.

I have listed these comments in chronological order. It allows one to see the progressive acceptance of TS because of the necessity for some way of relieving intolerable suffering. One can trace the steady increase of indications from terminal delirium to pain and dyspnoea, and on to psychological and existential suffering.

It is salutary to compare the comment of Dame Cicely Saunders in 1961 to that of Ventafridda in 1990. Moreover Ventafridda clearly indicates that this is not discussed publicly, or mentioned by Palliative care experts. There is a clear indication of a high level of difficulty in controlling symptoms, which require sedation to unconsciousness to relieve.

Hospice emphasizes the doctrine of double effect (a religious doctrine) as the justification for this practice, claiming that hastening death might occur in this process (it usually does), and that relief of pain and suffering is the sole intention of the process. Double effect doctrine supposes that death as an outcome is bad and unwanted - Corner clearly states that this is not so, and that honesty not hypocrisy should be more acknowledged in palliative care. A hastened death is the certain logical outcome of pharmacological oblivion, such that in the opinion of some, (Loewy, Quill, Hunt, Block and Billing) this process is a slow form of euthanasia. It is ambiguous and hypocritical to deny this, and to claim it as an ‘acceptable’ practice - it is only acceptable as a medical practice because it is better than the alternative of not relieving the suffering, and because it has quasi-legal status.

This section should leave no one in any doubt that death that is influenced by opioids and sedatives is common, and that deliberate sedation to relieve terminal suffering is not uncommon and its use is increasing. Despite a high level of medical intervention in the week before death, good symptom control is not achieved in 25-50% until deep sedation is used. It is also clear that such processes not only have the potential to hasten death but do hasten death, and that once this process commences death is unavoidable. Moreover it is clear that dying in coma in this process may be prolonged, taking some days. The process is clearly used for the relief of physical, psychological and existential suffering. It is also probable that this necessary treatment may be underused because of moral concern and legal fear.

PALLIATIVE CARE – COMMENTS ON CEASING FOOD AND FLUIDS

1. Printz

2. Bernat

7. Cherny

8. Gert

3. Emanuel

4,5. Miller

6. Wilks

9. Howard

10. Emanuel

11. Loewy

1. **Louise Printz - *Terminal Hydration, A Compassionate Treatment,* Archives of Internal Medicine - 1992:152-697**

"Compassionate, comprehensive yet appropriate treatment of the dying patient is difficult."

"When is lack of medical hydration more comfortable in the terminal patient? There is reason to believe that it is more comfortable for most terminal patients."

"As physicians, we can help prevent a slow painful death by not administering medical hydration to the patient who will not benefit from it. In terminal patients, we do not need to prolong the inevitable, nor, I believe, should we rush it. By being very attuned to our patient, by withholding medical hydration when appropriate, and by liberally giving medications a needed for comfort, we can ultimately allow the patient's comfort level and underlying condition to determine the timing of death, while we may help improve the quality of the death. **A good death may not be able to be achieved, but perhaps a better death can."**

2. **J. L. Bernat et al - *Patient Refusal of Hydration and Nutrition, Archives of Internal Medicine* - 1993:153-2723**

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

"Voluntary passive euthanasia is often presented as acceptable because it allows the patient 'to die a natural death', because the death was caused by the disease process, no person is assigned responsibility for the death. The freedom from responsibility for the patient's death is psychologically helpful for the physician."

"Physicians caring for patients dying of patient refusal of hydration and nutrition (PRHN) have an important responsibility to provide adequate symptom control."

"Physicians should be willing to prescribe narcotics and benzodiazepines in dosages sufficient to abate pain and other unpleasant sensations. They should not incorrectly limit the dosage of their prescriptions for fear of accelerating death; the intent should be to maintain adequate comfort during dying. The possibility of a hastened death as a complication of symptomatic treatment is an acceptable risk and does not count as PAS or VAE."

"There needs to be societal acceptance that physicians have a moral duty to respect the rational wishes of competent chronically ill but not terminally ill patients who wish to die by PRHN or other valid refusals of therapy. There is no reason why such patients should not have the same rights as the terminally ill to refuse life sustaining therapies including hydration and nutrition. The

American Academy of Nevrology recently published a position statement asserting that chronically ill patients with severe paralysis and intact cognition, whether terminally ill or not, have the right to refuse life sustaining therapy, including hydration and nutrition."

3. L. Emanuel, *Facing Requests for Assisted Suicide,* Journal of the American Medical Association - 1998:280-643

Offers the refusal of oral intake which is allowable if the patient has lost hunger and thirst as a consequence of their illness, and "cessation of oral intake in this protocol is not about choice to die, but about non-intrusion".

"As a further safeguard, the choice to refuse food and water should be limited to terminal patients. A practical definition of terminal for this step in this protocol is the same as that used for hospice eligibility, namely, a physician certified prognosis of 6 months or shorter in a patient with a non-curable illness."

"Evidence of suffering due to dehydration and energy deprivation is lacking for terminally ill patients, and some suggest that not eating or drinking, is, to the contrary, a positive experience."

4. Franklin G. Miller PhD, *A Time to Die: The Place for Physicians Assistance* (Book Review) by C. McKhann, *New England Journal of Medicine* - 1998:339-1562

Anecdotal evidence suggests that a peaceful death can be achieved by refusing food and water, provided the patient receives standard palliative and supportive care. The time required to bring about death by ceasing to eat or drink, typically from a few days to a few weeks. This alternative arguably displays greater evidence of self-determination of patients, and less threat to the professional integrity of physicians."

5. Franklin G.Miller, *Professional integrity in the home,* J.P.S.M. 1998:15: 138-9

"The patient was ready to die and sought a swift end once he had taken care of 'unfinished business'. Accordingly, one option that might have been worth exploring is forgoing food and water. Although morally challenging, this lies within the limits of the law and may be justified if voluntarily chosen by a competent and informed patient."

"Forgoing food and water can hasten death, but **typically it takes from a few days to up to a few weeks to die of dehydration."**

6. Michael Wilks (Chairman, BMA Medical Ethics Committee)

"Some people believe passionately that life must be preserved at all costs, but most people and certainly the majority of doctors accept there comes a point when treatment ceases to be a benefit for a patient."

" there comes a point where medical treatments, including artificial nutrition and hydration, are more of a burden than a benefit to the patient."

7. N.Cherny, N.Coyle, K.Foley, Guidelines in the care of dying cancer patients, Haematology/Oncology Clinics of North America, 1996:10; 261

"Artificial administration of nutrition by enteral or parenteral routes are medical interventions with the potential for associated morbidity. In patients facing imminent death, there are no data that they contribute to symptom relief; they are therefore non-essential and may be discontinued."

"In patients who are cognitively intact, dehydration can precipitate delirium and diminish interact ional function.

8. B.Gert, C.Culver, K.D.Clouser, *An alternative to physician assisted suicide,* expanding the debate, Ed. M.P.Battin

"Since the point of dying sooner is to avoid the pain and suffering of a terminal illness, stopping food only while continuing fluids is not a good method of dying because it takes a long time, often more than a month. However, when fluids are also stopped, dying is much quicker; usually unconsciousness occurs within a week, and death less than a week later."

"Further to what is widely assumed, dying because of lack of food and fluids is not physically unpleasant or painful if there is even minimal nursing care. When there is no medical treatment keeping the patient alive, stopping fluids may be the best way of allowing a patient to die. It is usually painless, it takes long enough for the patient to have the opportunity to change his mind, but is short enough that significant relief from pain and suffering is gained.

9. Dr. Philip Howard, Letter to *The Times* 28-6-99

"Withdrawal of fluids will cause the patient to die from dehydration, which is distressing to the patient, to the carers, and to relatives. It is disingenuous and inhumane to suggest to the contrary."

10. L. Emanuel, *Facing requests for assisted suicide* J.A.M.A. 1998: 280; 643

"Evidence for suffering due to dehydration and energy deprivation is lacking for terminally ill patients, and some suggest that not eating and drinking is, to the contrary, a positive experience."

"Recourse to physician assisted suicide however seems less rational with the availability of such options as refusing oral intake."

11. Erich H. Loewy, *Terminal sedation, self-starvation and orchestrating the end of life,* Arch.Int.Med. 2001: 161; 329-332

"The other, and in my view **macabre,** option spoken about in the recent literature is that patients who ask for physician assisted suicide be advised simply to stop taking fluids and nutrition and thus hasten their death."

"Suggesting to patients that they can starve themselves is not as much aimed at easing the patient's plight as it is aimed at letting the health care professionals off the hook – especially the legal hook."

"**Such a suggestion is, in my view, not an ethically legitimate, or even minimally acceptable, option."**

COMMENTARY

There is no doubt that patient autonomy is a fundamental ethic of medicine in general and palliative medicine in particular. It is also clear that patients have a fundamental right to effective treatment of suffering according to their assessment of their suffering. Issues of powerlessness, incapacitation, social isolation, loss of control, dependence, loss of cognition as well as pain and physical suffering are significant at the end of life and can lead patients to request a hastening of death. It is also clear that patients making these requests can be perfectly rational and are doing so in order to be relieved of intolerable suffering.

GENERAL COMMENTS ON PALLIATIVE CARE/ATTITUDES OF PC PHYSICIANS/OTHER DOCTORS

1. Doyle

2. McGee

3. Doyle

4. Sulmasy

5. Milstein

6. Ashby

7. Hutton

8. Librach

9. Zalcberg

10. Hunt

11. McKhann

12. Richards

13. Ashby

14. Meier

15. Christakis

1. Derek Doyle, *Have we looked beyond the physical and psycho-social ?,* J.P.S.M. 1992: 7; 302

"Let us first be clear that we are looking at spiritual and not religious issues. They are related but not synonymous."

"I have attempted to show that such spiritual questions are common to us all, whoever we are. They are not the product of religion through faith, although religion and religious practices both serve to answer them and may at the same time make their asking more poignant and painful."

"A human is not human if he or she never asks 'Why do I suffer? Who am I? Where is God? What is it all about?'"

"It would be naïve of us to expect a terminally ill patient to speak of something so intensely personal and possibly painful as a spiritual question when we have given him no reason to expect a helpful response."

2. Ellen McGee – *Can suicide intervention in hospice be ethical?,* Journal of Palliative Care*,* 1997:13;27

"Since its inception, hospice has seen itself as a moral enterprise; it shares a vision of what constitutes 'good dying'. This moral vision is unique in the secular health care field and animates hospice's answer in particular ethical dilemmas.

"Hospice presents one such clear position – hospice maintains that it has a vision of good dying; it presents an ideal of continued care**, of valuing the individual even when he does not value himself."**

3. Derek Doyle, *Foreword to Palliative Care Ethics,* Oxford University Press 2nd. Edition 1999 (Fiona Randall, R.S.Downie)

“It is often said that a metaphorical halo shines over specialist palliative care and its practitioners with the result that some of its claims and assumptions have gone unchallenged by all but a few.”

4. D.P.Sulmasy, *A biopsychosocial-spiritual model for the care of patients at the end of life,* The gerontologist 2002;291:493

“Clinicians, at a minimum, have an obligation to ensure that a spiritual assessment is performed for each patient”

“It is particularly useful to try to measure spiritual well-being, or its opposite, spiritual distress.”

“Perhaps more important in the care of dying patients is to understand their current manner of religious coping.”

This paper discusses use of the following scales

1. Pain scale
2. Meaning of life scale
3. Death transcendence scale
4. Religious coping measure and a Spirituality well-being measure
5. Daily spiritual experiences measure
6. To be developed – a dignity scale and a hope scale

5. *Introducing Spirituality In Medical Care*, J Milstein, JAMA 2008:299;2440

“When one member of a couple is afflicted with a profound, neurologically incapacitating injury or severe, progressive dementia, the unaffected spouse may be affected cognitively, emotionally and spiritually. In the face of such experiences, this spouse may enter a state of hopelessness, lose all sense of control and meaning, and become unable to cope. The consequences of not addressing the family’s loss and bereavement are well known.” During critical illness, particularly with end-of-life or life-altering situations, certain existential questions of ultimate meaning may arise.”

6. Professor M. Ashby (Professor of Palliative Care, Monash Medical Centre), *Medical Journal of Australia* - 1995:162-596-97

“Palliative care is a model of care, not a moral crusade, and should not be used as a strategic weapon in social debates.”

7. Nancy Hutton, Board Member of Palliative Medicine Academy, Medical Director – Community Hospice of Maryland, 28-2-07

The Palliative Medicine Academy (US) (“the nation’s leading organization of hospice physicians) has dropped opposition to ‘doctor assisted suicide’ and decided to take a neutral position.

“I think it’s taken as a way of providing comfort for unrelieved suffering, and so in that respect, it would be consistent with a palliative care approach.” **She says doctor assisted death is not the antithesis of palliative care.**

8. Larry Librach, PC Physician for 30 years, Mount Sinai Hospital, Toronto

“There’s a group of people who are very rational and very reasoned and who are suffering immeasurably and still want that option, of assisted suicide, and it’s becoming less clear to me that we can refuse these people that option.”

“We used to say palliative care would relieve all suffering, but that, of course, was nonsense. [I’ve] seen too much suffering to be glib about it anymore.”

9. J. Zalcberg - *In Palliative Care,* Medical Observer - 19/1/96

“This is intensive medicine. It is expensive medicine.

10. Roger Hunt , *A critique of the principle of double effect in palliative care*

“There would be little or no need to invoke the principle of double effect if palliative care treatments never hastened death.”

“My hope is that clinician’s will acknowledge that palliative treatments not only affect the quality of patient’s lives but also can effect the duration of the terminal phase. Clinicians should accept responsibility for discussing outcomes with patients, their families and colleagues.”

“The exclusive reliance on the clinician’s intention is dangerous because of the neglect of the patient’s viewpoint and wishes.”

“Death is not always a ‘bad’ outcome in the setting of intractable terminal suffering. Death is sometimes wanted by the patient, and is often seen as a ‘blessing’ by family and clinicians.”

11. Charles F. McKhann, *A time to die,* Yale University Press, 1999

“End of life concerns should be focused on the patient rather than on the physician or the law. Agony from advanced disease that is severe enough to make a person wish to have his life end is the same agony regardless of the mode of death, be it refusal of treatment, the double effect of drugs, suicide, assisted suicide, or euthanasia. The underlying reason that the patient wants earlier death is to end his suffering. Concerns of physicians and the law should be secondary. Physicians should be as supportive as possible, regardless of what is required, at a point in life when the patient’s needs are greater than ever, even if only for a short time. The laws that are imposed should be broad and general, leaving most decision making to patients and their physicians with as little oversight as possible. As physicians and the law increasingly respect the rights of patients, the needs for excuses to rationalize the intent to die or to assist in death will be reduced.”

12. Tessa Richards (assistant editor BMJ), *A better way to die,* BMJ 2007:334;830

Comparing birth and death - “Are we equally well prepared for dying and death? Speaking for myself, the answer is no. I dodged the issue before my own life-threatening surgery, and floundered as I witnessed my father’s slow decline from dementia. Practising medicine conferred familiarity, but not understanding, competence or even compassion. I learnt a lot through following his journey. Not from the half-dozen doctors he was nominally under, but from his nursing auxillaries, who without exception came from poor countries.”

13. Professor M. Ashby, *Medical Journal of Australia* - 1995:162-596-97

“In their criminal codes most societies deem themselves to have an interest in preserving the lives of their citizens which overrides any individual’s wishes for medical assistance in dying. This is unacceptable to many people who give the highest priority to personal autonomy and control over their life decisions. There is potential for alienating these people from mainstream medical services if their views are ignored or rejected in a paternalistic way**.**

14. D. Meier and L. Beresford J. Pall. *Preventing Burnout,* 2006; 9:1045

"There is a recognized syndrome of burnout. Its main components, manifested specifically in the workplace, are emotional exhaustion, a sense of cynicism or depersonalization, and feelings of low personal accomplishment."

"The potential for compassion fatigue or burnout in palliative care hasn't received the attention it deserves."

"the emotional price of palliative care is an essential part of what we do."

"For palliative care professionals in particular, work is much more than a job, and carries great personal commitment to patients, and to changing the system."

15. N. Christakis, *Too quietly into the night*, BMJ 2008;357;326

"The fact is that the everyday reality of death in the US – and elsewhere in the developed world, let alone in the undeveloped world – is abysmal."

"Our best estimate is that 40-70% of Americans die in pain. A large minority of these have other symptoms such as shortness of breath, nausea, or depression that are often even more distressing to patients than pain. More than 80% of Americans die in institutions. And roughly 25 to 75% of Americans place a significant burden on family caregivers in the course of their death".

"Yet one of the most compelling explanations of this sorry state of affairs is that those in our society who are dying constitute a particularly disempowered, even if numerous group. It may be fashionable in medicine to think about 'vulnerable populations', but it is hard to imagine a more vulnerable population than the dying, nor one that is more neglected or more invisible."

"we do not see marches of terminally ill people demanding recognition of their rights to more resources and more attention.

COMMENTARY

This section reveals a variety of attitudes to palliative care. Those of Doyle, McGee and Sulmasy clearly reveal a significant moral/religious position which pervades their PC practice. Hutton and Librach put a more reasoned position based on experience and respect. Hunt repositions the shaky endorsement of Sulmasy on double effect. Relying as double effect does on the physician's intentions, which are multiple, ambiguous and unproveable, it should play no part in public policy.

McKhann's comment on the centrality of the patient is fundamental.

INTENTION

1. **Chater**
2. **Wilson**

4. **Miller**
5. **Angell**

3. **3. Quill 6. Bernheim**

1. **S. Chater et al,** ***Sedation for Intractable Symptoms in the Dying*** **(A Survey of Experts), Palliative Medicine – 1998:12;255**

"These experts do not seem to equate their practice of sedating their patients with anything other than symptom control."

2. **W. C. Wilson et al.,** ***Ordering and administration of sedatives and analgesics during the withholding and withdrawal of life support from critically ill patients,*** **J.A.M.A. 1992: 267; 949**

Physicians ordered drugs to decrease pain in 88% of patients, to decrease anxiety in 85%, to decrease air hunger in 76%, to comfort families in 52%, and **to hasten death in 39%.** Hastening death was never the sole reason. The dosage of sedatives increased by 4.5 times and of analgesics by 3.5 times during this period.

3. **T. E. Quill, -** ***Palliative Options of Last Resort,*** **JAMA 1993:329;1039**

"Multi layered intentions are present in most, if not all, end-of-life decisions."

"If we do not acknowledge the inescapable multiplicity of intentions in most double effect situations, physicians may retreat from aggressive palliative treatment out of fear of crossing the allegedly bright line between allowing patients to die and causing their death. Our current ethical thinking and legal prohibitions reinforce self-deception, secrecy, isolation and abandonment when the exact opposite is needed."

4. **F.G.Miller,** ***Professional integrity in the home,*** **J.P.S.M. 1998: 15; 138-9**

"The intentions of clinicians, however, may be multiple and ambiguous, and the causal contribution of escalating dosages of morphine to the timing of terminally ill patients deaths may be difficult to discern."

5. **Marcia Angell (Editorial) –** ***Caring for the Dying – Congressional Mischief*****, NEJM 1999:341;1923**

"Furthermore, when the suffering of a dying patient is prolonged and intractable, a doctor who administers or prescribes large doses of a controlled substance may well have mixed intentions. Just as family members often feel a sense of relief along with their grief when such patients finally die, so doctors often wish both to ease suffering and to hasten death. The balance of those desires may vary from hour to hour, depending on the patient's condition…. If all attempts at palliation fail, as they sometimes do, then the hope of an easier death may give way to the hope for a faster one. That is, intention can shift.
It is absurd to imagine that doctors could be innocent in one hour, but deserving of 20 years in prison the next, simply because the desired outcome of treatment changed. What is important is whether doctors are doing their utmost to ease suffering in accord with their patient's wishes."

5. J Bernheim et al, ***Development of Palliative Care and Legalisation Of Euthanasia: Antagonism Or Synergy*****, BMJ 2008:336;864**

"Proponents of euthanasia argued that, similar to medical futility, there is also such a thing as palliative futility."

“Some Catholic palliative care workers accepted the regulation of euthanasia as a lesser evil than clandestine life termination or palliative futility.”

There was support for euthanasia from within palliative care. “The model they proposed was encapsulated by the term integral palliative care, in which euthanasia is considered as another option at the end of a palliative care pathway and the patient’s preferences came first.”

The Belgian legislation “stipulated that patients requesting euthanasia must be informed of the possibilities of palliative care, but do not require a palliative care team to be consulted before euthanasia.”

“The Flemish Palliative Care Federation, intent on avoiding a schism between palliative care workers, adopted an explicitly pluralistic stance. It stated “the view of the patient must be determining” and that “palliative care and euthanasia are neither alternatives nor antagonistic….euthanasia may be part of palliative care….caregivers are fully entitled to ethical limitations, but they must be expected to state these limitations candidly, clearly and above all in due time.”

“Regulatory and professional organizations implicitly or explicitly endorsed the concept of integral palliative care, which recognizes the right of patients to decide that further conventional palliative care is futile and to request and obtain physician assisted death.”

advance care planning, including:

a) ***avenues for individuals and carers to communicate with health care professionals about end of life care***
b) ***national consistency in law and policy supporting advance care plans in personal electronic health records, and***
c) ***scope for including advance care plans in electronic health records***

Dying with Dignity ACT supports the development of National Advanced Care Directives and especially their provision in electronic records for doctors. We have heard alarming accounts of doctors discounting documents provided by dying patients that reflect their wishes, and treating them as fraudulent. We supported the National Framework on Advanced Directives and liked the primacy given to the individual rather than the doctor when it comes to a person’s dying.

We would like to see the repeal of all state and territory laws making assisted dying unlawful so that people could record their **legitimate** wishes in relation to their deaths in Advanced Directives.

the availability and funding of research, information and data about palliative care needs in Australia.

It is clear to us that palliative care in Australia does not meet the needs of some older Australians or the terminally ill and that they are being forced out of the health system at the end of their lives. The fact that adults who want to discuss how their palliative care needs might be met using a definition of palliative care which does not concur with the senate committee’s definition and have been turned away by the committee shows that some Australians needs and wishes are being excluded by the palliative care system in Australia. There is a need for a broader definition of palliative care and there needs to be research done into how widely people want this broader definition to apply. Even if only a small number of Australians want the definition to be broader they are all Australians and should be included in research, planning, and data collection.