Pain Relief at the End of Life for People with Dementia: Presentation to Alzheimer’s Australia (Victoria)

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Pain Relief as a Human Right

- *We must all die. But that I can save him from days of torture, that is what I feel as my great and ever new privilege. Pain is a more terrible lord of mankind than even death itself.* (Albert Schweitzer. *On the Edge of the Primeval Forest*. New York: Macmillan, 1931, p 62).

- In 2004 the International Association for the Study of Pain noted that “Pain is a major public health issue throughout the world. The gap between an increasingly sophisticated knowledge of pain and its treatment and the effective application of that knowledge is large and widening.”

- The Association also noted that “the diverse sources of patients’ rights to pain relief ... lie along a spectrum of legal enforceability”; from guidelines to constitutional rights to legislative rights.
Pain Relief as a Human Right

- Although the right to pain relief is inferred in the UN Universal Declaration of Human Rights and other international Covenants, especially in those sections relating to an expressed right to health and health services, these do not necessarily carry legal weight.

- Legal and Constitutional Rights: In 1997, the US Supreme Court expressed support for a constitutional right to adequate palliative care in two cases (Washington v. Glucksburg and Vacco v. Quill). These judgments assisted doctors caring for terminally ill patients to deal with regulatory medical boards that were “ignorant or dismissive of the evidence that high-dosage prescriptions of opioids for treating pain and other distressing symptoms are safe, effective and appropriate.” (International Association for the Study of Pain, 2004; p2)
Aust/NZ College of Anaesthetists Statement on Patients’ Rights to Pain Management

• “Rights” of patients to management of pain include:
  – The right to be believed ... pain is a personal experience ... there is a great variability among people in their response to different situations causing pain.
  – (s.17 (3) ACT 2006 Medical Treatment (Health Directions) Act: In providing relief from pain and suffering to the person, the health professional must give adequate consideration to the person’s account of the person’s level of pain and suffering.
  – The right to appropriate assessment and management of pain;
  – Right to be cared for by health prof’s with training/ experience in assessment/management of pain ... Where such competencies are unavailable, patients s/be referred appropriately.
  – The right to appropriate effective pain management strategies ... supported by policies and procedures ...
Rights Under Australian Law

• The ACT 2006 Medical Treatment (Health Directions) Act contains an explicit statutory statement of the right to pain relief: s.17 (2) “The person (under the care of a health professional) has a right to receive relief from pain and suffering to the maximum extent that is reasonable in the circumstances.”

• In the SA 1995 Consent to Medical Treatment and Palliative Care Act, medical practitioners caring for terminally ill patients are protected from any criminal or civil liability if they administer treatment with the intention of relieving pain, providing such treatment is given with consent, in good faith, without negligence, and in accordance with “proper professional standards of palliative care.”
The Ethical Basis for Pain Relief

• Pain Relief in relation to the 4 primary ethical principles in Western society:
  – Beneficence: Do good – relieve pain
  – Non-Maleficence: Do no harm – do not cause pain/prolong dying/deprive patient of peaceful death
  – Autonomy: Right to refuse treatment but still be kept comfortable
  – Justice: lack of palliative care in rural/regional areas

• Other Ethical Principles
  – Compassion
  – Proportionality

• When Ethical Principles Compete:
  – Relieve pain vs Hasten death
Current Situation: Carers’ Stories - 1

- Case 1: Very frail elderly man, fractured his hip on a Friday afternoon; was admitted to hospital (in NSW).
  - Treating medical practitioner decided he was too frail for surgery.
  - He was clearly in agony – daughter requested more pain relief and a palliative care consultation; she was told that no palliative care staff were available on the weekend.
  - Nurses came to roll him – without additional pain medication; on the third occasion he looked at his daughter with terror in his eyes and said “No roll. No roll”.
  - Daughter threatened the nurses with physical violence if they rolled him again – they didn’t!!
Current Situation: Carers’ Stories - 2

• Case 2: Very frail elderly woman with a fractured leg.
  – She had been on Warfarin - treating orthopaedic surgeon had to wait for Warfarin to clear her system before he could operate;
  – No palliative care was organised for her, even though it was clear she was in agony;
  – When son and daughter begged staff to give her more pain relief they were accused by a nurse of “trying to kill” their beloved mother;
  – They were threatened by the orthopaedic surgeon: “If you don’t stop this nonsense, I will have no option but to order an autopsy (?) and a coronial enquiry” (latter may have been useful!)
  – She was left in agony for 6 days until she died.
Current Situation: Carers’ Stories - 3

• Cases Other than Pain:
  – (Wife) “First of all he was stubborn when he was in hospital; he wouldn’t eat - he was just starving himself. They couldn’t get him to eat … so they had to force-feed him. They put a tube down his nose and then they had to tie him in the bed, because he kept pulling it out. He just didn’t want it”.

Why is this Happening?

- Lack of training of medical practitioners in pain management:
  - Queensland research with 1300 health professionals, only 4% of surgeons and 23% of GPs had had any specific training in pain management – and often they are ordering post-op pain relief and/or caring for terminally ill patients.
- Professional arrogance (“I know it all, I don’t need advice from the palliative care team!”)
- Failure to recognise that death is approaching (or seeing death as failure)
- Confusion about what is/is not euthanasia
Confusion About what is/is not Euthanasia

• Confusion about what is, or is not, euthanasia leads to:
  – Inadequate pain management
  – Inappropriate continued use of medical technology
  – Fear among health professionals of legal consequences of care provision
  – Poor doctor-patient communication
  – Disillusioned patients/families/carers
Some commonly held beliefs are that euthanasia includes:

(a) respecting a patient's right to refuse further treatment; or

(b) withholding or withdrawing life support systems that have ceased to be effective or that will provide no real benefit to the patient; or

(c) giving increasing amounts of needed pain relief which may also have the effect of shortening the person's life

None of these is euthanasia
Definitions of Euthanasia

• The World Medical Association defines euthanasia as "the deliberate ending of a person's life at his or her request, using drugs to accelerate death".

• Definition used in studies by Steinberg et al, 1996a & b, 1997; Cartwright et al, 1998 & 2000
  – Euthanasia is a deliberate act intended to cause the death of the patient, at that patient’s request, for what he or she sees as being in his/her best interests (i.e. Active Voluntary Euthanasia – AVE).
Respecting a Patient's Right (Choice) to Refuse Treatment

• This is a legal and moral right possessed by every competent person, under both common law and, in some States/Territories, under statute law relating to assault; also by (now) non-competent patient by Refusal of Treatment Certificate or through instructions given to substitute decision-maker.

• A person may refuse any treatment, even if doing so will result in their death.

• Difficult area for some health professionals to accept, especially such things as a person refusing a blood transfusion because of religious beliefs.
Withholding/Withdrawing Futile Life-Support Systems

• Used to be called "passive euthanasia"; general agreement that that term is unhelpful - it can lead to the inappropriate continued use of invasive technology (e.g., ventilator, feeding tube, dialysis machine).

• Often it is not prolonging life, it is merely prolonging the dying process!

• Removal of futile treatment is good medical practice. However, no definition of futility in law; generally agreed, when burden outweighs benefits – but “burden” and “benefit” should be from patient’s viewpoint.
Giving Pain Relief Which May Also Shorten the Patient's Life

• Often referred to as "the doctrine of double effect" - primary intention is to relieve pain, secondary, unintentional effect may be the hastening of the person's death.

• Accepted by most religious and medical groups, including those who strongly oppose euthanasia.

• Not giving adequate pain treatment when needed may shorten life: patient may suffer complications such as life-threatening cramps or severe respiratory problems if severe pain is left untreated
Not Giving Pain Relief May Shorten the Patient's Life

• The Australian and New Zealand College of Anaesthetists “recognizes that severe unrelieved pain can have severe adverse physical and psychological effects on patients, with associated emotional, social and spiritual effects causing suffering in patients, their families and those close to them. At times severe pain can be extremely difficult to treat and management must be subject to the availability in each health care setting of appropriate, safe and effective methods.” (2004,p3)
Pain Relief: What does the law allow?

• Every person (competent or not) has the right to adequate control of pain and other symptoms, even at the risk of hastening death.

• People with dementia are often denied adequate pain relief.

• The Abbey Pain Scale is recommended for assessing pain in someone with dementia.

• Once assessed correctly, the right combination of drugs, in the right doses, at the right time intervals, will keep almost all patients comfortable.
Pain that is Difficult to Control

• As above, in a few cases pain may be difficult to control (e.g., neuropathic pain).

• Senior palliative care specialist - 3-5% of terminally ill patients may require Terminal Sedation:
  – Refers to use of sedative drugs to induce unconsciousness in terminally ill patients in order to relieve suffering (therefore supports ethical principal of beneficence), including anxiety, when other attempts at relief have failed.
  – Includes withholding or withdrawing artificial nutrition/hydration.
Palliative Care

• A palliative approach to care can be implemented very early after a diagnosis of dementia.

• Where possible establishing a relationship with the palliative care team early in the disease will assist efforts to monitor the patient’s progress and to know when additional support is needed.

• Palliative care can be provided in the home, in the hospital or a hospice or in a residential aged care facility – emphasis is on quality of life, dignity and comfort.
What Can be Done to Ensure Adequate Pain Relief at the End of Life?

• Educate community members (including people with dementia and their carers) and health professionals about:
  – Everyone’s right to adequate pain relief;
  – Use of morphine does not constitute euthanasia;
  – Leaving someone in pain can hasten death;
  – Multi-disciplinary teams, including palliative care staff, help ensure a peaceful, dignified death

• If necessary, commence legal proceedings
**US Legal Cases for Inadequate Pain Relief – 1 & 2**

- *Bergman v. Eden Medical Center*, California 2000; elderly cancer patient who did not receive adequate pain management, jury found that the physician had been reckless, entered a finding of elder abuse, and returned a verdict of $1.5 million for the patient’s pain and suffering.

- *James v. Philhaven*, North Carolina 1990; jury awarded a patient’s family $15M in a negligence case involving a man’s severe, under-treated pain from metastatic prostate cancer. Nurse failed to provide pain medications as ordered by patient’s physician. The nurse admitted withholding pain medications because she believed the patient was addicted to morphine.
US Legal Cases for Inadequate Pain Relief – 3

• California: Mr T, 85 years old, dying from progressive, painful lung cancer; suffers significant pain. Made AD requesting aggressive pain management.

• Dr. V. prescribed pain medication to be given “as needed,” i.e., when Mr T was in pain. Nursing staff at MD did not monitor, assess, or respond to his pain. Mr T discharged to nursing home. Dr. V. prescribed no pain medication for him. Mr T suffered severe pain during and following his transfer to n/home.

• Dr W took over his care; did not order pain medication for him until 3 days after admission; did not visit or examine Mr T for 17 days. Mr T’s family members frequently informed staff that Mr T was in unrelieved pain. At times, he cried out and asked his daughter to help him die because the pain was so terrible. Dr W did not call for consult with pain or palliative care specialist.

• Tort claim made for elder abuse and recklessness against hospital, 2 doctors and n/home. All settled out of court for substantial sums.
Would Such Cases Succeed in Australia?

• Australia is similar to the US in that each State/ Territory makes its own health law

• Current work with colleagues from School of Law at QUT and Medical School at UQ on the law relating to withdrawing/withholding life-sustaining medical treatment in NSW, Qld and Victoria;

• We will examine the US cases and see if any one of them could have succeeded in any Australian State/ Territory:
  – If so, be alert for possible cases
  – If not, other grounds that may succeed?
What can you do Now?

• Demand your right to adequate pain relief;
• Families/carers: be prepared to advocate/agitate for that right
• Make sure your Advance Care Plans are in place. This includes requesting that you be given enough pain relief to control your pain, even if that hastens your death. Probably useful to add: “This is not euthanasia!”
• Lobby – politicians, medical colleges, law advocates
• Educate the wider community, doctors, nurses, social workers, pastoral care workers – everybody!
• If necessary, involve the media

When people not only live well but also die well, we will have succeeded.
Contacts

– ASLaRC Aged Services Unit
  http://aslarc.scu.edu.au

– Alzheimer’s Australia
– www.alzheimers.org.au

– The National Dementia Helpline
  1800 100 500
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