

*To die, to sleep;
To sleep, perchance to dream. Ay, there's the rub,
For in that sleep of death what dreams may come,
When we have shuffled off this mortal coil,
Must give us pause*

– William Shakespeare's *Hamlet*

Death With Dignity or Obscenity?

By Jean Echlin, Nurse Consultant - Palliative Care & Gerontology

Part One **A Real Danger**

A deadly and distorted ideology is aggressively seeking to take hold in our culture. It calls itself *Compassion & Choices* or *Death With Dignity* or other similar names. Its leaders and adherents support and promote euthanasia and assisted suicide, which they call “aid-in-dying.” This movement's leaders insist that physicians, nurses or other health care providers prescribe and give lethal injections, or the gas, or the drugs necessary to kill a person, or for persons to kill themselves.

A Relationship of Trust?

Professional health care relationships – among doctors, nurses, patients and family members – are based on trust. Asking professional health care providers to kill, or give the means to kill, will destroy this trust relationship. We should never ask our professional care givers to provide us with the means of our death. Neither should our health care providers ever feel bound to comply with this request.

The movement for legalization in Washington State

Currently, several million dollars are being collected throughout the U.S. to assist proponents of *I-1000* that would legalize assisted suicide in Washington State. Unfortunately, many people in our culture have very little understanding of what this will mean in their future, in the future of their parents and the future of their children. Why are these dollars not being used to promote good pain management and excellence in end-of-life care?

By voting for the legalization of euthanasia and assisted suicide, you will help to authorize, potentially, the

death of yourself and/or family members regardless of age or ability to consent.

Take, for example, your 78 year-old mother who has been devastated and feels very depressed following the death of her spouse of more than 50 years. In addition, she has a treatable but possibly late stage illness. How will you respond? Is it not in your mother's best interest to get counseling in an attempt to treat her depression? If she were to call upon an advocate of *Compassion & Choices* or *Dying With Dignity*, she would likely be encouraged to take the quick and easy way out. An estimated 73% of all assisted suicide deaths in the State of Oregon, the only American state where assisted suicide is legal, are facilitated in some manner by *Compassion & Choices*. When the “Right to Die” lobby and the end-of-life decision-maker are the same people, there is no protection for your vulnerable mother.

Consider the real-life situation of a 54-year-old Oregon woman named Barbara Wagner. She was denied effective treatment for lung cancer but offered assisted suicide by the Oregon Department of Health. [see “*Death drugs cause*

uproar in Oregon” August 6, 2008; <http://abcnews.go.com/>

What would you do in this situation? Could you afford to pay for the chemotherapy to assist her self-determination to live longer?

It is easy to see that legal assisted suicide can quickly become coercion to die and “duty to die.”

Death is not the appropriate solution to pain and suffering; good palliative care is

The disciples of the cult of euthanasia and assisted suicide would have society believe that the logical solution for pain and suffering is death. They may even see the infliction of death or the provision of assisted suicide as part of hospice palliative care. They pursue with missionary zeal their gospel of death. Further, they often succeed in getting mainstream media to support their cause.

Those medical professionals and organizations who practice or support euthanasia and assisted suicide as “mercy killing” should not be involved in hospice palliative care. In addition, they should not sit on governing bodies, advisory councils, or committees that develop standards of practice for palliative care. This may mean that parallel programs not inclusive of assisted suicide and euthanasia may need to be developed.

Who is at risk?

If the law is changed to allow euthanasia and assisted suicide, those at highest risk will be:

- Older women (55 and above) or elderly fragile men
- Individuals with physical or mental disabilities
- Partners in scenarios of domestic violence
- Babies and children born with disabilities and birth anomalies
- Persons who are poor and disenfranchised
- Members of minority groups

Jean’s Way

Derek Humphry, co-founder of the *Hemlock Society*, put his notion of “self-deliverance” into practice in the death of his first wife, Jean. He and second wife Ann wrote *Jean’s Way*, the book that helped him rise to power and prestige in the cult of death. Later, he participated, with Ann’s help, in procuring the death of Ann’s parents – something she came to bitterly regret.

When Ann developed cancer, Derek responded by encouraging her to end her life. When she decided to seek treatment, he left her. But eventually she took her life.

Her last words to Derek include the following: “*What you did – desertion and abandonment and subsequent harassment of a dying woman – is so unspeakable there*

are no words to describe the horror of it.” [excerpt from Ann Humphry’s suicide note, quoted in *Deadly Compassion*, by Rita Marker].

This leads to the question, does assisted death really have anything to do with love and compassion or is it often a misogynistic act?

Why Discuss Misogyny?

Historically, women have been vulnerable to male authority in politics, law, government, religion and medicine.

Researchers Malphurs and Cohen published their findings in, “*A Statewide Case-Control Study of Spousal Homicide-Suicide in Older Persons.*” They studied twenty cases of homicide-suicide conducted over a two year period in the state of Florida. Their interest was not in euthanasia or assisted suicide, but mental health issues around suicide and homicide. Their study was published in the *American Journal of Geriatric Psychiatry* (March 2005).

They found that 25% of homicide-suicide perpetrators had a history of domestic violence. In the study, all of the perpetrators were men and 40% were care givers for their wives. Furthermore, they noted that 65% of homicide-suicide perpetrators and 80% of suicides where a man committed suicide alone were men who were depressed. All the perpetrators in this study were men who were described as dominating, controlling individuals. The research points out that “depression” is prominent in persons of all ages who commit suicide. It also points out that most often the husband is the perpetrator and the wife is the victim.

The cases of Tracy Latimer in Saskatchewan and Terri Schiavo in Florida follow a similar story line.

The State of Oregon

The Oregon Death with Dignity Act took effect in 1997. Data collected in that state reveal the flaws in the legislation. According to researchers Hendin and Foley [“*Physician-assisted suicide in Oregon: a medial perspective*” see www.michiganlawreview.org/archives/106/8/hendinfoley.pdf], safeguards for the care and protection of terminally ill patients under this law are being circumvented. One of the key problems seems to be the lack of appropriate data collected by the Oregon Public Health Division (OPHD) who are charged with monitoring the law. This organization failed to “ensure that palliative care alternatives to physician assisted suicide (PAS) are made available to patients” and they also failed to protect vulnerable patients by not ensuring that the safeguards are upheld.

This study further points out that “the unintended

consequences of (a single criterion of 6 months or less to live) is that it enables physicians to assist with suicide without inquiring into the source of the medical, psychological, social and existential concerns that usually underlie the requests for assisted suicide, even though this type of inquiry produces the kind of discussion that often leads to relief for patients and makes assisted suicide seem unnecessary.”

The Editorial Board for Oregon's largest newspaper, *The Oregonian*, opposes Washington state's *I-1000* initiative. They wrote, “Don’t go there! We won’t be endorsing it. Our fundamental objection is the same as it’s always been – that it’s wrong to use physicians and pharmacists to hasten patients’ deaths.”

They also point to lack of transparency in the Oregon experience: “Oregon’s physician-assisted suicide program has not been sufficiently transparent. Essentially, a coterie of insiders run the program, with a handful of doctors and others deciding what the public may know. We’re aware of no substantiated abuses, but we’d feel more confident with more sunlight on the program.”

Physicians are not required to be knowledgeable about the relief of physical and emotional pain and suffering. This situation is shocking and should be unacceptable under the law. Oregon's Death with Dignity Act protects doctors much more than patients.

The Netherlands

Of interest are the Dutch government reports (*Remmelink Reports*) about euthanasia and physician assisted suicide (available on the internet www.internationaltaskforce.org/fcthall.htm). The 1990, 1995, and 2001 reports are horrifying. In addition, a study published in the *New England Journal of Medicine* (May 2007) entitled: “End-of-life Practices in the Netherlands under the Euthanasia Act” states: “in 2005 there were

- 2,325 euthanasia deaths;
 - approximately 100 assisted suicide deaths, and
 - approximately 9,685 deaths related to terminal sedation.
- 550 deaths without request that were reported”.

In the previous Dutch Reports these deaths without permission or request were in the range of 1,000 persons per year. These deaths are often imposed by physicians without the knowledge of the patient or family.

The numbers in the Dutch studies *do not include* the euthanasia deaths of handicapped infants and children or children up to the age of 12 with life-threatening illnesses. This takes place under the recent Groningen protocol.

The studies *do include* patients with mental health/psychiatric problems. Such persons may be cognitively impaired and unable to understand the

consequences of their decisions.

Earlier Dutch reports indicated that doctors deliberately killed approximately 11,800 people each year by euthanasia, assisted suicide, or other intentional actions or explicit omissions. The most recent reports would indicate that these numbers have increased.

As noted by Alex Schadenberg, chair of the *Euthanasia Prevention Coalition (International)*, the decreased incidence of active euthanasia is directly related to the incredible increase in deaths by terminal sedation in the Netherlands.

Euthanasia is out of control in the Netherlands. People have good reason to be afraid of going into acute care or long-term care institutions. Some people carry a card stating their wish not to be euthanized.

This is unconscionable in terms of medical practice. The word “obscurity” in dying comes to mind.

The “death squad mentality” has no place in our health care systems

The legalization of euthanasia would remove a patient’s autonomy and put it into the hands of professionals with potential control issues; who may be angry, sadistic and abusive. We have all seen colleagues both at the bedside and in health care management who have significant personality flaws, and, lacking compassion for the pain and suffering of others, feel they can take the law into their own hands.

Have we learned from the past?

The doctors in Nazi-led Germany who experimented with various methods of killing people with disabilities (mental or physical) under the eugenic ideology will be replaced by doctors and nurses who are willing to take part in the deadly evil called euthanasia and assisted suicide.

Everyone should be concerned by the possibilities of euthanasia and assisted suicide changing the value and dignity that is attributed to the dying, chronically ill and people with disabilities. This is especially true in health care systems facing financial and resource cutbacks where death may be seen as more fiscally efficacious than life.

A 1998 study from Georgetown University’s Center for Clinical Bioethics found a strong link between cost-cutting pressures on physicians and their willingness to prescribe lethal drugs to patients – were it legal to do so. [Sulmasy, Daniel R. et al. “Physician resource use and willingness to participate in assisted suicide”, *Archive of Internal Medicine*, vol. 158, May 11, 1998]

Doctors and nurses should never be killers.

Are you really willing to leave this appalling legacy for the next generation?

Part Two

Real Hope for the Dying

Hospice Palliative Care is the provision of pain and symptom management for individuals experiencing life-threatening, life-limiting, progressive, or terminal disease. The cornerstone of excellence in this newer health care reform is the management of pain and other distressing symptoms. A person in pain is unable to focus on anything except their need for pain relief. Having to cry or plead for pain or anxiety medication leaves the patient feeling degraded demoralized and dehumanized. In cases like these their desperation is often distressing enough to make them wish for death. Individuals have the right to appropriate pain and symptom management.

In addition, palliative care focuses on emotional, social and existential suffering. This care may be combined with therapies aimed at reducing or curing the illness or it may be the total focus of care. Grief and bereavement follow-up may be a part of this caring process.

Many therapeutic modes exist to help with the pain experience. These include, but are not limited to, the use of narcotics, nerve blocks, surgery, radiation, chemotherapy, guided imagery and relaxation techniques, therapeutic touch, reiki, hypnosis, music and art therapy.

Programs of hospice palliative care take a multi-disciplinary team approach utilizing the skills of doctors, nurses, chaplains, social workers and physiotherapists, with the added benefit of trained volunteers.

Including these in the care of patient and family can provide enough quality end-of-life support to eliminate the desire for a premature death caused by euthanasia or assisted suicide. For the infrequent situations where pain and anxiety may appear unmanageable, "palliative sedation" may be considered. This is not euthanasia. It is good palliative care. The intention is to relieve pain and suffering, not to hasten death.

Palliative Sedation or Terminal Sedation?

It is important to note that there is a difference between "palliative sedation" and "terminal sedation." Unfortunately the literature does not recognize this.

Palliative sedation is medication given to relieve the distress of a terminally ill patient in their last hours or days when other methods of pain management have failed the patient. This only happens in a low percentage of patients – approximately 2 to 5 percent who have a pain escalation/surge at the very end of life. According to the *Journal of Hospice and Palliative Nursing*,

(2006;8(6):320-327) in the article: "The Process of Palliative Sedation" four criteria should be present:

- Symptoms that are unbearable and unmanageable
- A current do not resuscitate order (DNR) must be in effect
- A terminal diagnosis
- Death must be imminent within hours to days

It would be helpful to have a separate consent for palliative sedation. This would avoid any confusion around treatment plans. The intent of palliative sedation is to provide pain and symptom relief and not to hasten death.

On the other hand, "terminal sedation" as it is practiced in the Netherlands appears to be sedation followed by dehydration with the explicit intention of causing death.

One of the most significant findings in current literature indicates that the use of opiates (morphine, hydromorphone, fentanyl, etc.) when properly titrated according to the patient's pain intensity, do not hasten death. Also, this is one reason narcotics are not the drugs of choice for euthanasia or assisted suicide.

What does "terminal" mean?

One of the most difficult clinical assessments is the determination of when a human being is actually "terminal." A disease can be labeled terminal at diagnosis, as in terminal cancer. This does not mean that a person is imminently dying. In fact, the life span may be anywhere from months to years. It is often difficult for the most astute diagnostician to predict the actual end stage or terminal stage of disease. This is true of the major categories of disease such as cardiovascular, neurological, cancer, renal failure, diabetes etc.

How dare we assume that a diagnosis of a life-

threatening illness means that a person is “terminal?” One significant lesson learned from the bedside of a patient of mine is: “Do not let anyone label me “terminal.” I will tell you when it is my time. Give me a measure of hope and speak to my living!” These were the words spoken by a 38 year old man who desperately wanted to live.

Individuals facing life-threatening disease are usually depressed. Depression is treatable even in late stage disease. Thus, euthanasia and assisted suicide represent a threat to people both needing medical and psychological support for clinical depression.

Hospice Palliative Care – The Great Hope

Everybody needs to have access to quality end-of-life care through hospice palliative care programs. Further, medical practitioners, nurses, pharmacists and other members of the health care team should keep informed of newer methods of pain and symptom management. This should be a mandatory requirement through the various licensing bodies.

According to Dr. M. Scott Peck in his book, *Denial of the Soul*: “Failure to treat pain is medical malpractice.... it is one of the worst crimes in medicine today.” His words ring true and he too suffered the pain experience.

Today, there is no excuse for any individual, be they adult or infant, to experience an agonizing death. We have an armamentarium of methods and pharmaceuticals (medications) to modify physical pain and death anxiety. Unfortunately, too many of our health care providers, particularly nurses and doctors, are not effectively trained in the principles and practices of this newer health care reform (30 years) called Hospice Palliative Care. Neither are they educated in the newer methods of pain relief for acute, chronic and end-stage disease.

A Voice of Experience

In my 29 years as a palliative care nurse consultant, I have been at the bedside of more than 1,000 dying individuals. It is my learned experience that persons who receive timely, appropriate and expert pain and symptom management, including attention to their significant issues, do not ask for assisted suicide or euthanasia. According to

Dr. Neil MacDonald in the *Oxford Textbook of Palliative Medicine*, proper pain management can actually extend the life span as patients experience improved quality of life. Palliative care is a life-giving therapy, not a life-limiting therapy. Dying with dignity can only be achieved with expert hospice palliative care. This is the compassionate choice and should be available for every individual in Canada and the United States, throughout their life span. Expert hospice palliative care requires a commitment of health care dollars, strong community and institutional and home health care and compassionate support for vulnerable people.

Jean Echlin, R.N., M.S.N., is a pioneer in Hospice Palliative Care. In 2004, the Ontario Palliative Care Association (OPCA) recognized her 26 year contribution to hospice palliative care by selecting her for the prestigious “Dorothy Ley Award of Excellence” for her part in “fostering the true spirit of Palliative Care in Ontario.” Echlin formerly served on faculty, University of Windsor’s Faculty of Nursing, and was director of nursing at Windsor Regional Hospital’s Metropolitan Campus. As coordinator and clinical nurse specialist, then executive director, Jean was instrumental in the development of the Hospice of Windsor & Essex County Inc. which is recognized as exemplary in Canada. In 1988, Jean moved to London, Ontario and established the Palliative Care Consultation Team in the heart of tertiary care at University Hospital, London Health Sciences Centre. She is also recognized as a distinguished public speaker, educator and free-lance writer. Jean is an independent nurse consultant; formerly vice-president Euthanasia Prevention Coalition; serves on the Advisory Council of the deVeber Institute of Bioethics and Social Research; is a member of the Honour Society of Nursing and member Emeritus of the Registered Nurses Association of Ontario.