

9.
'A gentle, peaceful and easy death'
.....Euthanasia or Palliative Care?

Moira Camilleri

On July 29th 1826, Dr. Karl Marx delivered an address on the occasion of his installation as Associate Professor of Medicine at the University of Goettingen. In this address, published later as *De Euthanasia Medica*, Dr. Karl Marx speaks of euthanasia as that science '*which checks oppressing features of illness, relieves pain, and renders the supreme and inescapable hour a most peaceful one.*'

Dr. Marx's treatise on medical euthanasia is in fact an early nineteenth-century treatise on palliative medicine, capturing in its essentials the dominant contemporary consensus to date about how Palliative Medicine should be practiced. Aside from the advances in palliative medicine available today, as compared with the palliative medical knowledge of a 170 years ago, the major difference between Marx's palliative medicine and Palliative Medicine today centres on the meaning and use of the term euthanasia. Today, euthanasia means exactly *what Marx excluded* from his use of the term, namely, the administration of death to the dying - the hastening or advancing of death.

With every generation since then and before that, people have been thinking, writing and proposing legislation about euthanasia. Arguments from either side have been weighted with moral, religious, ethical, social, human and scientific issues. We too debate euthanasia, propose laws which seek to protect that which is sacred to us; life itself, dignity, control, faith, religion, pulling the favours towards and against its use.

A gentle peaceful easy death.....this is the way Solzhenitsyn describes the dying of older folk in "The Cancer Ward". People did not fight against death. They did not pretend they were not going to die. They prepared themselves quietly and departed easily as if it were just moving into a new house.

The euthanasia we are now debating in the media, in the courts, and in countless publications is linked to the fact that so many people today do not die "as if they were just moving into a new home". People fear they will not be able to die in this gentle easy way. They fear they will have little or no control over their dying. They fear ' a twilight life tethered to feeding tubes or respirators. As they have been doing for over twenty years, people are now still, and with increasing intensity, echoing Montaigne' statement, "*It is dying, not death, that I fear*"

Patients fear the uprooting of their lives by the disease and the dying process. It is the uprooting of one's family life, work, friends and routine, interests, hobbies, mobility, independence. It is the uprooting of the environment in which they have grown up, which they have built, in which they have nurtured a life: the environment in which the photos, furniture, objects, bring to life the person's past. It is the environment from which the patient must frequently leave to undergo treatment, investigations, and finally, to die, often tethered to life-prolonging technology.

Patients fear the enslavement within relentless pain and distressing symptoms. They fear what they think Palliative Care has to offer, a release from pain at the cost of their being plunged into a lingering state of semi-consciousness, of being doped with stupor, while all around sit and await one's death. Some find the prospect of this particular type of loss of control to be quite unbearable. Pain may be relieved but the suffering not.

Suffering cannot be predicted, so that those who care for the dying must look for it and learn to recognise it, because patients never complain of it. It may be manifest as anger, depression, sadness, grief, unhappiness, melancholy, rage, withdrawal, yearning. Its other name is anguish. If suffering is to be relieved, one needs an ear to listen a mind to understand and a heart to stand firm. There are no medicines for suffering, there are only people who will support and try to understand.

When the objectives of Palliative Care can be realised, the patient will end his days in comfort, he and his family will be enabled to cope with dying, they will feel secure rather than anxious, they will be assured of competent care which will not be withdrawn, they will be encouraged and enabled to be open with each other, and the family will later be offered support, if need, in their bereavement.

The actual achievement will not always reach those heights, of course, and it will be dishonest and useless to pretend that dying will always be, or could be, made dignified and comfortable.

To minimise, suffering, it is necessary for palliative services to be adequately funded, and for the effectiveness of treatments to be evaluated. However, palliative care will never eliminate all suffering. When a person is socially isolated and alienated, it would be foolish to expect palliative care to work miracles, and so sometimes, the outcome is meagre indeed.

Terminally ill patients experience an array of distressing symptoms despite the provision of palliative care. Patients commonly experience progressive weakness, which causes loss of function, diminished quality of life, and dependence, and there is no effective treatment to increase their strength. We witness people suffering disfigurement, nausea, suffocation, incontinence, pain, psychological distress,

confusion and more. Dying is always sad, often difficult and occasionally overwhelming.

But what do we do when we cannot find a language within which we can suffer these uncertainties together? Patients become depressed from time to time and may ask for release from life, to flee into autonomy, into an act of seemingly ultimate control: the act of ending one's life, of destroying that consciousness within which one senses one's own essential isolation, as well as one's profound dependency. What are we to do? Apart from continuing to provide excellent care, there are no agreed human answers to their problem, as indeed there are no answers to many of life's most difficult challenges.

The demands for rapid, painless death, and the debates these demands provoke, are a signal that we all, at the beginning of this century have entered a very deep crisis about how we understand, experience, and should bear the human condition.

It is not enough just to oppose euthanasia: we have to be able to put forwards better strategies of care, realistic of attainment and respectful of human life. It has been suggested that if doctors communicated well with patients and families, respected patient choice of treatment, knew when not to continue treatment which served no good purpose and was unwanted, and were familiar with the principles of palliative care, there would be little need to discuss euthanasia at all. But would that be the complete answer?

Would universal, good palliative care be enough to meet the call for euthanasia?

Acknowledging that there is a distinction between euthanasia and palliative care is central to the controversy on euthanasia. It may be that this distinction is clinically, ethically, and legally

essential and logically defensible. The defense of this distinctions and their meaning rest upon three points:

1. the goals and mandates of palliative medicine:

- to help those, who need not die now, to live as fully as they possibly can;
- to help those who can no longer live, to die on time, not too early not too late.
- To help those who must now die, and who are dying, to die in peace and with dignity.

2. Doctors do not possess unlimited authority to intervene in the bodies and lives of sick people.

- Each intervention must be justified through the clinical goals that come to predominate as a disease progresses. When treatments, including chemotherapy and life-sustaining treatments, have been start, as justified by an earlier governing clinical goal, and are now doing more harm than good, the ethically critical question is not, 'are doctors justified in discontinuing the treatment?' but rather, "is there any justification for continuing these treatments?"
- Treatments designed to restore health, function or consciousness become futile as the disease progresses irreversibly and may even be harmful. In these situations, it is correct to speak of allowing a person to die. This differs from euthanasia in intent, in act, and in professional mandate. Even when the doctor is motivated by compassion, the intent of euthanasia is to *cause death immediately*. The intent of discontinuing life-prolonging treatment is to *cease hindering an inevitable process from reaching its timely end*.

- With the act of euthanasia the doctor assumes, however temporarily, a mandate of *total dominion over a human life in extremis*. The act of discontinuing life-sustaining treatments from patients who are in the advanced stages of disease implies that the mandate of doctors over human life is *limited to accompanying and serving a dying patient* with all the scientific and compassionate skills of comforting a life that cannot be saved. *Acceptance or rejection of this limit marks the difference between palliative medicine and euthanasia.*
- 3. One of the essential elements of dying with dignity is freedom from pain, and the various kinds of bodily and mental fatigue and distress, that can dominate consciousness and leave free no psychic space for the personally important things people want to think, say and do before they die.**
- Pain separates the dying persons from themselves and from their loved ones: it can drive the dying from coping, control and integration to chaos and hopelessness.
 - Patients have a right to request and doctors an obligation of fidelity to the dying to employ, every proportionate means available to relieve suffering and agony provoked by pain and symptom distress. Administering medications in combinations, dosages and frequencies needed to relieve effectively the suffering of the dying is logically, clinically and ethically totally different from the act of administering death. These two acts differ both as to end and as to means. The goal of palliative medicine is emancipation, the freeing of the dying person's consciousness from the domination of pain. The goal of euthanasia is death.

- The distinction between the administration of death, which is what euthanasia is, and the administration of relief from suffering, which is what palliative medicine is, should serve as a directive for law, ethics, medical education and healthcare planning. Doctors must not be barred by any law of the state or by any dictate of morality from freeing the dying, as best their knowledge and skills allow from the agonies of advanced and terminal stages of disease. Patients should never have to beg for relief because doctors' unenlightened fears. It is indeed foolish to deny patients relief from suffering because of unfounded fears and concerns that effective relief of pain will shorten life.

Where competent palliative medicine and care are not available, health care planners should set the organisation and equitable delivery of such care as a top priority of a civilised health care system. To substitute this with pro-euthanasia arguments is, if anything apathetic, ignorant and short-sighted: can we afford these to become premises in an argument favouring the legalisation of the administration of death?

The clinical goal of palliative medicine underlying the discussion of ethical issues encompasses the co-ordination of knowledge, skills, reflection, and compassion to allow us, at the end of our days, to die as Philip Aries outlines:

Death must simply become the discreet but dignified exit of a peaceful person from a helpful society. A death without pain or suffering, and ultimately, without fear.

References

Oxford Textbook of Palliative Care: Chapter 5. *Ethical Issues in Palliative Care*.

Margaret O'Connor, *Palliative Care and the Euthanasia debate in Australia*. European Journal of Palliative Care 1998; 5 (1)

Anthony Smith: *Euthanasia - good medical practice or murder?* European Journal of Palliative Care, 1999; 6 (4)

Helen Walsh: *Euthanasia - a European debate*. European Journal of Palliative Care, 2000; 7 (4)

Kay Koetsier, *The Intent to Kill*. Voluntary Euthanasia Society of Victoria Report, November 1994, page 6

Jessica Corner, *More openness needed in Palliative Care*. British Medical Journal, Vol.315, 8 November 1997

Roger Hunt, *The Limits of Palliative Care*. The Age, October 1996

Brian Pollard Stuparich, J. (ed), *Palliative Care - is it the Answer?* 1992

Peter McCullagh Stuparich, J. (ed), *Euthanasia and Attitudes towards others: why is it an issue now?* 1992