Palliative Care: Broadening the Vision

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For almost 30 years I have frequently been in contact with people confronted by the many different kinds of distress that stem from mortality. I learned very early that these are not limited to problems such as pain and nausea and dyspnea at the time when death is approaching. They are not limited to physical symptoms, and they are not limited to the period immediately preceding death.

Distress can also involve what would be called thoughts or emotions, and it can occur long before death is imminent. Fear is common, and so is a feeling of being powerless. Palliating these requires more than medical attention; it requires attention to matters of policy and practice.

I first articulated my growing awareness in the "Quarterly Retort" for the April - June 2004 issue of Free To Go, the newsletter I produced for 10 years. Here is what I wrote: THE WORLD HEALTH ORGANIZATION SAYS:

No country should consider legislation allowing for physician-assisted suicide or euthanasia until it has assured for its citizens the availability of services for pain relief and palliative care. (Cancer Pain Relief and Palliative Care, 1990)

WE REPLY:

The WHO makes two assumptions:

- (1) that there is an "either-or" relationship between palliative care and aid in dying, and
- (2) that palliative care is everyone's first choice (people only settle for aid in dying if they can't get palliative care).

Neither of these assumptions is justified.

- (1) Many people want both options they want palliative care during phases 1 through 6, then they want aid in dying so they can skip phases 7 and 8.
- (2) Even among people who are content with only one of the two options, a hastened death may be the first choice; some people have no desire for an extended experience of their final decline, preferring instead to "quit while they're ahead".

I had seen numerous cases where someone's supposedly golden years were turned to tin by the fear of what lay ahead as their bodily breakdown progressed. Many suspected that nothing short of terminal sedation would be able to completely obliterate their tormenting symptoms.

However, this process might require that they spend their last weeks or months in an institution, at great expense to their fellow citizens and at risk of an infection which would prevent them from donating their organs or their cadaver. If they had always been unselfish and public-spirited people, this prospect dismayed them. They did not want to be taken advantage of, in their helplessness, by people who were well-intentioned but had concerns different from their own.

What they wanted, and what we should establish, is a system which palliates psychological and spiritual pain as well as physical pain. This includes providing assurance that a thoughtful and enduring desire for death will be respected."