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The Scholl Institute of Bioethics is a nonprofit, Judeo-Christian organization that addresses bioethical issues including euthanasia, physician-assisted-suicide, the withholding or withdrawing of food and water from non-dying patients, brain death, organ transplantation, genetic engineering, and the rights of disabled or mentally ill persons.

The Decision to Accept or Refuse Hospice Care Must Always Remain with the Patient

By Sr. Beth Momburg, SSS, MSG

In a recent publication entitled Do you Know Your Rights as a Patient? (Scholl'15) two items stand out under the subtitle "You have the Right". You have the right to have your spiritual, cultural, and personal values respected. Secondly, you have the right to refuse care. When talking about hospice care each of these "rights" play a vital role.

Hospice is an approach to care for a person who has been diagnosed with a terminal illness and has less than six months to live. A multidisciplinary team works together, not to cure the underlying lethal disease, but to provide for the person's physical, emotional, and religious needs while managing pain and discomfort during the last days. (Scholl Bioethics Review 6/06).

The above is a description of hospice at its best as envisioned by its founder, Britain's Dame Cicely Saunders, MD, in 1967. She believed, "You matter because you are you. You matter to the last moment of your life, and we will do all we can, not

only to help you die peacefully but to live until you die."

In this "snapshot" as envisioned by the founder in 1967, why would anyone refuse hospice care? The fact is in the last thirty years much has changed.

"Profound changes in philosophy and end of life practices have altered hospice care...much of the philosophy of euthanasia advocates has been absorbed into the contemporary Hospice movement"
Rabbi Louis Feldman, PhD.

In a summary paragraph from an article published by the Scholl Institute of Bioethics by Rabbi Louis Feldman, PhD. said, "Profound changes in philosophy and end of life practices have altered hospice care." He further noted "much of the philosophy of Euthanasia advocates has been absorbed into the contemporary Hospice movement".

Given the current state of hospice it is easy to see why not everyone would want to receive such care at the end of their life. The refusal can be based on the belief that their personal or spiritual values will not be respected by the hospice team or organization providing the care.

Many, not all, hospice-care organizations today

have eliminated the last line in Dame Saunders's vision, "We will do all we can, not only to help you die peacefully but to live until you die." Some hospice-care organizations "are walking on the edge of euthanasia" wrote Rabbi Feldman (Bioethics Review 6/06).

To believe that my personal values and or spiritual beliefs would not be respected by a hospice team or organization would be a more than valid reason to refuse such care. This refusal is the right of any patient. Hospice is defined as "an approach of care," and in any publication that enumerates patient rights, the right to refuse care is always mentioned.

Herein lies the importance of ensuring that the decision to accept or refuse hospice care remains the decision of the patient and not a physician or other medical professional.

While it is often assumed that the patient would make this decision in partnership with his or her physician or medical team, in practice this may not always be the case. In recent years, many hospice organizations have become "for profit."

This shift can set up a dynamic that encourages physicians to attempt to force hospice care on persons who do not want it and who have made their refusal very clear.

In the past year I had the occasion to be involved in just such a situation. A dear friend and colleague had been diagnosed with cancer. I was a part-time caregiver for her. She was a leader in the pro-life movement and founder of the Scholl Institute of Bioethics. She was well versed in the current state of the hospice movement and some of the difficulties with the "care" being provided. From the onset of her diagnosis, she had told her doctors, care team, and all others that she did not want hospice care at any time.

It was during what was to be her last acute-care hospitalization that the "push" for hospice began.

She was placed in a step down/rehab unit before being sent home. This is where, may I say, the coercion to accept hospice care began in force.

It is important to note that we had in place around the clock custodial and in-home nursing care through a home health agency. The acute care hospital was fully aware of this. Her full-time in-home caregiver was even with her in the hospital.

The staff and physician of the rehab facility took this forcing of hospice care to a whole new level when they said they would not release her to go home until she agreed to hospice.

The refusal on the part of the staff prompted a call by her to her durable power of attorney for health care. This representative told the supervisor of the facility and the physician that they were holding my colleague against her will, that she had ample medical care at home, and that a physician was supervising that care. The facility and physician relented on the spot and she was released to home within two hours.

Such an incident would never have happened if the patient's rights had been respected. Somehow in today's understanding of hospice care others seem to think they have the right to make such determinations. Like any other approach to care or treatment, this decision must remain with the patient.

Sr. Beth Momburg, SSS, MSG Vice President, Scholl Executive Committee.

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