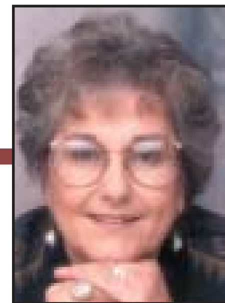

TO WALK HUMBLY...CREATING WORKABLE POLICIES FOR END-OF-LIFE CARE

by Leah Curtin RN PhD(h)

The experts say one should never use the term 'futile care,' most especially not around families. Care is never futile, but medical interventions sometimes are. And that is the point: how do you know for sure that further medical care is futile; and when you *do* know, how do you communicate this to patients and families, and finally, in the face of inevitable death, how do you provide care that comforts and soothes, that prepares families for loss while it helps patients leave life with their dignity and hope intact? Most of all, how do you do this in today's busy, bottomline driven institutions?

It may sound impossible, but the Denver Consortium of Hospitals has come up with work-able definitions, the policies to actualize them, and a set of recommendations to apply them. This is not to say that it is with-out controversy, it is merely to say that it is worth study.

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A consortium of metropolitan Denver, Colorado hospitals drafted a set of guidelines for determining futility in the use of critical care resources. Dubbed the Denver GUIDE, their recommendations include:

1. Further medical intervention is futile in an adult with four or more systems failing for over 3 days (the literature supports a similar conclusion, although the cut-off is 7 days rather than 3).
2. Patients in a persistent vegetative state should not be transferred to the ICU.
3. Intensive care admissions should be limited when it comes to patients with end-stage dementia.
4. Long term acute care patients who are in a persistent vegetative state should not receive prolonged mechanical ventilation.
5. Long-term chronic patients with end-stage dementia (i.e., bed or chair-bound patients who also cannot converse in a meaningful way) should be treated palliatively when they become acutely ill. Transfer to a hospital is only indicated for palliative care which often is better provided at home or in a long term care facility.
6. There should be compelling reasons to start long-term enteral tube feedings for patients with end-stage dementia - such as a patient's advance directive indicating that he or she would want long term enteral feeding.
7. CPR should not be provided to chronically ill patients who are near death.

The University of Toronto Joint Centre for Bioethics developed a useful and livable Model Policy on Appropriate Use of Life Sustaining Treatment. It suggests 11 steps that should start as soon as the provider is aware of potential conflict in the care of the patient. Space limits this article to four:

1. The health team should reach consensus regarding the range of appropriate treatment
2. In collaboration with the health team, the responsible MD should:
   - Communicate the patient's prognosis and his/his family's wishes for treatment
   - Explore why patient/ family wish to continue treat-ment that is not medically indicated,
   - Discuss with patient or surrogate the rationale for with-holding or withdrawing medical life support treatments
   - Describe palliative care measures, which emphasize patient comfort and dignity
   - Offer to put patient/family in contact with social work, chaplains, and ethics committee members and so forth to help their information needs
   - Document pertinent details of this communication in the patient's chart.
3. The MD or another team member should negotiate an acceptable plan of treatment with the family or patient.
4. Patient and family should be given a chance to seek a second opinion if desired.

For more information on recommended written policies, see www.utoronto.ca/jcb/

Discussion, debate, and clarity of language and values help all of us cope with death and dying. And it is about the only way that ethical behavior can be defined and translated into everyday practice. Where the professions fail, the state steps in and mandates change, as in Oregon. While the work in end of life care is far from finished, it has come a long way in the last decade.

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