

Testimony concerning MDS 3.0
on Behalf of
the American Academy of Hospice and Palliative Medicine,
And Americans for Better Care of the Dying

June 2, 2003

Contact: Joanne Lynn, MD, MA, MS

202-895-2658

jlynn@rand.org

Nearly half of elderly Medicare beneficiaries spend some time in nursing facilities while living with fatal illness and we die in those facilities or after a short time in a hospital. Thus, nursing facilities are becoming a major part of the last phase of life for most Americans. The Academy of Hospice and Palliative Medicine is the organization representing physicians and nurses who serve people nearing the end of life. Americans for Better Care of the Dying is an educational organization devoted to engendering reliable and sustainable care so that patients can count on living comfortably and meaningfully through to the end of life.

The Minimum Data Set serves a number of functions in nursing facilities – ensuring that residents have comprehensive evaluation, triggering specific assessment and intervention activities, and allowing assessment of quality. In each of these functions, the new Minimum Data Set must start recognizing the critical role of nursing facilities in serving those who are living with fatal chronic illness.

Specifically, we call on the Centers for Medicare and Medicaid Services to include the following in the new MDS 3.0.

1. Advance Care Planning

The proposed MDS 3.0 actually seems to have eliminated even the very thin record of advance care planning that was in the old version. That course would not serve these residents well. This section should be re-introduced and should address the following as yes-no questions.

- Proxy decision-maker clear?
- Contact information clear?
- Decision to forgo resuscitation?
- Decision to forgo hospitalization generally?
- Decision to forgo artificial feeding/hydration?
- Decision to use sedation if essential?
- Preference to use hospice?

The first two, answered “no,” should lead to an intervention plan.

The next five, if “no,” should lead to an intervention plan IF the prognosis question below shows resident is likely to die soon.

2. Prognosis

The appropriateness of accepting weight loss and loss of ADL and of assuring adequate advance care planning turns, in part, on the likely proximity to death. However, most residents in nursing homes have quite ambiguous prognoses until very near to death. Thus, the useful categories will be the following, of which the resident should be classified in one.

- Imminently dying (within a few days), or
- Prognosis limited enough to be eligible for hospice, or
- Fatal chronic illness, but not eligible for hospice, or
- Stable of non-life-limiting chronic illness

The first two, when first marked for any one patient, should initiate a response to assure good advance care planning for likely dying (including spiritual and family issues), to assure good symptom management, and should remove the need to respond to weight loss or ADL loss.

3. In the list of treatments and procedures, MDS 3.0 should add “Palliative Care Program of Consultation”
4. If the resident is in the first three categories above – dying, hospice eligible, or fatally ill but not hospice eligible – then the diagnosis list should be marked as to the diagnoses contributing to shortened lifespan.
5. The section on discharge potential could be reshaped to include the prognostic information and the preference to stay at home through death by adding these questions (as yes-no questions) –
 - Resident is likely to have his or her fatal illness at this time?
 - Resident is likely to live out the end of life in this facility? (if yes – split by likely prognosis of 6 months for hospice eligibility or longer)
 - Resident wants to enroll in hospice care?
6. Symptom assessment - The most prominent symptoms to track are depression, pain, dyspnea, fatigue, delirium, and bowel problems. Some of these are probably adequately noted for screening purposes, but pain and dyspnea need to be enhanced in the MDS, noting the character, frequency and intensity (with triggers to initiate response for both when serious). Should also document whether the symptoms are responsive to the plan of care.

In sum, the fact that nursing facilities now support many Americans who face serious illness and death should be evident in some key data elements in the MDS 3.0