PRACTICAL CONSIDERATIONS FOR IMPROVING CARE FOR PERSONS LIVING WITH ALS AND THEIR FAMILIES

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August 10, 2013

Comparing ALS to other fatal chronic conditions
(e.g., CHF, CRF, COPD, CVA, CA, dementia, frailty)

Different

- Mostly in prime of life, with family, jobs, homes, "volunteer" caregivers
- Mostly no other serious health problems
- "Blameless" in origin
- Mostly painless and insidious
- Can expect to confront questions of artificial feeding and ventilation
- Very much aware/thinking to the end of life

Similar

- Progressively disabling
- Challenging to predict decline, death
- Patients/family want "normalcy"
- Reliant on local long-term supports/services (inadequate already and will worsen soon)
- Terribly ineffective medical care
- Care is neither comprehensive nor coordinated

Recommendations FOR the Committee's work

1. Be thoughtful and deliberate about the relationship of ALS to long-term care generally
2. Be conversant and forthright about dying
3. Confront the inadequacy of support for caregivers
4. Confront the costs

Recommendations BY the committee

1. Quality measures
    1. 24/7/365 coverage by the same team, including services in the home
    2. Patient/family satisfaction – especially with planning for ventilation and for death
    3. Patient/family confidence
    4. Conventional measures of long-term care
    5. Financial impact on the family
    6. Caregiving burden and caregiving meaningfulness
    7. Rate of using and stopping ventilation, and rate of appropriate sedation to avoid air hunger
    8. NOTE – be very careful about measuring quality by survival time

Recommendations BY the committee

2. Involve AHRQ in health services research

3. Involve ACL – Area Agencies on Aging, geographic demonstrations

4. Lead a public discussion to plan and re-design long-term care, and especially to deal with financing and service delivery organization