



Long Term Care Coordinating Council
State Plan for Alzheimer's and Related Disorders Working Group

Workforce Sub-Group

9:00 – 10:00 am

Friday, February 15, 2012

Healthcentric Advisors

235 Promenade Street, Suite 500

Providence, RI 02908

1. Dementia Training / Education Survey
 - a. Early Results
 - b. Remaining Outreach/Targeting – The survey still needs to reach physicians offices and urgent care and emergency room physicians. Gail is working on the possibility of using Healthcentric's lists for this purpose.
 - i. Lindsay also recently sent the survey out to adult day programs and is expecting at least a dozen responses.
2. End of Life Planning and Care for Dementia Patients
 - a. Presentation by Jency Jacob, MD – A medical director at Home and Hospice Care of Rhode Island, Inpatient Palliative Care Consultant at the Miriam Hospital, and Outpatient Palliative Care Consultant at Rhode Island Hospital Cancer Center.
 - b. *Presentation available upon request.*
 - c. The trajectory of Alzheimer's disease is so difficult to predict so it is not necessarily a sharp linear decline like with cancer, for example.
 - d. Decline can and often does happen over many years. We don't necessarily think of it as a terminal illness (loose ability to walk, communicate, other ADLs. This makes it hard for families to recognize when there's been a

decline at a certain point in time. This also makes it hard for clinicians to bring up goals of care – when is the right time to bring it up?

- e. Eating problems: 90% - unable to chew, pocketing food, swallowing are all concerns with dementia patients. Feeding tubes are inserted into 1/3 of nursing home patients with dementia. Patients are often put on a modified diet, one-to-one feeds with a caregiver are better interventions – health doesn't improve with a feeding tube, aspiration still a risk with a tube, etc. Rates of fever and pneumonia high as well.
- f. Pain management – This means that clinicians often have to measure pain and other discomforts by non-verbal cues. 96% of HCP's would choose comfort over intervention but patients are still receiving interventions at end of life.
- g. Dementia has the most variability as far as median survival rate – this is the main barrier to hospice enrollment. FAST, a different hospice eligibility assessment tool, accounts for this. It uses the inverse of normal childhood development milestones.
- h. Hospice can really be appropriate for patients once they lose the ability to walk (1 year out) and palliative care should be involved several-a dozen years out when they lose ability to hold a job and handle simple finances (incipient/mild). This information can be used to help clinicians understand where dementia is going and when PC and hospice would be appropriate. We need to improve awareness of the FAST model.
- i. Cycle of illness, staffing up, hospitalization, decline in function and cognition and then a return to the NH – this cycles over and over until there is an intervention.
- j. Caregiving for dementia means far more strain on the care provider.
 - i. Improve:
 - 1. 1 – early palliative care
 - ii. triggers
 - 1. 2 – refer to hospice
 - 2. 3 – collaboration

3. 4 – research

- k. A person meets hospice criteria when they're at the last 6 months of life, but on average people are using it for 7-9 days. Many are making just over the limit for Medicaid and are on Medicare only.
 - l. Transitions – need to discuss trajectory and not just code status (its not just pneumonia – its an acute illness in the context of a larger disease that's on a trajectory).
 - m. Length of time palliative care has been around at medical centers really dictates how progressive they are and how well they're approaching PC. How can we enable PC to be involved early on? Need to improve education/access to PC at patient level as well. Its not too well developed thus far in RI.
 - n. NH dementia training – not just with behaviors but also education and empowerment among staff so they know they're able to take this step and start a conversation with the family. Often times the nurse is the person who recognizes it, but they're not sure they can begin the conversation.
 - i. No mandatory dementia training at nursing home, but could really help identify pain.
 - o. Hospitalists – are they getting trained? Some have done training but its probably an area that could grow.
 - i. “Hard Choices for Loving People” – decision making points for families
3. The meeting was adjourned at 10:13 am.