



End-Of-Life Care

END-OF-LIFE CARE Meeting Summary of Expert Panel April 16, 2001

Panel Members:

Charlene Farrell, Joan Armbruster, John Grey, Debbie Ruppert, Sam Kapourales, Dr. Alvin Moss, Cathy Chadwell, Sallie Hunt, Dr. Sue Warren, Larry Robertson, Linda Sovine, Mary Emmett

Sallie Hunt, Chief Policy Officer, West Virginia Health Care Authority welcomed everyone. She stated that SB 458 resulted in the establishment of the Quality Utilization Advisory Group (QUAG) and that the QUAG had identified "End-of-Life Care" as one of four focus areas to improve quality. During the Spring of 1999, a panel of individuals, at the request of the QUAG met to create a picture of end-of-life care in West Virginia. Today, we extend that effort and look forward to establishing a process for continuously improving the quality of life for all people at the end of their lives.

Sallie reported that the Hospice Standards (CON) were revised. Also, the Health Care Authority was given responsibility in SB 239 for management of data on controlled substances (2-4). The data could be used for statistical reports, education and public health efforts. The legislature also passed HB 2815 - requiring physicians and nurses in West Virginia to obtain two hours of continuing education every two years on content pertinent to end-of-life care.

The discussion centered on defining a set of indicators that could measure the quality of end-of-life care in West Virginia. This "report card" on end-of-life care could be used to establish or change policy to enhance the quality of life at the end of life. Indicators proposed by the panel are as follows:

- Pain Management
- Satisfaction with Pain Management by residents in Nursing Homes -- data obtained from the MDS. Question: How is pain assessed? Who makes the assessment?
- Satisfaction with pain management expressed by individuals and or family members receiving Hospice Care - measure to be developed by hospice and reported in the annual survey of hospice by the Health Care Authority. Larry Robertson indicated that he would work with the Hospice Council of West Virginia to identify the specific question/questions to ask that would become part of the annual survey. Specify - how pain is assessed and whomakes the assessment.
- Satisfaction with pain management expressed by individuals and or family members receiving Palliative Care - measure to be developed by palliative care teams, recorded on the palliative-care data collection instrument. Specify how pain is assessed and who makes the assessment.

- Satisfaction with pain management expressed by individuals receiving Home Health Care - check measurement recorded by Oasis.
- Transfers from one care setting to another in the last two weeks of life.
- Transfers from nursing home to hospital - data from UB 92.
- Transfer from hospital to home or nursing home - data from UB 92.
- Number of hospitals with Palliative Care Teams - data available through palliative care network.
- Number of nursing homes with Palliative Care Teams - data available through palliative care network.
- Number of persons who die in nursing homes, hospitals, homes - data available through Vital Statistics.
- Number of persons who receive hospice and die in the nursing home - data from Hospice Survey.
- Number of persons receiving hospice care at the time of death - data from Hospice Survey.
- Addendum to Death Certificate -- follow-up survey with family or caregiver.
- How good was pain management? Overall, how satisfied were you with pain management?
- Were the individual's preference (wishes) respected?
- Place of death?
- Did the individual receive hospice care?
- Days in acute care (hospital) prior to death?
- Was the person at peace?
- Did the family experience peace?
- Race of the person who deceased.
- Did the person receive care, at any time during the last 30 days of their life, in an Emergency Department?
- Communication with the family by care providers at the end of life!
- Were opportunities for bereavement counseling or support groups offered to the family? Did the family use bereavement counseling?
- Did caring for the deceased create a financial burden for the family or caregiver? If so, how?
- Respect for an individual's preferences -
- Number of individuals who state they have an advance directive upon admission to a hospital - add this data element to UB 92 form.
- Number of individuals in West Virginia who state they have an advance Directive -- data from BRFSS.
- Physician Orders Scope of Treatment (POST) - Emergency services respect for individual preferences during transfer from one setting to another - data available from Department of Emergency Services.
- Adequacy of reimbursement - specifically noted was the lack of resources for bereavement counseling.

The following time-line was suggested for development of the quality indicators for end-of-life care. The next meeting would occur during May, with a presentation of the information to the QUAG during June. Revisions to the indicators would be made during July and August with a suggested presentation time of September to the State Health Advisory Group.