FR3- Care of the Actively Dying

Friday, March 23
11:00 AM- 12:00 PM

Session Description
This session will discuss the special care needs of the actively dying resident, the special care needs of those in the last few hours to days of life, and review the barriers to meeting those needs. An interdisciplinary protocol developed at the Gouverneur Skilled Nursing Facility will be presented as an example of a successful model to overcome these barriers.

Learning Objectives
Identify four common physical findings associated with active dying.
Recognize five common institutional barriers to provision of optimal care for the actively dying.
Strategize solutions to overcome these barriers in their institutions.
Recognize how the actively dying phase may affect the care planning for different members of the interdisciplinary team.

Presenter(s): Jeffrey Nichols, MD, CMD; Sydonie Clementson, RN; Yvonne Torres, MSW

Presenter(s) Disclosures: All speakers have reported they have no relevant financial relationships to disclose.
BACKGROUND

- Estimates are that 40% of all deaths will occur in Nursing Homes by 2020.
- Palliative care services have often "moved upstream" with discussions and programs before death is imminent. Many of these residents already have defined goals of care which exclude hospital transfer and heroic interventions.
- The trajectory of decline for most of the common causes of death in the nursing home is NOT sudden death.

WHAT IS ACTIVELY DYING?

- Demonstrating clinical signs typically suggesting death within a few hours to 2 days (maximum 1 week)
- Signs may include cold extremities, mottled extremities or both.
- Usually have abnormal vital signs including hypotension, tachycardia, profound bradycardia, fever, or hypothermia—all signs suggesting circulatory collapse and inability to maintain homeostasis.
- Typically have minimal or absent ability to tolerate oral fluids.
- May have progressive hypoxia/cyanosis despite standard treatments.

NOT ACTIVELY DYING

- Hospice eligible or terminally ill
- Significant weight loss with minimal caloric intake but tolerating fluids or receiving IV or clysis.
- Oxygen dependent
- Goals of care include hospitalization or invasive procedures to prolong life.
- Abnormal labs alone without symptoms or other signs

BARRIERS IN CARE OF ACTIVELY DYING IN NURSING HOME

- No practitioners available on-site if new orders are needed
- Limited on-site availability of needed medications, many on Beers list
- Time needed to coordinate new care plan for a palliative care crisis
- Needed information not easily retrieved from medical record or not on chart
- Limited availability or absence of key staff on nights and weekends
- Highly variable knowledge and training of frontline staff.
COMMON SYMPTOMS OF ACTIVELY DYING

- Dyspnea (with or without hypoxia)
- Pain (new or worsened)
- Changes in Respiration (commonly known as Death rattle)
- Agitated delirium
- Dry mouth, trouble swallowing, Decrease oral intake

PRACTITIONER AND FAMILY DISSATISFACTION WITH CARE ACTIVELY DYING RECEIVE

Karen Brown “Not the Death He Wanted” NYTimes Jan. 6, 2018
Ira Byock response January 15, 2018. The term is “bad care.”

12.3% of Hospice patients have no professional visits by hospice in last 2 days of life (review of 661,557 hospice deaths 2014).
1.74 times less likely if NH resident
3.35 times less likely for Sunday death.

JOAN TENO ET. AL “EXAMINING VARIATION IN HOSPICE VISITS BY PROFESSIONAL STAFF IN THE LAST 2 DAYS OF LIFE JAMA INT. MED 2016; 173(3) 364-370

THESE ARE NOT INDIVIDUAL TEAM MEMBERS INADEQUACIES, THEY ARE SYSTEMS PROBLEMS.

TEAM COMPOSITION

- Team Leader: Sydonie Clementson, RN, ADN, Nurse Educator
- Nursing Team members DON, LPN, CNA
- Director of Social Work
- Medical Director
- Recreation Director
- Chaplain
- Dietitian
- Quality Improvement Facilitator
- Director of Admissions
- Respiratory Therapist
- MJ HS Hospice Social Worker

IDEAL FOR A QAPI PROJECT APPROACH
GOUVERNEUR SKILLED NURSING FACILITY
- 295 bed facility on Manhattan’s Lower East Side, serving a historically poor and extraordinarily ethnically diverse population
- Post Acute Care Division of NYC Health+ Hospitals
- Affiliate of NYU Langone and Rusk Institute. Teaching site for NYU Langone Geriatric Fellowship
- Teaching site for Metropolitan Hospital Palliative Care Fellowship
- Contract relationship with MJHS Hospice
- Average 42 deaths in the facility during the year prior to initiation of the protocol, the majority on hospice.

CREATION OF A PROTOCOL
- Triggered by MD order (can be Telephone Order if necessary)
- Special alert to care team and family/responsible party
- Notification to nursing supervisor and security regarding off-hours and overnight visiting
- List of frequently-needed medications for consideration of prn orders provided to Medical Staff and units
- Medical staff education regarding de-prescribing for actively dying

DEPARTMENTAL ISSUES
- Social Work: special needs of family, resident and staff
- Pastoral Care: special pre-morbid (e.g. Last Rights/Sacrament of the Sick) and post-morbid needs (rituals around care of the body/burial)
- Therapeutic Recreation (support materials, music, actively dying box)
- Medical Records (chart availability of key contact information and burial plans)
- Respiratory (oxygen and fans)
- Nursing: increased rounding frequency with check for symptoms, update care plan, enhanced oral care
- Dietary: comfort needs, stop trays

CASE STUDY
- An 80 year old primary Cantonese speaking male was admitted initially for short term rehabilitation after an episode of bacterial pneumonia, but was quickly noted to be failing and transferred to long term care.
- Patient had known non-small cell lung cancer and MRI in hospital had confirmed spread to multiple thoracic nodes. Wife and resident agreed to hospice referral and palliative approach on MOLST.
- Resident was an active Buddhist involved with his religious group
- Resident gradually declined over two months with fatigue, anorexia, and weight loss.
- His blood pressure declined and breathing was more rapid with markedly decreased alertness over a few hours

Case Study Continued
- Actively Dying Protocol initiated
- Wife and monks notified. Wife stayed overnight at bedside.
- Oxygen therapy, sublingual morphine concentrate (pm, lorazepam, pm, and pm anticholinergic ordered. All other medication discontinued.
- Only oxygen and morphine were actually used.
- Son and daughter-in-law came the following day and were also present at bedside when he died quietly.
- Monks came immediately to initiate bedside service for the dead.

OTHER ASPECTS OF GOUVERNEUR PROTOCOL
- All residents on protocol are placed on 24-hour nursing report.
- Contact information for pastoral care staff appropriate to the resident is posted at the nursing station.
- Social work calls all families of the deceased one week after death to address any additional needs.
- Aspects of the protocol as appropriate were introduced to staff and are reviewed with new employees during departmental orientation.
- Details were those appropriate to Gouverneur organizational structure and would need modification based on the variances among facilities in departmental organization, resources, patient population, etc.
INITIAL EXPERIENCE

- After approximately one year, the protocol has been initiated approximately 25 times for 23 residents.
- 2 residents were removed from the protocol for between 2 and 6 weeks due to improved condition, only to have it reinstated prior to actual death.
- 3 residents died on the protocol who were not on hospice.
- The protocol has been initiated earlier than might be ideal, with average time on the protocol slightly longer than one week.
- Charts of patients who died in the facility not on the protocol were reviewed. None would have been appropriate due to either goals of care or lack of clinical indicators suggesting imminent death.