Hospice in the Assisted Living: the ‘How To”.

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Learning by Trial and Error

Recognizing the Need for Training

Obvious to Everyone

Objectives

- Recognize the benefits of hospice and palliative care.
- Recognize barriers that may impede provider relations and delivery of services.
- State 2 ways hospice and the ALF staff can promote optimal team functioning.
- Identify how Administrators attitudes effect hospice care in their facilities.

Old Model of Cure-Care Continuum
Where We Want to Be

Next Model of Cure-Care Continuum

Goals and Emphasis of Care

- HOSPICE
  - Medical Model
  - 24hr Care giving available.
  - Professional in charge of Plan of Care
  - Attention to Relief of Suffering

- ASSISTED LIVING
  - Social Model
  - Assisted care according to contract
  - Patient/family in charge of Plan of Care

Goals and Emphasis of ASL

- HOSPICE
  - Team Communication
  - Skill in Care of Dying & Bereaved
  - Continuity of Care Across Settings
  - Life Closure
  - Quality Improvement

- ASSISTED LIVING
  - Patient/family communication with staff
  - Staff is grieving
  - Staff not experts in care of dying.
  - Staff is family

Determine goals & elements

- Flexible enough for growing & changing needs of residents & facility
- Program goals are for facility & not for individual residents or families, should be complimentary

Resident Population

- Includes residents experiencing a debilitating, life limiting condition
- Population of nursing facilities divided into 3 groups of residents with:
  - short-term rehabilitation
  - chronic long-term diseases
  - terminal illnesses
### Resident Population
- Expand or narrow program as facility adjusts to changes in philosophy, care practices, & population
- Facility needs to select what population it would like to target first

### Resident Population: Assisted Living
- AL residents likely to have chronic conditions & may be experiencing progressive decline
- Some AL facilities specialize in end of life care & may expand care focus to palliative care
- Requirements for extensive assistance with ADL's & complex medical needs supplemented by family & community resources
- If requirements can be handled, resident will be able to remain in place throughout palliative care experience
- Some residents may experience needs that are beyond what an AL facility is equipped to provide

### A palliative care program can serve many populations:
- People with
  - disabling or congenital conditions requiring LTC
  - acute, severe illnesses where cure is goal, but illness & treatment challenging to residents & families
  - progressively chronic & debilitating conditions or symptoms, or diseases that cause symptoms that are difficult to manage

### Populations
- Seriously & terminally ill residents who are unlikely to recover or stabilize & for whom care will be needed until death
  - families need care through death & bereavement
  - People identified as suffering
  - People who meet Medicare guidelines for hospice admission.

### Inclusion into a palliative care program determined by:
- Symptom management
- Decline
- Diagnosis
- Weight loss
- Identifying residents having unsatisfactory outcomes, unmanaged symptoms, psychosocial issues, or other factors
- Using hospice criteria for admission as a baseline

### Inclusion into a palliative care program may be determined by:
- Use of specific indicators, residents with two or more may be added
- Examples of these indicators include the following:
  - Weight loss
  - Ulcers
  - Increase in falls
  - Infections
  - Change in mental status
  - Change in functional abilities
  - Change in continence of bowel or bladder
Hospice Eligibility

Medicare Benefit Policy Manual

An individual is eligible
- has a terminal illness with a life expectancy of six months or less
- if the terminal illness runs its normal course.

Resident & Family Centered Care

- Recognizes uniqueness of each resident & family
- Resident defines family
- Family
  - people who support & care for resident & those the resident has a significant relationship
- Resident & family determine goals & preferences for care planning
- Health care team supports & guides family & resident in decision making process

Questions to ask

- What are residents’ expectations of care?
- What does resident want?
- Does resident want to live no matter what?
- Does resident want to be kept comfortable regardless of treatment effects?
- Is it more important to be alert than it is to be comfortable?
- Do they expect to go home from facility after a recovery period?
- Do they understand if they have a terminal illness?

Timing of Palliative Care

- Palliative care begins with diagnosis of life limiting condition & continues to a cure or until death & into bereavement for family
- Resident’s condition may deteriorate, or may come to facility already diagnosed
- Evaluated on admission for palliative care program with a formal identification tool
- Indicators should be identified on assessment document
- Tool will depend on criteria facility identifies for inclusion into a program

Comprehensive Care

- Holistic multidimensional analysis to identify & work to relieve suffering
- Requires regular resident-centered processes for:
  - assessment
  - diagnosis
  - care planning
  - interventions
  - evaluation
  - follow up

Comprehensive Care

- Set up guidelines so care planning team automatically evaluates residents who may benefit from palliative care
- Recommendations relating to care made by anyone, with criteria
- Resident’s goals for care guide determining if should be in palliative care program
Interdisciplinary Team
- Palliative care team set up to meet resident’s needs
- Include individuals based on services needed
- Core team members include members from medicine, nursing, & social work

Additional team members to consider
- Volunteers
- Bereavement specialists
- Hospice employees
- Chaplains
- Psychologists
- Pharmacists
- Direct care staff
- Dietitians
- Activities coordinators
- Case managers
- Specialty therapists (physical, occupational, speech)

Attention to Relief of Suffering
- Primary goal to relieve as much suffering & burdens imposed by illness & treatment as possible
- Suffering occurs from many areas
- Suffering in one area often influences another
- Identifying cause of suffering can aid in alleviating

Nebraska Information
- 20 Assisted living and LTC facilities interviewed and 6 different Hospice agency team members (Social Workers, and RN's) asked ‘How should hospice be done in the assisted living facility?’ ‘What does Hospice look like when it is done right?’
- Facilities were from Scottsbluff to Omaha.

Communication Skills
- Good communication skills necessary
- Skills include
  - appropriate & effective sharing of information
  - active listening
  - determining goals & preferences
  - assisting with medical decision-making
  - effective communication
Communication ideas/ASL

- Hospice can and should explain benefits. Emphasizing that 24 hr care is not part of the benefit.
- ASL staff and hospice staff should set up initial care plan with patient/family input.
- Hospice should come out in 24-48 hr after referral.

- The same team members for all the hospice patients in their facility improves communication.
- Notify staff of changes in plan of care.
- Communication books
- Resident chart documentation.
- Notify who is going to obtain physician orders. Update if orders not obtained.

Communication Ideas/ASL

- Educate staff (med aides) as to what to look for and when to call hospice team. 'Don't assume we know'.
- Using the resident’s pharmacy for drugs works best and getting emergency drugs from their own sources.

- More counseling and one on one would be helpful.
- Hospice should ask ASL staff ‘What do you think?’
- Do everything the team can to keep the resident in their ‘home’.
- Resident’s service agreement needs to be updated. Copy for hospice to see if needed.

Provide what is promised

- Let ASL staff know before discussing with resident and family that resident may be discharged.
- Standing orders are helpful.
- Hospice can build relationship with family.
- Range orders don’t work.
Communication Ideas/ASL

- Identify types of services needed: how often and by whom. Include waiver workers, and private caregivers etc.
- Clearly identify who does what and update the resident.
- Hospice should attend all deaths, especially when asked to come.

Communication Ideas/Hospice

- Call referrals even when not sure if resident qualifies for hospice benefits.
- Make time to have staff available for developing the initial Plan of Care.
- ASL should identify who to communicate with and how. (cell phone to MA on call) or charge nurse?

Communication Ideas/Hospice

- Death Policy in place so we can follow it.
- With waiver residents-who is responsible for communication POC to them.
- ASL to instruct Hospice RN’s as to the procedure for obtaining physician orders and documentation in their facility.
- ASL staff to notify Hospice RN when there is a significant event e.g a fall.

Communication Ideas/Hospice

- Help ASL staff to recognize grief and not view it as a weakness.
- Allow time to have ASL staff express their feelings, needs and concerns.
- Use communication book but write only what anyone could read. Use voicemail, emails, phone calls etc.

Communication Ideas/Hospice

- Use standing orders but don’t order meds until they are initiated.
- Order meds without ranges so MA’s don’t have to call and/or make assessments and decisions.
- Order meds on a schedule and see more often in order to assess for side effects and effectiveness.

Communication Ideas/Hospice

- Leave written communication in place ASL staff will read it.
- Hospice should be proactive with total assessments.
- Get staff input before making changes in POC.
- Share family dynamics and concerns.
Are we listening?

Skill in Care of Dying & Bereaved

- Team members must be knowledgeable in caring for needs of dying residents & families
- Must also be knowledgeable in:
  - prognosis
  - signs, & symptoms of dying
  - bereavement issues
  - grieving process
  - age specific needs
  - Referral to a hospice program

Continuity of Care Across Settings

- If resident has injury or illness that is a change in condition Hospice should be notified.
- If ambulance transfer is necessary Hospice should be notified first to arrange or approve.

Continuity of Care Across Settings

- Collaborate to ensure
  - quality care,
  - effective communication,
  - continuity of care
  - emphasis on preventing crisis & unnecessary transfers
  - Palliative care works to prevent crises

Barriers Impeding Relations and Delivery of Services

- Late referrals
- Miscommunication or lack of communication between ASL staff, Hospice team, resident / family and caregivers.
- No choice in hospice agencies
- Lack of respect and awareness of each team member’s abilities and roles.

Perceived Barriers - Attitudinal

- “owning” their settings
- “knowing what is best for the patient”,
- Distrust toward hospice
- Emotional state

Journal of Palliative Medicine: Perceived Barriers to Stable Provider Relations and Medication Delivery in Hospice-Facility Experiences in Nursing Homes and Private Homes, vol 13, Number 3, 2010
**Perceived Barriers-Site readiness**
- Ill-defined hierarchy
- Poor communication
- Disagreements among care providers
- Responsibility overload
- Differences in care priority, education and training. Not ready to accept Hospice guidance.

**Administration is key**
- Administrators were surveyed and the top four elements it reflected were emotional/social support, quality of care, rapidity of death, and end of life care coordination.
- End-of-Life Care coordination received the most favorable rating overall.

**Administration is key**
- Need to be committed to concept of Hospice and what it takes to provide it in the facility.
- Give residents options for care settings when level of care is highest.
- Residents will stay in their ‘home’ with adequate planning, education and support.

**Equitable Access**
- Access to palliative care available to all residents regardless of:
  - Age
  - Race
  - Ethnicity
  - Sexual preference
  - Ability to pay

**Quality Improvement**
- Committed to high quality care
- Evaluated regularly & systematically
- Core areas focus on safety & reducing caregiving errors
- Other areas for improvement include:
  - Timeliness
  - Resident-centered approach
  - Effectiveness
  - Accessibility & Equitableness
  - Evidence-based Practice
  - Efficiency

**Quality Improvement**
- Promoting better quality of life
- Providing treatments & promoting total body health can help avoid additional suffering, stress, & symptoms
Promoting Good Quality Care

- Quality and nature of resident-staff and ASL-hospice staff relationships are critical.
- Length of Stay in the facility and how well the staff knew resident associated with quality of resident-staff relationship.

Promoting Good Quality Care

- Respectful collaboration
- Clear communication, use of complementary knowledge and skills of staff
- Shared expectations about the care.
- ASL administrator support for residents dying in place with hospice services.

Summary

- Identifying residents who would benefit from a palliative care/hospice program
- Set guidelines that allow flexibility to meet needs of residents who are suffering
- Education on communication skills, care of the dying, interdisciplinary team, & quality improvement processes

Four Things to Say Before Goodbye

- Forgive me
- I Forgive you
- Thank you
- I love you
- Goodbye!