Title: END-OF-LIFE CARE

Guidelines: End-of-Life Care

Purpose: To provide quality patient and family centered care for participants through the end of life via comprehensive interdisciplinary care with attention to the relief of suffering, effective communication, care for the dying and bereaved, and quality improvement. Intent is to perform this care in the home whenever possible.

Procedure:
1. End-of-Life Committee (EOL) – A committee will be formed specifically to promote quality in end of life care in the organization.
   a. Composition of the EOL Committee:
      i. Required (core membership):
         1. Physician or Nurse Practitioner
         2. Day Center Director
         3. Registered Nurse
         4. Social Worker
         5. In-home Services Supervisor
      ii. Other members of the EOL Committee can include but is not limited to:
         1. Certified Nursing Assistants or Personal Care Assistants
         2. Dietician
         3. Physical Therapy
         4. Occupational Therapy
         5. Transportation
         6. Therapeutic Recreation
         7. Pharmacy Personnel
         8. Chaplain (highly recommended)
b. Frequency of EOL Committee meetings:
   i. The committee will meet on a regular basis. The meeting will be scheduled to last approximately one hour.

c. Guideline Review
   i. The EOL committee will meet annually to discuss and revise the guidelines specific to maintaining and improving EOL service standards as provided within the PACE organization.

d. Goals and functions
   i. The primary goal of the EOL committee is to promote quality end-of-life care for the participants and participant’s families.
   ii. The EOL committee will actively monitor the participants who are receiving EOL services.
   iii. The EOL committee will review and maintain the end-of-life educational materials that are given to families and participants.
   iv. The EOL committee will coordinate, and promote continuing education and provide clinical support specific to end-of-life care for staff.

2. New Participant Orientation
   a. All new participants to PACE will receive information regarding end-of-life care.
      i. During intake process
      ii. At initial assessment
      iii. At post-enrollment care conference if applicable
      iv. Ongoing as appropriate

3. Criteria for participants to receive end-of-life care
   a. Any member of the PACE interdisciplinary team may alert the EOL committee when they believe a participant would benefit from evaluation for EOL care.

   b. Criteria for end-of-life committee consideration:
      i. Life limiting diagnosis as identified (through consensus) by two separate medical providers.
      ii. Significant likelihood of death within six months.
iii. Participant and family agreement to primarily palliative medical treatment for current medical problems.

4. Initial implementation of end-of-life care: family care conference
   a. When a participant is determined to be eligible for EOL care they and their family will be offered a family care conference. Focus of conference:
      i. Presentation to the participant and family that the participant is approaching end-of-life.
      ii. Participant and family wishes and needs.
      iii. Advance care planning and code status documentation,
      iv. Purpose and goals of EOL care
      v. Functions of the EOL committee.
      vi. The plan to be enacted at the participant’s death.
   b. Representatives of the EOL committee will be present at the care conference to provide education in support of informed decision making.
   c. During the care conference participants and caregivers will receive information about end-of-life care; what to expect as part of the participant’s decline, information about the bereavement program, anticipatory grief, and any other materials deemed appropriate by the EOL committee.
   d. During the meeting the participant’s care plan will be reviewed and recommendation will be made to the IDT regarding the participant’s transition to EOL care.
   e. At this time, the participant’s reference sheet will also be completed or updated (attachment xxx) ; including important phone numbers, funeral home, plan of action, and resources to access
   f. After the initial family care conference, additional conferences will be provided on a PRN basis, specific to participant and family need.

5. Criteria for participants inclusion on the transitional care monitoring list and implementation
   a. Participant’s that are considered for inclusion on the transitional care monitoring list characteristically are either facing a life threatening illness, significant geriatric
decline, have a had a recent acute exacerbation of an illness but do not currently meet criteria of end-of-life care, or are eligible for EOL services but decline these services.

b. Any member of the PACE interdisciplinary team may alert the EOL committee evaluation.

c. Participants who meet criteria will be discussed at least bi-monthly for either continued monitoring, inclusion in the EOL program, or removal from the monitoring list.

d. Monitoring will include discussion of inclusion criteria, medical decline, family dynamic issues, and acceptance of EOL issues.

e. Psychosocial, emotional, and spiritual support can be offered to the participant and family in regards to their specific EOL needs.

6. Organizational Monitoring of EOL participant status

a. Interdisciplinary Team Meeting

i. Participants receiving end-of-life care will be reviewed weekly during the Interdisciplinary Team meeting. More frequent review will be determined by participants needs especially during active dying phase.

b. Weekly EOL Committee meeting

i. EOL Participants will be reviewed weekly at the EOL committee meeting, in order to discuss and assess currently provided services, and what additional interventions should be enacted.

ii. Transitional Participants will be reviewed every other week at the EOL committee meeting, in order to discuss and assess currently provided services, and what additional interventions should be enacted.

7. Homebound Participants

a. Participants at a stage of disease that requires that they be home or bed bound will receive visits from nursing at a minimum of every two weeks. Visit frequency will be increased based on participant’s needs. These visits will focus on:

i. Pain and symptom management.

ii. Educating participants and caregivers re: physiologic signs to expect at the end of life.

iii. The plan to be enacted at the participant’s death.
iv. Appropriateness of the care setting.

b. Participants at a stage of disease that requires that they be home or bed bound will receive a visit or a phone call from a social worker at a minimum of every 2 weeks. Visit frequency will be increased based on participant’s needs. These visits will focus on:

   i. Advance care planning issues including advance directives and funeral arrangements.

   ii. Participant’s wishes and the appropriateness of the care setting

   iii. Provide psychosocial support to participant and family regarding the dying and grieving process.

c. Participants at a stage of disease that requires that they be home or bed bound will receive visits from the physician or advanced practice professional at a minimum of every month. Visit frequency will be increased based on participant’s needs. These visits will focus on:

   i. Pain and symptom management.

   ii. Educating participants and caregivers re: physiologic signs to expect at the end of life.

   iii. Counseling participants about treatments and procedures, and reducing medications as appropriate.

   iv. Any other medical related questions about disease process from participants or caregivers.

8. End-of-life services in an institutional setting:

   a. For participants requiring a higher level of care which cannot be provided in the home setting transition to an institutional setting will be arranged.

   i. Criteria for consideration of transfer to an institutional setting may include:

      • Uncontrolled pain
      • Intractable nausea and vomiting
      • Psychosocial issues affecting participant’s well being
      • Uncontrollable behaviors
      • Intractable seizures
      • Other medical situations deemed appropriate for an institutional setting
      • Respite for caregivers
      • Patient and family preference and tolerance
ii. Options for institutional placement depending on level of care needed may include:

   1. Skilled Nursing Facilities
   2. Assisted Living Facilities
   3. Other

iii. End-of-life committee will provide oversight of the participant when they are in an institutional setting for their end of life care. Care may include:

   - Medication
   - Durable medical equipment
   - Volunteer visits
   - Chaplain visits
   - Social Work visits
   - Certified Nursing Assistant visits
   - Physician visits
   - Advanced Practice Professional visits
   - Registered Nurse visits

9. At time of death and/or immediately after death
   a. The designated PACE clinical staff will be contacted to pronounce the participant’s time of death and coordinate release of the body with the coroner. At all times the body will be treated with respect according to the cultural and religious practices of the participant and the family.
   b. The chaplain (as available) and social worker will be contacted to offer support to the caregivers if appropriate or needed.
   c. The designated PACE clinical staff will notify the following of the participant’s death:
      i. PACE Medical Director
      ii. PACE On-call Primary Care Provider
      iii. PACE Center Director
      iv. PACE In-home Services Supervisor
      v. Participant’s Community Primary Care Provider if applicable
   d. The designated PACE clinical staff will dispose of medication in accordance with PACE organization’s policies for the destruction of medication / controlled substances OR will document education provided to family regarding the need and appropriate means of medication disposal.
   e. The designated PACE clinical staff or a person designated by the registered nurse will contact the chosen funeral home when the family is ready.
f. At the appropriate time arrangements will be made to have durable medical equipment collected.

10. Bereavement Care
   a. At the family care conference and throughout the dying process participants and family will be given information on anticipatory grief and suggestions on gaining a sense of closure during the dying process.
   b. Following the death of a participant social worker or chaplain will contact the primary family caregiver of the deceased participant to offer condolences and support. At this time the participant’s social worker or chaplain (as available) will also provide information on community resources that families can access for support following a death and remind them of the available bereavement program.
   c. During the end-of-life committee meeting following a participant’s death the family member/s will be included in the bereavement program.
   d. The bereavement program follow-up program will consist of an initial phone call to support caregivers and family by the chaplain (as available) or social worker, signing of a condolence card, follow up phone calls as appropriate, and a grief mailing series sent to identified caregivers at 1, 3, 6, 9, 11, and 13 months after the participant’s death.
   e. Each participant that dies may have their picture displayed in the day center for 1-4 weeks.
   f. A memorial service may be held in the day center on a regular basis to honor and remember participants.

11. End-of-Life Education for staff:
   a. Will happen on a regular basis for all staff in accordance with organizational policies.