

COMPLEMENTARY APPLICATION OF THE MODEL FOR ADVANCE CARE PLANNING

General Issues in Planning at the End of Life

- Planning other issues patients face at the end of life is critical
 - Ensures that patient needs and expectations are respected by:
 - Health care professionals
 - Family members who will survive them
- While it would be ideal if all patients and families prepared for death well in advance of the final hours of their lives, most patients with advanced illnesses and their families have neither discussed nor prepared for their death
- As patients approach the last hours of their lives, they have a last chance to:
 - Finish their business
 - Create final memories
 - Give final gifts
 - Say their good-byes
- If appropriately assisted, considerable advance planning can be accomplished around many of these issues
- The 5–step model for eliciting, documenting, and following advance directives can be used to:
 - Guide these decision-making processes
 - Document patient choices
- As these important tasks are generally more than individual physicians can handle, other members of the interdisciplinary team can help patients and families complete their business and get their affairs in order

Preparation for the Last Hours of Life

- Planning for death involves understanding the perspective and wishes of:
 - Patient
 - Family
 - Caregivers
- Factors that may come into play include:
 - Personal expectations
 - Individual agendas
 - Fears or phobias
 - Opinions about acceptable setting(s) for care
- These factors need to be clarified in order to avoid:
 - Any one person altering the course of care unexpectedly
 - Interference with the patient's wishes
- Anticipate and respect personal, cultural, and religious values, beliefs, and practices
 - Missed rites/rituals or errors made by unknowing caregivers may have grievous consequences in the eyes of the patient or family members
- Loss, grief, coping strategies
 - Some family members have a need to give care
 - Others do not have this need
 - Allow each to participate as closely as makes him/her comfortable
- Educating and training for patients, families, and caregivers may include:

- Communicating about end-of-life issues
- Tasks of caring
- What to expect
- Physiological changes and symptom management

Advance Practical Planning. Advanced planning strategies can also help patients...

- Settle their financial and legal affairs
- Determine final gifts
 - Bequests
 - Organ donation
- Indicate preferences regarding
 - Autopsy
 - Burial, cremation
- Plan funeral or memorial services
- Determine guardianship of children or other dependents
- Express permission to family to build new lives

Choice of Caregivers

- The choice of caregivers for each patient is crucial as vulnerability increases
- Issues related to designating family members as caregivers:
 - Patients may or may not want family members to care for them
 - Family members may or may not be able to assume responsibilities for caring
 - They should have the opportunity to be family first
 - Family members should be designated as caregivers only if both they and the patient agree to the role
- All caregivers need to have the opportunity to change their role if:
 - They feel the stress is too much
 - They are not getting enough chance to finish their personal business with the patient

Choice of Setting

- Setting chosen for death should be as acceptable as possible to the patient, the family, and all caregivers
- Weigh burdens and benefits of all potential settings. Setting should:
 - Permit family presence with patient
 - Allow for privacy, intimacy
- Factors to consider if patient wishes to die at home:
 - Potential family burden: risk to career, personal economics, health
 - Number of available caregivers and personal resources
 - Family fear of ghosts (will family be able to live in the home afterwards?)
- Identify alternate inpatient settings that can serve as backup:
 - Hospice or palliative care facility
 - Skilled nursing facility
 - Acute care facility
- Depending on the resources that are locally available, and whether the staff is skilled in this kind of care these alternative settings may lead to a far better outcome

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