PREPARING FOR THE LAST HOURS OF LIFE

Creating the Setting for the Last Hours of Life During the last hours of their lives, all patients require skilled care around the clock. This can be provided in any setting as long as the professional, family and volunteer caregivers are appropriately prepared and supported throughout the process

- The environment must:
  - Allow family and friends access to their loved one around the clock without disturbing others
  - Be conducive to privacy and intimacy
- Medications, equipment, and supplies need to be available in anticipation of problems, whether the patient is at home or in a health care institution
- As the patient’s condition and the family’s ability to cope can change frequently, both must be reassessed regularly and the plan of care modified as needed
- As changes can occur suddenly and unexpectedly, caregivers must be able to respond quickly
  - This is particularly important when the patient is at home, if unnecessary readmission is to be avoided

Caregiver Preparation

- If the last hours of a person’s life are to be as rewarding as possible, advance preparation and education of professional, family, and volunteer caregivers is essential, whether the patient is at home, in an acute care or skilled nursing facility, a hospice or palliative care unit, prison, etc.
- Everyone who participates must be aware of:
  - The patient’s health status
  - His or her goals for care (or the parents’ goals if the patient is a child)
  - Advance directives
  - Proxy for decision-making
- Other important aspects of caregiver preparation include:
  - Knowledge about the potential time course, signs and symptoms of the dying process, and death (and their potential management)
  - Understanding that what they see may be very different from the patient’s experience
- If family members and caregivers feel confident...
  - The experience can provide a sense of final gift giving
  - For parents of a dying child, confidence can leave a sense of good parenting
- If family members and caregivers feel unprepared and unsupported...
  - They may spend excessive energy worrying how to handle the next event
  - If things do not go as hoped for, family members may live with frustration, worry, fear, or guilt that they did something wrong or caused the patient’s death
- Physicians will need to establish in advance whether potential caregivers, including professionals who work in institutions, are skilled in caring for patients in the last hours of life
  - Don’t assume that anyone, even a professional, knows how to perform basic tasks
  - Those who are inexperienced in this particular area will need specific training (including knowledge about body fluid precautions)
  - Written materials can provide additional support to caregivers when experts are not present

Unpredictability of Death

- Although we often sense that death will either come quickly (over minutes) or be protracted (over days to weeks), it is not possible to predict when death will occur
- Some patients may appear to wait for someone to visit, or for an important event such as a birthday or a special holiday, and then die soon afterward
- Others experience unexplained improvements and live longer than expected
- A few seem to "decide to die" and do so very quickly, sometimes within minutes
- While we may give families or professional caregivers an idea of how long the patient might live, always advise them about the inherent unpredictability of death
Essential Skills for Physicians During the Last Hours of Life

As virtually all physicians will care for dying patients and their families, the approaches to care in the last hours of life are essential skills for physicians. This module discusses the specialized care required during the last hours of life in 3 parts. These specialized approaches are applicable whether the patient is at home or in an institutional setting.

- **Part I: Physiological Changes and Symptom Management During the Dying Process** discusses the physiological changes that occur as patients are dying and approaches to the management of associated symptoms
- **Part II: When Death Occurs** discusses preparation for expected death and what to do when death occurs
- **Part III: Loss, Grief, and Coping** discusses loss and the assessment and management of normal and complicated grief reactions

Much of the work that can be done to prepare for the last hours of life is covered elsewhere in this curriculum. It is important that physicians know that patients have had the opportunity to prepare for the end of their lives and arrange for the legacies they would like to leave, e.g., bequests, organ donation, gifts, etc.

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