WHEN TO CONSIDER PALLIATIVE / HOSPICE EOL CARE
Palliative / hospice end-of-life care can assist with:

- Pain and symptom control
- Emotional, social, and spiritual suffering
- Home services, medications, nurse case mgmt.
- Determining eligibility for supportive services
- Facilitating patient and family conferences to define goals of care, including advance directives

ALS
Rapid progression in last year
Impaired breathing at rest
Insufficient nutrition / hydration
Recurrent aspiration pneumonia
Upper urinary tract infection
Sepsis
Recurrent fever
Decubitus ulcers

Dementia
Inability to walk
Incontinence
Fewer than six intelligible words
Albumin < 2.5 or decrease PO intake
Frequent ER visits

Diseases with short prognosis
Esophageal cancer
Pancreatic cancer
Glioblastoma
Liver cancer
Gall bladder cancer
Any cancer with generalized metastases; metastasis to brain, liver, bone; or unresectable

Multi-system failure
Frequent ER visits
Albumin < 2.5
Unintentional weight loss
Decubitus ulcers
Homebound / bed-confined

SHARING BAD NEWS

First Step in Planning Care
- Helps develop therapeutic relationship
- Discuss agenda of patient/family first
- Let physician priorities flow naturally from the patient/family
  - e.g. discussion of resuscitation and other advance directives

Discussion Agenda
- Physical care - Setting and level of residential care
- Social care - family and financial issues (e.g. dependence/disability)
- Emotional care - Sources of support
- Spiritual care - Sources of meaning

Physician Role
- DO NOT DELEGATE sharing bad news
- Sharing bad news is physician’s role
- Patients often accept bad news only from MD
- MD best prepared to interpret news and to offer advice

Physician Preparation
- Confirm medical facts; plan presentation
- Make only one or two main points; use simple, lay language

Setting the Stage
- Choose appropriate private environment (neither hall nor curtain provide privacy)
- Have tissue available
- Allot enough time (20-30 minutes minimum with documentation)
- Determine who should be present
- Turn beeper to vibrate (avoids interruptions, demonstrates full attention)
- Shake hands with the patient first
- Introduce yourself to everyone in the room
- Always sit at eye level with patient at a distance of 50-75 cm
- Ask permission before sitting on edge of bed
- Arrange seating for everyone present if possible (helps put patient at ease, prevents patient from hurrying)

Starting the Conversation
ASK: How do pt./family understand what is happening?
  What have others told them?
WAIT: 15-30 seconds to give opportunity to respond
LISTEN: Response may vary from “I think I am dying” to “I don’t understand what is happening.”
  - How much does patient want to know?
  - Ask patient if he/she wants to know prognosis
  - Patient may decline conversation and designate a spokesperson

Source: Bailey, A. The Palliative Response (modified for BCBSRI/Brown University project)
When Family Wants to “Protect” Patient

- Honor patient’s autonomy
- Meet legal obligation for consent
- Promote family alliance and support for the patient
- Ask what family is afraid will happen
- Offer to have family present when you speak to the patient (so they can hear patient’s wishes about knowing status/prognosis)

Sharing Bad News

- Give a warning to allow people to prepare
- Briefly state only one or two key points
- Use simple language

STOP:

- Ask questions to assess understanding
- Recommended statement for terminal illness: “I wish we had a treatment for this illness.” (Humble statement; leaves open the possibility of the miraculous; helps change the focus from “cure” to palliation and support)
- Do not minimize severity of news

Response to Emotions of Patient, Family, and Staff

- Be prepared for a range of emotions
- Allow time for response
- Communicate nonverbally as well as verbally (usually acceptable to touch arm)

Suggest a Brief Plan

- Medical plan (e.g. control dyspnea, home assistance to help deal with weakness)
- Ancillary support (e.g. social work visits, pastoral care visits)
- Introduce advance care planning (“Sometimes when people die, doctors try to bring them back to life…Have you considered whether you would want this or not?”)
- Discuss timeline

Offer Follow-up Meeting

- When? Usually within 24 hours
- Who? For current and additional family members
- Why? To repeat portions of news
- How? Offer to contact absent family members. Get permission to share news if necessary
- Next meeting, upcoming decisions, suggest flexible timeline

Ending the Meeting

- **ASK:** “Do you have any questions?”
- **WAIT**
- **ANSWER**
- **STAND** - An effective way to end the conversation

For more information, go to www.hospice.va.gov/Amosbaileybook/