

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 mgt.
- 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

Multi-system failure

Frequent ER visits

Albumin < 2.5

Unintentional weight loss

Decubitus ulcers

Homebound / bed-confined

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

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/

Heart disease

CHF symptoms at rest
EF of < 20%
New dysrhythmia
Cardiac arrest, syncope, or CVA
Frequent ER visits for symptoms

Liver disease

PT > 5 seconds
Albumin < 2.5
Refractory ascites
Spontaneous bacterial peritonitis
Jaundice
Malnutrition and muscle wasting

Lung Cancer

Advanced disease stage
Albumin < 2.5
Calcium \geq 12.0
Metastasis to brain, bone
Decreasing functional status

Pulmonary disease

Dyspnea at rest
Signs or symptoms of right heart failure
O2 sat on O2 of < 88%
P CO2 > 50
Unintentional weight loss

Renal disease

Not a candidate for dialysis
Creatinine clearance of < 15 ml/minute
Serum creatinine > 6.0

Stroke – Acute

Secondary coma > 3 days
Dysphagia

Stroke - Chronic

Post-stroke dementia
Poor functional status
Unintentional weight loss
Serum albumin < 2.5

Source: Bailey, Amos. *The Palliative Response* (modified for BCBSRI/Brown University project). For more information, go to www.hospice.va.gov/Amosbaileybook/