

## Helping the Patient and Family Accept the Patient's Terminal Condition and "Let Go"

In a 2011 unpublished study of 50 consecutive palliative care consultations at West Virginia University Hospital, 33% of the patients and families were unprepared for the patient's imminent death. In his widely read *Hard Choices for Loving People, 6<sup>th</sup> ed.*, Chaplain Hank Dunn writes, "The real struggles [with end-of-life decisions] are emotional and spiritual. People wrestle with letting go and letting be."

### Why Families May Be Unprepared

- Acute change in patient's condition
- Prognosis not previously communicated
- Prognosis communicated but not heard/understood
- Denial
- Lack of knowledge of advance care planning so issues not faced
- Orientation toward cure; planning is postponed till "later"

### Get the patient's/family's perspective-hear their story

- "He's always bounced back before."
- "She knows I'm here. She blinks her eyes."
- "I can't bear to lose her."
- "If we don't feed her (with a tube), she'll starve to death."
- "I feel guilty for not having visited Mom more often. I want to talk to her one last time."
- "Mom's a fighter."

### Explore the patient's/family's understanding of the current medical situation

- Educate about symptoms, signs, lab results, X-rays
- Interpret for family
- Have them see what the health care team sees-transparency (may include X-rays, wounds, gangrene, CPR, etc)
- Review the implications of past decisions-e.g., no more surgery

### Estimate prognosis

- Obtain additional tests, X-rays, consultations to increase certainty
- Say the patient is "dying" if he/she is

### Achieve "transparency"-enable the family to see what we see

- Show family lab results and X-rays
- Show family wounds
- Use patient decision aids or pictures

**Identify and encourage social and spiritual support**

- Who does the family decision-maker rely on for strength?
- What is the role of faith?
- Are there spiritual issues?
- Would the patient/family like to speak to a chaplain/clergy?

**Give the patient/family time while clarifying what parameters are to be watched-response to antibiotics, patient becoming more awake, etc**

**Ask how the patient would want the final chapter of his/her life story to read-inquire about funeral arrangements, etc.**

**Force the issue (rarely)**

- Family member may be in complete denial despite all the above
- Other family members agree to limited treatment
- Ethics consultation to confirm reasonableness of setting a limit
- Set a time in advance so family members can say “goodbye”