

Helping the Patient and Family Let Go

- A major problem in 33% of the last 50 palliative care consults
- Patients and 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
- 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"