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”