USING THE SIX STEP PROTOCOL IN OTHER SITUATIONS

When Language is a Barrier

- Use a skilled translator who is:
  - Familiar with medical terminology
  - Comfortable translating bad news
- Meet with the translator before the interview to:
  - Brief them on what will be said
  - Reassure them their role is only to translate
  - Verify that they will be comfortable translating the news you are about to give
- Avoid family as primary translators
  - Confuses roles in family unit
  - May raise issues of confidentiality
  - Family members may not know how to translate medical concepts
  - Family members may modify news to protect patient
  - Instead, encourage family to:
    - Supplement the primary translation
    - Support patient and other family members
- During the interview:
  - Sit in a triangular arrangement so that you can:
    - Face and speak directly to the patient
    - Yet still turn to look at the translator
  - Speak in short segments, and then give the translator time to convey the information
  - Verify the patient’s and family’s understanding and check for an emotional response
- There are several services in North America that offer translation by telephone if there is no one directly available
- See information on Medical Interpreters in Module 13: Cultural Issues

Why Do Patients Ask about Prognosis?

- Patients frequently ask about prognosis
- There are many motivations for this request
- Some want to have a sense of their future so they can plan their lives
- Others are terrified and hope that you will reassure them

What to Do Before Responding to Patient Inquiries

- Before directly answering their questions about prognosis, inquire about their reasons for asking. Questions might include:
  - What are you expecting to happen?"
  - "How specific do you want me to be?"
  - What experiences have you had with others with a similar illness?"
  - "What experiences have you had with others who have died?"
  - "What do you hope/dream will happen?"
  - "What is your nightmare about what will happen?"
- Consider the implications of the prognostic information you provide
  - Patients who wish to plan their lives want information that is more detailed
  - Those who are terrified may do better with answers that are more general

Responding to Inquiries about Prognosis
• Definitive answers, e.g., "You have 6 months to live," run the risk of producing:
  o Disappointment, if the time proves to be less
  o Anger or frustration, if you have underestimated the patient’s lifespan

• Consider responding by giving a range of time that encompasses an average life expectancy, such as:
  o "Hours to days"
  o "Days to weeks"
  o "Weeks to months"
  o "Months to years"

• Alternatively, indicate averages such as:
  o "One third of people will do well a year from now, half will live about 6 months; exactly what will happen for you, I don’t know."

• After giving a range, it may help to emphasize the limits of prediction by saying something like:
  o "What this will mean for you I can’t tell. We need to hope for the best, while we plan for the worst. We can’t predict surprises and should plan in case something happens. Over time we’ll have a better sense over time how things will evolve for you."

• Always caution patients and families that unexpected surprises can happen
  o Suggest that they get their affairs in order so they won’t be so vulnerable if something unexpected does occur
  o Reassure them that you will be available to them to deal with issues and support them throughout their illness, whatever happens
  o Help clarify what can be realistically expected and distinguish this from what might be wished for, or what is most feared
  o Identify the miraculous for what it is—something outside of usual experience that happens exceedingly rarely

**Caregiver Communication**

• The sharing of information among caregivers is critical
• Maintain a chart or log book close to the patient that can be shared by all who provide care, including physicians
• Pooled information can help:
  o Facilitate a continuous plan of care
  o Avoid constant repetition of questions
  o Avoid unwanted activities

• It will be most effective if the chart or log book includes:
  o Goals for care
  o Treatment choices
  o What to do in an emergency
  o Likes and dislikes
  o Things to do and or not to do
  o Contact information for family, physicians, and other members of the interdisciplinary team

• Ensure that data is recorded accurately and accessible to everyone

*The EndLink program is funded with a grant from the National Cancer Institute grant (R25 CA76449) to Sara J. Knight, Ph.D., at the Robert H. Lurie Comprehensive Cancer. This material used in this document was adapted from the EPEC project (Education for Physicians on End-of-life Care).*