Welcome to the fifth and last module on the topic of End of Life Family Care Conferences.

In this module, we review the elements of a care plan and the process of providing some emotional closure to what was undoubtedly a difficult meeting for the family.

Care planning has three main steps, as shown in this slide. Your first goal is to summarize the discussion. This is critically important. Repeat to the best of your ability what the family has told you in terms of their decisions, wishes, or requests. Then, ask them to confirm what you’ve said, and to correct any piece of your understanding. Failing to confirm what you’ve heard can lead to unwanted or omitted follow-up steps.

Here are various examples of how to summarize the family wishes. Check the Moodle Website for others.

Here is an example of how one provider summarized his understanding of the family wishes. Note his recommendation for an intermediary step while the family waits to discuss the situation with others.

After confirming the family wishes, then clearly list your follow-up steps in terms of notes to the patient’s chart, new orders, treatment changes and schedules.

These general follow-up steps apply regardless of whether the family wishes to continue with aggressive interventions, needs more time to decide, or elects to begin comfort care immediately. Should the family chose comfort care, your follow-up steps might include such things as:

- arranging the transfer of the patient out of the ICU to a quiet, more peaceful room
- entering code status revisions in the electronic medical record
- writing orders to withdraw treatments, change medications
- making accommodations for last rites or other religious practices to be carried out; and
- providing referrals to funeral homes or mortuaries

Depending on the patient and situation, it may be appropriate to bring in a care team member to talk about organ donation and autopsy services.

After listing your follow-up steps, explain to the family how care for their loved one will continue. When will you meet again to revisit the patient status or their decision? How will you communicate the care plan to the other providers and services who are involved with its
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effected? Who on the care team will be responsible for the patient after you leave? Who should the family call if they have questions? Check the Moodle website for useful phrases.

Treatment does not stop when a family elects comfort care. As Bradley and Brasel state, an end-of-life care plan acts like a contract with the family. It spells out what you as a provider team will do for them and with them. The main thing to assure them is that the team will still be monitoring their loved one, managing his or her symptoms, and checking in with the family to see what else they might need. This shared, concrete plan reassures them that you are not abandoning them.

Ok let’s talk now about “emotional closure.” The way you end the conversation is every bit as important as the way you start it. The worst thing you can do is to rush out of the room once the “business” end of the meeting concludes. You need to spend just a little more time relating to the family members, person to person.

Many families have questions about the dying process. Many want to better understand what role they can play as their relative dies. What can they do? How can they help? Encourage them to be present in whatever way feels natural to them. If they ask, tell them it is okay to touch or hold their loved one; to speak, sing, or pray with them. If the patient is dying in the hospital, tell them it’s ok to bring a favorite blanket, a treasured photo, or other objects to make the room feel more familiar. When possible, support other requests, such as bringing an iPod with favorite music.

Before you leave, offer some parting words that convey sympathy, commitment to the patient and to the family, and encouragement. Here are some effective phrases to use before leaving the room.

Here is an example of how one provider said goodbye to the family.

Ok, time to go! Here is a simple checklist to add to your mental tool box.

We hope these modules have increased your awareness and stimulated some thoughts about end of life family care conferences. We encourage you to read the articles linked on the Moodle website, and to observe and actively participate in family conferences whenever possible. Talking with your mentors and reflecting on these conversations should help you become more resilient in the face of loss, as well as more confident, effective, and fulfilled in your role. We look forward to hearing from you at our upcoming teaching session on End of Life.