PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #227
THE FAMILY MEETING: END OF LIFE GOAL SETTING AND FUTURE PLANNING

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Background End-of-life goal setting is a key palliative care skill, typically occurring as part of a family meeting (see *Fast Facts* #16, 65, 222-226). This *Fast Fact* discusses an approach to goal setting when the expected length of life is short.

Establishing patient-centered goals Here is an example of how to start the conversation (the patient should be given sufficient time to respond to each of these questions):

I/we have discussed your current condition and that time may be short. With that in mind –

- *What are you hoping for now?*
- *What is important to you?*
- *What do you need to accomplish?*
- *Who do you need to see in the time that is left?*

Common responses invoke family, home, and comfort; often surviving until a specific future family event/ date or visit with a key family member is described as an important goal. Re-state your understanding: *What I hear you saying is that you want to be home, comfortable, and survive until your daughter gives birth – you hope to meet your next grandchild*. **Note:** if you believe the patient's goal of survival to a specific event/date is not practical, it is important to say so and discuss alternative plans.

Recommend a care plan based on the goals Once the goal(s) is/are established, you can then review the patient's current treatments (e.g. antibiotics, chemotherapy), monitoring (e.g. pulse oximetry), planned tests (e.g. colonoscopy), and medications (e.g. anti-hypertensives), and decide which will help meet, or not, the patient's goals. Anything that will not help meet the goals should be discussed for potential discontinuation. Depending on the specific disease/patient condition, other issues that are naturally discussed at this point include:

- Future hospitalizations, ICU admissions, laboratory and radiology tests.
- Resuscitation orders/code status (see *Fast Facts* #23-24).
- Current/future use of blood products, antibiotics, artificial hydration/nutrition.
- If present, the potential continuation or stopping of dialysis or cardiac devices.
- Role of a second (or third) opinion.
- Exploration of experimental therapy.
- Exploration of treatment options the patient or family may bring into the conversation.
- Disposition options to best meet the goals (e.g. home hospice referral).

Note: There is *no* need to ask about each option as a yes/no question (*Do you want blood products?*). Based on what you know about the patient's goals, make a recommendation about what should and should not be done in light of the patient's goals, condition and prognosis. If you are unsure, you can explore the issue with the patient/family (*Given that your dad wanted to get home as soon as possible and yet he was also willing to do easy things that might help him live longer, I am unsure whether it makes sense to stay in the hospital an extra day or two to finish the antibiotics. What do you think he would say?*).

'Long-shot' goals If patients are going to pursue 'long-shot' or experimental therapy, perhaps even against the recommendation of the treating team, it is useful to ensure the following:

- Reinforce the team's respect for the decision, and desire to make sure the treatment has the best possible chance of working.
- Simultaneously try to maximize quality of life *in the present*, including the best possible pain and symptom management and support.
- Encourage the patient and family to prepare in case treatment is not successful and the patient dies sooner rather than later. Useful language is to say, *I'd encourage us all to hope for the best, but prepare for the worst*.

- Reinforce that the team will not abandon the patient and family even if the decision is not what is being recommended.

Close the meeting Following this discussion, restate your understanding of the patient's goals and agreed-upon next steps to meet those goals, invite and answer questions, and close the meeting.

Discussion & documentation Discuss the goals with key staff not in attendance (e.g. consulting physicians, patient's nurse, discharge planner, primary care provider). Document the goals, preferably using a templated family meeting note (see Reference 1): who was present, what was discussed (e.g. treatment options, prognosis), what was decided, next steps.

Debriefing A useful step after every family meeting is to debrief the process – what went well, what could have been improved and, most importantly, addressing the emotional reaction and needs of the care team.

References

1. Clinical Tools. Center to Advance Palliative Care. Available at: http://www.capc.org/tools-for-palliative-care-programs/clinical-tools/. Accessed August 4, 2009. Free registration required.
2. Back A, Arnold R, Tulsky J. *Mastering communication with seriously ill patients: balancing honesty with empathy and hope.* New York, NY: Cambridge University Press; 2009.

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Version History: Originally published October 2009; copy-edited August 2015.