FAST FACTS AND CONCEPTS #223
THE FAMILY MEETING: STARTING THE CONVERSATION

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Background  Fast Fact #16 gives a concise overview of running a family meeting. Fast Fact #222 provides a list of preparatory steps in planning for a family meeting to discuss end-of-life goals; this Fast Fact reviews the early steps of the actual meeting.

1. Introductions & setting goals for the meeting
   - The meeting leader begins the meeting by introducing him or herself, and suggesting that each person present (medical team and family/community) introduce themselves including their relationship to the patient.
   - The meeting leader should summarize the meeting goals (e.g. We are here to discuss next steps in the care of Mr. Jones) and ask the family to confirm these goals and/or add other agenda items.
   - Note: if you do not know the patient or family well, take a moment to build relationship. Ask a non-medical question such as I am just getting to know you. I had a chance to look at your chart and learn about your medical condition but it does not say much about your life before you got sick. Can you tell us about the things you liked to do before you got sick? Similarly, if the patient is not able to participate in the meeting, ask family to describe the patient prior to his becoming ill: As we get started, can you describe what Mr. Jones was like before he became ill?

2. Determine what the patient/family already knows  This step is essential as it guides you in providing a synthesis of the medical information (see below). Always invite the patient and all family members to provide their understanding of the medical information. Examples of opening lines:
   - Tell me what the doctors have told you about your condition?
   - Can you describe for me your sense of how things are going?
   - For patients who have been declining from a chronic illness, you can ask: Tell me about the past 3-6 months: what types of changes have you noted?  The patient or family will typically describe changes in terms of function (physical or cognitive) and quality of life.

3. The Medical Review  Once you know what the patient/family understands, you are in a good position to confirm their understanding, or provide new information/correct misunderstandings. First, ask if you can bring them up-to-date about what is going on; asking shows politeness and also signals that they should attend to what you are trying to say. The clinician most closely aligned with the patient’s ongoing treatment should begin this discussion, supplemented with information from consulting services if relevant. Do not provide information using medical jargon or in an organ system approach (e.g. The creatinine is improving, but there is a new pleural effusion and the heart rate has become irregular). A more patient-centered approach is to provide a succinct summary of the current condition, without any medical jargon, focusing on the issues of most importance, which are usually function/quality/time. Give a ‘bottom-line’ statement: ‘getting worse,’ ‘not going to improve,’ ‘dying and time is likely very short.’
   - The worsening weakness and pain you describe is from the cancer which is growing despite the chemotherapy.
   - You are telling me that despite the recent hospitalization, you are not able to do as much around the house; unfortunately your lung disease is getting worse despite all our best treatments.
   - Despite our best efforts, your wife’s brain injury from the car crash is getting worse. She can no longer stay awake or move her arms/legs.

Using the ‘D word’ if relevant: when a patient is clearly deteriorating and death is likely within the next days to weeks, or even a few months, it is appropriate to use the word dying in the conversation. Both patients and surrogates find that saying the word dying, if done compassionately, is helpful in clearing what is often a confusing and frightening situation. I’m afraid we have run out of options to shrink the cancer. Based on your declining function, I believe you are dying.
4. **Silence**  Whether or not you use the word *dying*, when you have presented bad news (such as information about disease progression), the next step is for you to allow silence, and let the family/patient respond. In truth, no matter what you might imagine the response from the patient/family to be once the bad news is delivered, you really cannot predict their emotional reaction (e.g. relief, anxiety, anger, regret, fear). This silence can be uncomfortable; resist the urge to fill it with more facts as they will not be heard. Not all patients/families express emotions at this point and instead respond practically (*Well, what happens next then?*). This is fine, but you need to wait, silently, to see what response the patient/family demonstrates. In addition, even practical questions have underlying emotions (*Are you sure? Or – There must be something you can do?*). It is important to respond to both the factual aspect of the question (*Yes I am sure. Or – There are no more effective treatments available.*), as well as the emotional level (*I wish I had better news for you. Or – I wish our treatments worked better than they do.*).

When the patient/surrogates openly acknowledge that current treatments are no longer effective, that death is coming, they will generally ask one or all of the following questions: *How long? What will happen? Will there be suffering? What do we do now?*  Your response at this point should be to address prognosis in terms of time, function, and symptoms, as best you can (see *Fast Facts #13,141,143,149,150*). This will answer the first two questions; the last questions will require more discussion of patient-centered goals (see *Fast Fact #227*).

**References**


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