



Case: You are asked to attend a family meeting of Mr. Jones, a 76-year-old man with hepatocellular cancer. A day earlier, the doctors told him that he was not a transplant candidate and his oncologist said that given his progressive cancer it was very unlikely that he would ever receive more chemotherapy. The doctors believe that Mr. Jones only has weeks to live.

The meeting is with the patient, his wife and his eldest daughter. After spending time answering their questions and talking to them about hospice, they agree that going home with hospice is a good idea. While the patient still hopes for a miracle, he believes his wife and daughter need more help and that hospice is the best way to provide it.

As the meeting is wrapping up, the patient's wife turns to you and says, "How long does he have to live? I know that you cannot predict exactly, but I really do want to know how long this is going to be."

What should you do?

Healthcare providers regularly have a difficult time talking about prognosis. Because prognostic information often involves giving bad news, we dread making the patient sad and dealing with his or her emotional reaction. Studies also suggest that healthcare providers are afraid that by talking frankly about prognosis, patients or families will give up and their prognostication will turn into a self-fulfilling prophecy.

Even if one does talk about prognosis, it is hard to know how much information to give. While most studies show that patients want prognostic information even when it is bad, a significant minority do not want information. Patients are less likely to want as full information as they become sicker.

The studies on family members' desire for information show they typically want more information than the patient. For example, family members may want information about how much time they have to take off work, or how to tell when the person is close to dying.

Given these wide variations in what people want to hear, how can a health care provider ever please everyone when talking about prognosis? What do you do when the patient wants you to be a cheerleader and the family needs the facts? In the above case, it seems disingenuous to avoid the wife's explicit question, but you worry that being explicit about prognosis may be more information than the patient wants to hear.

The key in this situation is to **ASK EACH PARTY ABOUT THEIR DESIRE FOR INFORMATION before** giving prognostic information. Thus, in the case described above, one might turn to the patient and say, "Your wife would like to hear more about what might

happen when you get home, including your prognosis. Is this something that you want to know as well?" (One would also check in with the daughter).

If the patient does not want the information, one can say "Given that you are not really interested in all the information your wife wants, would it be ok if I talk to her separately after our meeting together?" This allows her to get the information she needs without burdening the patient.

If the patient wishes to hear prognostic information, the next step is to negotiate how much information he and his wife *both* want to know. For example, while the patient may wish to know if he will be alive to see the Masters, his wife might want more specific information regarding the percentage of people who are alive in 30 or 60 days. It is important before you provide information that you are clear about their informational needs.

If both of them want the same information, the healthcare provider can straightforwardly deliver the information—even difficult information about poor prognosis. If the information differs, one will need to provide the information to each individual separately. Often one can talk to the patient while doing a physical exam and to the family member after the completion of the meeting.

It is important to remember that patients and family members are likely to have an emotional reaction to the prognostic information. This is true even if they have asked for it. It is important that the healthcare provider empathically acknowledge these reactions. For example, one could say "it looks like the information was not what you were expecting" or "what is your reaction to this?" or "I can see that this is upsetting."

Finally, as with all information, it is important to check for understanding. Patients and families often misinterpret complex medical information, either hearing only the bad or the good aspects of the message. Thus, healthcare providers should check whether the patient/family heard the message that you intended to convey. For example, one might say, "tell me what you are taking away from this discussion" or "what will you tell family members who were not here about what we discussed?"

References:

Back AL, Arnold RM. Discussing Prognosis: "How much do you want to know?" Talking to patients who are prepared for explicit information *J Clin Oncol* 24:4209-4213, 2006

Back AL, Arnold RM. Discussing Prognosis: "How much do you want to know?" Talking to patients who do not want information or who are ambivalent. *J Clin Oncol* 24:4214-4217, 2006

Clayton JM, Butow PN, Arnold RM, Tattersall MHN. Discussing life expectancy with terminally ill cancer patients and their carers: a qualitative study. *Supportive Care in Cancer*, 2005 Sep;13(9):733-42.



Pennsylvania Task Force for Quality at the End of Life releases *Improving End-of-life Experiences for Pennsylvanians* report to Governor Rendell

In January 2005, Governor Rendell responded to a poor performance rating for the state in a national report commissioned by the Robert Wood Johnson Foundation by appointing a statewide Task Force for Quality at the End of Life. The Task Force was asked to recommend improvements in Pennsylvania's capacity to maintain quality of life of people with serious or advanced illnesses and improve the state's performance on a number of benchmarks for quality end-of-life services.

Institute faculty and staff and members of the Coalition for Quality at the End of Life (CQEL) have worked hard on the Pennsylvania Task Force for Quality at the End of Life, helping to coordinate, author, compile, and edit the Task Force's report to Governor Ed Rendell. The report was released to the Governor on Monday February 5, 2007 in Harrisburg. The State Task Force Report recommends strategies for addressing the needs of people with serious or advanced illnesses, and those who care for them, which have a significant impact on their quality of life. It is intended to accomplish the following:

- 🍂 Create momentum for change at a policy, systems, and grass roots level.
- 🍂 Mobilize stakeholders for action by providing information and pathways toward reform.
- 🍂 Energize local citizen action groups, and provide them with information and motivation to organize and demand change.



Secretary of Aging, Nora Dowd Eisenhower, speaks at the press conference for the release of the report flanked by Institute Director David Barnard (fourth from left) along with other Task Force members (from *Quality at the End of Life Report Released the Secretary's Notes to the Aging Services Network*, Issue 16, February 2007 newsletter accessible at <http://www.aging.state.pa.us/aging/lib/aging/Jan07.pdf>.)

Links to the Report

- 🍂 **Report released to the Press: *Improving End-of-life Experiences for Pennsylvanians*.**
<http://www.aging.state.pa.us/aging/lib/aging/DOA-102forweb.pdf>
- 🍂 **Full Report: *End-of-Life Care in Pennsylvania: Final Report and Recommendations*.**
http://www.aging.state.pa.us/aging/lib/aging/DOA-task_force_long_report_final_2007_2.pdf
- 🍂 **Interview about the report with Institute Director David Barnard in Physicians' News Digest:**
<http://www.physiciansnews.com/spotlight/307pa.htm>

Dr Richard Payne will Deliver a Special Lecture March 19th at the Herberman Conference Center, on Disparities in End-of-Life Care

RICHARD PAYNE, M.D., Director of the Institute on Care at the End of Life at Duke University and internationally known expert on pain relief, palliative care, oncology, and neurology is coming to Pittsburgh. He will be delivering a special lecture, *Disparities in End of Life Care: What Do We Really Know, and What Can We Do?* at the Herberman Conference Center, Cancer Pavillion, adjacent to Shadyside Hospital starting at 5pm. Payne has served on numerous panels and advisory committees, many at the national level. He has given expert testimony to the U.S. Congress and the President's Cancer Panel in the area of healthcare access disparities in cancer care, pain management, palliative medicine, and end-of-life care. Payne now chairs the board of directors of the Foundation for Hospices in Sub-Saharan Africa and sits on the board of directors of the National Hospice and Palliative Care Organization. The Institute is partnering with CQEL, the Center for Minority Health, Jewish Health Care Foundation, United Way, UPMC Cancer Centers, and Vitas Hospice to bring this special guest lecturer to the area. Please RSVP by Thursday, March 15 to 412-623-3651.



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The Institute Presents the Hospice Foundation of America's 14th Annual Teleconference Live-Via Satellite on March 22

The Institute to Enhance Palliative Care is bringing the Hospice Foundation of America's 14th Annual Teleconference *Living With Grief: Before and After the Death* to Pittsburgh live-via satellite. The teleconference will be moderated by Frank Sesno, professor of public policy and communication at George Mason University and special correspondent with CNN. It will explore the most current theoretical perspectives on loss and grief as experienced by persons throughout a life-limiting illness and by survivors after the death. The panel will focus on areas where understandings of grief have been challenged. The program will be useful to range of professionals who provide bereavement counseling or work with the bereaved. The information will also be helpful to individuals who offer education on loss, grief, dying or death.

The teleconference will be held at the Herberman Conference Center #202A adjacent to UPMC Shadyside Hospital's Thursday, March 22, 2007 from 1:30 pm to 4:30 pm with a panel discussion to follow. The program is free of charge. Continuing education contact hours (CEs) will be available for nurses, social workers, clergy, counselors, funeral directors, psychologists, physicians, EMS personnel, EAPs and nursing home administrators for a cost of \$25.

To reserve a place or for more information call 412-578-3666.