

THE HOPKINS HOPKINS HOSPITAL
MEDICAL INTENSIVE CARE UNIT / OSU 117

GOALS OF TREATMENT DECISION AND SUPPORTIVE QUESTIONS

Prepare: meet with staff prior to family mtg. to establish medical facts, and voice
concerns; arrange for a quiet setting; plan for adequate time; determine patient
competence, or appropriate surrogate, assure all appropriate staff and family attend
the meeting.

- What are the team concerns about the situation?
- Are there conflicts among team about patient's treatment, goals of care, etc...
- Are all of the consultant services on board with treatment plan?

Establish what's known by the patient and family.

- Tell us what you understand about the patient's condition?
- What have other doctors told you about your condition?

How to handle information

- What does the patient/family want to know?
- How do you want me to handle information about your illness?
- Some patients want to make all decisions for themselves while others prefer to have someone else make those decisions. How do you want to handle this?

Deliver information

Simple language, sensitively given, give opinion of likelihood of survival if
it is appropriate to the situation. Don't be afraid to say "dying".

- I'm afraid I have some bad news. I wish things were different, but the test results are not good. The test results show X.
- This is what we know about your father's condition right now (give specific details). We are doing X Y and Z. We're doing everything we can but we may find in 48 hours (or other specified time frame) that it is not working.
- Your father's heart (brain, liver, kidneys) are very damaged. If he survives this hospital stay, he will be in a coma, not able to talk to you, etc...
- I feel badly to have to tell you this, but the tests are back and it is not what we hoped for.
- I would not be surprised if [the patient] died within the next month/week/day/hours (use this to communicate prognosis).
- I can't give you an exact time, but in my experience patients with your condition live weeks/months/years to ... weeks/months/years (give ranges)

Respond to emotions

Give time for the information to sink in, silence is appropriate. Verbally recognize emotions (don't ignore the elephant in the room). Touch the family members hand, shoulder if appropriate. Offer water, to call someone if needed.

- I wish the news were different
- What worries you the most?
- Tell me more about how your feeling about what I just said
- Is there anyone you would like me to call?
- I'm sorry to have to tell you this
- I wish things were different, how can we move forward? How can I help?
- You appear to be angry. Can you tell me what you are feeling?

10. I can't make that decision for my loved one to turn off the machines"

Response: "What do you think your brother would have wanted? If he were sitting here right now, what would he say?" Listen. "We will help you with this decision. Patients in your brother's condition usually do not survive. And if they do, they have a long road of recovery ahead with many possible complications (Or, they live their lives, not waking up, in a nursing home etc.) Is this what you think your brother would have wanted?"

11. "If we take the ventilator off my mother, I feel like I would be killing her"

Response: "Would your mother have wanted to be kept alive on a ventilator?" "We understand this is a difficult decision. We will help you honor your mother's wishes to not artificially prolong her life. We will assure her dignity and comfort."

12. "How long will she live?"

Response: "In my experience, considering your mother's disease(s) and the condition she is in right now, I think she may live for a few hours to a few days (or a few days to weeks, weeks to months-give ranges)

Response: "We can hope for the best but we also need to prepare for the worst"

13. "I'm afraid my husband will be in pain"

Response: "We are carefully watching him for signs that he is uncomfortable. He is on X Y Z medications to assure his comfort. Because you know him best, you can help by letting us know if you think he is in pain"

JHH Resources:

Hospital Ethics Committee Beeper: 3-6104

Website with hospital end of life policies:

www.insidehopkinsmedicine.org/cpm/

Pain Management

www.insidehopkinsmedicine.org

then click on ICPM under Policies

Home Hospice Medications

OPD ONC pharmacy 2-1517

Chaplain Office 5-5842

Palliative Consult Service 4-5284

References

End of Life Physician Education Resource Center (EPERC)

www.eperc.mcg.edu

Communication Phases Near the End of Life

Medical College of Wisconsin

Establish care goals and Rx

Determine what is important to the patient and family. Before ending the discussion, affirm what you will be doing for the patient. Characterize Rx in terms of time limited trials-allows Rx to continue while time allows prognosis to become clearer.

- We've talked about what we know at this point. Now lets talk about the future and what we can expect to happen.
- Can we review the overall goals for your care? Do you have an advanced directive? What is most important in your life right now?
- We want to help you live meaningfully in the time you have. What are you expecting?
- What are you hoping for?
- Help me understand what your husband was like before he got sick. What was important to him?
- Sometimes people have conversations with their families about what to do if they get very sick (while watching a television show, visiting a seriously ill friend or relative, etc). Has he ever said anything about how he would want to be treated if he was in that situation and couldn't make decisions for himself?
- Based on everything you know about him, what do you think he would want in this situation?
- What would he tell us if he was sitting here right now?
- If your father should die in spite of our current therapy, do you want us to use heroic measures-to press on the chest and do CPR, to put a tube in his lungs to try to get the heart and breathing started again?
- Don't say: "Do you want us to do everything possible?", "I think we should stop aggressive therapy." Do say, "We need to change the focus to keeping him comfortable. Are there family members who need to see him?"

Establish a plan

- a. to meet agreed upon goals
 - b. more time to evaluate
 - c. time limited trial (be specific on what you are looking for, i.e., signs of improvement or worsening)
 - d. curative/palliative,
 - e. comfort care/palliative.
- We need to do further tests. We will meet again on... to get another update, see if we met the goals we have established, and we can talk better etc...
 - We are looking for his kidneys to start working again, liver studies to improve, etc... If we don't see an improvement in X days, we will need to talk again.
 - We will make sure he is comfortable and continue X Y and Z treatments
 - If we don't see an improvement in X Y Z in one week I would suggest we discontinue the medications maintaining blood pressure
 - Lets discuss what we can do to fulfill your wish to stay at home
 - What can we do for you (the family)? Are we meeting all of your needs? Are we meeting your spiritual needs?

Answering Difficult Questions

1. "We want you to do everything."
Response: "Tell us what you are hoping for your loved one. What are your expectations?" Try to probe this to get concrete information--do they expect pt to get back to work, what kind of life are they expecting pt will have. When presenting treatment options, review the benefits and the burdens of potential treatments.
 "We still want you to do everything to save him." (this after several discussions)
2. **Response:** "We will continue his (abx, blood products, breathing support etc) for the next (x) hours/days and reevaluate his condition at that time. Is there family who needs to see him?"
 "We expect God to work a miracle."
3. **Response:** "We also hope for a miracle. And if God is going to do that, your loved one will show signs of improvement (be specific). But if that does not happen, we will do everything possible to make sure he is comfortable.
 "He's a fighter. He'll pull through this."
4. **Response:** "Tell us what he was like before this event." Listen.
Response: "Did he ever express his wishes to you about what he'd want if he became very sick? Does he have an advance directive?" Explain.
 "He's been brought back from the dead before... recovered from coma... bad infection... survived major surgery... He'll come through this."
5. **Response:** "What was his life like after the surgery, coma etc? This is what he faces now." Then give current clinical picture and how it may differ from previous experience.
 Family does not agree with patient's wishes for no life-sustaining treatment.
Response: "Mr. X has clearly indicated his wishes for no life-sustaining treatment. Please tell us what your concerns are." Follow-up question: "What are you hoping for?"
 "So what CAN you do for my loved one?"
6. **Response:** "Your loved one has not responded to (xyz) therapy as we had hoped. We recommend a focus on keeping him comfortable and having you spend as much time as possible with him. We will do everything possible to assure he is not in pain, not suffering, not restless. We will control his seizures (other ax). Are there other family members who need to be here?"
Response: "Is he dying?"
7. **Response:** "Yes." (if survival is unlikely. Allow time for family response.) "And we are going to do everything possible to make sure he is as comfortable as possible, with his pain, his breathing etc." Or, "He is not actively dying at this time. But he is critically ill. We will need to see how he responds in the next 24 hours (etc.)"
Response: "We don't know yet. Right now we are doing more testing (etc). We need more information on xyz. His chances of surviving are not good (if that is the case, and do not give percentages. The family member will almost always be viewed in the 10% of survivors)."