

RESPONDING TO EMOTION

1. Reflect thoughts, emotions or behavior

- It seems like you are having a hard time deciding between ___ and ___...
- You have been feeling _____...
- I see that you are crying...
- You seem very ...

2. Affirmation & respect

- Thank you for describing your feelings and thoughts.
- I can do a better job as your doctor when I know how you are feeling.
- Please tell me more about the sadness you are feeling.

3. Summarize/paraphrase

- We have been talking for a while about how things are going for you. Let me see if I can summarize what you have said, then you can let me know if I'm on track ...

4. Make a plan

- How can I help? or, What, if anything, would make a difference for you?
- I would like to check in with you next week and see how things are going. In the mean time, please let me know if you need to talk before then.

5. Dealing with Anger

- It sounds like/appears like you are angry?
- You appear angry, can you tell me what is upsetting you?

- So, you are telling me that you are angry about ____, is that correct?
- I wish things were different; how can we move forward? How can I help?

NURSE emotions

- Name the emotion – You sound frustrated.
- Understand – I can not imagine what it is like to be so sick.
- Respect – I really respect your serving as your mom's surrogate.
- Support -- I want you to know that regardless of what happens I will be there for you.
- Explore – Tell me more.

ASK-TELL-ASK

COMMUNICATION PHRASES NEAR THE END OF LIFE

Determining Decision Making Capacity

- Can you explain to me your current condition? What have the doctors told you?
- Tell me the options for treating "X" that we have just discussed.
- Explain to me why you feel that way?

Advance Care Planning

- I'd like to talk with you about possible health care decisions in the future. This is something I do with all my patients so I can be sure that I know and can follow your wishes. Have you ever completed an Advance Directive?

- What do you understand about your health situation? How do you feel things are going?
- If you were unable to make your own medical decisions, who would like to make them for you? Have you spoken to this person?
- If you are very sick and dying, have you thought about what the end would be like or how you would like it to be?
- Have you discussed your wishes with your family? In my experience a real conversation is helpful for your X. When people have not spoken to their loved one, it is very hard for them to be sure what you would have wanted.

Breaking Bad News

- What have you been told about your condition?
- I'm afraid I have some bad news. I wish things were different, but the test results are not good; the (test name) showed X.
- Address emotional reaction - see Responding to Emotion
- I want to be sure you understand what we have talked about; can you summarize for me what we have discussed?
- Write down any questions that come to mind, let's plan to meet again (time/date)..

Quality of Life –phrases that will help you understand the illness's impact

- How has your disease interfered with your daily activities; How are you getting along with family and friends as a result of your illness?
- Have you been feeling worried or sad about your illness?

- What symptoms bother you the most? What concerns you the most?
- How have your religious beliefs been affected by your illness?
- Many patients wonder about the meaning of all this—do you?
- What concerns you the most?
- How have you made sense out of why this is happening to you?
- What could you do that would help you feel that this is a meaningful time for you and your family?
- How do you want to be remembered by those you are close to?

Prognosis

- Tell me how you spend your day; how much time do you spend laying down or resting—is it more or less than 50% of the time; has this changed recently?
- Has anyone talked to you about what to expect? What do you think is ahead?
- Do you have any sense of how much time is left? Is this something you would like to talk about?
- Although I can't give you an exact time, in general, patients with your condition live ___ wks/months to ___ wks/months.
- Based on what you have told me, and what I see, I believe you are dying.

Goal Setting

- Knowing that time is short, what goals do you have for the time you have left—what is important to you? What do you need to do?
- What are your goals for this last phase of your life?
- What would be left undone if you were to die this week?

Talking with Surrogate Decision Makers

- These decisions are very hard; if (patients name) were sitting with us today, what do you think he/she would say?
- Can you tell me why you feel that way?
- How will the decision affect you and other family members?
- I believe that (patients name) is dying.
- I do not want you to feel like you are making medical decisions. That is my job. You can help by telling me what your mom would have wanted if she was here.
- I want you to be able to look back on this six months from now and be sure that you did what your mom would have wanted.

Discussing Artificial Feeding/Hydration

- What do you know about artificial ways to provide food?
- All dying patients lose their interest in eating in the days and weeks leading up to death; this is the body's signal that death is coming.

- I am recommending that the (tube feedings, hydration, etc.) be discontinued (or not started) as these will not improve his/her living; these treatments, if used, may only prolong his/her dying.
- Your (relation) will not suffer; we will do everything necessary to ensure comfort.
- Your (relation) is dying from (disease); he/she is not dying from dehydration or starvation.

Cross-Cultural – Understanding others views of illness

- I know different people have very different ways of understanding----illness...Please----help----me understand how you see things.
- What do you call the problem? Tell me what you think the illness does; What do you think the natural course of the illness is? What do you fear?
- Who do you turn to for help? Who should be involved in decision making?
- How do you think the sickness should be treated? How do you want us to help you?
- Some people like to know everything about their disease and be involved in all decision making. Others do not want all the news and would rather the doctor talk to XX? Which kind of person are you? How involved do you want to be in these decisions?

Discussing Palliative Care or Hospice Referral

- To meet the goals we've discussed (summarize goals) I've asked the Palliative Care Team to visit

with you; they are experts in treating the symptoms you are experiencing. They can help your family deal with the changes brought on by your illness.

- You've told me you want to be as independent and comfortable as possible. Hospice care is the best way I know to help you achieve those goals. Hospice is a program that helps the patient and family achieve the goals you've just described. It's a team of people that help meet the patient's and family's physical, psychological, social and spiritual needs.

Death Pronouncement

- I wish there was more we could have done; I'm very sorry for your loss. This must be very difficult for you; Is there anyone I can call for you?
- In the days and weeks to come, please contact me if I can answer any questions about your (insert relation's name) illness.

DNR ORDERS

Note: only discuss CPR/DNR following a Goal Setting discussion

A. When CPR is not medically indicated **

- You have told me that your goals are _____. With this in mind, I do not recommend the use of artificial or heroic means to keep you alive. If you agree with this, I will write an order in the chart that when you die, no

attempt to resuscitate you will be made. Is this acceptable (ok)?

B. Sustained requests for CPR when it is not medically appropriate/indicated

- What do you know about CPR?
- This decision seems very hard for you. I want to give you the best medical care possible; can you tell me more about your decision?
- What do you expect will happen? What do you think would be done differently, after the resuscitation, that wasn't being done before?
- **NOTE: if you will honor the request for CPR.** I understand your desire for CPR, but I will need some direction if you survive, since you will almost certainly be on a breathing machine in an ICU. It is very likely that you will not be able to make decisions for yourself. Who do you want to make decisions for you? Can you give me some sense of how long we should continue life support if you are not able to make decisions and there is no improvement in your condition.
- **NOTE: if participating in CPR violates your professional judgment.** I understand your desire for CPR, but in my medical judgment, performing CPR would only increase your suffering and not prevent your dying. Although I would like to continue caring for you, I am unwilling to participate in CPR; it may be appropriate for you to find another physician to provide your care.

** Expected death from a chronic life-limiting disease: advanced metastatic cancer with poor and declining functional status, renal failure on dialysis, multi-organ failure; advanced dementia; end stage liver or cardiac disease, etc.

C. When CPR is medically indicated if consistent with patient goals/wishes

We have discussed your current illness. Have you given any thought to how you would like to be cared for at the time of death? Sometimes when people die, or are near death, especially from a sudden illness, life support measures are used to try and 'bring them back', alternatively, we could focus solely on keeping you comfortable. How do you feel about this?

D. Asking about DNR orders without asking about the procedure

Are you the kind of person who--if something horrible happens--would be willing to go through "hell" for a 5% chance of surviving to discharge? Unfortunately, we cannot change the fact you have (underlying disease). Regardless of what we do there will be a 95% chance you will not make it. Because of age or primary disease, some people would want to try for any chance of getting better, while others would not want to go through multiple treatments and ICU for such a low chance of surviving to discharge.

DEALING WITH FAMILIES WHO MAKE DECISIONS YOU THINK ARE WRONG

- A. is the surrogate the correct one?
- B. Does the family understand the prognosis?
 - a. Tell me what others are telling you about your loved one's condition
 - b. Give information consistently, simply and using multiple modalities (print, verbal)

C. Despite understanding, why do they disagree?

a. Dealing with denial

I know how much you were hoping for good news.
I wish things would have worked out different.
I wish there was more that we could do.
This must be devastating for you.

b. Dealing with Guilt

I am not asking you to make the medical decision. I would never ask a family member to make a decision like this for their loved one. I want you to help me understand what your Mom/Dad would have said if s/he was sitting here and understood what we have been talking about.
I can see how hard this is for you. I respect your trying to follow your Dad's wishes even though you would do something different.

c. Dealing with mistrust

d. Hoping for a miracle

Can you tell me more about what a miracle would look like to you?

In addition to a miracle cure, can you tell me what else do you hope for?

- e. Is there a specific concern if you have a child?
- f. Who will you talk to if you have a concern?

OTHER TOPICS/PHRASES

- A. Ask
 - a. How is treatment going for you?
 - b. What concerns you most about your illness?
 - c. As you think about your illness what is the best and the worst that might happen to you?
- B. I know you are hoping for the best. I wonder if you have thought about what we might do if things do not go well.
- C. Spirituality questions
 - a. Is faith(religion/spirituality) important to you in this illness?
 - b. Has faith been important to you in other times in your life?
 - c. Would you like to talk to a religious counselor?
- D. Coping/Social supports
 - a. How have you coped with hard times in the past?
 - b. Who are the most important people in your life now?
 - c. On whom do you depend and confide about your illness?
 - d. How are the important people in your life coping with the illness?
- E. Financial questions
 - a. How much of a concern are financial issues for you?
- F. Ask if the patients have children they care about (or care about them)
 - a. Do you have children at home?
 - b. Tell me about their personalities
 - c. Have you told them about your illness?
 - d. What did you say?

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