

advance care planning

It's all about communication

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think about it. **talk** about it. **share** it.

Foundations for the Conversation

SELF AWARENESS / SELF REFLECTION

- If you were in their position, how might you react or behave?
- What might you be hoping for? Concerned about?
- What do we (the health care team) have to offer and what can the patient / family expect from us as quality care?

INFORMATION / KNOWLEDGE

- Health care providers have a key role in providing information to patients / families about choices.
- Need to ensure that accurate and consistent information is presented by the team.

SETTING THE STAGE

- To minimize distraction, talk in person while sitting down

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Starting the Conversation

- One of the biggest barriers to difficult conversations is how to start them
- Health care professionals sometimes avoid such conversations, for fear of frightening the patient / family or leading them to think there is an ominous problem the health care team is not being open about.
- The topic of Advance Care Planning can be introduced as an important and normal component of any relationship between patients and their health care team.

"It's very helpful for us to understand what is important to you in your care... what your hopes and expectations are, and what you are concerned about."

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Context of Current Circumstances

Seek patient / family understandings about current health status

“How have things been for you in the time leading to this admission?”

“What is your understanding of your current health?”

“When you think about the future, what is most important to you?”

*“It is helpful when patients and families share their thoughts about treatments they would or would not want as part of their care.
What are your thoughts?”*

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Starting the Conversation - Connecting

There are a couple of considerations that can be useful when connecting to people about health care scenerios and initiating the discussions. Remember:

- Most people facing serious illness have concerns about what lies ahead, how the illness will unfold, how it will affect them, and what can be done about it
- Most people living with potentially life-threatening illness have times where their mind wanders to the scary “what-if” places (what if the chemotherapy doesn’t work; what if he’s not able to get off the ventilator; etc.)

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Starting the Conversation – Sample Scripts 1

“I’d like to talk to you about how things are going with your condition, and about some of the treatments that we’re doing or might be available.

“It would be very helpful for us to understand what is important to you in your care, what your hopes and expectations are, and what you are concerned about. “

Can we talk about that now?”

(assuming the answer is “yes”)

“Many people who are living with an illness such as yours have thought about what they would want done if [fill in the scenario] were to happen, and how they would want their health care team to approach that.”

“Have you thought about this for yourself?”

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Starting the Conversation – Sample Scripts 2

“I know it’s been a difficult time recently, with a lot happening.

“I realize you’re hoping that what’s being done will turn this around, and things will start to improve. We’re hoping for the same thing, and doing everything we can to make that happen. ”

“Many people in such situations find their mind wanders to some scary ‘what-if’ thoughts, such as what if the treatments don’t have the effect that we hoped?”

“Is this something you’ve experienced? Can we talk about that now?”

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“DON’T TELL HIM... It will take away hope and he’ll just give up”

- Sometimes families want to block information from being shared with the patient, even when the patient is competent.
- Consider helping family understand how that takes away any opportunity for closure, such as saying goodbye and tidying up loose ends in life.
- Ultimately, the patient has the right to accept or decline information. Not everyone wants to know all details; some will defer to family.

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CHECKING WITH THE PATIENT.

How much information they want to know

- The competent patient has final say about how much they want to know. Some would rather defer to family, particularly if it includes health care professionals

Sample Script

“As you know, we’ve been doing some tests to look into the symptoms you’ve been experiencing. Those results are starting to come in now.

We’ve found that some people want to know everything about their illness, such as results, prognosis and what to expect. Others don’t want to know very much at all, perhaps having their family more involved.

How involved would you like to be regarding information and decisions about your illness?”

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Pacing Information – Titrating to Effect

- Information can be sensitively paced in the conversation, by titrating increasingly focused details as determined by the response of patient/family.
- This is much like titrating a medication to effect, with the intended outcome being the sharing of information with patient/family in an honest yet compassionate manner.

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Pacing Information – Titrating to Effect

EXAMPLE.... 56 yr male, smoker, seen in office a few days after Emergency Dept. visit for productive cough, weight loss. Chest XRay shows large lung tumour, almost certainly a primary CA

“I’ve asked you to come in so that we can go over some test results from your visit to Emergency.”

“There is an area on the XRay which is very concerning.”

“On the left lung there is a shadow, which is thought to be due to a growth, or tumour.”

“Although we would need more tests to be sure, this has the appearance of a lung cancer.”

NOTE

Simply being asked to come in is already the first bit of information that this is something serious. The second clue will be the demeanor and body language of the physician.

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Pacing Information – Titrating to Effect

- In the example provided, the information was consistently honest, yet increasingly direct and blunt.
- At any point during the process there may be indication that the patient fully understands the message, at which point next steps can be discussed.

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Helping Family And Other Substitute Decision Makers

- Rather than asking family what they would want done for their loved one, ask what their loved one would want for themselves if they were able to say.
- This spares the family from a very difficult responsibility by placing the ownership of the decision where it should be: with the patient.
- The family is the messenger of the patient's wishes, based on their intimate knowledge of him / her. They are merely conveying what they feel the patient would say rather than deciding about their care .

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Helping Family And Other Substitute Decision Makers

EXAMPLE

“If he could come to the bedside as healthy as he was a month ago, and look at the situation for himself now, what would he tell us to do?”

OR

“If you had in your pocket a note from him telling you what to do under these circumstances, what would it say?”

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Helping Family And Other Substitute Decision Makers

- In situations where death will be an inescapable outcome, family may nonetheless feel that their choices about care are life-and-death decisions (treating infections, hydrating, tube feeding, etc.)

It may be helpful to say something such as:

“I know you’re being asked to make some very difficult choices about care, and it must feel that you’re having to make life-and-death decisions.”

“You must remember that this is not a survivable condition, and none of the choices you make can change that outcome. ”

“We are asking for guidance about how we can ensure that we provide the kind of care that he would have wanted at this time.”

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An Approach To Decision Making

- The health care team has a key role in providing information related to technical or medical issues...
 - reviewing/explaining details about the condition, test results, or helping explore treatment options
 - indicating when a hoped-for outcome or treatment option is not medically possible
- Patient / family must have a central role in considerations relating to their value / belief systems (such as whether life is worth living with a certain disability) or to experiential outcomes (such as energy, well-being, quality of life)

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Goal-Focused Approach To Decision Making

- Treatment goals can either be **physiological** (e.g. measurable clinical outcomes such as blood tests, scan results) or **experiential** (i.e. outcomes that the patient will experience such as well-being, quality of life, energy)

There are 3 main categories of potential interventions:

- Essentially certain to be effective in achieving intended physiological goals, and consistent with standard of medical care
- Virtually certain to be ineffective in achieving intended physiological goals (such as CPR in the context of relentless and progressive multisystem failure) or inconsistent with standard of medical care
- Uncertain potential to achieve physiological goals, or the hoped-for goals are not physiological/clinical but are experiential

GOAL-FOCUSED APPROACH TO DECISIONS

GOALS UNACHIEVABLE, OR INCONSISTENT WITH STANDARD OF MEDICAL CARE

DISCUSS

Explain that the intervention will not be offered or attempted.

PROVIDE a process for conflict resolution, if needed:

- Mediated discussion
- 2nd medical opinion
- Ethics consultation
- Transfer of care to a setting/ providers willing to pursue the intervention

UNCERTAIN ABOUT OUTCOME, OR GOALS ARE NOT PHYSIOLOGICAL BUT EXPERIENTIAL

CONSIDER therapeutic trial, with the following:

- Clearly-defined target outcomes
- Agreed-upon time frame
- Plan of action if ineffective

GOALS ACHIEVABLE AND CONSISTENT WITH STANDARD OF MEDICAL CARE

PROCEED if desired by patient or substitute decision maker

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EVOLVING CONVERSATION

Discussions about **goals of care evolve** through the course of a person's illness and are shaped by the context of the current situation

Re-visited over time or as **things change**

The entire health care team has an important role in **guiding goals of care** discussions

Advance care planning ultimately ensures that we are all on **the same page** in providing quality care!

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YOU ARE NOT ALONE!



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