

7 STEP PROTOCOL TO NEGOTIATE GOALS OF CARE

For many physicians, negotiating goals of care with patients and families who are facing the end of the patient's life can be difficult, particularly when there is a conflict between aspirations and what is medically likely or possible. To have a greater chance of achieving a successful outcome, physicians might use the following modification of the 6-step protocol for communicating bad news (see Module 2: Communicating Bad News).

1. Create the right setting

- Sit down
- Assure privacy and time

2. First, determine what the patient/family know

- Clarify the current situation
- Understand the context in which decisions about goals of care should be made
- For example...
 - If the patient thinks he or she has indigestion and the physician thinks it is life-threatening myocardial infarction
 - The determination of goals of care will have to wait until there is agreement on the clinical situation

3. Ask how much the patient/family want to know and discuss with you

- If they do not want to discuss goals of care, determine whom you should talk to
- Some patients and families will ask the physician to decide
- When there is time, try to engage them in the decision-making process rather than provide them with answers

4. Explore what they are expecting or hoping for

- Focus on what you will do to help them achieve those goals
- As appropriate, identify those things that you can't do, either because they will not help achieve the goals or because they are not possible

5. Suggest realistic goals

- As the physician brings a wealth of scientific knowledge about the patient's illness, its natural course, the experience of patients in similar circumstances, and the effects that contemporary health care may have, this must be shared to assist with decision-making
- Suggest realistic goals (e.g., comfort, peace, closure, loving care, withdrawal of interventions, etc) and how they can be achieved
- Work through unreasonable or unrealistic expectations

6. Respond empathically to the emotions that may arise

7. Make a plan and follow through

Identifying Goals to Hope For: False Hope May Deflect from Other Important Issues

- One of the chief obstacles to negotiating goals of care in the face of life-threatening illness and poor prognosis is the issue of hope (the feeling that what is wanted will happen)
- Unfortunately, this false sense of hope may deflect the patient and family from finding final meaning and value, and closing their lives together

- At a time when people most need closeness, the collusion of a lie may serve to push them apart. When surveyed, most Americans said they would rather know the truth about their illness
- All physicians would agree that a positive attitude and a sense of hopefulness should be maintained throughout the course of an illness

True skill to help find hope for realistic goals

- The true skill of the physician is in his or her ability to help patients and families find hope for realistic goals, which can change with time
- Some physicians find it useful to frame discussions using words like:
 - Everyone hopes to win the lottery, but it's not appropriate to plan your life as if you are going to win the lottery
 - We can hope for the best, but we also need to plan for the worst

Cultural Considerations

- Cultural differences may require the physician to modify his or her approach to determining goals for care
- Some cultures prefer that medical information, particularly that of a life-threatening prognosis, be given to the family and not the patient
- Among other cultures (e.g., some Navajos), it is not good to raise a negative prospect at all
 - Moving the conversation to the third person may circumvent this:
 - "If you were hearing a story about someone who was facing an illness that could not be cured...how would you want that story to describe how best that person could be helped?"
- As cultural generalizations may not apply to given individuals, it may be a useful approach to ask the patient early on in the relationship
 - How he or she would like information to be handled and who should be making decisions
 - It may be useful for this conversation to take place in the context of a **family meeting so that all can hear the same information** (see Module 2: Communicating Bad News and Module 13: Cultural Issues)

Communicating Prognosis: Tendency to Overestimate Prognosis

- Patients and families rely on physicians for answers to 2 fundamental questions when they seek medical care:
 - "What is wrong with me?" and "What will happen to me?"
- Prognostication is never easy
 - Studies suggest that evidence-based prognostication does not explain customary medical practice
 - Even when physicians refer patients for hospice care, they tend to **markedly overestimate prognosis**
 - Consequently, patients live for only days or weeks once referred to home hospice care, rather than the months of life that the physician thought remained
 - In the SUPPORT study, physicians tended to make significant errors in both directions (overestimates and underestimates) when predicting the lifespan for patients in the ICU

Understanding Helps Coping and Planning

- Prognosis is crucial to patients and families for several reasons
- Most importantly, an understanding of what might happen helps them to cope, respond, and plan for their future
- Without reasonable information about what the future is likely to bring, patients and families may choose treatments they would otherwise decline, and miss important opportunities for growth and life closure
- Knowing that life is likely to be short may open opportunities for increased support from the health care system (e.g., they may be eligible for the Medicare Hospice Benefit if the patient's prognosis is less than 6 months)

Ways of Communicating Prognosis

- Consider offering a range that encompasses average life expectancy (e.g., hours to days, days to weeks, weeks to months, or months to years)

- Alternatively, consider offering averages: "People with your (your child's) illness circumstances can live for a long or a short time. About half live for about 3 months"
- There is a lot variation for the other half: Some find it is best to plan for little time, and hope for more time

Use of Language: Language with unintended consequences

- Well-intentioned physicians may say things that will have unintended consequences
- What the listeners understand may be quite different from what the physician intended
- Some examples of questions that can have unintended consequences include:
 - Do you want us to do everything possible?
 - Will you agree to discontinue care?
 - We'll refrain from extraordinary measures?
 - It's time we talk about pulling back?
 - I think we should stop aggressive therapy
 - I'm going to make it so he won't suffer
- The unintended message of these statements may easily be that the patient and family expect imminent abandonment and see only a stark choice between aggressive curative intent and giving up

Language to Describe Goals of Care

- In order to prevent unintended consequences, it is useful to develop facility with language that reinforces the goals of appropriate medical care for someone with advanced progressive illness and a life-threatening prognosis
- Some examples include:
 - I want to give the best care possible until the day your child dies
 - We will concentrate on improving the quality of your life
 - We want to help you live meaningfully in the time that you have
 - I'll do everything I can to help you maintain your independence
 - I want to ensure that your father receives the kind of treatment he wants
 - Your child's comfort and dignity will be my top priority
 - I will focus my efforts on treating your child's symptoms
 - Let's discuss what we can do to fulfill your wish to stay at home

Setting Goals and Priorities for Treatment and Care

Clarify Goals and Treatment Priorities

- The patient's goals for care should guide the therapies and care that patients and families choose and receive
- In addition to helping them to establish overall goals, physicians can assist patients and families to clarify priorities for treatments and care as they negotiate an initial plan of care together
- Subsequently, whenever the patient's goals (or parents' when the patient is a child) are uncertain or might be expected to change, goals and treatment priorities should again be clarified
- Review is recommended at several types of juncture:
 - Significant change in health status (e.g., worsening prognosis or unexpected recovery)
 - Change in life expectancy (e.g., advanced age or serious life-threatening illness)
 - Change in setting of care (e.g., from hospital to nursing home or vice versa)
 - Change in treatment preferences (e.g., decide to discontinue dialysis or other therapies)
- If the prognosis allows you to delay this conversation, give the patient time to acclimatize
- With a little time to settle, patients are more likely to again stabilize their goals and priorities

Determining Priorities for Treatment and Care

- Once overall goals have been determined, the physician can help the patient (or parents if the patient is a child) to determine his or her priorities for treatment and care
- Priorities should be based on individual patient values and preferences as guided by specific clinical circumstances
- Priorities will be influenced by information from the physician and other health care professionals
- The physician will want to describe the possible priorities and be open to the feasibility of others

- Values and preferences will be elicited and clarified through physician-patient discussions
- Questions that can be used to elicit patients' values and goals for medical care at the end of life:
 - What are you expecting?
 - What do you most want to accomplish?
 - What is most important in your life right now?
 - What are you hoping for?
 - What do you hope to avoid?
 - What do you think will happen?
 - What are you afraid will happen?
 - What do you expect the end to be like?
- Examples of patient values and preferences:
 - No matter what happens, I want us to stay at home, No more hospitals
 - I'm worried what all of this will cost my family
 - What I fear most is pain
 - I would like to be alert and aware as long as possible
 - I just hope I have time to finish my memoirs
 - If I live to see my daughter married, I'll die happy
 - When death comes, I want my family around me
 - I don't want my wife to have to quit her job to take care of me
 - My wish is never to be hooked up to machines
 - It's important to me to live as long as possible, and to go out fighting
 - It is important to me to try everything there is to cure my child
 - I don't want my child hooked up to machines

When the Physician Cannot Support the Patient's Choices

- Typically occurs when goals are unreasonable, illegal
- Set limits without implying abandonment
- Make the conflict explicit
- Try to find an alternate solution

Example of Physician Responses:

"I understand that your first priority is to live as long as possible by having a heart transplant. Unfortunately, I'm not able to do that because of your other health problems. Is there an alternative way that I can help you achieve your goal of living as long as possible?" or "I understand your goal is not to be a burden to your family and you would like me to assist you to die. Unfortunately, I cannot do that. Is there an alternative way that I can help you so that you will not be a burden?" More intractable differences are addressed elsewhere. .

Decision-Making Capacity

- Decision-making capacity implies the ability to understand and make medical decisions for oneself
- Occasionally, patient choices that are unsupportable suggest that he or she is losing decision-making capacity
 - Reassess your patient if this seems possible
 - Any physician can determine, does not require a psychiatrist or a court ruling
- Patient with decision-making capacity must:
 - Understand information
 - Use the information rationally
 - Appreciate the consequences
 - Come to a reasonable decision for him/her
- Capacity varies by decision
- Other cognitive abilities do not need to be intact

When a Patient Lacks Decision-Making Capacity

- When patients lack the capacity to express their own values and preferences for medical care, others must determine goals

- Proxy decision-maker should be sought to help clarify the patient's goals and consent to specific care plans
- Appropriate proxy is a person selected in advance for this role by the patient (see Module 1: Advance Care Planning), or a person who has knowledge of the patient's values and preferences and is willing and able to serve in this capacity
- When the patient has not preselected a proxy decision-maker, this usually falls to the next-of-kin. Legal criteria for proxy selection vary from state to state (see Module 15: Legal Issues).
- Sources of information: taken together this information will allow an assessment of what the patient would have judged (i.e., a substituted judgment)
- Written advance directives
 - Patient's verbal statements
 - Patient's general values and beliefs
 - How patient lived his/her life
 - Best interest determinations

- The physician should guide the proxy/surrogate in understanding his or her role in determining what the patient would have wanted based on available information
- Where information is lacking, it becomes necessary to try to determine what would be in the best interest of the patient
- This is often, but not always, the same conclusion and often errs more toward life prolongation
- Why is this process helpful:
 - Respects patient
 - Builds trust that the health care team is acting in the best interest of the patient
 - Reduces guilt and decision regret

- Practical ways to elicit patient values and preferences in discussions with proxy decision-makers:
 - Help me to understand what your husband was like before he got sick. What was most important to him?
 - Has he ever said anything about how he would want to be treated if he could no longer make decisions for himself?
 - What would he say in this situation?
 - Do you have any other family members or friends who have experienced serious illness? Did he or she express how he or she would want to be treated in that situation?
 - Based on everything you know about him, what do you think he would have wanted in this situation?

- Many of the approaches that work for an advance care planning discussion also work for establishing immediate goals of care, whether working with the patient or a proxy
 - In particular, it can help to go through a worksheet again, using predrafted scenarios, goals, and treatment options, prior to returning to the situation at hand
 - Often clarity and perspective return with this exercise for getting a broad perspective and allow a comfortable settling into current goals

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