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Abstract

There are many possible goals of medical care, from prevention, to cure, to prolongation of life, to achieving a good death. No one goal is inherently more valid than another, and multiple goals may apply simultaneously. In general, attempts to reverse illness or restore health can be pursued at the same time as efforts to relieve suffering and improve quality of life. Specific clinical skills are needed for negotiating care goals. The physician must be able to identify what is reasonable for the patient to hope for, to adjust according to the patient’s culture, to convey prognosis even with all its uncertainty, to use appropriate language, to set limits if necessary, and to manage care even when the patient lacks decision-making capacity.

Key words

culture, decision making, goals of care, hope, hospice, incapacity, language, limit setting, palliative care, prognosis, quality of life, treatment priorities, uncertainty

Objectives

The objectives of this module are to:

• understand different goals and how they interrelate and change
• understand how to use the 7-step protocol to negotiate goals of care
• be able to communicate prognosis and its uncertainty
• understand how to tell the truth and identify reasonable hope
• be able to use language effectively
• be able to set limits on unreasonable goals
• be able to adjust care and communication according to culture
• understand how to identify goals when patients lack capacity

Clinical case on trigger tape

The patient is Ben Worth, an 80-year-old former schoolteacher. It has been 4 years since he was diagnosed with Alzheimer’s disease. He has lived in a nursing home for the last 6 months. At his current baseline, he is confused and sometimes agitated. His speech is repetitive and mainly nonsensical. He is dependent for all his activities of daily living. Yesterday, he developed fever and lethargy and was transferred to the hospital. The admitting diagnosis was pneumonia. The physician, who met Mr Worth and his wife only yesterday, has a discussion with Mrs Worth about the goals for Mr Worth’s medical care.
**Introduction**

Every one of us has a sense of who we are, what we try to do, how we determine and relate to events in our lives, and what we hope for. Over time, we have developed a very personal sense of what brings greatest meaning and value, and adds most to the quality of our lives. The daily choices we make are based on our experiences and the goals and expectations we have for our future. Over the course of our lives, these change.

At one time or another during our lives, most of us will confront significant illness and the possibility that we will die. When this occurs, we will make choices for our care based on our diagnosis and prognosis, the potential benefits and risks associated with various therapies, and our personal priorities. In doing so, we will have a very personal sense of how aggressive we would like our physicians to be in addressing our illness, our priorities for treatment, and what things we would like to do both in the outside world and personally.

Over time and in different circumstances, our goals for care, our treatment priorities, and the things we would like to achieve will likely change. Most of us will get upset if our expectations for treatment are not met. Most of us will become angry and lose trust if things are done to us that we do not want.

Our patients and their families also have very personal hopes and goals for their lives. As they confront life-threatening illness, they may start by hoping that nothing is wrong, that the diagnosis is not true. As they realize the full meaning of the illness, most patients will hope for a cure and long life. As each patient realizes that the illness will take his or her life, most will shift to hope for the absence of suffering and a good death. As their hopes change, so will their goals for care and their priorities for treatment. Each trajectory of changing goals is unique.

Before developing or negotiating any plan of care, a physician must clarify patient and family goals for care and current treatment priorities. Regular review of these goals and priorities can help the patient, family, physician, and health care team to strive for the same outcomes, and avoid missing divergent expectations or providing unwanted therapies.

This module presents an approach for eliciting a patient’s goals for care (or parents’ goals when the patient is a child) and clarifying his or her treatment priorities. While it focuses on patients who are nearing the end of their lives, the process can be used at any time during a person’s illness.

**Potential goals of care**

Since the beginning of medicine, there have been 2 overall aims of care: to cure disease and to relieve suffering. Within these are numerous possible goals for health care, including complete cure, avoidance of premature death, maintenance or improvement in function, prolongation of life, relief of various types of suffering, improvement of quality
of life, preservation of control, a good death, and support for families and loved ones. No one goal is inherently more valid than another; all are legitimate goals of medicine and each will be applied differently by the individual in his or her particular circumstances.

**Historically, a dichotomous division of goals of care**

While the primary goal of medicine in the last century was to provide comfort, in the latter half of the 20th century there have been significant developments in science and technology. In the fight against illness and death, modern medicine has focused primarily on curing illness and prolonging life as it has fought aggressively against death. In the process, less attention has been paid to the management of symptoms, the relief of suffering or care of the dying.

In the 1960s and 1970s, the hospice and palliative care movements were born in the United Kingdom, the United States, and Canada to fill a growing void and provide care for the dying. Historically, hospice in the United States has been primarily restricted by the Medicare hospice benefit to the last 6 months of a person’s life, and programs have tended to serve only patients with cancer when cure was no longer possible. More recently, hospice and palliative care programs have been evolving into medical practices and programs that focus on relieving suffering and improving quality of life for patients with a broader range of prognoses.

Figure 1 below shows the division between goals of care if medical decision making occurs in a dichotomous way where the focus is first on therapies with a curative intent, and only when they are no longer effective does the intent shift to relief of suffering.
Figure 1: A dichotomous intent

This figure is representative of the current situation driven by the Medicare hospice benefit where prognosis must be six months or less and patients must agree to forego any therapy with a curative intent before they can avail themselves of this benefit. However, many patients, families, and professionals are not prepared to give up therapies aimed at cure and life-prolongation in order to focus totally on relief of suffering. Consequently, an unintended consequence of the original legislation is that the majority of dying Americans are never referred to hospice programs.

Moreover, studies show that patients with life-threatening illnesses, and their families, will experience multiple symptoms and have ongoing needs for psychological, social, spiritual, and practical support throughout their illness.

Why should the relief of suffering not be pursued at the same time as cure and life-prolongation? Do not wait to focus on the relief of suffering until all attempts at cure have been exhausted or the patient and family plead for such efforts to stop. With earlier access to symptom management and supportive care, patients and families may feel better, continue more of their normal lifestyle, and maintain more capacity to fight their illness and sustain treatment.
Multiple goals of care

As patients and families experience life-threatening illness, several aspects become apparent to the observant clinician:

**Multiple goals apply simultaneously.** Although goals may seem to stretch along a continuum in a linear fashion, in fact the patient and physician may seek both disease control and symptom palliation together. They may not consider a therapeutic intervention (eg, chemotherapy), unless it addresses both goals. In clinical practice this is more the rule than the exception.

**Goals may be contradictory.** A patient may want prolongation of life as the overriding goal but also insist that nothing should be done that increases discomfort. The physician knows, however, that treatments aimed at curing disease, such as a surgical operation or chemotherapy, may unintentionally cause temporary or permanent functional deterioration and suffering. It is the physician’s role to help the patient and family understand the balance between the benefits and burdens of a particular treatment.

**For a particular patient, some goals take priority over others.** Over the course of a lifetime, or the course of an illness, the relative weight given to each goal may change in response to numerous factors. It is only in the context of an individual’s life that an adequate balance of goals can be achieved. Clinical decisions routinely require prioritization among potentially contradictory goals. Such tradeoffs are an inevitable part of medical care.

Goals may change

As patients approach the end of their lives, goals of care and treatment priorities frequently change:

**Some goals take precedence over others.** As a patient’s prognosis and health status worsen, the goals of prevention, cure, or avoidance of death may become less important as they become less possible. At the same time, the goals of maintaining function, relieving suffering, and optimizing quality of life may become the focus of care.

**Ideally, this shift in focus of care is gradual.** It is usually negotiated over time. An abrupt transition from primarily curative care to primarily palliative care is rarely appropriate.

**The shift in goals is an expected part of the continuum of medical care.** Changes occur throughout the patient’s life and illness. The physician plays a key role during all phases of the continuum. In all situations, the nature and course of the illness, and the patient’s and family’s goals for care, should determine the relative emphasis on cure vs palliation.

**When the dying patient is a child.** It is often particularly hard for the parents and family to shift away from their hopes for cure. The realization that the disease will take their
child’s life may come quite late for many parents. Consequently, the pattern for changing goals of care can be somewhat different than when the patient is an adult. To help parents prepare, the physician will want to explicitly include a goal of comfort along with the goal of cure from the beginning of treatment planning. In other words, curative and palliative treatments can coexist from the time of presentation. When curative goals are no longer appropriate, this strategy permits some aspects of the treatment plan to continue until death, rather than necessitating a change from one goal to another with its implications for abandonment and “giving up hope.”

**Primary Emphases of Care for Those With Different Goals Related to Life-Threatening Illness or Injury**

<table>
<thead>
<tr>
<th>Aspect of Care</th>
<th>Curative</th>
<th>Life-Prolonging, Palliative</th>
<th>Symptomatic Palliative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on disease</td>
<td>Eradicate</td>
<td>Arrest progression</td>
<td>Avoid complications</td>
</tr>
<tr>
<td>Acceptable adverse effects</td>
<td>Major</td>
<td>Major-moderate</td>
<td>Minor-none</td>
</tr>
<tr>
<td>Psychological attitude</td>
<td>“Win”</td>
<td>“Fight”</td>
<td>“Accept”</td>
</tr>
<tr>
<td>Preference for CPR</td>
<td>Yes</td>
<td>Probably</td>
<td>Probably not</td>
</tr>
<tr>
<td>Hospice candidate</td>
<td>No</td>
<td>No</td>
<td>Probably</td>
</tr>
<tr>
<td>Symptom prevention/relief</td>
<td>Secondary</td>
<td>Balanced</td>
<td>Primary</td>
</tr>
<tr>
<td>Support for family</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Advance care planning</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Bereavement support</td>
<td>Not usually</td>
<td>Sometimes</td>
<td>Usually</td>
</tr>
</tbody>
</table>


The concurrent integration of goals of care (rather than a dichotomous approach) can be particularly important for progressive illnesses that will be predictably fatal. Medical treatment for most illnesses will only change the natural course of the disease and prolong life, but not provide a cure (eg, for most cancers, AIDS, chronic obstructive pulmonary disease, congestive heart failure, diabetes, renal failure, etc).
In contrast to the previous dichotomous model of care, Figure 2 below shows how the relief of suffering can integrate into the continuum of care desired and needed by the patient and family during an illness.

**Figure 2: The interrelationship of therapies with curative and palliative intent**

Initially, more focus may be on therapies intended to cure the illness or prolong life. Later, the relief of suffering may become increasingly important or even the total focus of care. But therapies with a palliative intent are not an alternative, to or an abrupt change from, the preceding care plan.

To redress the tendency to dichotomize curative and palliative care, many palliative care programs are striving to expand the availability of services. By doing so, the interdisciplinary care focused on symptom control and supportive care so well provided by hospice programs can be available to all patients with any life-threatening diagnosis, at any time during their illness when they have symptom control or supportive care needs, and are prepared to accept such care.
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. Ensure privacy and time.

2. **First, determine what the patient/family know.** Clarify the current situation and 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. **Explore what they are expecting or hoping for.** Focus on what you will do to achieve those expectations and hopes. As appropriate, identify those things that you cannot do, perhaps because they will not help achieve the goals or because they are not possible.

4. **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. After sharing this information, 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.

5. **Respond empathically** to the emotions that may arise.

6. **Make a plan and follow through.**

7. **Review and revise periodically, as appropriate.**

Negotiating goals across communication barriers

**Communicating prognosis**

As part of the decision-making process to determine the goals for their care, patients and families rely on physicians for answers to 2 fundamental questions: “What is wrong with me?” and “What will happen to me?” In the case where the patient is a child, parents want to know: “What is wrong with my child?” and “What will happen to my child?”

The issue of 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. Secondarily, knowing that life is likely
to be short may open opportunities for increased support from the health care system (eg, they may be eligible for the Medicare hospice benefit if the patient’s prognosis is less than 6 months).

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 seem to markedly overestimate prognosis in that 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.

A number of ways of communicating prognosis have been developed (see Module 2: Communicating Bad News). Consider offering a range that encompasses average life expectancy (eg, hours to days, days to weeks, weeks to months, or months to years). Alternatively, consider offering averages: “People with your 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.”

**Truth-telling and maintaining hope**

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). Hippocrates stated, and Osler continued to advocate for the medical convention that physicians should express hope to the patient and family that the patient will enjoy a full recovery from the current illness, even if it is not true. This principle has been mistakenly taken so far as to administer treatments that are known to be ineffective, all in the service of maintaining hope.

However, when surveyed, most Americans said they would rather know the truth about their illness. Unfortunately, a 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.

Physicians agree that a positive attitude and a sense of hopefulness should be maintained throughout the course of an illness. To achieve this end, some find it useful to frame discussions using words like:

- we can hope for the best, but we also need to plan for the worst

Whatever approach, 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.
Language with unintended consequences

In any physician-patient communication, 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 that may be significantly misinterpreted by patients 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.

From each of these statements, the patient and family may interpret the unintended message that they are about to be abandoned. As a result, they may see only a stark choice between aggressive curative care and giving up.

Language to describe the 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.
- Let’s discuss what we can do to have your child die at home.

Cultural differences

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. Families may insist on this. Among other cultures (eg, 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 the best way to help?” As cultural generalizations often do 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 patient’s disposition (see Module 2: Communicating Bad News).

**Determine specific treatment priorities**

Once overall goals have been determined, the physician can help the patient, proxy, or parent to discuss the priorities for specific treatment and care approaches. 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 (see Module 1: Advance Care Planning, and Module 2: Communicating Bad News).

Here are some examples of 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 values and preferences that may be expressed by patients include:

- 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.

Reviewing goals and specific treatment priorities

Whenever the patient’s, proxy’s, or parent’s goals are uncertain or might be expected to change, goals and treatment priorities should again be clarified.

Review is recommended at several types of juncture:

• when patients have a significant change in their health status (eg, additional diagnosis, worsening prognosis or unexpected recovery)
• when a patient realizes they have a limited life expectancy (eg, advanced age or serious life-threatening illness)
• with a change in the setting of care (eg, from hospital to nursing home or vice versa)
• with a change in the patient’s treatment preferences (eg, decide to discontinue dialysis or other therapies).

If the prognosis allows you to delay this conversation, give the patient time to acclimatize to his or her new circumstances. With a little time to settle, patients are more likely to again stabilize their goals and priorities.

When the physician cannot support a patient’s choices

Occasionally, the physician will be confronted with a situation where the patient, proxy, or parent has goals and treatment priorities that the physician cannot support. Typically, this occurs when goals are unreasonable or illegal. The challenge for the physician is to set limits on what he or she will do, without implying abandonment or destroying the relationship of trust and loyalty that has developed.

If this situation occurs, it is generally more useful to make the conflict explicit and then offer to help find a solution. For example, “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 (see Module 1: Advance Care Planning; Module 5: Physician-Assisted Suicide; and Module 9: Medical Futility).

**Reassess decision-making capacity**

Occasionally, choices that are unsupportable suggest that the patient is losing decision-making capacity. Reassess your patient if this seems possible.

Decision-making capacity implies the ability to understand and make medical decisions for oneself. It can usually be determined by any physician. It does not require a psychiatrist or a court ruling. For a patient to have decision-making capacity, he or she must be able to understand the information, use it in rational ways to come to a decision, appreciate the consequences of the decision, and have that be a reasonable decision for him or her. For example, consider a man who refuses an amputation of a gangrenous leg. He needs to demonstrate that he understands the information about the condition and the options for care, that he could die if it is not amputated, and that this is a rational decision for him. The patient can meet criteria for decision-making capacity for a particular treatment (decision-specific capacity), and yet not be competent to handle his or her practical, financial, and legal affairs. Further, decision-making capacity may vary depending on the treatment decision (see Module 3: Whole Patient Assessment, and Plenary 2: Legal Issues).

**When a patient lacks capacity**

When patients lack the capacity to express their own values and preferences for medical care, goals must be determined by others. For patients who lack decision-making capacity, a proxy decision maker should be sought to help clarify the patient’s goals and consent to specific care plans.

Generally, the 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. For children, this role almost always falls to the parents. For adults, 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 Plenary 2: Legal Issues).

The physician should guide the proxy/decision maker to understand 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.

To the extent that they are known, the patient’s values and preferences should be used to determine the goals of care. Written advance directives, the patient’s verbal statements, his or her general values and beliefs, and how the patient lived his or her life can all be useful. Together they allow an assessment of what the patient would have judged (ie, a
substituted judgment). Fundamentally, the process demonstrates respect for the patient, and builds trust that the physician and the health care team are acting in the interests of the patient. Further, by focusing on the wishes of the patient, there is reduced guilt or decision regret for the proxy, family members, the physician, and the health care team.

Here are some 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.

**Summary**

In summary, it is important to determine the goals of care with patients and families from as early a stage as possible in the course of serious or chronic illness. The patient, with the help of the family, determines the goals with guidance from the physician and the health care team. Hospice and palliative care goals can be integrated with other goals, which may appropriately change over time. A 7-step approach to negotiating goals has been offered, along with suggestions for identifying reasonable hope, for adjusting care to the patient’s culture, for setting limits when goals are unreasonable, for helpful language that avoids unintended communication of abandonment, and for handling goal choices when the patient is no longer competent to decide.
Key take-home points

1. Everyone has a personal sense of what brings greatest meaning and value, and adds most to the quality of our lives.

2. As we confront significant illness and the possibility that we will die, we will each make choices for care based on our diagnosis, prognosis, the potential benefits, burdens, and risks association with various therapies, and our personal priorities.

3. Over time, our goals for care and treatment priorities will change.

Potential goals of care

4. There are 2 overall aims of medical care: to cure disease and to relieve suffering. More personal and specific goals also exist within these overall aims.

5. Many physicians have been trained to focus on diagnosis and treatment of the patient’s disease by using a medical problem-oriented method. They have not been trained to pay attention to relief of symptoms and other issues that heighten patient suffering as an explicit goal of medical care.

The interrelationship among goals of care

6. Many patients, families, and professionals are not prepared to give up therapies aimed at cure and/or life prolongation, and totally focus on relief of suffering.

7. Early access to symptom management and supportive care may help patients and families feel better, continue more of their normal lifestyle, and maintain more capacity to fight their illness and sustain treatment.

8. Multiple goals may apply simultaneously.

9. Goals may appear to be contradictory.

10. Some goals take priority over others.

11. Goals may change near the end of life.

7-step protocol to negotiate goals of care

12. Create the right setting.

13. Find out what the patient/family know.

14. Find out how much they want to know.

15. Explore what they are expecting or hoping for.

16. Suggest realistic goals.

17. Respond empathically.

18. Make a plan.
Identify goals to hope for

19. When surveyed, most Americans (>80%) said they would rather know the truth about their illness.

Cultural differences

20. Some cultures prefer that medical information, particularly that of a life-threatening prognosis, be given to the family and not the patient.

Communicating prognosis

21. Physicians tend to markedly overestimate prognosis. Consequently, they tend to refer patients to hospice much too late.

Clarify goals and treatment priorities

22. In addition to helping patients and families establish overall goals for care, assist them to clarify priorities for treatments and care.

23. Review goals when patients have a significant change in their health status, have limited life expectancy, change their setting of care, or change their treatment preferences.

24. If the physician cannot support the patient’s choices, it is generally more useful to make the conflict explicit and then offer to help find an alternate solution.

When a patient lacks capacity

25. When a patient lacks the capacity to express his or her own values and preferences for medical care, goals must be determined by a proxy decision maker based on either the patient’s previously expressed preferences, or what would be in the best interest of the patient if expressed preferences are lacking.

Pearls

1. No one goal is inherently more valid than another.

2. Set goals before determining treatment plan.

3. Ask early in the relationship how the patient would like to handle information sharing.

4. Always expect hopefulness—the object of hope changes with time.
Potential pitfalls

1. Failure to discuss expectations.
2. Giving unwanted interventions. Most of us will become angry and lose trust if things are done to use that we do not want.
3. Thinking that the “problem-oriented” approach is the same as setting goals.
4. Failure to refer to hospice or palliative care programs. The majority of Americans (80%) are never referred to hospice or palliative care programs.
5. Language with unintended consequences.
6. Offering a false sense of hope. The collusion of a lie may only push patients and families apart.
7. Excessively optimistic estimates of prognosis.

Resources


