MiPCT Palliative Care Webinar: *Leading a Family Goal Setting Meeting*

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Continuing Education Credit

- To receive continuing education credit for the Leading Goals of Care
  - Attend the live web based webinar on September 10, 2014 from 12p-1p.
  - Complete the electronic evaluation form including your contact information provided immediately following the presentation.
  - Your certificate of completion will be emailed to you
  - Continuing education credits can not be issued to those that do not attend the live webinar.

Purpose and Intended Audience

- Program is intended for physicians, nurses and other healthcare professionals to enhance their understanding and provide information to lead a family goal setting meeting.

Objectives

- Describe a 10 step approach to a family goal-setting meeting.
- List three reasons for clinician-family conflict over end-of-life goals.
- Describe two approaches to resolving conflicts over end-of-life goals.

Disclosure Statement of Financial Interest

- I, David Weissman, MD

Have reported no relevant conflict of interest for the purpose of the MiPCT Webinar, Palliative Care-Leading Goals of Care

Goals of Care

- Physical, social, spiritual or other patient-centered goals that arise following an informed discussion of the current disease(s), prognosis, and treatment options.
  - *Improved pain control*
  - *Attend family event in six weeks*
  - *No further hospitalizations*
  - *Travel to visit relative*

When?

- Routine outpatient visit, chronic life-limiting disease
  - Difficult to schedule sufficient time for thorough discussion
  - Difficult to anticipate all possible scenarios
- Time of crisis
  - Worst possible time to make difficult decisions.

The Patient-Family Meeting

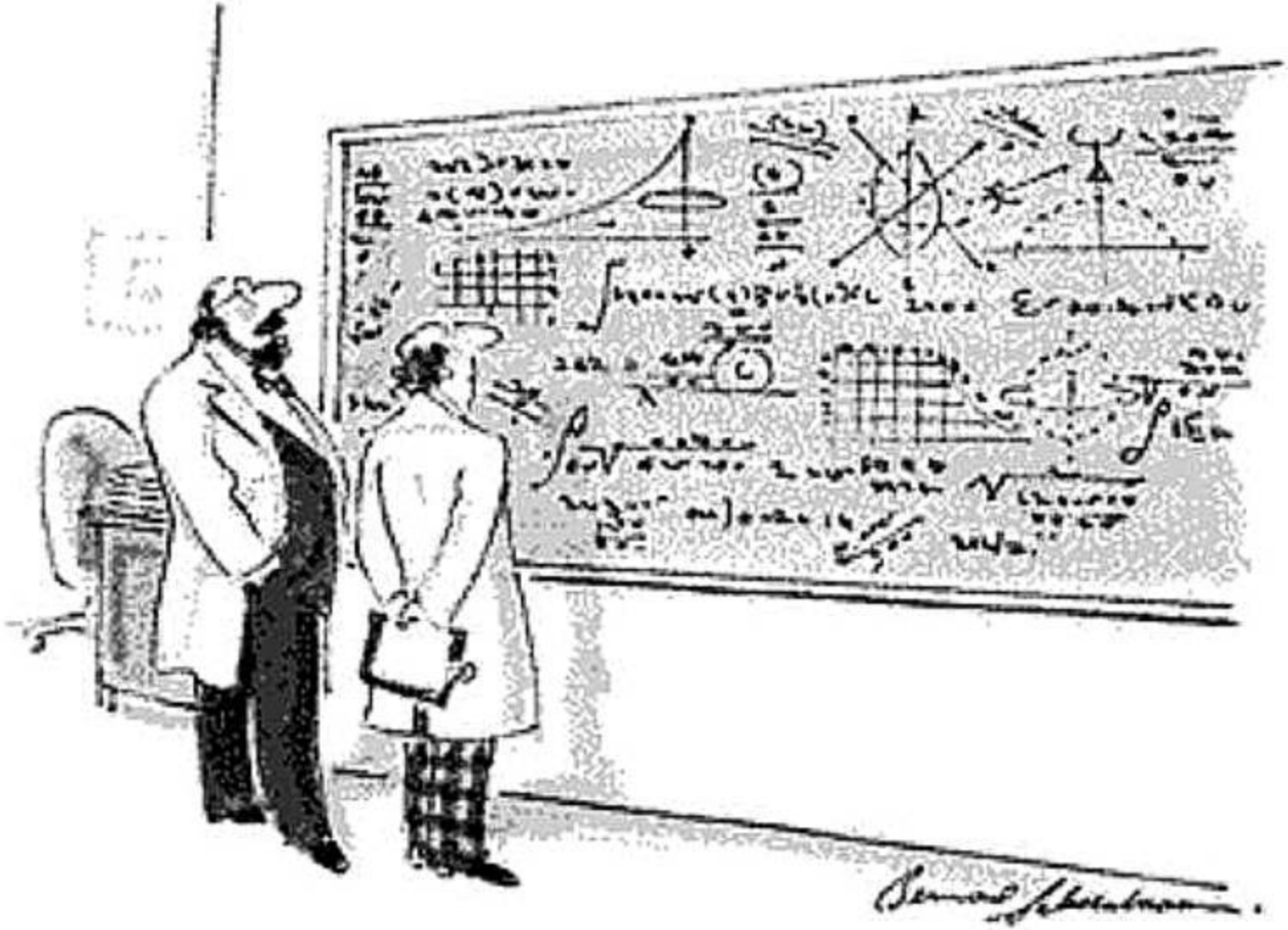
- Opportunity for shared-decision making process in establishing goals near the end of life
  - Patients/Surrogates want an opportunity to discuss the *Big Picture*
  - *Primary Palliative Care:* Core Skill
  - *Specialist Palliative Care*: difficult situations
    - Pt-Family-Clinician conflict
    - Uncertain outcomes

Meeting leadership

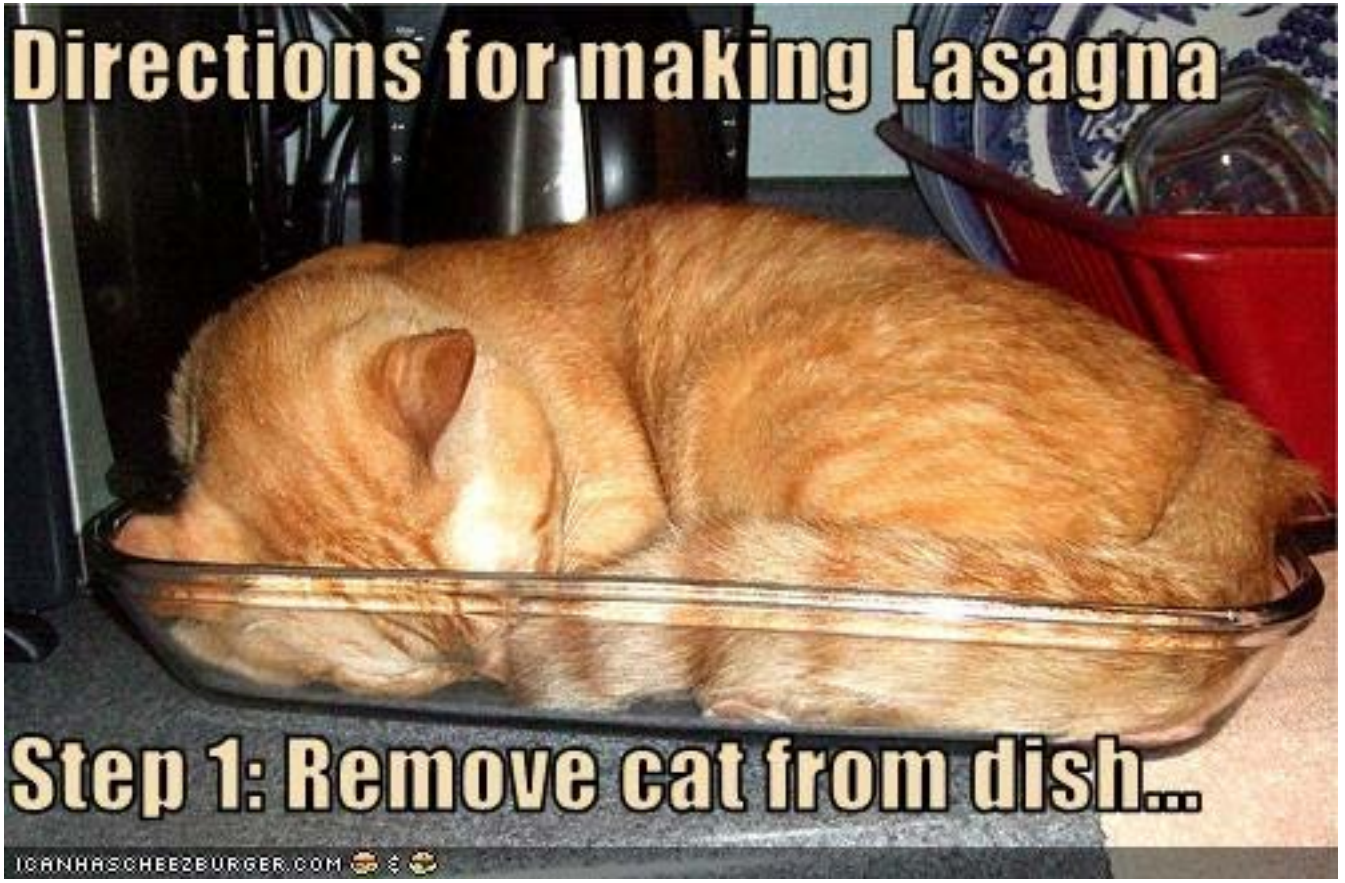
- A ‘team sport’ to include physician, nursing, social service, and chaplains, as dictated by the clinical situation.
- Skill set necessary for successful outcome
  - Group facilitation skills
  - Counseling/emotional reactivity skills
  - Knowledge of medical and prognostic information
  - Willingness to provide leadership in decision-making

Summary of Key Steps

1. Pre-meeting planning
2. Proper environment
3. Introductions/Build relationship
4. What does the patient/family know?
5. Medical review
6. Silence, respond to emotions
7. Present options
8. Manage conflict
9. Transform goals into a medical plan
10. Summarize and document



"Oh, if only it were so simple."


Directions for making Lasagna
Step 1: Remove cat from dish...
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1. Pre-Meeting Planning

- Review medical history/treatment options/prognostic information
- Coordinate medical opinions between consultants/primary physicians
- Obtain patient/family psychosocial data from care team members
- Review Advance Care Planning Documents:
  - ✓ Surrogate designation
  - ✓ Special instructions

What is medically appropriate?

- Based on the current medical facts, what current and future medical interventions (tests, procedures, drugs, etc.) are likely to improve, or not, the patient's current condition:
  - ✓ **Function**
  - ✓ **Quality**
  - ✓ **Time**

2. Environment

Choose a Proper Environment

- Quiet, comfortable, chairs in a circle
- Invite participants to sit down

When a participant is not sitting, what is the message??

3. Introductions: *Build Relationship*

- Introduce yourself, have participants identify themselves and their relationship to patient
- Review your goals; ask family if these are the same or different from their goals
  - *What other issues are you hoping to review today?*
- Establish ground rules
  - Everyone can talk
  - Limit interruptions

- Build relationship
  - For patients with whom you have no established relationship, it is important to quickly build trust.
  - For patients, or families, ask a non-medical question:

"I know about Mr. Jones' illness, but I was wondering if you can tell me something more about him as a person, what were his hobbies?"

4. What is known?

- Make no assumptions; Determine what the patient/family already knows?
  - *What do you understand about your condition?*
  - *What have the doctors told you?*
  - *How do you feel things are going?*
- *Chronic Illness: tell me how things have been going for the past 3-6 months—what changes have you noticed?*

5. Medical Review

- Present medical information succinctly.
  - Present the big picture
  - Speak slowly, deliberately, clearly
  - No medical jargon

    “your cancer is growing, there is no further chemotherapy which can halt the spread of cancer, based on your declining function and weight loss, I believe you are dying”.

    “this is your third hospitalization for COPD this year, my sense is that overall, your function is getting worse, you are not able to do as much”.

6. Silence, Respond to Emotions

- Allow silence, give patient/family time to react and ask questions.
- Acknowledge and validate reactions prior to any further discussion.
- Invite questions.
- One of three scenarios usually emerge:
  - Acceptance
  - Uncertainty
  - Non-acceptance

When there is *acceptance…*

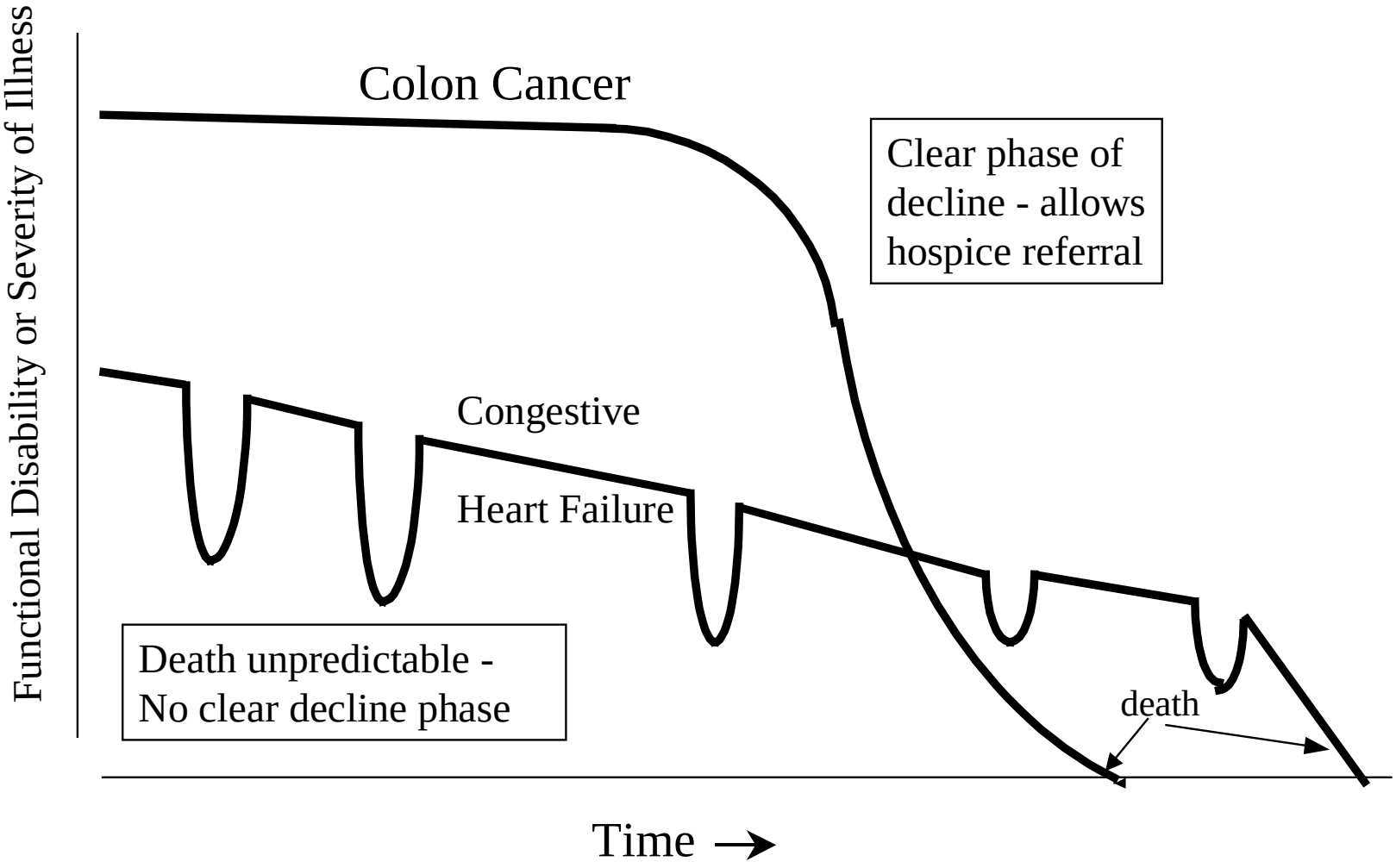
- All patients/families ask, or are thinking of, these questions:
  - *How much time?*
  - *What will happen?*
    - *Will there be suffering?*
  - *What do I (we) do now?*

7. When there is uncertainty

- There are generally two broad care options:
  - A. Continue aggressive care aimed at restoring function.
  - B. Withdrawal of some or all life-sustaining treatments.

To help patients and families arrive at a decision, the most critical piece of information is often your prognostic estimation.

Illness Impact Trajectory*



Prognostication

- Answering *"how long do I have?"*
  - Confirm that information is desired:

    "is something you would like me to address"
  - If you have a good sense of the prognosis, provide honest information using ranges.

    "In general, patients with your condition live anywhere from a few weeks to 2-3 months"

    "its very hard to say with your illness (COPD), but my best estimate is that you have less than one year, and death could come suddenly, with little warning".
  - Address emotional reaction.

Prognostication

- What if patients don't ask about their prognosis?
  - It is difficult set goals if the issue of *how much time*, is not addressed. Patients can be prompted by asking them: *"has anyone talked to you about time?"*
    - If yes—ask what they were told; if their estimate is close to yours, confirm this; if not, tell them your estimate.
    - If no—ask if they would like to discuss—see prior slide.

Making Recommendations

- Patients and families want the clinician to help them make decisions.
- Yet, clinicians are fearful of making recommendations:
  - introducing personal bias
  - bad outcome leading to malpractice claim
  - paternalism
    - Distorted concept of patient autonomy

Get at the patient's "voice"

- When the patient is not able to participate:
  - Bring a copy of their Advance Directive to the meeting
  - Ask the family: *"if your father were sitting here, what would he say"*

When acceptance is absent …

- *What are you trying to tell me?*
- *How can you be sure?*
- *I want a second opinion.*
- *There must be some mistake.*
- *I (we) will never give up.*
- *I have a strong faith that things will get better.*

What goes through your mind when you hear these comments?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Conflict

- When you hear conflict *(How can you be sure?)*, think **emotion**, rather than assume a problem of factual understanding.
  - Clarify any factual misunderstanding.
- Make an empathic statement ..
  - *This must be very hard.*
  - *You have fought really hard for a long time.*
  - *I can't imagine how hard this must be for you.*

Communication has nothing to do with what you say and everything to do with what the other person hears.

Anon

8. Managing Conflicts

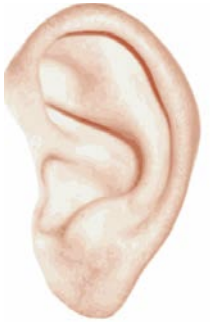
- Conflict surrounding care decisions, as patients near the end of life, are very common.
  - This is a time of emotional turmoil, uncertainty, and fear—among both the patient/family and the health care team.
  - Conflicts provide information.

Managing Conflict

1. Recognize conflict
2. Listen
3. Listen to yourself
4. Identify causality
5. Reconcile
6. Summarize/Document

1. Recognize Conflict

- Not every conflict will be recognized by visible anger: Look/Listen
  - Body language
    - Facial expression
    - Posture



  - Choice of words
    - Mute
    - Cynical
    - Insensitive

Recognize Conflict

- Interactions
  - How individuals are relating to others
- Inability to make decisions
- Decisional instability
- Clinician reactions--**Listen** to your body:
  - Fight or Flight reaction
  - Anger/Frustration
  - Anxiety

Name the Problem

- Avoidance is a natural defense when in conflicted situations—but usually not the best strategy.
- Naming the problem, out loud, is an effective means of starting a meaningful dialog among the conflicted parties.

It seems like you are very angry, can you talk about what is making you angry?

2. Listen

- **In conflict, the angry person needs to:**
  - Vent-Be Heard
  - Get the listener's attention.
  - Be understood

Anger

- Anger is often an expression of fear...
  - fear of loss/abandonment
  - fear of the unknown
  - fear of death

3. Listen to Yourself

- Conflict makes us uneasy, we may feel under attack; our natural inclination is to become defensive, which will only worsen the conflict.

4. Identify Causality

- Conflicts emerge due to issues that are:
  - internal to the patient/family
  - due to patient/family-health care provider interactions
  - both

The Patient/Family

- Common sources of conflict
  - Lack of accurate information
  - Guilt/Fear
  - Grief/Time
  - Lack of trust
  - Cultural/Religious conflict
  - Dysfunctional family system
  - Health Care team issues

The Health Care Team

- We are frequent contributors to conflict situations when ...
  - we provide inaccurate prognostic information
  - we push families to make life/death decisions without providing a recommendation
  - we use our personal cultural/religious beliefs to influence decisions
  - we use our fear of malpractice as an excuse to “do everything”
  - we are too specialized, with no single advocate in charge of patient care.

5. Reconcile

- Reconciliation—the process by which a mutually agreeable solution to the conflict is found.
  - Remember, acceptance of dying is a *process*; it occurs at different times for different family members.
  - Remember, a sudden illness or illness in a young person makes acceptance of dying more difficult for everyone.
  - Remember, prior family conflicts, especially concerning alcohol, drugs or abusive relationships, make decisions very hard to achieve.

Reconcile

- Provide leadership
  - Make clear recommendations based on your knowledge and experience
- Remember the patient
  - Conflicts often occur when the patient is unable to speak for themselves
  - We reflexively want to please the family, but this is not always in the patient's best interest
- Accept the limits of your own influence
  - You will not be able to "fix" severely dysfunctional families, nor change deeply held cultural values that conflict with your desired outcome.

Moving forward …

- Ensure that everyone has the same medical information; information should be clear and unambiguous
- Ensure that a relationship of trust exists between the doctor and family
  - without trust, there can be no basis for shared decision making.

Moving forward …

- Establish a time-limited trial
  - *Let's continue full aggressive support for another 72 hours, if there is no improvement in _____, lets meet again and re-discuss the options*.
  - Clearly define the elements of improvement: e.g. mentation, oxygenation, renal function, etc.
- Schedule a follow up meeting
- Other options
  - Palliative care consultation
  - Ethics consult
  - Involvement of other mediators (e.g. personal minister)

When reason/time fails …

- ✓ Major psychiatric diagnosis?
- ✓ Unresolvable cultural/religious differences?

- Professional duty to the patient vs. maintenance of autonomy.
  - Invoke futility policy (if available)
  - Transfer care
  - Accede to “unreasonable demands”

9. Translate goals into a plan

We have discussed that time is short. Knowing that, what is important to you… What do you need/want to do in the time you have left?

Typical responses

- Home; Family; Comfort
- Upcoming life events (e.g. wedding anniversary)

Translate goals into a plan

- Mutually decide with the patient on the steps necessary to achieve the stated goals.
- Common issues that need discussion include some or all of the following:
  - Future hospitalizations or ICU
  - Diagnostic tests
  - DNR status
  - Artificial hydration/nutrition
  - Antibiotics or blood products
  - Home support (Home Hospice) or placement

When trying to decide among the various treatment options, a good rule of thumb is that if the test or procedure will not help toward meeting the stated goals, then it should be discontinued, or not started.

10. Summarize and Document

- Summarize areas of consensus and disagreement
- Caution against unexpected outcomes—the dying patient does not always die!
- Provide continuity
- Document in the medical record
  - Who was present, what was decided, what are the next steps
- Discuss results w/ other allied health professionals not present

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References

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