

5.2 Goals of Care

Key Points

1. Helping patients identify, express, and achieve their Goals of Care is a key role for the physician. Aids include reviewing sources of personal meaning, convening family conferences, and considering hospice and palliative care.
2. Open discussion is the key to helping choose the best pathway for the patient.
 - Review the current clinical condition with the patient as an introduction to identifying, prioritizing, and setting Goals of Care.
 - Discuss Goals of Care (medical, social, emotional, and spiritual) in the context of the prognosis. If it is true, say something like, “This is an illness that man cannot cure” to steer the conversation to Goals of Care other than cure.
 - The physician may propose as Goals of Care better symptom control, improvement of function, care at home, time with family and friends, and avoidance of unwanted and potentially burdensome interventions.
 - Respond to unrealistic or illegal goals by making the conflict explicit, setting limits without implying abandonment, and offering to assist in other ways.
3. Truth-telling is crucial at Life’s End. Honesty allows patients and families to understand the seriousness of the situation so that they can address important issues they might otherwise neglect. In discussing prognosis:
 - Acknowledge uncertainty and pace the conversation;
 - Use a range of time to predict life expectancy;
 - Choose language carefully to avoid unintended meanings.

Never say:

 - “to withdraw care”
 - “There is nothing left to do.”
 - “I think it is time to stop aggressive care.”
 - “I am asking you to agree to stop care.”
 - “Do you still want us to do everything?”

Instead, say:

 - “We will always care for you (your loved one).”
 - “Sometimes the burden of therapy outweighs the benefit.”
4. Focusing on the possible in the face of the impossible can help patients and providers find meaning, hope, and satisfaction in the midst of broken situations.

Goals of Care



The Palliative Response

Goals of Care Parameters

Who?

- Helping patients identify, express, and achieve their Goals of Care is a key role for the physician

Why?

- Defining Goals of Care can help patient, family, and medical providers choose wisely among the options for medical care

When?

- Goals of Care change over time and must be reassessed

Communication about Goals

Language

- Physician must use language carefully to communicate and work together effectively with patients

Patient-centered goal setting

- Goals are often multiple and even contradictory
- Physician can help patient identify, prioritize, and achieve Goals of Care

Exploring Patient's Sense of Meaning

- Who am I?
- What are my roles?
- What do I like and dislike?
- What do I hope for?
- What gives me joy or meaning?
- What do I fear?

Open Discussion Is Vital

Importance of open discussion that may be outside of the routine physician-patient discussion

- Understand what is important to the patient
- Build trust
- Identify sources of support
- Key to helping choose the best pathway for the patient

Review Current Clinical Condition

- Ask patient to describe understanding of illness and treatment plan

Always a good idea

Even though physician may have already stated diagnosis and prognosis

- Restate the key healthcare issues, especially if:

Time has elapsed since last discussion

New people are part of the discussion

Discussing Goals in Context of Prognosis

State the truth

- If it is true, it is good to say something like...
"This is an illness man cannot cure"
- Advantage of this statement
Humble
Leaves open the possibility of the miraculous
Clear language
Helps steer the conversation to Goals of Care other than cure

Possible Goals of Care

Medical

- Cure of disease
- Good Quality of Life
- Maximum quantity of life
- Improvement of function
- Better symptom control
- Sense of personal control

Possible Goals of Care

Social-Emotional-Spiritual

- Location of care other than hospital or nursing home
- Support for family and loved ones
- Making memories with friends and family
- Creating a legacy
- "Taking care of business"
- "Getting things in order"
- Reconciliation—making peace

Palliative Care

Ideal for Complex Goals

- Interdisciplinary
- Symptom-focused
- Access to maximum support not always available in settings of treatment
Hospital
Home
Nursing home

Truth-Telling

- Prognostication is hard
Physicians typically overestimate survival
- Honesty is important at Life's End
Allows patients and families to understand seriousness of situation
Fosters addressing, rather than neglecting, important issues
- Offer both honesty and hope
Skilled clinician can be honest while helping find hope for realistic Goals of Care

Discussing Prognosis

- Acknowledge uncertainty
Explain that unexpected events can change prognosis
Offer to be honest and inform patients of changes in status as they wish
- Pace the conversation
Allow people time to respond
Be led by desire for information and ability to process it

Discussing Life Expectancy

Best to use a range of time when making a prognosis:

Hours to days
Days to weeks
Weeks to months
Months to years

The Palliative Response

Avoiding Unintended Meanings

Choice of Language

- We will always care for you (your loved one)
- Sometimes the burden of a therapy outweighs the benefit
- Never say...
Withdraw care
There is nothing left to do
I think it is time to stop aggressive care
I am asking you to agree to stop care
Do you still want us to do everything?

Suggesting Goals of Care

- Better control of symptoms
- Care at home when appropriate
- Time with family and friends
- Avoidance of unwanted and potentially burdensome treatments/interventions
- Improvement in function

Aids to Suggesting Goals of Care

- Review sources of personal meaning
Identify goals
Prioritize goals
Choose goals
- Convene a family conference
Can help resolve differences in Goals of Care between patient, family, and providers
- Consider hospice/palliative care
May provide resources to achieve goals

When Goals Are Unrealistic or Illegal

- Make the conflict explicit
*I understand that you want to live alone...
But I cannot send you to an unsafe place*
- Set limits without implying abandonment
*I understand that you were hoping to have surgery to remove the tumor...
But the surgeons are saying it is not physically possible*
Are there other ways we can help you with this problem?

Goals of Care

Reframe and Foster Hope

Focusing on the possible in the face of the impossible can help patients and providers find meaning, hope, and satisfaction in the midst of broken situations.

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Selected Readings

Overview of Palliative Goals

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Goals Regarding Site of Death

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