

End of Life Series
**Discussing End
of Life Care**

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Objectives

- Discuss American's view of end of life care.
- Explain how to prepare for an end of life discussion.
- Identify how to discover patient's goals of care.
- Explain how to discuss advance directives.

American's view of End of Life...

- Findings from a 1999 National Opinion Study for National Hospice Foundation...
 - Americans are reluctant to speak to a terminally ill parent about death and the need for end of life care
 - 1 in 4 not likely to talk with a terminally ill parent about their impending death

American's view of End of Life...

- Findings...(continued)
 - Americans are not willing to contemplate their own end of life care needs
 - 24% put in writing how they want to be cared for
 - 36% have told someone how they would want to be cared for
 - 19% have not thought about end of life care

American's view of End of Life...

- Findings...(continued)
- People 45 and over have a very limited understanding of hospice.
 - 20% do not know meaning of the term
 - 12% describe it as care for the dying
 - 2% mention pain relief
 - 7% mention support for the patient and family

Before the Initial Meeting

- Do your home work
 - Is there a living will, healthcare surrogate, DNRO on the chart?
 - Review progress notes - is the family aware end of life care will be discussed with the patient?

The Initial Meeting

- If appropriate contact the family to set an appointment for this discussion with the patient.
 - Intent is emotional support
 - Family may be the decision maker

Listen Carefully

- Listen carefully to family
- BEWARE
 - Don't tell him he is dying...
 - He will just give up if he knows...
 - I am his "decision maker"...
 - Don't talk to him until I get there...

Tips for the Family...

- Be a good listener.
- Keep in mind this is a conversation not a debate.
- Listen for the wants and needs of the patient.
- Show empathy and respect by addressing these needs and wants in a truthful and open way.

Tips for the Family

- Make it clear that the information to be discussed is important.
- Acknowledge the patient's rights to make life choices - even if you don't agree with them.

Provide information to family

- Remember confidentiality.
- Explain patient's rights.
- Explain legality of living wills
- Explain the duty of healthcare surrogate.
- Explain how competency to make health care decisions is determined.
- Explain your intent to the family.

Select an appropriate setting

- Not a spur of the moment discussion.
- Quiet comfortable place free of distraction.
- During conversation remember to focus on maintaining a warm and caring manner throughout the conversation.
- Use nonverbal communication to offer support.

Meeting with the Patient and Family...

- "Tell me what your physician has told you about your illness."
- Remember denial is a wonderful defense mechanism - more may have been said - to the patient or the family.
- Stick with the facts during your discussion.
- Build the conversation from the information the patient acknowledges.

Meeting with the Patient and Family

- Identify patient's goals of care
 - "What do you hope for as you live with this condition?"
 - "What do you fear?"
 - "If you were to suddenly die soon, what would be left undone in your life?"
 - "How are you and your family coping with your condition?"
 - Arrange care to meet the patient's priorities

Hospice Care...

- This may be the appropriate time to discuss the expertise of Hospice.
- Review patient's priorities and explain how hospice can address their concerns - or have hospice on hand to address patient's/ family concerns.

Hospice Care...

- Expertise in Pain and Symptom Management.
- Expertise in assisting patient and their family in coping with patient's condition.
- Bereavement if appropriate.
- Expertise in assisting patients with their unfinished business.

Hospice Care...

- Hospice care is focused on Patient/ family comfort and dignity.
- Hospice care is tailored to the patient's needs and wishes.
- Hospice services are available 24 hours a day, 7 days a week, 365 days a year.

Meeting with the Patient and Family

- If patient's goals seem unrealistic try:
 - "Tell me what you know about other people who have had this condition."
 - "Tell me what you know about this disease."
 - Never say, "do you want everything done?"
 - Never say, "there is nothing more to be done."
 - Talk instead about life to be lived and what CAN make it better or more comfortable

How to Discuss Advance Directives...

- Try -- "I would like to talk about how you would like to be cared for."
- Explain that the goal is to make everyone aware of the kind of care they would like so that we can respect and honor their wishes.

How to Discuss Advance Directives...

- Try - "If sometime you were unable to speak for yourself, who should speak for you about health care matters?"
 - Does this person know about this responsibility?
 - Does he or she know what you want?
 - What would you want?
 - Have you written this down?

How to Discuss Advance Directives...

- Assist the patient in preparing or obtaining the needed documents if necessary.
 - Living Will
 - Healthcare Surrogate, Durable Power of Attorney
 - DNRO

Reflections...

- End of Life Care is difficult to discuss and is best discussed prior to a crisis.
- Discussing end of life choices does not indicate a medical failure.
- Failure is the act of failing to offer relief in suffering.
 - Physical
 - Psychological
 - Spiritual

Reflections

- Death is an undeniable, unavoidable part of life.
- It can be a time of personal growth, of reconciliation or even self discovery.
- Terminally ill patients hope that we will relieve their suffering and help them to discover that their lives do in fact have meaning and value.

Summary of Objectives

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