End of Life Issues in Stroke

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Conflict Disclosure Information

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- No potential conflicts of interest to disclose

Objectives

- Define palliative care and hospice care
- How to identifying patients who would benefit from palliative care and hospice
- How to help patients express their goals of care
- Discuss stroke specific end of life issues

What inspires me to provide end of life care?

- "To cure sometimes, to relieve often, to comfort always."

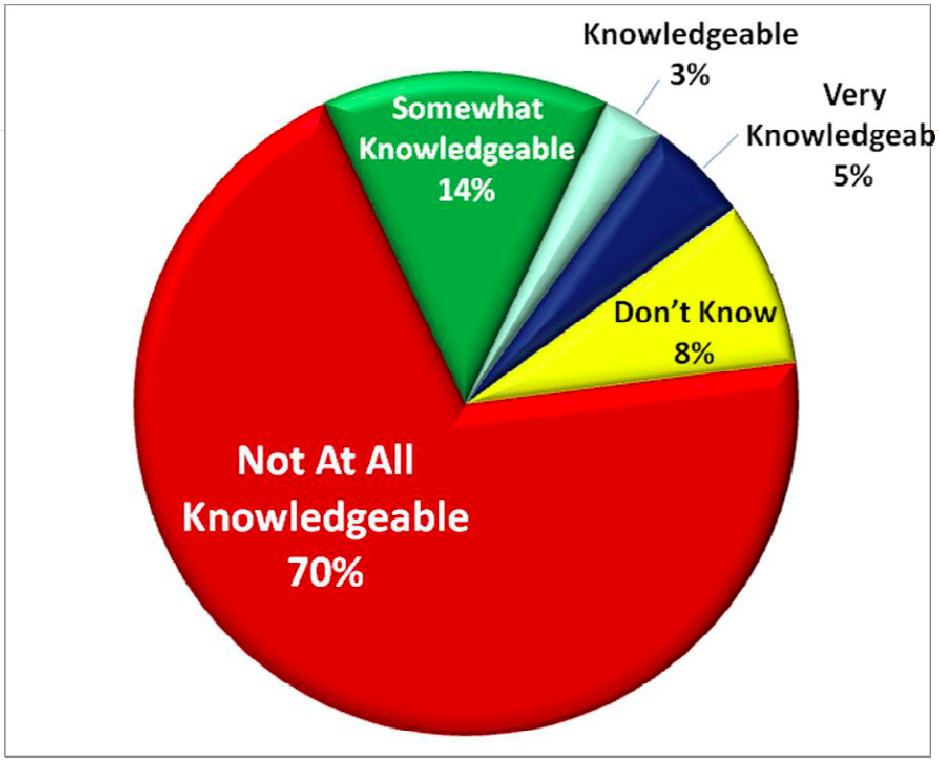
- There is always something that we can do.

- If we define death as failure, we will always fail.

Laughter is good for you.
Drip and Ship?

What is Palliative Care?

- Research confirms palliative care is a relative unknown among consumers. There is a clear need to inform consumers about palliative care and provide them with a definition of palliative care.



•Data from a Public Opinion Strategies national survey of 800 adults age 18+ conducted in June 2011

What is Palliative Care?

- Specialized medical care for people with serious illnesses.
- Focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - **whatever the diagnosis**.
- The overall goal is to improve quality of life for both the patient and their family.
- Provided by a team including physicians, nurses, and other specialists who work with a patient's other physicians to provide an extra layer of support.
- Appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment

What is Hospice?

- A program designed to provide palliative care for some patients at home when life expectancy is six months or less
- Covered by Medicare and Medicaid
- Covered by private insurance plans with enhanced home care benefits (Some of which have broader coverage than Medicare)

Medicare Hospice Key Points

- Patients certified as terminally ill with a life expectancy of **less than six months** may elect to receive hospice care.
- A multi-disciplinary team collaborates with patient and family to provide hospice care.
- Hospice services include medical equipment and supplies, medication for pain and symptom-control, grief counseling and bereavement support.
- Hospice benefits cover hospital services for short-term symptom-control and temporary respite care to relieve family caregivers. They do not cover curative treatments or extensive evaluations inconsistent with the hospice approach.

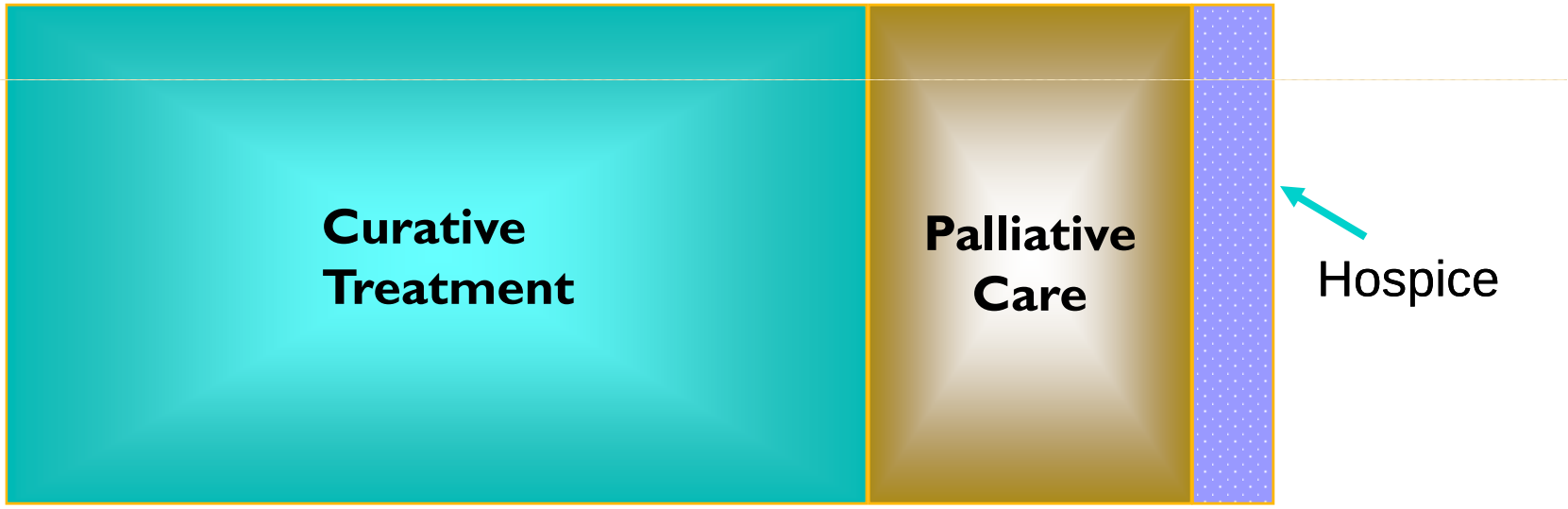
Medicare Hospice Key Points

- Medicare continues to cover treatment for conditions other than the terminal illness.
- Patients, initially certified for two 90-day periods, may be re-certified for an unlimited number of 60-day periods if the condition is still terminal with life expectancy within six months.
- Discharge from hospice occurs if prognosis improves or if patient wishes to seek curative treatment. Patient may be readmitted if becomes eligible due to declining health.

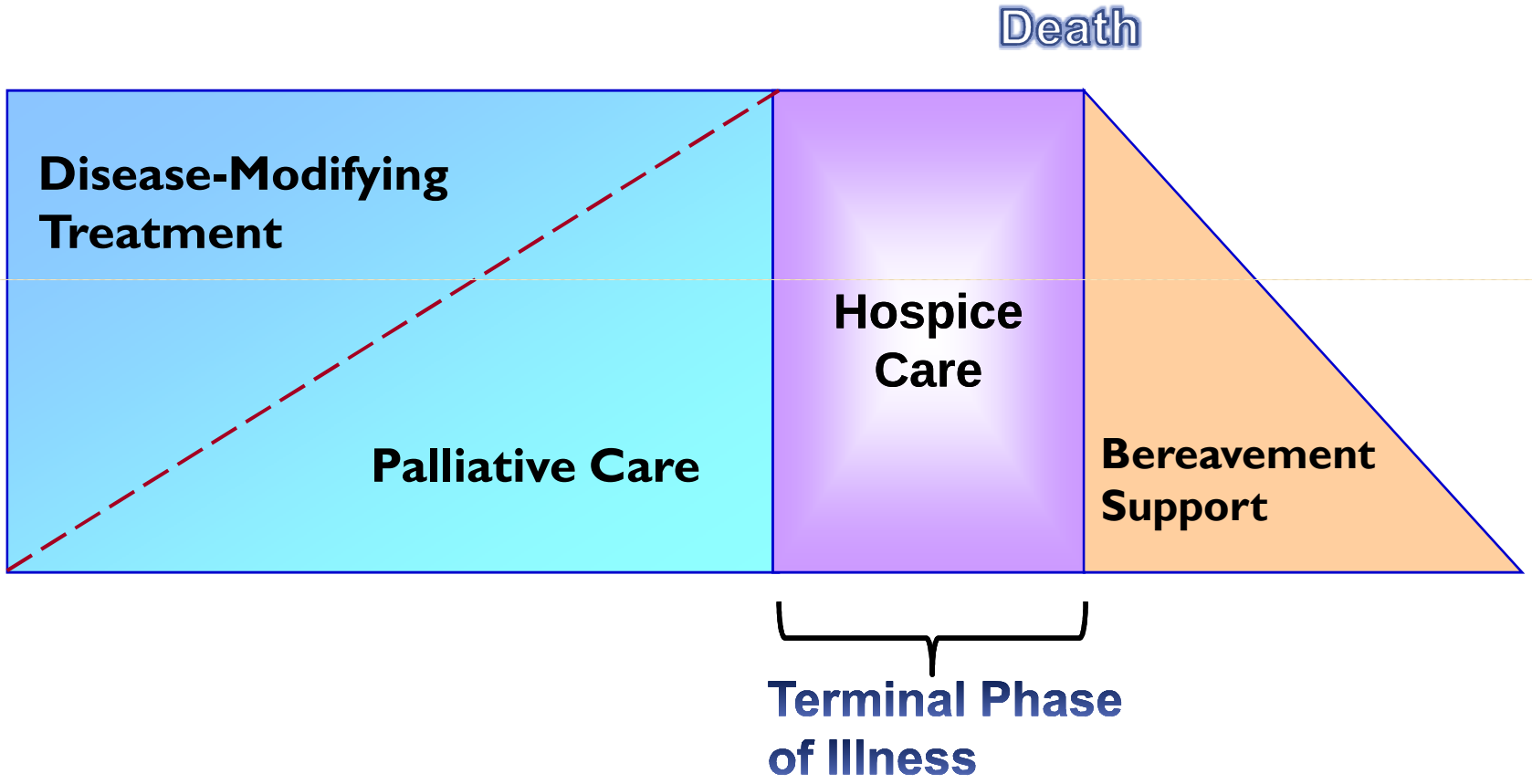
Palliative Care vs. Hospice

- Palliative care is NOT the same as hospice care.
- Palliative care may be provided at any time during a person's illness, even from the time of diagnosis. And, it may be given at the same time as curative or disease modifying treatment.
- Hospice care always provides palliative care but it is focused on terminally ill patients-people who no longer seek treatments to change the course of their illness & who are expected to live for about six months or less.

Classic Model of Care



Recommended Model of Care



NQF, 2006

Natural Allies

- Value added to hospices by palliative care includes increase in referrals, earlier referrals, less crisis intervention, continuity of care and the safety net of an inpatient setting if home management is not possible.

Why is this so important?

- 90% of Americans would prefer to receive end-of-life care in their homes rather than in hospitals or nursing homes.
- Instead, 50% of persons dying in the United States die in hospitals, 25% in nursing homes, 15% in personal homes, and 10% suddenly outside the hospital.

Why is this so important?

- In the US, 44% of dying persons receive hospice care and even then usually for less than the 2 weeks.
- This means that most persons are receiving aggressive disease modifying treatment up until the time they die.

Why is this so important?

- Unfortunately many patients endure potentially avoidable suffering during this period of their lives.
- As a medical community we have the opportunity to dramatically improve our patients' quality of life during this part of their lives by helping to prevent or alleviate suffering.

Team Approach

- To best address all aspects of a patient's suffering, a multidisciplinary team is essential and is composed of:
  - The patient and their loved ones
  - Nurses and physicians
  - Social workers
  - Case managers
  - Pastoral counselors
  - Primary care physician
  - Hospice team

Identifying a Potential Candidate for Palliative Care/Hospice

- Cancer
  - Any patient whose cancer is metastatic or inoperable
- Heart Disease
  - CHF symptoms at rest; EF of <20%; New dysrhythmia; Cardiac arrest; syncope or CVA; Frequent ER visits for symptoms
- Pulmonary Disease
  - Dyspnea at rest; Signs or symptoms of right heart failure; O2 sat on O2 of <88%; PCO2 >50; Unintentional weight loss

Identifying a Potential Candidate for Palliative Care/Hospice

- Dementia
  - Inability to walk; Incontinence; Fewer than 6 intelligible words; Albumin <2.5 or decrease PO intake; Frequent ER visits
- Liver Disease
  - PT >5 Seconds; Albumin <2.5; Refractory ascites; SBP; Jaundice; Malnutrition and muscle wasting
- Renal Disease
  - Not a candidate for dialysis; Creatinine clearance of <15 ml/minute; Serum creatinine >6.0
- Failure to Thrive
  - Frequent ER visits; Albumin <2.5; Unintentional weight loss; Severe Pressure ulcers; Homebound/bed-confined

Goals of Care

- 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.

Goals of Care

- **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.

Goals of Care

- The physician may propose as Goals of Care:
  - Better symptom control
  - Cure
  - Maximum quantity of life
  - Improvement of function
  - Care at home
  - Time with family and friends
  - 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.

Goals of Care

- Truth-telling is crucial at life's end. Honesty allows patients and families to understand seriousness of situation so that they can address important issues that 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

Words Are Important

Avoid saying:

- "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"

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.

SPIKES Protocol

- The protocol (SPIKES) consists of six steps.
- The goal is to enable the clinician to fulfill the four most important objectives when disclosing "bad" news:
  - gathering information from the patient
  - transmitting the medical information
  - providing support to the patient/family
  - eliciting the patient's collaboration in developing a strategy or treatment plan for the future.

1. SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer Walter F. Bailea, Robert Buckmanb, Renato Lenzia, Gary Globera, Estela A. Bealea and Andrzej P. Kudelkab The Oncologist August 2000 vol. 5 no. 4 302-311

SPIKES Protocol

- S—SETTING UP the Interview
- P—Assessing the Patient's PERCEPTION
- I—Obtaining the Patient's INVITATION
- K—Giving KNOWLEDGE and Information to the Patient
- E—Addressing the Patient's EMOTIONS with Empathic Responses
- S—STRATEGY and SUMMARY

Advance Care Planning

Discussion of Advance Directives should be a routine part of care.

An AD discussion should include:

- Designation of surrogate
- Documentation of healthcare preferences
- Review of the AD document
- Encouragement to discuss AD with family
- Scheduling future time to review completed document and address questions
- A plan for distribution of document to surrogate, family members, physicians and faith community representative

Advance Directives are not equivalent to DNAR (Do Not Attempt Resuscitation) orders.

Advance Care Planning

- While an inpatient implement a DNAR and/or DNI order if appropriate
- Out of hospital DNAR (especially for Hospice patients)
- DNR does NOT mean do not treat

Substituted Decision Making

- When a patients wishes are unknown and they lack capacity for decision making then the patients surrogate can be their voice.
- It is important to offer these surrogates guidance on how to approach this type of substituted decision making.
- Remind them that this is NOT about what they want, they are the voice of the patient.

End of Life Stroke Care

- Stroke kills almost **130,000** Americans each year—that's **1 in every 19 deaths**.[1]
- Stroke is a leading cause of serious long-term disability.[2]
- Many of the deaths occur during the acute stages of stroke and, about 50% of all stroke deaths occur in hospitals.[3]

1. Kochanek KD, Xu JQ, Murphy SL, Miniño AM, Kung HC. Deaths: final data for 2009 Adobe PDF file [PDF-2M]. National Vital Statistics Reports. 2011;60(3).
2. Roger VL, Go AS, Lloyd-Jones DM, Benjamin EJ, Berry JD, Borden WB, et al. Heart disease and stroke statistics—2012 update: a report from the American Heart AssociationExternal Web Site Icon. Circulation. 2012;125(1):e2–220.
3. Technical appendix from vital statistics of the United States, mortality, 2001. www.cdc.gov=nchs=data=statab=mortfinal 2001_work307.pdf. CDC=NCHS, National Vital Statistics System, Mortality. (Last accessed March 1, 2009).

Common Treatments Reviewed

- Mechanical Ventilation
- Artificial Nutrition
- Tracheostomy
- Antibiotics
- IV fluids
- Location of care (rehab/SNF/home)

Determining Poor Prognosis

- Patients who do not die during the acute hospitalization for stroke tend to stabilize with supportive care only.
- Continuous decline in clinical or functional status over time means that the patient's prognosis is poor.

1. Reference: U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Internet. Accessed April 29, 2010. Available at http://aspe.hhs.gov/daltcp/Reports/impquesa.htm#appendixC.

Determining Poor Prognosis

- Acute phase immediately following a hemorrhagic or ischemic stroke strong predictors of early mortality:
  - Coma or severe obtundation secondary to stroke beyond 3 days duration
  - In post-anoxic stroke, coma or severe obtundation, accompanied by severe myoclonus, persisting beyond three days past the anoxic event

1. Reference: U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Internet. Accessed April 29, 2010. Available at http://aspe.hhs.gov/daltcp/Reports/impquesa.htm#appendixC.

Determining Poor Prognosis

- Comatose patients with any 4 of the following on day 3 of coma had 97% mortality by two months:
  - Abnormal brain stem response
  - Absent verbal response
  - Absent withdrawal response to pain
  - Serum creatinine >1.5 mg/dl
  - Age >70
- Dysphagia severe enough to prevent the patient from receiving food and fluids necessary to sustain life, in a patient who declines, or is not a candidate for, artificial nutrition and hydration.

1. Reference: U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Internet. Accessed April 29, 2010. Available at http://aspe.hhs.gov/daltcp/Reports/impquesa.htm#appendixC.

Determining Poor Prognosis

- Certain findings on neuroimaging such as a massive intracerebral hemorrhage with intraventricular extension.

1. Reference: U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Internet. Accessed April 29, 2010. Available at http://aspe.hhs.gov/daltcp/Reports/impquesa.htm#appendixC.

Determining Poor Prognosis

- In the chronic phase, the following clinical factors may correlate with poor survival in the setting of severe stroke
  - Age greater than 70
  - Poor functional status, as evidenced by Karnofsky score of < 50%
  - Post-stroke dementia, as evidenced by a FAST score of greater than 7

1. Reference: U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Internet. Accessed April 29, 2010. Available at http://aspe.hhs.gov/daltcp/Reports/impquesa.htm#appendixC.

Determining Poor Prognosis

- Poor nutritional status, whether on artificial nutrition or not:
  - Unintentional progressive weight loss of greater than 10% over past six months
  - Serum albumin less than 2.5 gm/dl, may be a helpful prognostic indicator, but should not be used by itself.

1. Reference: U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Internet. Accessed April 29, 2010. Available at http://aspe.hhs.gov/daltcp/Reports/impquesa.htm#appendixC.

Determining Poor Prognosis

- Medical complications related to debility and progressive clinical decline. It is assumed that these patients similar to those with end-stage dementia.
  - Aspiration pneumonia
  - Upper urinary tract infection (pyelonephritis)
  - Sepsis
  - Refractory stage 3-4 decubitus ulcers
  - Fever recurrent after antibiotics

1. Reference: U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Internet. Accessed April 29, 2010. Available at http://aspe.hhs.gov/daltcp/Reports/impquesa.htm#appendixC.

Artificial Nutrition

- Physicians in general over estimate the benefits of NG/PEG tube feeding in stroke patients.
- There is a lack of evidence to show a significant survival benefit and studies that do show a reduction in fatality notice that this comes at the expense of poor outcome in functional status
- Thus the patients goals of care are paramount in this decision (quality of life vs. quantity)

1.Hanson LC Physicians' expectations of benefit from tube feeding, J Palliat Med. 2008 Oct;11(8):1130-4. doi: 10.1089/jpm.2008.0033.

2. Dennis MS Effect of timing and method of enteral tube feeding for dysphagic stroke patients (FOOD): a multicentre randomised controlled trial. Lancet. 2005 Feb 26-Mar 4;365(9461):764-72.

Artificial Nutrition

- The alternative to artificial nutrition is offering careful oral feeding/pleasure feeding with the goal being to improve the patient's quality of life rather than just maintaining nutritional status.

Mechanically Ventilated Stroke Patients

- Inpatient mortality 55% (48-70%) [1]
  - 30-day mortality 58% (46%-75%)
  - 1-2 year mortality 68% (59%-80%)

- Survival post terminal extubation [2]
  - 25% die within an hour
  - 69% die within 24 hours
  - Median 7.5 hours
  - Majority experience agonal/labored breathing following extubation

1. Holloway, *JAMA*, 2005; ;294(6):725-733.
2. Mayer, *Neurology*, 1999

Terminal Symptom Management

- Some patients who are actively dying may have no symptoms
- Others may have pain, dyspnea, restlessness, delirium, upper airway congestion

Terminal Symptom Management

- Opioids are the standard of care for management of terminal dyspnea and pain
- Opioids are NOT associated with hastening death in this situation
- Significantly decrease tachypnea/dyspnea
- Secretion management with anticholinergic medications such as glycopyrrolate.

Terminal Symptom Management

- Delirium management with neuroleptics/antipsychotics/benzodiazepines
- Management of seizures
- If palliative sedation is allowed, pain and symptom control can be achieved 100% of the time.
- The double effect principle

Time Limited Trials

- All treatments have potential benefits and harms
- Often, time will tell when it comes to determining benefit or harm
- It is helpful to use the idea of a time limited trial when starting an intervention with unknown or uncertain benefits.

Hospice Care for Stroke

- Hospice is not about death, it is about living.

Hospice Care for Stroke

- Setting of care will depend on severity of symptoms (home vs. inpatient care)
- Patients qualify for hospice care when the goals of care is primarily comfort.
- 2 physicians feel that the patient's life expectancy is less than 6 months if the condition runs its natural course given the treatments the patient wishes to accept
- Decline artificial nutrition and be unable to maintain hydration/caloric intake naturally.
- Current history of aspiration unresponsive to or not a candidate for therapy

Hospice Care for Stroke

- In the chronic phase, documented signs of decline even with treatment/supportive care.
  - >10% weight loss over previous 6 months
  - >7.5% weight loss over 3 months
  - Albumin <2.5
  - Aspiration pneumonia/sepsis/UTI with sepsis
  - Stage 3-4 pressure ulcers
  - Clinical signs of dehydration and documented inadequate caloric/fluid intake

Hospice Care for Stroke

- Hospice will facilitate as good a quality of life as possible for the patient and family by making it possible to care for a dying patient at home
- The expectation is a natural death as free from pain and suffering as possible
- Addressing all domains of suffering physician/emotional/social/spiritual.

Thank you!

- Any questions?