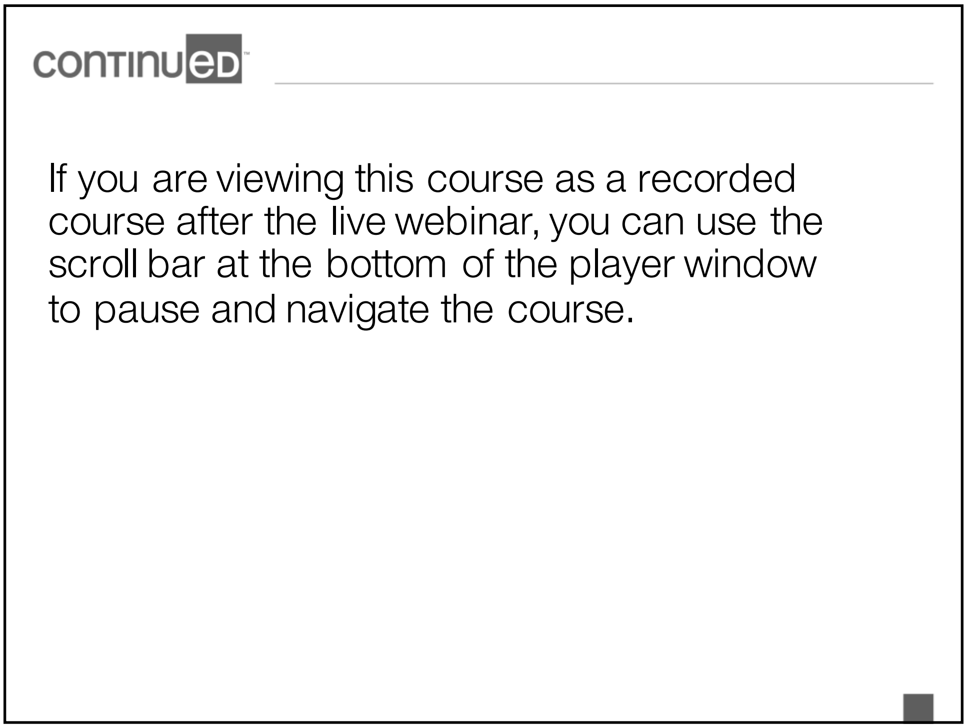

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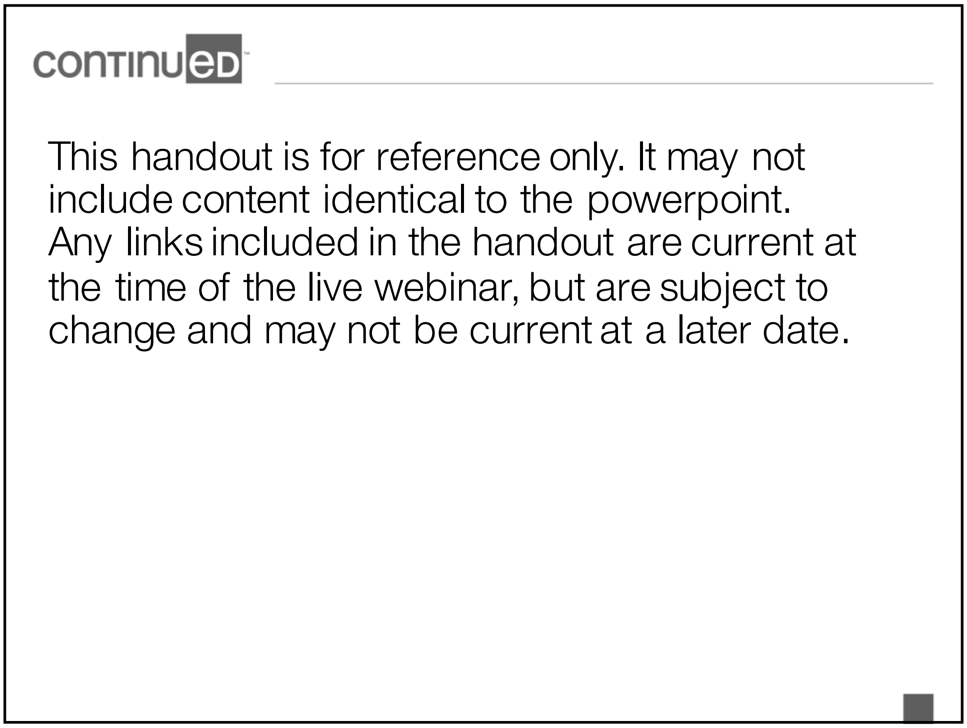

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Decision Making for Alternate Nutrition and Hydration Part 1

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DISCLOSURES

- Financial disclosures:
  - Honorarium from SpeechPathology.com
  - Legal consultant/expert witness
  - Private practice
- Non-financial disclosures:
  - Quality Insights of Pennsylvania

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Part 1 Content

Part 1 will review concerns that impact the decision- making process for patient and families, such as religious beliefs and culture. Various advance directives will be discussed as well as resources to help the patient and the family with this often difficult choice.

As a result of this course, participants will be able to:

- 1) identify religious viewpoints regarding artificial hydration and nutrition
- 2) identify three advance directives patients may complete to identify their choices
- 3) identify criteria that is important to the patient and family in making this decision.

Agenda – PART 1

Factors to Consider

- Influence of Culture
- Influence of Religion
- Advance Directives
- Resources
- Family and patient criteria for decision making

Artificial Nutrition – NG Tube

High rate of pulmonary aspiration & self extubation

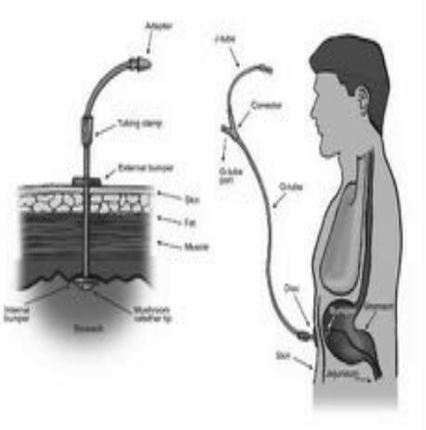
- Short term placement
- Monitor placement to prevent serious complications from displaced feeding tube
- Pulled out of position by pt. or staff
- Migrate upward with vigorous
- coughing or vomiting
- Displaced into posterior oral pharynx,
    - Provides route for aspiration of formula into lungs

(2)

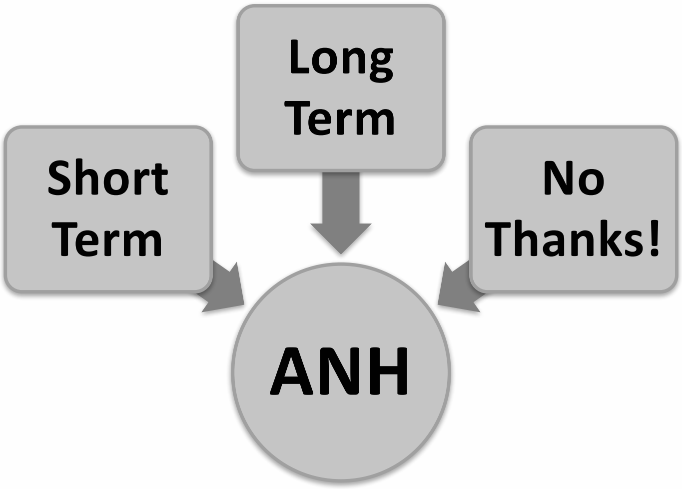
Artificial Nutrition

- Gastrostomy Tube (G Tube)
- Percutaneous Endoscopic Gastrostomy (PEG)
  - Tubes into stomach through abdominal wall
  - Aspiration of gastric contents/acid
- Jejunostomy Feeding Tube (J tube)
  - Tube into upper intestines
  - Aspiration of bile
- Preferred method for long term artificial feeding and/hydrating patients (1)
- $58.17 for case of 24 8 ounce cans

(2)



Choices?



Long Term

Short Term

No Thanks!

ANH

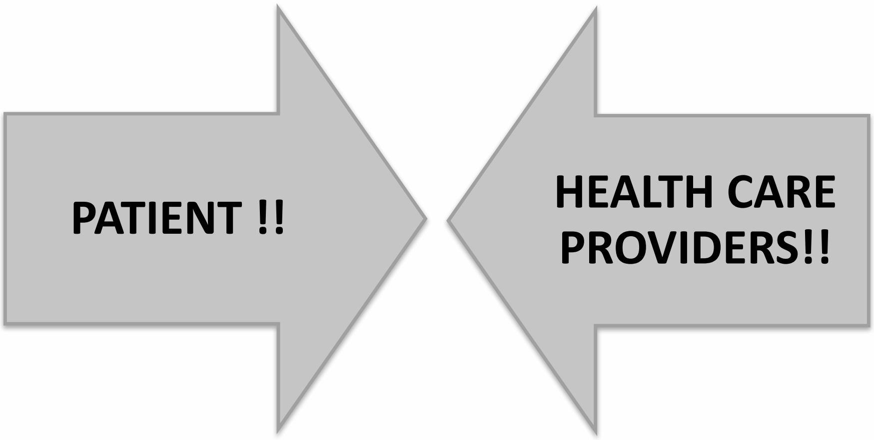
Statistics

- Total estimated annual cost per person for 1 yr. of PEG tube feeding is $31,832 (3)
- **Disuse atrophy**

Measurable within first 72 hours – Giselle Mann

  - Impact on swallowing muscles great
  - High % of fast twitch fibers
  - Difficult to reverse without normal swallow
  - Especially on modified diet or PEG

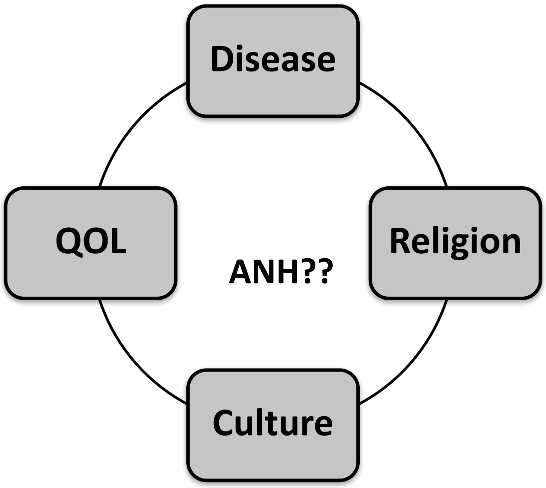
TWO DIFFERENT VIEWPOINTS!!



PATIENT !!

HEALTH CARE PROVIDERS!!

PATIENT: Many Influential Factors To Consider!



CULTURE:

Patient ***AND*** Health Care Providers!!

- Ethnic minorities = 1/3 of US population (4)
- Pt. may want to know truth **but** family wants to protect pt. from truth
- Don't generalize all individuals!

European American Asian/Middle Eastern

European American	Asian/Middle Eastern
Favor directives	Protect pt. from bad news
Limit treatment at EOL	Family makes decisions
Primarily future oriented	Primarily present oriented
Prefer **direct eye contact**	Some groups past oriented
Prefer **large amount of personal space**	**Not likely to make direct eye contact** with those perceived to be in authoritative positions
Value privacy	Low volume
Low to moderate amount of touching	**Small amount of personal space**
	Little touching in public (5)

African Americans

- Object to limiting treatment
- Prefer aggressive treatment
- More likely dc'd to extended care
- When death inevitable, **2X** as likely as Caucasians to request life sustaining treatment

- **Older African Americans**
- May distrust healthcare system based on hx of segregation/discrimination
- Strong religious beliefs
- "Fictive kin" – people considered family but not linked by blood ties
- Primarily present oriented
- Prefer **direct eye contact**
- **Moderate amount of touching**
- **Comfortable with small personal space** (5)

Native Americans

- Reject directives
- Tribal leader
- Self fulfilling prophecy
- Primarily present oriented
- **Not likely to make direct eye contact** w those perceived to be authoritative
- **Small amount of personal space**
- **Use touch lightly**

Hispanics

- Less likely to institutionalize or use hospice – denotes giving up
- More likely to use CPR, ANH intubation, than Caucasians
- Dr. knows best – Mexican Americans
- Heavily influenced by Catholic beliefs
- Family makes decisions to spare pt. unnecessary pain – detrimental to pts to know of seriousness of illness
- Primarily present oriented
- **No direct eye contact** w those perceived to be authoritative
- **Small amount of personal space**
- **Value touching** (5)

Japanese

- May agree to ANH based on **wishes of families/dr.**
- Preference for natural death & fighting cancer valued as important
- 40% pts in survey prefer **not being informed** of bad news
- 1 study – 30-50% general public said **ANH is minimum standard of care**
- 30% believed ANH relieved symptoms
- 1 study – 40% of drs/20% of nurses – IV is minimum standard of care
- **32% believed allowing pt. to die under dehydrated conditions is ethically impermissible**
- 24% Japanese oncologists regard withdrawal of life supporting treatment as **never ethically justified** (6)

Japanese

- ANH considered a basic standard to be continued until death
- Withdrawal or withholding ANH not acceptable in national sample of less than 6,000 Japanese older adults (16) (17)
- Recently developed clinical guidelines for provision of ANH at the end of life (18)

Chinese

- "Eating is as important as the emperor"
- Worry pt. will starve to death and become a "starving soul" after death
- Utilize TCM = traditional Chinese medicine
- Herbal remedies
- **Eldest male child is primary decision maker**
- Decision inclined toward **family's best interest**, but perhaps not pt.'s.

- Provision of food/drink is basic act of caring
- Feeding has powerful symbolic & social significance
- **ANH believed to be against Filial piety – honor family and conformance to norms**
- Up to 62.9% pts w terminal cancer wish ANH & have insufficient knowledge
- Many believe ANH prevents dehydration/starvation
- Cannot overemphasize importance of food intake in Chinese culture

(7)

Hong Kong Chinese

- Values pt.'s family involvement in treatment decisions
- ANH commonly placed in pts who fail to obtain sufficient dietary intake or at risk of aspiration w oral feeding
- **Believe tube feed only a medical intervention when used to administer meds**
- **Life preservation is primary obligation** of health professionals
- ANH is basic sustenance care that reverses malnutrition and dehydration
- Believe aspiration risk higher in oral feeding than tube feeding
- **Decrease in swallowing ability perceived as disease complication requiring intervention**
- Preparing food is usual way for Chinese to express love for loved ones (8)

Indian Culture

- Relatives may push for ANH in belief **pt. suffering** from hunger
- Practice alternative Indian systems of medicine – supported by gov't initiatives
- Hospice perceived as place for pts without families to die
- **Collusion** – info withheld
- More than ½ cancer pts in India unaware of their diagnosis/treatment
- Feeding terminally ill symbolic
  - gain more time for pt.
  - families see it as basic act of caring
  - drs. see it as improving quality of life and succor (assistance)(9)

Living with Grief: Ethical Dilemmas at the End of Life
Hospice Foundation of America

- **Asians/Latinos living in US** want **everything done**
- **5 yr. study in N. California:**
  - ANH at death in Hispanic/Asian/Pacific Islanders **5.2** times that of non Hispanic Caucasian group
- **In North America,** withholding diagnosis from pt. may be grounds for legal action
- **Chinese, East Indian, Filipino, Hmong, Iranian, Korean, Latino, Russian, Vietnamese** prefer family spokesperson be informed first before pt. is told

RELIGION:
Patient *AND* Health Care Providers!

Religious Beliefs (10)

Pt. has right to decide; no extraordinary effort, relief of suffering

- American Baptist
- Episcopal
- Buddhism
- Hinduism
- Islam
- Jehovah's Witness
- Lutheran Missouri Synod
- Presbyterian
- 7th Day Adventist

Religious Beliefs (10)

Roman Catholic

- ANH if benefits outweigh burdens
- Disagreement as to meaning
- Pope John Paul – ANH is NOT medical act, morally obligatory and withdrawal of ANH in PVS is euthanasia by omission
- ONLY relates to PVS – not other terminal states

Protestant

- Comfortable w life sustaining therapies
- If little hope of recovery, most will understand, accept withholding or withdrawal of therapy (19)(20)

Greek Orthodox

- no position on end-of-life decisions, since task of Christians is to pray and not decide about life and death.
- Withholding or withdrawing of artificial nutrition is not allowed even if there is no prospect of recovery (20)(21)

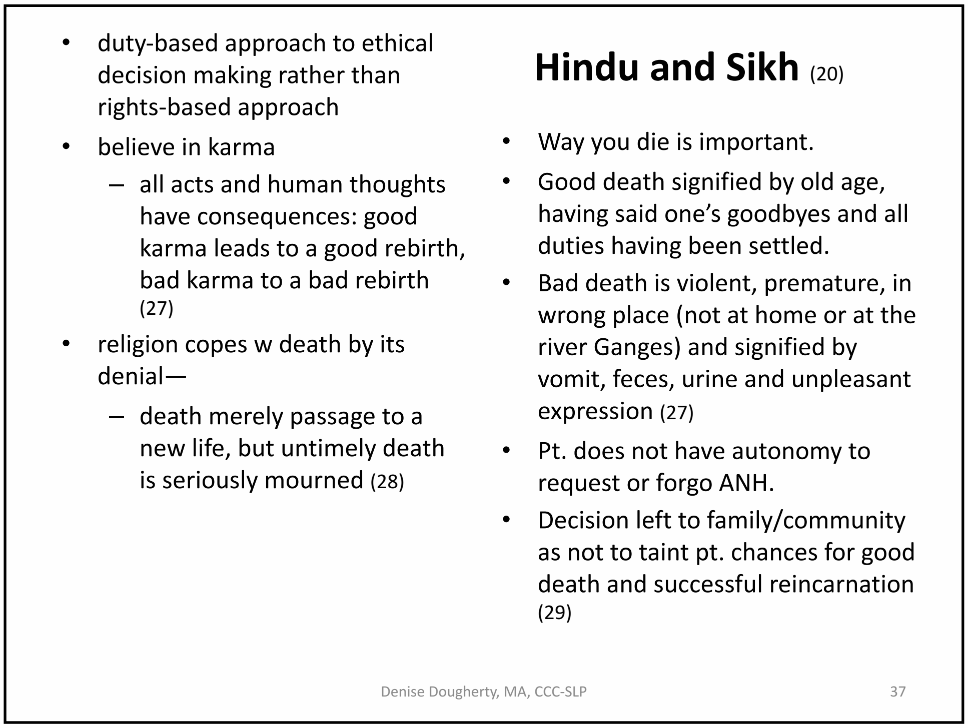
Jewish

- reform, conservative orthodox, w orthodox Jews being most religious.
- Food/fluids regarded as basic needs and NOT treatment.
- Withholding food/fluids from dying pt. (or pts w other disorders) is unrelated to dying process and therefore is prohibited and regarded as form of euthanasia (22) (20)
- Mostly concerns incompetent patients, who make up majority of ICU pts [23) (20)
- if competent dying pt. refuses treatment, including food/fluids, he/she should be encouraged to change his/her mind regarding food and fluids, but should not be forced against his/her wishes (24) (20)
- When pt. approaches final days of life, food and fluids may cause suffering and complications
  - permissible to withhold food and fluids if that was pt.'s wish.

The Four Tenets of Jewish and Secular Medical Ethics (20) (25)
1. “**Autonomy** in Judaism means an individual's decision-making is his own, but should comply with Jewish beliefs and medical authority.”
2. “**Beneficence** in Jewish teaching implies religious Jews should attempt treatments, which would extend life and impart benefit.”
3. “**Non-malfeasance** implies it is the individuals’ responsibility to avoid harming themselves and their god given bodies.”
4. “**Justice**, which can be interpreted as fairness in limiting or denying treatment or care based on availability and resources.”

Islamic (20)

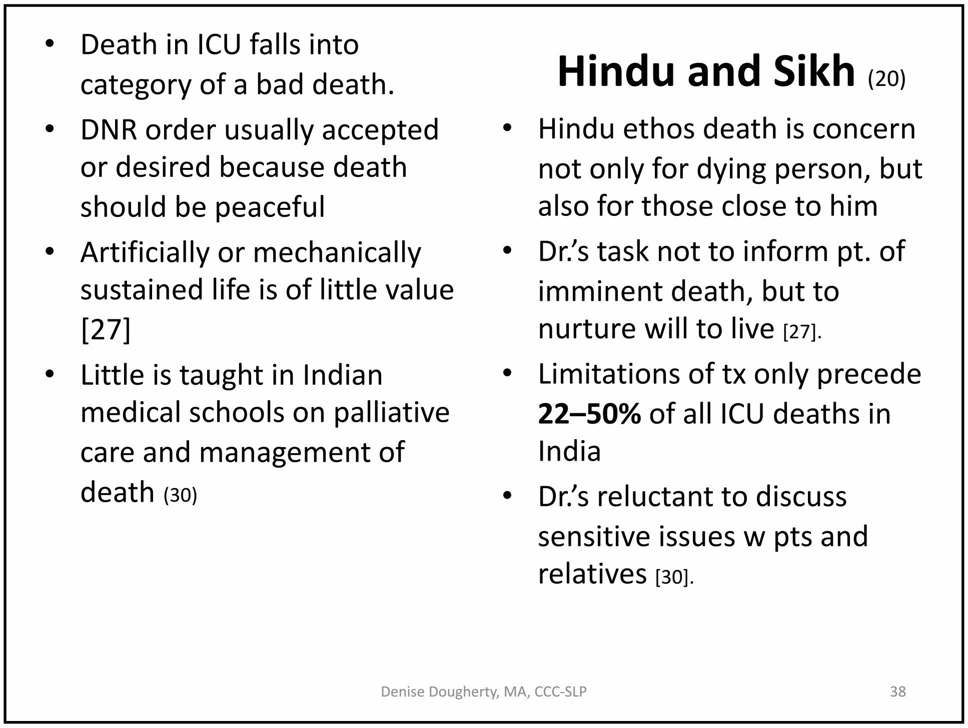
- Life sustaining treatments can be withheld/withdrawn in terminally ill when
  - Death inevitable
  - Treatment won’t improve condition or QOL
  - Decision to withdraw futile treatment seen as allowing death to take natural course.
- Never hasten death –
  - only abstain from overzealous treatment –
  - Islamic principle of “ no harm and no harassment”
- Basic nutrition should not be discontinued (26)
- ANH withdrawal would starve pt. to death
  - a crime according to Islamic faith.
- Collective decision taken on basis of informed consent
  - consultation w pt.'s family, and involving all those providing health care, including attending physician (three for withdrawing life support for brain death)
  - also applies to pts in persistent vegetative state (26)



Hindu and Sikh (20)

- duty-based approach to ethical decision making rather than rights-based approach
- believe in karma
  - all acts and human thoughts have consequences: good karma leads to a good rebirth, bad karma to a bad rebirth (27)
- religion copes w death by its denial—
  - death merely passage to a new life, but untimely death is seriously mourned (28)

- Way you die is important.
- Good death signified by old age, having said one's goodbyes and all duties having been settled.
- Bad death is violent, premature, in wrong place (not at home or at the river Ganges) and signified by vomit, feces, urine and unpleasant expression (27)
- Pt. does not have autonomy to request or forgo ANH.
- Decision left to family/community as not to taint pt. chances for good death and successful reincarnation (29)



Hindu and Sikh (20)

- Death in ICU falls into category of a bad death.
- DNR order usually accepted or desired because death should be peaceful
- Artificially or mechanically sustained life is of little value [27]
- Little is taught in Indian medical schools on palliative care and management of death (30)

- Hindu ethos death is concern not only for dying person, but also for those close to him
- Dr.'s task not to inform pt. of imminent death, but to nurture will to live [27].
- Limitations of tx only precede **22–50%** of all ICU deaths in India
- Dr.'s reluctant to discuss sensitive issues w pts and relatives [30].

Buddhist (20)

- Important to inquire about attitudes held by Buddhist pt./family who come from a particular culture.
- Certain attitudes shared by most Buddhists.
- No mandate/moral obligation to preserve life at all costs
  - Would be denial of human mortality
  - No specific Buddhist teachings on pts in persistent vegetative state
  - Keeping pt. alive artificially w ANH is not mandatory in Buddhism. (38)(39)

Confucian and Taoist (20)

- Topic of death is generally taboo
- Prohibits dr.'s. from discussing death in much detail w pt. or family.
- Maintaining hope very important in care of dying
  - Hope prevents suffering by avoiding despair.
  - Face-to-face interviews w 40 Chinese seniors 65 years + showed all respondents rejected advance directives (31)
- Chinese more likely to prefer family-centered decision making than other racial/ethnic groups (32)
- In Confucian concept, family or community should be given information, coordinate pt.'s care (33) and protect pt. from burden of knowledge (34)

Considerations! (20)

- Strict ethnic and religious background is not the only factor taken into account when dealing with end-of-life decisions.
- Recent immigrants generally adhere rather strictly to rules of the religion and culture of their place of origin (35, 33)
- 2nd or 3rd generation immigrants often have acculturated to dominant bioethics of their new country (36)
- When facing death, pts. tend to fall back on traditional cultural or religious background (34)(37)
- People who classify themselves as belonging to a religion do not necessarily attend church or follow any of the religion's rulings.

Religious Beliefs

- lead to clashes and discussions between patients, families and medical professionals
- physicians can help to prevent these conflicts by becoming knowledgeable and respecting their patients' faiths and beliefs. (20)

PATIENT
AND
ADVANCE DIRECTIVES

Concerns

- **Informed consent** for PEG routinely poor.
- ***Ethical burden of providing only beneficial care lies w both MD ordering and MD placing feeding tube***
- Extensive anecdotal evidence suggests families unsure about PEG **feel pressured to consent & often regret decisions**

One large community teaching hospital documented adequate discussion of PEG –

  - specific benefits, burdens, alternatives in **only 0.6%** of placements (11)

Hastings Center Principles of Practitioner's Responsibilities

- Established in 1969
- Independent, nonpartisan nonprofit bioethics research institute in NY
- Publish numerous reports
- http://www.thehastingscenter.org
- Many free resources
- Subscription to journals
- Act within ethical mandates of professions & reasonable standards of practice

- **First obligation to pt.**
    - **Obligated** to respect pt.'s choice or surrogate,
    - affirm values of compassion & human dignity **without** ethical compromise
  - Can remove ourselves from pt. care
    - Pt. abandonment?
  - Might better serve pt. by providing education
    - **NPO vs. right to aspirate**
    - Swallowing precautions & strategies

Advance Directives

- **Pts. often don't know**
  - Disease process – how will it work; what can I expect?
  - Treatment **options** - not just one you want pt. to do!
  - Possible side effects – if I **do** treatment OR if I **don't**!

  - Pts. must clarify their goals so sensible treatment options can be offered
    - **Values History Forms available (MA, NM, PA)**
    - **Ottawa Personal Decision Guide - www.ohri/ca/programs/clinical_epidemiology/OHDEC/decision_aids.asp**
    - **Numerous states have forms to assist with identifying values**
  - Helps SLP, other professionals **EXTRACT THEIR** own values from decision making process

Values History Form

(12)

OVERALL ATTITUDE TOWARD LIFE & HEALTH

- Goals for future?
- How satisfied are you with your life achievements?
- What makes life worth living?
- What do you fear most? Frightens/ upsets you
- What activities do you enjoy?
- Describe your current state of health?
- How do health problems/disabilities affect you, family, work, your ability to function?
- How do you feel about health/disabilities? What do you want others to know about this – dr, friends family
- Difficulties getting through the day, performing activities (eating, preparing food, sleeping , dressing, bathing)?
- What do you want to say about your general health to someone reading this?

PERSONAL RELATIONSHIPS

- What role family/friends play in your life?
- How do you expect friends, family, others to support your decisions regarding medical treatment you may need now or in future?
- Have you made any arrangements for family/friends to make medical treatment decisions on your behalf? Who agreed to make decisions for you and in what circumstances?
- What general comments would you like to make about personal relationships in your life?

Values History Form

(12)

THOUGHTS ABOUT INDEPENDENCE AND SELF SUFFICIENCY

- How does independence, dependence affect your life?
- If you were to experience decreased physical & mental abilities, how would that affect your attitude toward independence & self sufficiency?
- If current physical/mental health gets worse, how would you feel?

LIVING ENVIRONMENT

- Have you lived alone or w others over past 10 yrs.
- How comfortable have you been in you surroundings? How might illness, disability or age affect this?
- What general comments do you want to make about your surroundings?

RELIGIOUS BACKGROUND AND BELIEFS

- What's your spiritual, religious background
- How do beliefs affect your feelings toward serious, chronic or terminal illness?
- How does your faith support you?
- What general comments do you want to make about your beliefs?

RELATIONSHIPS W DOCTORS & OTHER HEALTH CAREGIVERS

- How do you relate to your drs.? Comment on trust decision making, time for satisfactory communication, respectful treatment
- How do you feel about other health care providers (nurses, therapists, chaplains, social workers)
- What else do you want to say about drs. & other health care providers?

Values History Form

(12)

THOUGHTS ABOUT ILLNESS, DYING & DEATH

- What general comments do you want to make about illness, dying, death?
- What is important to you when you are dying (physical comfort, no pain, family members present, etc.)
- Where would you prefer to die
- How do you feel about use of life-sustaining measures if you were suffering from an irreversible chronic illness (Alzheimer's), terminally ill or in a permanent coma?
- What general comments do you want would to make about medical treatment?

FINANCES

- What general comments do you want to make about your finances & health care?
- What are your feelings about having enough money to provide for your care?

FUNERAL PLANS

- What general comments do you want to make about your funeral, burial or cremation?
- Have you made funeral arrangements? If so, with whom?

LEGAL DOCUMENTS

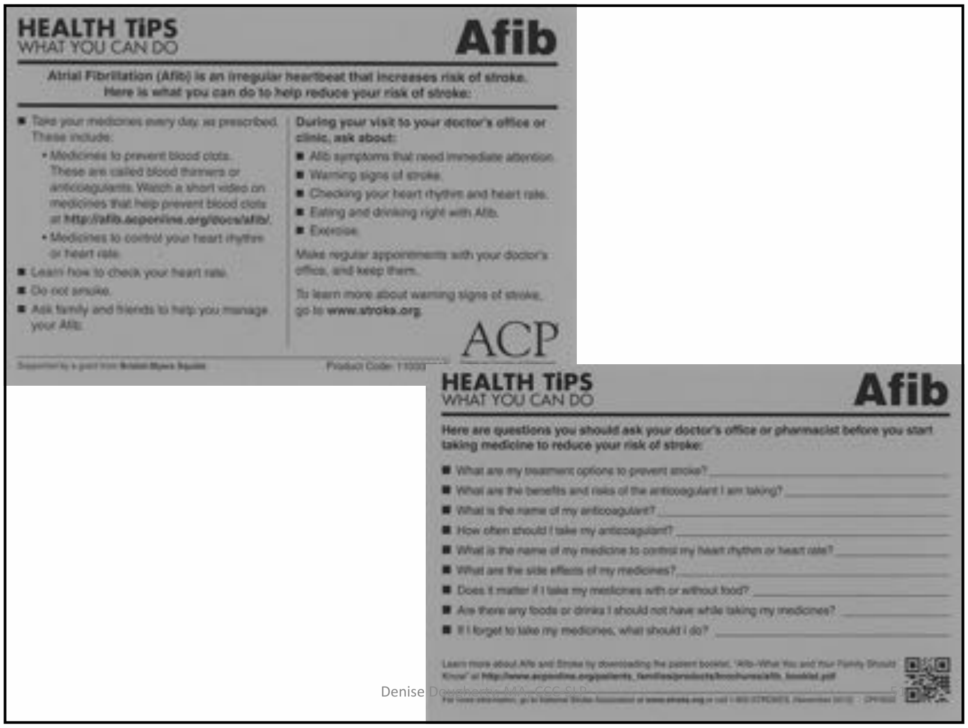
USA Weekend reported in Feb 13-15, 2009 article

Pts. forget 40-80% of info once they leave dr. office

- **www.foundation.acponline.org**
  - Health literacy solutions – health tips
  - Specific medical conditions (copd, dementia, etc.)
  - Suggested questions to ask dr.
  - Download electronic version or tablet form

PEACE brochures

- PDF files for dr.
  - Improving your End of Life Care Practice
- PDF files for pts.
  - Living with a Serious Illness: Talking with Your Doctor When the Future is Uncertain
  - When You Have Pain at the End of Life
  - Making Medical Decisions for a Loved One at the End of Life



HEALTH TiPS
WHAT YOU CAN DO
Afib

Atrial Fibrillation (Afib) is an irregular heartbeat that increases risk of stroke. Here is what you can do to help reduce your risk of stroke:

- Take your medicines every day, as prescribed. These include:
  - Medicines to prevent blood clots. These are called blood thinners or anticoagulants. Watch a short video on medicines that help prevent blood clots at **http://afib.acponline.org/docs/afib/**.
  - Medicines to control your heart rhythm or heart rate.
- Learn how to check your heart rate.
- Do not smoke.
- Ask family and friends to help you manage your Afib.

During your visit to your doctor's office or clinic, ask about:

- Afib symptoms that need immediate attention.
- Warning signs of stroke.
- Checking your heart rhythm and heart rate.
- Eating and drinking right with Afib.
- Exercise.

Make regular appointments with your doctor's office, and keep them.

To learn more about warning signs of stroke, go to **www.stroke.org**.

ACP

Supported by a grant from **Bristol-Myers Squibb**

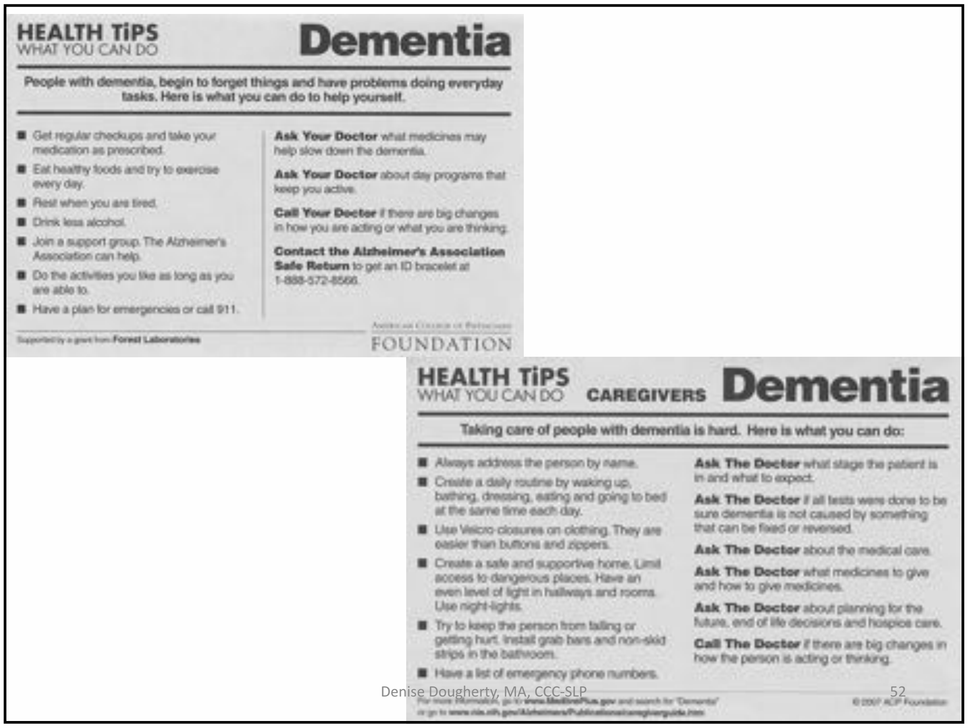
Product Code: 1100

HEALTH TiPS
WHAT YOU CAN DO
Afib

Here are questions you should ask your doctor's office or pharmacist before you start taking medicine to reduce your risk of stroke:

- What are my treatment options to prevent stroke? ________________
- What are the benefits and risks of the anticoagulant I am taking? ________________
- What is the name of my anticoagulant? ________________
- How often should I take my anticoagulant? ________________
- What is the name of my medicine to control my heart rhythm or heart rate? ________________
- What are the side effects of my medicines? ________________
- Does it matter if I take my medicines with or without food? ________________
- Are there any foods or drinks I should not have while taking my medicines? ________________
- If I forget to take my medicines, what should I do? ________________

Learn more about Afib and Stroke by downloading the patient booklet, "Afib–What You and Your Family Should Know" at **http://www.acponline.org/patients_families/products/brochures/afib_booklet.pdf**



HEALTH TiPS
WHAT YOU CAN DO
Dementia

People with dementia, begin to forget things and have problems doing everyday tasks. Here is what you can do to help yourself.

- Get regular checkups and take your medication as prescribed.
- Eat healthy foods and try to exercise every day.
- Rest when you are tired.
- Drink less alcohol.
- Join a support group. The Alzheimer's Association can help.
- Do the activities you like as long as you are able to.
- Have a plan for emergencies or call 911.

Ask Your Doctor what medicines may help slow down the dementia.

Ask Your Doctor about day programs that keep you active.

Call Your Doctor if there are big changes in how you are acting or what you are thinking.

Contact the Alzheimer's Association Safe Return to get an ID bracelet at 1-888-572-8566.

Supported by a grant from **Forest Laboratories**

American College of Physicians
FOUNDATION

HEALTH TiPS
WHAT YOU CAN DO
CAREGIVERS Dementia

Taking care of people with dementia is hard. Here is what you can do:

- Always address the person by name.
- Create a daily routine by waking up, bathing, dressing, eating and going to bed at the same time each day.
- Use Velcro closures on clothing. They are easier than buttons and zippers.
- Create a safe and supportive home. Limit access to dangerous places. Have an even level of light in hallways and rooms. Use night-lights.
- Try to keep the person from falling or getting hurt. Install grab bars and non-skid strips in the bathroom.
- Have a list of emergency phone numbers.

Ask The Doctor what stage the patient is in and what to expect.

Ask The Doctor if all tests were done to be sure dementia is not caused by something that can be fixed or reversed.

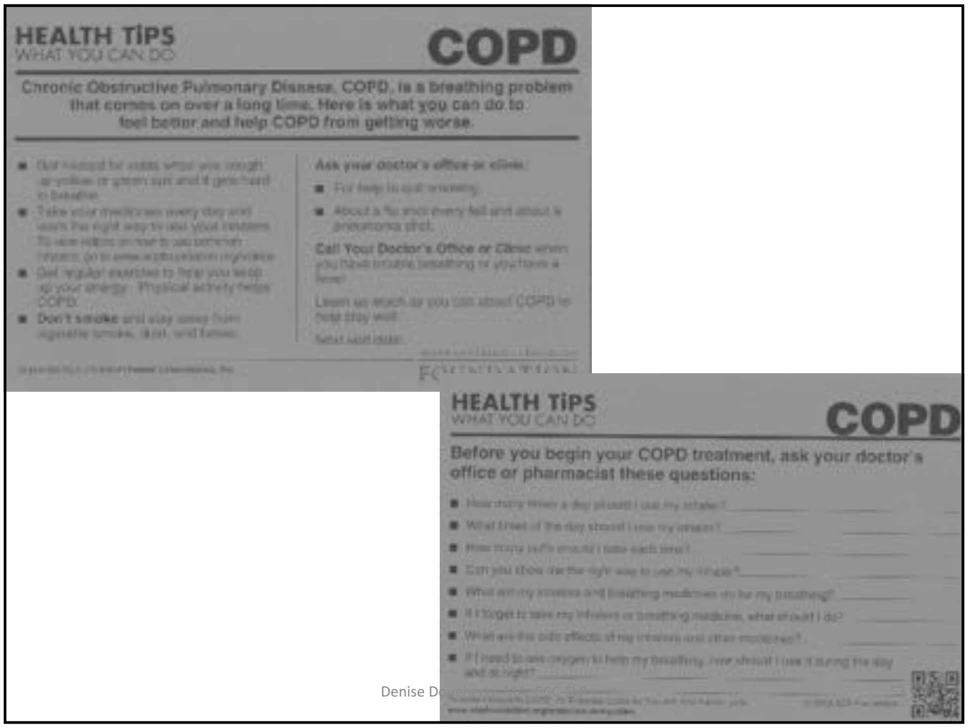
Ask The Doctor about the medical care.

Ask The Doctor what medicines to give and how to give medicines.

Ask The Doctor about planning for the future, end of life decisions and hospice care.

Call The Doctor if there are big changes in how the person is acting or thinking.

For more information, go to **www.MedlinePlus.gov** and search for "Dementia" or go to **www.nia.nih.gov/Alzheimers/Publications/caregiverguide.htm**



HEALTH TiPS
WHAT YOU CAN DO

COPD

Chronic Obstructive Pulmonary Disease, COPD, is a breathing problem that comes on over a long time. Here is what you can do to feel better and help COPD from getting worse.

Ask your doctor's office or clinic:

HEALTH TiPS
WHAT YOU CAN DO

COPD

Before you begin your COPD treatment, ask your doctor's office or pharmacist these questions:

Advance Directives:
less successful because

- Focused on legal right to refuse unwanted medical treatments
  - Reflects legislative origins of advance directives
- **Must focus on underlying goals & values instead**
- **7th -8th grade language used** to discuss life sustaining treatments, advance directives/forms
- Too vague or too medically specific instructions to be helpful in common clinical situations
  - “If I am close to death…”
  - “If I am in a persistent vegetative state…”
  - Vague instructions result in vague expressions of wishes
    - “Do not keep me alive w machines”
    - “Let me die if I’m a vegetable”

Advance Directives:
less successful because

- **Once directives completed, planning considered finished**
  - **Rarely** make efforts to reopen conversation as health declines
  - Only repeated question required by Patient Self Determination Act is
    - **"Do you have advance directives?"**
- **Pt. want family involved in decision rather than making decision alone**
  - Many non-Western cultures favor this
    - Native American
    - Hispanics
    - Asian
    - Middle eastern

Living Will

- **Many only allow terminally ill pts to make wills**
- Only apply to treatments not wanted – ignore treatments desired
- Vague language – "heroic measures, meaningful quality of life"
- Most laws don't legislate penalties if providers choose to ignore them
- Providers may have concerns as to forgery, pt. thinking of cancelling it etc. (25)

Medical Directives

- Written instructions re: desired care if incapacitated
- **Don't need to be terminally or seriously ill**
- More concrete language describing medical problems/treatment than living wills
- Addresses major surgery, dialysis, TF, CPR ventilators, transfusions, antibiotics
  - PVS/coma w no hope of regaining awareness
  - Brain damage/disease w pt. permanently incoherent
  - Any painful condition expected to bring death

Mini-Mental Status Exam

- **Relevant for memory, attention, language**
- Know how pt. makes decisions
  - Reasoning
  - Ability to understand consequences
  - No substitute for critical observation of this process
  - Clinicians who observe & interact w pt. day to day
    - Better positioned to evaluate quality & consistency of pt.'s decision making ability

- **Brief Cognitive Assessment**
  - **www.thebcat.com**
- **SLUMS**
  - **aging@slu.edu**
- **Montreal Cognitive Assessment – MOCA**
  - **www.mocatest.org**

Websites

- **http://public.findlaw.com/**
  - Type advance directives in search box
  - Living Wills for an overview of each state
- Check Attorney General website, Bar Association website for your state

- **www.caringinfo.org**

800-658-8898

National Hospice & Palliative Care org.

- **www.noah-health.org:**
  - New York Online Access to Health
- Patient’s Rights & Resources
- **Advance Directives by State**
- PDF available
- General information regarding various forms

Standards of Decision Making

- **Prior explicit articulation- also referred to as Subjective**
  - expression of capacitated person's wishes – most reliable info about their preferences
- **Substituted judgment – also referred to as limited objective**
  - decision by others based on formerly capacitated person's inferred wishes. Knowing what we do about person's behavior, values, prior decisions, what we think pt. would want in these circumstances
- **Best interest – also referred to as pure objective**
  - Decision based on what reasonable person in pt.'s situation would want. Use when incapacitated person never made known treatment wishes & preferences cannot be inferred. (50)

- Making Choices –
  - Long Term Feeding Tube Placement in Elderly Patients
  - https://decisionaid.ohri.ca/docs/Tube_Feeding_DA/PDF/TubeFeeding.pdf

Informed Consent and Refusal

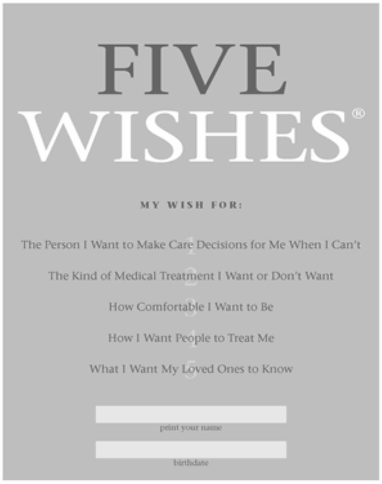
- **Basic elements**
  - Decisional capacity
  - Disclosure by dr. of sufficient info relevant to decision
  - Understanding info disclosed
  - Voluntariness in acting w/o compulsion or coercion
  - Communication of **consent/refusal** of proposed medical intervention (40)

Physician Orders for Life Sustaining Treatment

www.polst.org

- Website identifies states w programs
  - 27 states w versions of **POLST/MOLST/POST/MOST/IPOST**
- **2 page form signed by MD or nurse practitioner to be valid**
  - Photocopies & faxed forms legal & valid
- **Any incomplete section implies full treatment for that section**
- Oral fluids & nutrition must always be offered if medically feasible
  - **No artificial nutrition by tube OR defined trial period of artificial nutrition by tube OR long term artificial nutrition by tube**
- If comfort can't be achieved in current setting – even w someone w comfort measures only – **transfer pt. to setting able to provide comfort**
- **Review periodically AND when**
  - Pt. transferred from one care setting/level to another
  - Substantial change in health status
  - Pt.'s treatment preferences change

Five Wishes www.agingwithdignity.org(14)



FIVE WISHES®

MY WISH FOR:

1. The Person I Want to Make Care Decisions for Me When I Can't
2. The Kind of Medical Treatment I Want or Don't Want
3. How Comfortable I Want to Be
4. How I Want People to Treat Me
5. What I Want My Loved Ones to Know

print your name

birthdate

888-594-7437

28 languages – sample forms on website

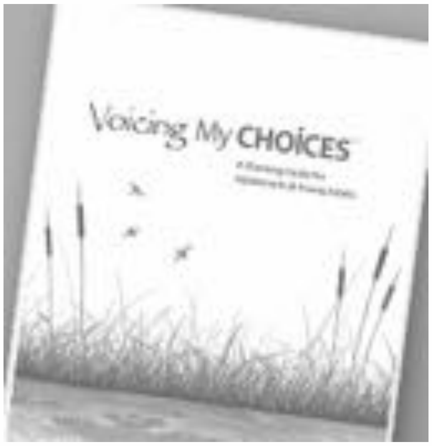
Used in all 50 states

Meets legal requirements for an advance directive in 42 states and DC

8 other states – 5 Wishes can be attached to state form

Voicing My Choices (14)

- Adolescents and young adults living with serious illness
- Age 12-18
- PLANNNG GUIDE - Not a legally binding document
- Provides necessary info to provide tx and care requested by pt.
- Under age 18, parent or guardian has legal rights to make healthcare decisions



Voicing My CHOICES

My Wishes (14)

- Pediatric patients
- Seriously ill children
- Age 5-11

Five Wishes Valid in:

Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Illinois, Iowa, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Oklahoma, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Vermont, Virginia, Washington, West Virginia, Wisconsin, Wyoming

- May attach it to state forms – **Alabama, Indiana, Kansas, New Hampshire, Ohio, Oregon, Texas, Utah (14)**

5 Wishes (14)

- Takes away any prior advance directives
- Considered a legal document
- Choose health care agent and **two alternates**
    - **Make decision to REQUEST, TAKE AWAY or NOT PROVIDE medical treatment including TF, other treatments to keep me alive**
- Sign, witness; **notarize in some states**
    - **17 states offer notarization in lieu of witnesses**
    - **NC, SC, MO and WV require notarization**
- Wallet cards

Treatment I want/don't want

- If close to death…
- Permanent/Severe Brain Damage, no expectations to recover…
- In coma, not expected to wake up or recover…
- Other Conditions Under Which I do not wish to be kept alive…
    - Must identify conditions

- **Want** life support or ANH
- **Don't want** life support or ANH – if it was started, stop!
- Want life support or ANH **if** dr believes it can help **BUT stop** if not helping condition or symptoms

Let Me Decide – New Grange Press Dr. W. Wm. Molloy http://www.letmedecide.ie/

(15)

- Let Me Decide Series – book, video
- Pt. lists what unacceptable level of functioning means to them
- Additional sections identify treatments
  - If loss of functioning **Not Acceptable**, **Not Reversible**
  - If loss of functioning **acceptable** and/or **IS reversible**

  updating directive every 12 months w new signature and date

Basic: **regular diet, fluids by mouth** but NO attempt for special diets, IV fluids or tubes

Supplemental: supplements/special diets (high calorie, fat or protein supplements)

IV: nutrients by IV (water, salt, carbohydrate protein, fat)

Tube: NG or PEG

Others

www.empathchoicesforcare.org

– print living will

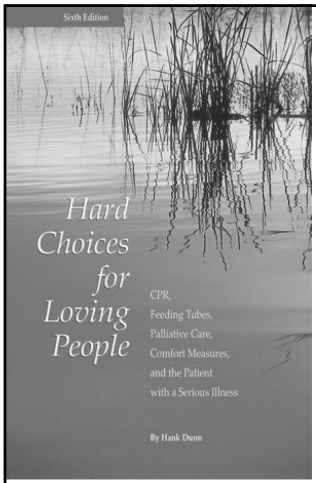
–Specific rules for Arizona, Connecticut, Hawaii, Indiana, New Hampshire, North Carolina, South Carolina, Utah, West Virginia, Wyoming

–Requirements may change – confirm with your state

–Many states include “Not valid if pregnant”

Project Grace - www.projectgrace.org

- ANH during end stage of disease, permanent unconscious state, permanent confusion or total dependence

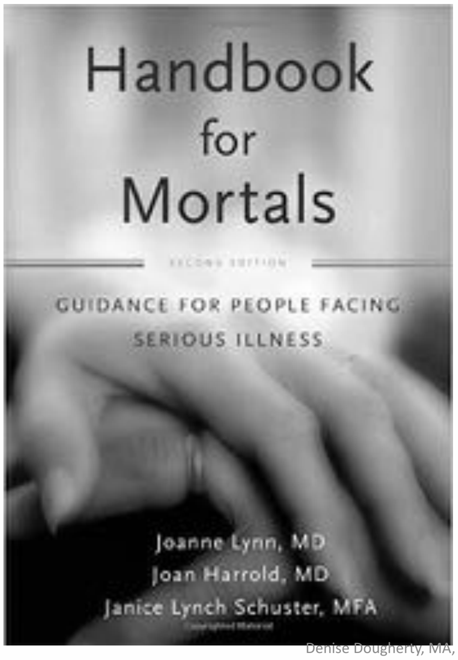


Hard Choices
For Loving People
www.hardchoices.com

Chapter Two: Feeding Tubes

- The Benefits of Artificial Feeding
- Artificial Feeding in Non-Responsive Patients
- The Burdens of Artificial Feeding
- The Case For Artificial Feeding in Most Circumstances
- The Case against Artificial Feeding in Some Circumstances
- Intravenous (IV) Artificial Hydration
- Does Withholding or Withdrawing Artificial Feeding Cause a Painful Death?
- The Difference Between Withholding and Withdrawing
- Artificial Feeding and the Dementia Patient
- Artificial Feeding and Children
- A Time-Limited Trial

download 20 page sample
Available in Spanish, Chinese, Japanese



“Readers will learn what decisions they will need to face, what choices are available to them, where to look for help, how to ease pain and other symptoms, what to expect with specific diseases, how the health-care system operates, and how the entire experience affects dying persons, their families, and their friends.”

Palliative Care

- Improve quality of seriously ill pt.'s life w support during/after treatment
- **Any time during illness**, from diagnosis on
- Palliative care **&** curative care at same time
- Drs. may not use - see this as giving up
- Hospices may provide palliative care as separate program or service - very confusing to pts/families. (7)
- **USA Today Aug. 19, 2010** –New England Journal of Med - pts w lung cancer in palliative care survived 3 months longer than those w standard medical care – **11.6 months vs. 8.9 months**

Additional Websites

- **www.capc.org** = Center to Advance Palliative Care
- **geripal.com** – geriatric and palliative care blog
- **www.medscape.com** – March 2012 issue on oncology – special report on palliative care
- **www.medscape.com** – August 20, 2012 Special Report - Tough talks from Medscape Oncology
  - How and why to talk to the dying pt
  - How to have difficult conversations with pts, families
  - Psychosocial needs matter most at end of life
  - 5 (incorrect) reasons oncologists avoid bad news talks

Hospice or Enhanced Palliative Care

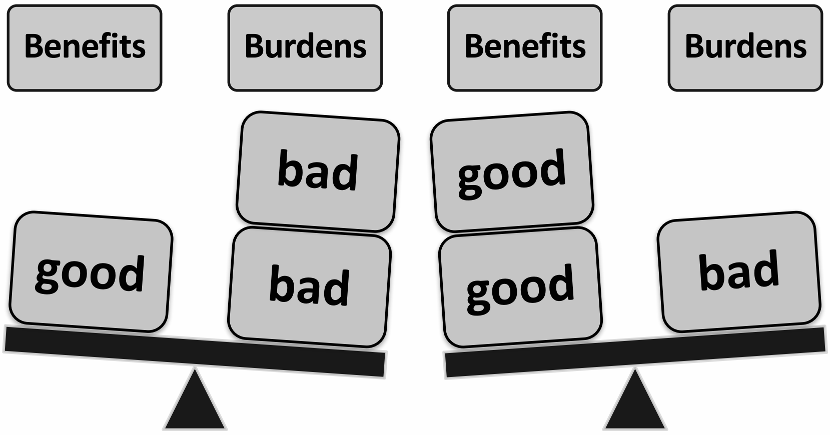
- Focus on relieving symptoms/supporting pts. w life expectancy of **months not yrs.**, & families.
- Special care - nurses/others trained to work w dying pts. & families
- Help pts at EOL make best use of remaining time – QOL
- Hospice care in NH
- Bereavement counseling for families at least 1 yr. following death
- **USA Today Aug 19, 2010** – New England Journal of Medicine – pts. W lung cancer using hospice live approx. month longer than other pts
- Nov/Dec 2005 Hastings Center Report
  - Over **700,000** pts. who die each yr. received hospice services

Comfort Measures

- Keep one comfortable
  - **DNR & possible DNH (do not hospitalize)**
- Control pain and nausea
- Oxygen for breathing difficulties w offer of sedation
- Control anxiety – meds on PRN basis
- Medicate for delirium
- Support emotional and spiritual needs
  - Unlimited visiting hrs. – clergy, family, special friends
  - Soothing music
- Mouth care
- Bowel regimen

PATIENT AND QOL

Which Way Are Scales Tipped? Benefits vs. Burden



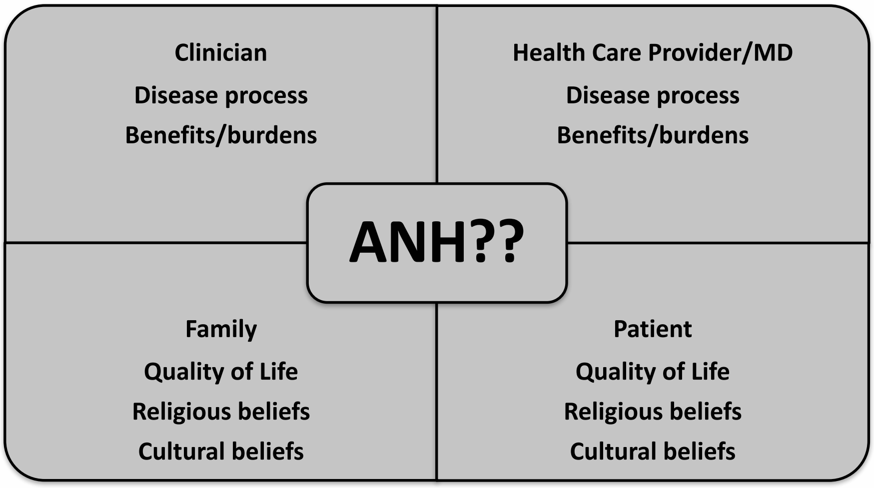
Benefits

Burdens

Benefits

Burdens

Decision: Joint Responsibility!



Clinician
Disease process
Benefits/burdens

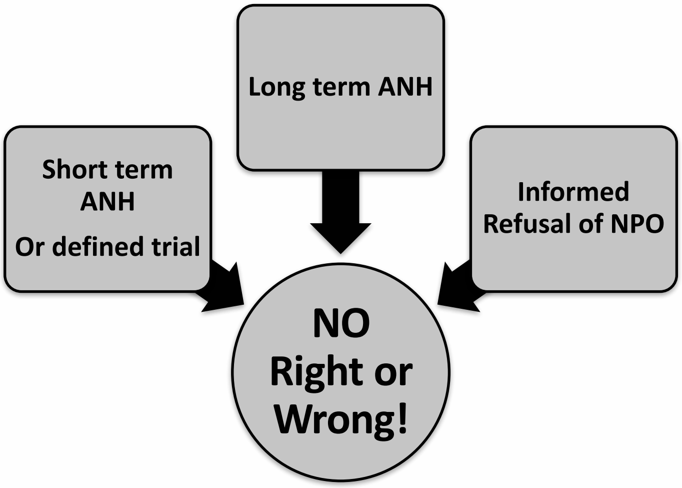
Health Care Provider/MD
Disease process
Benefits/burdens

ANH??

Family
Quality of Life
Religious beliefs
Cultural beliefs

Patient
Quality of Life
Religious beliefs
Cultural beliefs

Patient SPECIFIC!!



Long term ANH

Short term ANH
Or defined trial

Informed Refusal of NPO

NO Right or Wrong!

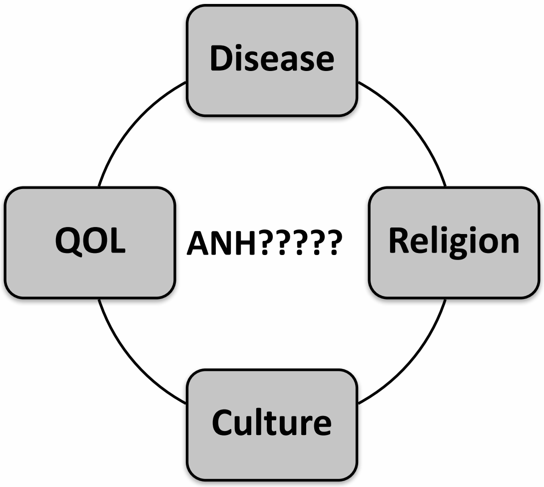
Individuality (41)(42)(43)(44)

1. Is the decision right for this particular pt. at this particular time and in this particular place?
2. Has the decision been re-evaluated on a daily or even hourly basis?
3. Has pt. autonomy been sacrificed for sparing professional and/or family distress?

Individuality (41)(42)(43)(44)

1. Has open ongoing communication been central to the process?
2. Has adequate support been provided to pt., family, and staff to ensure successful outcome, regardless of what course of action is taken?

Patient: Many Influential Factors To Consider!



Key Points

- All decisions are patient specific!
- Culture and religious convictions need to be considered
- Advance Directives make wishes known
- Values History Form often valuable in identifying what is important
- Sensitivity needed for pt./family values, beliefs involved in decision making

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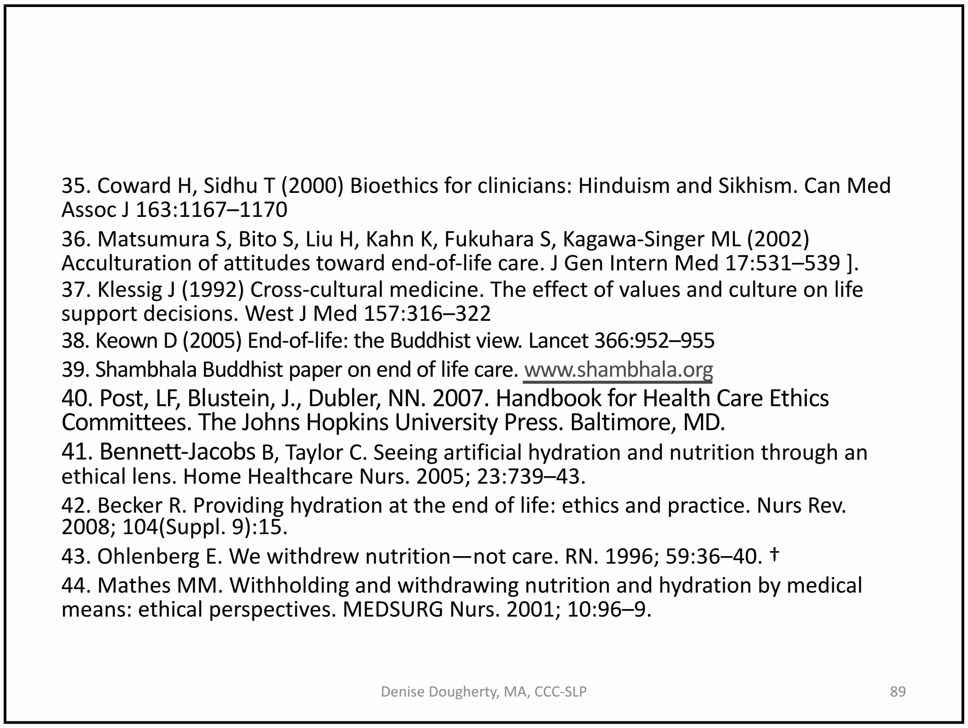

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