MGS ANNUAL CONFERENCE APRIL 27 2018

Wellness Agenda: Healthy Communities. Healthy You.

Quality of Life at the End of Life: Hospice, Ethics, Palliative Care

I'M NOT AFRAID TO DIE ……

I JUST DON'T WANT TO BE THERE WHEN IT HAPPENS

WOODY ALLEN

PRINCIPLES OF ETHICS

- Beneficence- doing more good than harm
- Nonmaleficence- do not intend to do harm
- Autonomy- includes allowing individuals to defer decision making to others
- Justice – no recognized right to health care in the US, Use of resources and health care technology are uneven and reflect biases in age , gender „ race and ethnic origin

INFORMED CONSENT

- Enables patients to have a say in the care they receive
- Needs to explain the condition at hand and associated risks, benefits and alternatives of each therapeutic option
- Has evolved from a paternalistic approach to shared decision making
- To give consent one needs to have decision making capacity

DECISION MAKING CAPACITY

- Understanding
- Appreciation
- Reasoning
- Choice

COMMON MYTHS ABOUT DECISION MAKING CAPACITY

- It is an "all or nothing " phenomenon
- Cognitive impairment means lack of decision making capacity
- It is a permanent condition
- Patients with psychiatric disorders lack decision making capacity
- Only mental health experts can asses decision making capacity

HIERARCHY OF SURROGATES

- Appointed guardian if any
- The individual to whom patient has given durable power of attorney that includes the authority to make health care decisions
- Spouse or state registered Domestic partner
- Children of patients >than 18 yrs. of age (consensus vs majority)
- Parents of patients
- Adult siblings

KAREN ANN QUINLAN

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- On April 14, 1975, after an evening out with friends during which she consumed alcohol and sedatives, the 21-year-old New Jersey resident stopped breathing and lapsed into a coma.
- one of the the first "right to die" case in U.S. legal history.
- the court ruled that "no compelling interest of the state could compel Karen to endure the unendurable" and allowed her to be taken off life support.
- Quinlan's story didn't end there: weaned from the respirator, she survived for nearly 10 more years, dying of pulmonary failure on June 11, 1985 in a New Jersey nursing home.

NANCY CRUZAN

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- The *Cruzan* case set several important precedents
- It established that the right to die was not a right guaranteed by the Constitution.
- It set out rules for what was required for a third party to refuse treatment on behalf of an incompetent person.
- It established that absent a living will or clear and convincing evidence of what the incompetent person would have wanted, the state's interests in preserving life outweigh the individual's rights to refuse treatment.
- It left it to the states to determine their own right-to-die standards, rather than creating a uniform national standard.

BRITTANY MAYNARD

BRITTANY MAYNARD

- Advocate for the right to die
- Died at age 29 from a Brain tumor- Astrocytoma
- Moved from CA to OR
- Passed away on 11/1/2014 surrounded by her family
- Final face book post- "Goodbye to all my dear friends and family that I love. Today is the day I have chosen to pass away with dignity in the face of my terminal illness, this terrible brain cancer that has taken so much from me ... but would have taken so much more."[

ADVANCED DIRECTIVES

- California was the first state to pass a law creating living wills in the late 1970's
- Patient self determination act passed in 1990 encourages facilities that receive Medicare funding to offer patients information on advanced Directives upon admission
- Some DPOA gives surrogates the right to make decisions even if patient has not lost decision making capacity

PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT

- Developed in Oregon to help convey preferences of nursing home patients across health care sites
- Takes into account patient prefences for issues such as antibiotic use , nutrition , vasopressors, ventilators , dialysis , feeding tubes or any other medical procedures
- Can be customized

LESSONS FROM LA CROSSE , WI

- 96% of those who die have advanced directives (national level – 30%)
- Over the last 30 yrs , end of life discussion are common place , EVERYONE talks about it
- Patients and family are the center of the process
- While the document is standard , the process for each patient is unique and intimate
- Medical records are easily accessible

THE FUN FACTS

On the plus side , Death is one of the few things that can be done just as easily as laying down – Woody Allen

WHY ARE WE AFRAID ?

- Inadaequately treated physical distress
- Fragmented care systems
- Poor or absent communication among clinicians, patients and families
- Strain on family care givers and support systems

PALLIATIVE CARE VS . HOSPICE

- Palliative care involves interdisciplinary care that aims to improve physical and emotional suffering, improve QOL, optimize function and assist with decision making and offered in the course of DISEASE MODIFYING treatment
- Hospice is specialized palliative care for people who have 6 months or less to live if their disease takes its normal course OR they have elected to focus on comfort measures and forego curative measures
- Hospice became a Medicare benefit in 1982

COMMON SYMPTOMS AT END OF LIFE - PAIN

- Acute vs chronic
- Nature of pain – Somatic , Visceral, Neuropathic
- Cognitively impaired individuals may exhibit pain by withdrawal, agitation or resistance to care
- At end of life , one may need to consider alternative routes of delivery

COMMON SYMPTOMS AT END OF LIFE – CONSTIPATION

- One of the most common and distressing symptoms
- Opioid medications, reduced mobility and poor fluid intake
- Start prophylactic laxatives at initiation of opiates
- Stool softners- docusate
- Stimulants – Senna , Bisacodyl
- Osmotic laxatives – Lactulose , polyethelene glycol
- Enemas
- Methylnaltrxone
- Lubiprostone

COMMON SYMPTOMS AT END OF LIFE – NAUSEA AND VOMITING

- Subjective sensation mediated through stimulation of GI tract lining, the chemoreceptor rigger zone, vestibular apparatus or the cerebral cortex
- Present in 40 to 70 % of patients with cancer
- ABH gel does not work and should not be used
- Chemo receptor trigger zone – dopamine antagonists, Serotonin antagonists,Neurokinin I receptor antagonist
- GI tract – pharmacokinetic agents, antacids , corticosteroids
- Vestibular – antihistamines, anticholinergics
- Cerebral Cortex- Benzodiazipines, canabinoids

COMMON SYMPTOMS AT END OF LIFE – DIARRHEA

- Affects 7 to 10 % of patients with cancer
- 3 or more unformed bowel movements in a 24 hr period
- If due to laxatives, then temporary cessation and delayed reintroduction at a lower dose
- Treatments include bile acid sequestrants, pancreatic enzymes, octreotide(anti secretory)

COMMON SYMPTOMS AT END OF LIFE – BOWEL OBSTRUCTION

- Multiple causes- intraluminal , compression, volvulus, fecal impaction, adhesions, ileus due to radiation
- Symptoms – hypersalivation, nausea, colicky pain, anorexia , weight loss
- Surgical options – endoscopic stenting, diverting ostomies
- Mainstay is medical management
- Anti secretory agents – glycopyrolate, octreotide
- Anti spasmodic agents- scopalomine, hyoscamine

COMMON SYMPTOMS AT END OF LIFE – ANOREXIA AND CACHEXIA

- Most distressing for families
- High calorie supplements and prescription appetite stimulants not shown to be ineffective
- Use ice chips , moist towels ,lozenges to alleviate dry mouth
- Enteral feedings associated with higher rate of complications and burden of illness

COMMON SYMPTOMS AT END OF LIFE – DELIRIUM

- 50 % of delirium is reversible
- Maybe hypoactive or hyperactive
- Treat with antipsychotics on a scheduled basis
- At end of life sedating antipsychotics such as chlorpromazine are more effective
- BEWARE of benzodiazepines causing paradoxical agitation

COMMON SYMPTOMS AT END OF LIFE – DYSPNEA

- Most effective treatment are opioids – act centrally and decrease perception and do not decrease respiratory drive
- If patients are on opioids a 25 to 50% dose increase may be needed
- Nebulized Morphine and fentanyl
- Oxygen
- Cool air across face stimulates the 5th cranial nerve and has a central inhibitory affect on dyspnea
- Benzodiazepines only if anxiety is predominant

COMMON SYMPTOMS AT END OF LIFE – COUGH

- Normally maintains patency of airways , only treat when it causes significant distress
- Look for underlying cause and treat – diuretics- heart failure, antibiotics- infections, anticholinergics- secretions
- Dextromethorphan- structurally related to opiates , central suppressant
- Methadone syrup- longer half life
- Nebulized lidocaine

COMMON SYMPTOMS AT END OF LIFE – LOUD RESPIRATIONS

- Caused by secretions that build up in the pharynx through which air oscillates up
- Not felt to be uncomfortable for patients but very distressing for loved ones
- Best to prepare loved ones for acceptance of symptoms
- Treatment in anti secretory and anti cholinergic drugs with significant adverse effects

COMMON SYMPTOMS AT END OF LIFE – DEPRESSION

- While standard anti depressant may work , time may be limited
- Psycho stimulants – methylphenidate
- Cognitive behavioral therapy and active listening
- Dying patients need to hear and say 4 things "Please forgive me , I forgive you , thank you and I love you