“End of Life Issues- What you need to know?”

Rochester Recreation Club for the Deaf
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Supporters

- Deaf Health Community Committee Members
  - Cathie Armstrong
  - Michael McKee
  - Mistie Cramer
  - Matt Starr
  - Patrick Sullivan
- University of Rochester’s Center for Community Health
- Rochester Recreation Club for the Deaf (“REAP”)
Special Guest Presenters from Minnesota

- Anita Buel, Deaf Community Health Worker Program Director
- Barbara Schmidt, Founder of Deaf Hospice Education and Volunteers.
- They will present tonight through VP Conference
- Thanks to ZVRS for technical support
Overview

- End of Life Overview
- What is the dying process?
- What are advanced directives?
- Terminal care and hospice
Dying Process

Days or weeks prior to death:

- Rapid decline in activity
  - Lose interest in eating and drinking
  - Sleeping more
  - Lose interest in surroundings
  - Communicate less or become quiet

http://static.howstuffworks.com/gif/dying-4.jpg
True or False?

- What percentage of adults have never had a talk about end of life issues and plans?
  - 42%

Dying Process

Days or weeks prior to death (cont):

- Difficulty swallowing
- Mouth becomes dry (choke easily)
- Loss of bowel or bladder control

Dying Process

Hours before death:
- Breathing patterns change ("Cheyne-Stokes")
- Coughing due to fluid buildup in lungs- ("death rattle")
- Skin turns grayish
- Varying levels of wakefulness (coma to fully awake)
Dying Process

Hours prior to death:

- Hallucinations or delusions ("seeing their loved ones" or "white light")
- Even with coma, person still can hear or feel surroundings

http://www.wholejoy.com/scienceofwholenessparttwo/ndelight.jpg
End of Life Issues?

- CPR
- Intubation
- Shock
- Feeding Tubes
- Intravenous fluids

http://02varvara.files.wordpress.com/2009/02/icu1.jpg
Cardiopulmonary resuscitation (CPR)

- What is the survival rate when a person gets CPR for the following situation:
  - Person is elderly?
    - Less than 5%
  - Person has severe chronic disease?
    - Less than 1%
  - Person is hospitalized?
    - 15%
  - TV shows like “ER” or “Grey’s Anatomy”?
    - 66%

www.compassionandsupport.org/.../death_dying
Cardiopulmonary resuscitation (CPR)

- Low survival rate for older individuals with severe illnesses
- Risk of CPR increases with age
  - Broken ribs
  - Punctured lungs
  - Bruises
Intubation

http://www.aurorahealthcare.org/healthgate/images/Fl00029_96472_1.jpeg
Intubation

- Intubation often leads to mechanical ventilator ("machine breathes for you")
- Can be difficult to get off of machine
- Sedation (placed asleep)
Shock

- Also known as defibrillation
- Effective
- Can leave a burn on body

http://cdn.24.com/files/Cms/General/d/94/f600cd49d6bc4d5f8fe9bf442f14a9ee.jpg
True or False

- Do feeding tubes improve survival?
  - False! They do not improve mortality or quality of life.
Feeding Tubes and IV Fluids

- Dying person may decline food and drinks
- Holding fluids and food is not painful
- During the dying process, starvation leads to high levels of ketones → delusions, “euphoria” or hallucinations
- Providing feeding tubes or IV fluids can prolong dying process and be painful
Life Saving Procedures?

- Many procedures may extend life but quality of life remains poor
- The procedures are costly
- They are stressful for patients and families
True or False?

- New York does not allow family members to make health care decisions for loved ones who are unable to make a decision unless the patient had signed a health care proxy
  - Was True!
  - Now False!

[www.compassionandsupport.org/.../death_dying]
Advanced Directives

- June 1st allowed close family members to make health care decision if reasonable . . .

- But this process is not easy!

- To be safe and sure, get your advanced directives filled out!
End-of-Life costs are high!

- Average Medicare cost (27%):
  - $53,432 (Minnesota)
  - $93,842 (California)

- Often more health dollars are spent at end-of-life than entire lifetime of a patient.

- Poor quality of life for patients (aggressive care) and caregivers become stressed/exhausted.

- Alternative?
Plan ahead!

- Accept our own mortality
- Discuss with family & your doctor
- Less costly
- More peaceful, more humane care
- Hospice care
- Palliative care: relief suffering
- Better quality of life
True or False?

- Advanced directives only start when you are not able to make your own health care decisions?

- True!
Advanced Directives

- Written instructions showing how you want future medical decisions made
- Only if you are unable to communicate or make the decisions yourself
- Orders health care professionals to follow these wishes
Advanced Directives

- Health care proxy
- Living will
- Do Not Resuscitate Orders
- MOLST
Additional comments from Minnesota’s Deaf community experiences

- Consider Long Term Care (LTC) insurance
- Make several copies of HCP/Living Will
- Place a note on refrigerator for First Responders (Police/Fire/Ambulance) indicating location of Advanced Directives in the home.
Additional comments from Minnesota’s Deaf community experiences

- Clarify communication needs and rights with family members, especially with CODAs, when a family member is receiving hospice care.

- Be careful with the meaning of word, “Dying” to avoid embarrassing miscommunications that someone has died.
NYS Health Care Proxy (HCP)

- Tell HCP who will make decisions for you (only if you cannot make your own decisions)
- Discuss with your “agent” your wishes, including organ donation
- Do not need a lawyer (2 witnesses, not “agent”)
- Write down specific examples
- Give “agent” a signed copy
- Can cancel at any time
- Not the same as Living Will
Living Will

- A legal document
- Informs your wishes about medical treatments, not financial assets
- Varies by state
- Becomes effective when incapacitated
- Do not need to choose “agent”
- Good idea to have both HCP & Living Will
Hospice

- Provides comfort and support to patients who are dying
- Provides support for families of dying patients
  - Counseling for grieving
- Goal is to improve quality of life of dying patient
- Provides all types of care but focuses on pain control
- Most hospices take place in the home or at nursing homes (not hospitals)
Hospice Programs

- Can be used when:
  - Person is not expected to live >6 months
  - Terminal illness
  - Desire only comfort care (no life saving procedures)

http://www.spartanburgregional.com/RegionalHospice/PublishingImages/hospice%20doctor-patient.jpg

Hospice Programs

- They do offer:
  - Pain relief through medications
  - Antibiotics if necessary
  - Treatment of dry mouth and constipation
Questions???

- Thank you!
- Next Deaf Health Talk July 15 at 7 pm
- Topic is “Eye Health”
- Dr. Ramchandran from the University of Rochester will present!
- Will be at National Center for Deaf Health Center at 120 Corporate Woods not Deaf Club