

“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



<http://www.nlm.nih.gov/medlineplus/magazine/issues/spring08/images/nursinghome.jpg>



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%

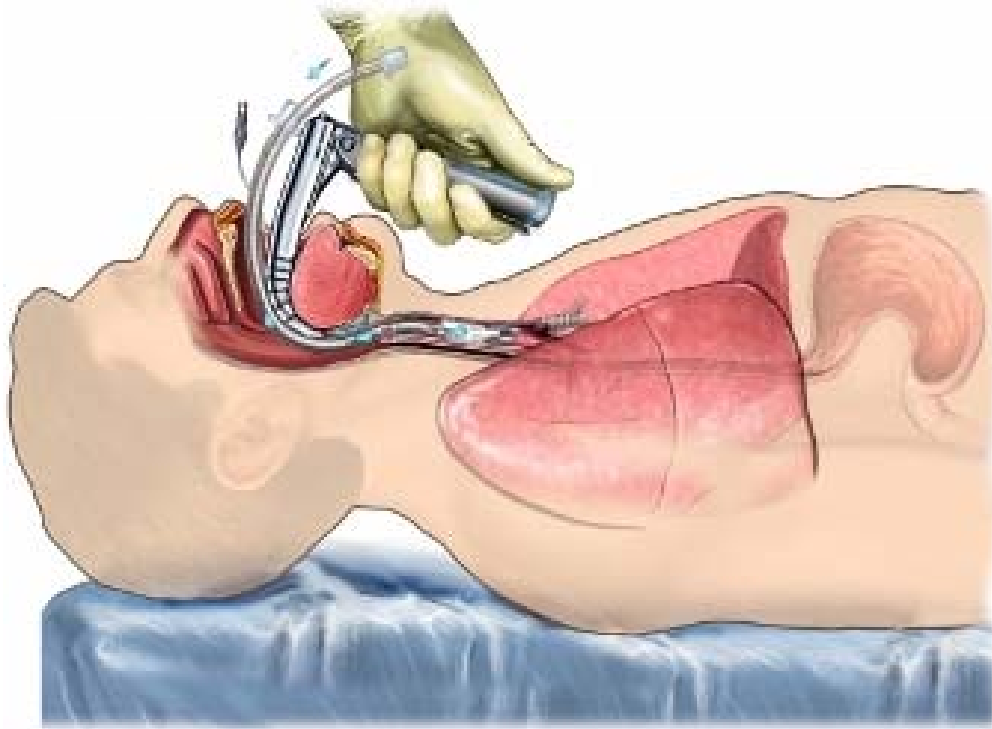


Cardiopulmonary resuscitation (CPR)

- 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/FI00029_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!



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>

http://www.hospicefoundation.org/pages/page.asp?page_id=47055



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

