

## Straight talk! An open and honest conversation about dying...

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## About me...

- 18 years as director of Oregon Hospice Association
- MBA in nonprofit management
- Published in NEJM and other medical journals
- Speaker re EOL care in Oregon
- Member of Oregon and national task forces re hospice and EOL
- Hospice caregiver in 1996
- Diagnosed with MS in 1990
- Diagnosed with SS in 2000

## Americans are planners!

- Careers
- Weddings
- Families
- Vacations
- To-do lists

## Except...

- About the end of life
  - Forcing others to take over when we're
    - Most vulnerable
    - Most in need of understanding and comfort
    - Most longing for dignity

From "End of Life Decision-Making"  
*Family Caregiver Alliance*

## Objectives

- Outline issues we need to think—and talk—about
- Identify resources that can help
- Talk openly and honestly about anything
  - When we're making decisions for ourselves or for our loved ones

## Why is it so hard to talk about dying?

- Don't want to think about it
- My father got mad when I brought it up.
- We didn't want to take away his hope.
- It's too insensitive.
- In my culture, it's an insult.
- Let's look at the bright side.
- Why bother?

## When we do talk about dying, what do we say?

- He didn't make it.
- She passed away.
- We put the dog to sleep.
- Mommy's in heaven.
- He kicked the bucket...

## ..And what do our doctors say?

- "There's nothing more we can do."
- This is never true!

## Rights at the end of life

- pain relief
- refuse treatment
- make wishes known in advance
- hospice and “palliative” care
- physician aid in dying in Oregon

## Oregon’s Death With Dignity Act

- Add experienced-based information to data void
- Not defend ODDA
- Not debate whether assisted dying—or hastening death—is right or wrong

## Assisted Dying: A Legal Option in Oregon

- No longer matters whether physician-assisted dying is right or wrong
- Allowable in state
- Dying Oregonians eligible for *both* hospice and ODDA

## Provisions of ODDA

- Allows terminally-ill adult to request prescription for self-administered lethal medication
- Prohibits euthanasia
- “Physician-assisted suicide” accepted term to describe provisions of law
- Ending life is *not* suicide under Act

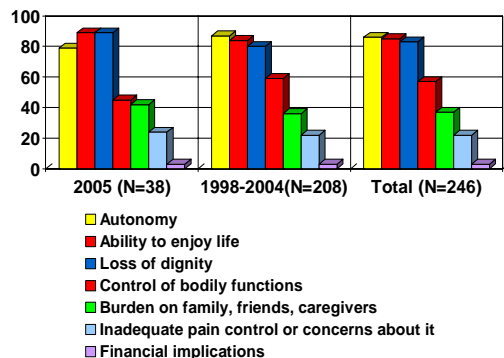
## Patient Requirements

- Oregon resident
- 18 years of age
- “Capable”
  - Able to make and communicate health care decisions
- Terminal illness with 6 months or less to live
- Request must be voluntary

## Perspective

- 240,000 Oregonians died between 1998 and 2005
- 246 used physician-assisted suicide
- 239,754 did not

## Patient Concerns



## Why do so few Oregonians use assisted suicide?

- Because most reasons people give for believing assisted suicide should be legal can be “fixed” in ways that
  - Require no additional legal sanction
  - Practiced throughout country
- Dying Americans can choose from among all

## What are your choices?

- Control pain and other symptoms
- Refuse or withdraw treatment
- Seek hospice and palliative care
- Make decisions in advance
- Appoint health care power of attorney

## Who should you talk to?

- Friends and family members
  - Be open and honest about your concerns
- Your doctor
  - Tell him or her how much you want to know about your illness, your prognosis, treatment options, and hospice

## What should you talk about?

- Who will make decisions for you?
- What care would you want? Or fear?
- Do you want to be resuscitated?
- Do you want to go to the hospital?
- How will your care be paid for?
- What is covered by your insurance?
- What happens when a person dies?

## What are advance directives?

- Written instructions that communicate wishes about care and treatment
  - Living will
- Medical power of attorney
  - Health care representative, agent, proxy or surrogate

## What are doctor's orders?

- DNR
  - Do not resuscitate
- AND
  - Allow natural death
- POLST
  - Physician orders for life sustaining treatment

## Why do you need an advance directive?

- So that medical personnel and your loved ones will know what you would prefer if you are unable to speak for yourself
- So that medical personnel will know who can speak for you if there's disagreement

## What care may be included in an advance directive?

- Artificial feeding
- Mechanical ventilators
- CPR
- Antibiotics
- Dialysis
- Other invasive procedures

## What other instructions might you include?

- That you *do not* want life-prolonging treatments if you will never recover your physical or mental health
- That you *do* want your life prolonged as long as possible

- What you would want under certain conditions
  - if you have dementia
  - if you're in a coma
  - if you have advanced disease
- That you'd want comfort measures or hospice

### What happens if you don't make your wishes known?

- Default is that everything will be done to keep you alive
- Family members and friends will undergo the stress of having to make decisions on your behalf without knowing what you would have done

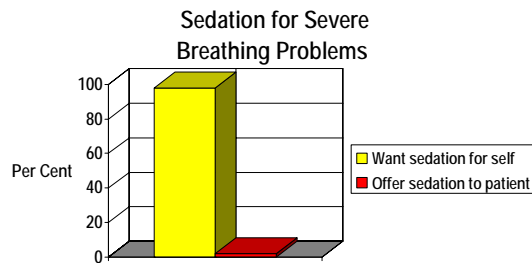
**An advance directive is a "gift" you can give your loved ones**

### What about pain and suffering?

- Dying Americans can have comfort measures, including pain medication, to relieve pain and other symptoms, even if death hastened as effect
  - Pain can be relieved
  - Sedation may be necessary for a few
  - Pain, breathlessness, nausea can be relieved
- No American should die in pain

## Hospital Doctors

Lynn, Goldstein, Annals Int Med, 5/20/03



## Is there a time to begin refusing treatment?

- Americans can say “no” to treatment, even if others disagree
  - Antibiotics
  - Ventilators
  - Tube feedings/IVs
  - Curative treatment or treatment to prolong life
- Americans can stop eating and drinking
- Provisions to refuse treatment can be made in advanced directives

## What is hospice?

- Focus on comfort, not prolonging life, when life expectancy limited
- Support for families and caregivers
- Provided by team of doctors, nurses, home health aides, social workers, counselors, and trained volunteers
- Provided wherever individual is—at home, in a hospice residence, nursing home, foster home, hospital

## What is palliative care?

- Focus on comfort, but prolonging life still part of goal
- Provided by hospice and palliative care teams of doctors, nurses, social workers, and other counselors
- Provided most often in hospitals but moving into homes, nursing homes, other settings

## Does Medicare/Medicaid cover hospice?

- Eligible for Medicare Part A or Medicaid
- Doctor and hospice medical director certify terminal illness and life expectancy of six months or less
- Patient or surrogate chooses hospice care instead of routine Medicare/Medicaid for terminal illness
- Medicare does not yet cover palliative care

## What's included in hospice?

- Plan of care includes
  - Doctor and NP services
  - Nursing care
  - Medical equipment and supplies
  - Drugs to control pain and other symptoms
  - Short term hospital care
  - Respite care

## What's included in hospice? (cont.)

- Home health aide and limited homemaker services
- Physical and occupational therapy
- Speech therapy
- Social worker services
- Dietary counseling
- Spiritual care counseling
- Grief counseling for family and caregivers

## What does hospice pay for?

- Hospices manage the total care and costs of treating terminal illness
  - Medical services
  - Outpatient drugs and most supplies
  - Counseling and bereavement
- Exclusions
  - Room and board
  - Attending physicians or NPs
  - Services unrelated to terminal illness
  - Treatment to cure terminal illness

## How much does the patient pay?

- Hospices may charge a \$5 co-pay for prescription drugs
- Hospices may charge 5% for inpatient respite care
- Treatment unrelated to terminal illness
- Patients get few or no bills

## How long does hospice last?

- No limit under Medicare
- Doctor and medical director periodically re-certify that patient has life expectancy of six months or less, if disease follows its normal course

## Why would hospice stop?

- Medicare beneficiaries have "right" to federal Hospice Benefit
- Hospice patients have "right" to stop anytime and resume regular Medicare
- Patients get better or want to seek cure

## People have nothing to lose in hospice care!

- "Win-Win"
  - If patient doesn't like hospice care he or she can quit
  - If patient gets better, he or she will be discharged...

### What are we afraid of?

- Hospice addresses fears people give for wanting physician-assisted dying
  - Dying in pain
  - Dying in the hospital
  - Being hooked up to machines
  - Being alone
  - Being a burden
  - Losing control
- Oregonians can have both hospice and physician-assisted dying

### What's the #1 complaint about hospice?

- Why didn't we know about you sooner?
  - 50% of all hospice patients die in fewer than 19 days
  - Eligible for hospice when life expectancy is 183 days

### Why are referrals to hospice delayed?

- Doctors don't want to talk about dying either...
  - Doctors wait for patients to ask
  - Patients wait for doctors to tell them "bad" news
- Patients "demand" more treatment

### What happens when hospice referrals are delayed?

- More likely to suffer unnecessary crisis
- More likely to have futile treatment
- More likely to have unrelieved pain
- Less likely to experience a comfortable death

## What we don't know can hurt us!

- Give doctors “permission” to be open and honest—and to tell the truth

## Resources

- Medicare Hospice Benefit
  - <http://medicare.gov>
- Links and resources about end of life care
  - <http://oregonhospice.org>
  - <http://nhpco.org>
  - <http://polst.org>
  - <http://ohsu.edu/ethics>
- Advance directives for every state
  - <http://caringinfo.org>