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An open and honest conversation about choices, because we are, like it or not, facing a life-threatening illness...

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The 15th Annual Cheri Woo Scleroderma Education Seminar in Portland Oregon
Credentials

- 28 years experience
  - Consultant about end-of-life issues and options (2008-present)
  - CEO Oregon Hospice Association (1988-2008)
- MBA in nonprofit management
- Co-investigator of research about EOL
- Member of Oregon and national task forces re hospice and EOL
- Hospice caregiver
Goals

- Share our concerns about living with Scleroderma
- Share our experiences living in Oregon and Washington, our “laboratories” of the states
- Talk openly and honestly about what we would want, if we—or our loved ones—were dying
- Every option is on the table
Some question as to whether we should talk about Oregon’s Death With Dignity Act today—that it may be too depressing.

However, data from Oregon reveal that people with systemic sclerosis are among those most over-represented in the use of the ODDA.
People who worry most about what will happen in the future are those who are most likely to consider asking their doctor for a prescription.
Therefore, physician aid in dying will be first “on the table”

We will talk about why so few people use a prescription to hasten their deaths

We will talk about all options that are available at the end of life—

and, in the process, assure that the conversations we have with our doctors and our families will allow us to have the good death all of us hope to have
Utilization: 991 total —not thousands annually as predicted

- 2015
  - 218 prescriptions
  - 132 used medication
- 1998 to 2015
  - 1,545 prescriptions
  - 991 used medication

http://www.public.health.oregon.gov/ProviderPartnerResources/Evaluationresearch/deathwithdignityact/Pages/index.aspx
Perspective

- 550,000 Oregonians died between 1998 and 2015
- 991 hastened death
  - Less than .2 of 1 percent
  - Less than .4 of 1 percent in 2015
18 Years Experience
Oregon’s DWDA (1998-2015)

- 991 ingested medication
  - Median Age 71
  - 51% male
  - 45% married
  - 72% college educated
  - 99% died at home
  - 98% had insurance
  - 91% enrolled in hospice

Oregon Department of Human Services February 2016

- DWDA Deaths

- Malignant neoplasms (%)
- ALS or Lou Gehrig's disease
- Chronic lower respiratory disease
- Heart disease
- HIV/AIDS
- Other

2015 (n=132)

1998-2015 (n=859)
Why do people ask for AID?

- Future concerns motivate requests for aid in dying.

- People who use aid-in-dying have illnesses with especially distressing symptoms, and can expect to suffer as their condition worsens and disease progresses.
Losing autonomy (%): 92
Less able to engage in activities making life enjoyable (%): 90
Loss of dignity (%): 79
Losing control of bodily functions (%): 48
Burden on family, friends/caregivers (%): 41
Inadequate pain control or concern about it (%): 25
Inadequate pain control or concern about it (%): 3
Financial implications of treatment (%): 2

1998-2015 (n=991)
Hospice is very, very good at addressing needs related to pain.

And this is why pain is so very, very low on the list of reasons why people use aid in dying in Oregon.
Patient Concerns

- Losing autonomy (%)
- Less able to engage in activities making life enjoyable (%)
- Loss of dignity (%)
- Losing control of bodily functions (%)
- Burden on family, friends/caregivers (%)
- Inadequate pain control or concern about it (%)
- Financial implications of treatment (%)
91% of patients who ingested medication to hasten their deaths were enrolled in hospice.
Hospice is not as good at addressing needs related to autonomy.

And respects the patient’s wishes when he or she determines that his or her life is no longer meaningful or dignified.
Patient Concerns

- Losing autonomy (%)
- Less able to engage in activities making life enjoyable (%)
- Loss of dignity (%)
- Losing control of bodily functions (%)
- Burden on family, friends/caregivers (%)
- Inadequate pain control or concern about it (%)
- Financial implications of treatment (%)

1998-2015 (n=991)
Who benefits the most?

- Those who do NOT use the DWDA may be those who gain the most comfort
  - 1 of 200 persons who considers a request will ingest medication
  - 1 of 25 persons who makes a request will ingest medication

Hospice and Aid in Dying?

- Yes—and it is highly recommended.
- Hospice is uniquely qualified to anticipate, palliate and manage the symptoms of a terminal illness
- The hospice team is in a position to monitor the well-being of a patient and family
- Attending and consulting physicians gain confidence in knowing the hospice team is addressing patient/family needs
Hospice workers agree that DWDA offers comfort

- Patients ask for prescription on day 1
- Qualify for prescription on day 15,
- And get on with living

Because they have a plan, just in case
Oregon’s hospice and palliative care professionals agree, too, that conversations have improved since Oregon’s law put dying on the table. A request for a prescription can precipitate conversations about all end-of-life options.
An explanation for “very low rate of assisted” death may be the high quality of care provided by Oregon’s hospices.

- Ganzini et al, “Experiences of Oregon nurses and social workers who requested assistance with suicide”, NEJM 8/22/02
What about palliative sedation?

- Americans have right to be sedated into a coma, if pain and symptoms cannot be managed.
Hospitalists
Lynn, Goldstein, Annals Int Med, 5/20/03

- Want sedation for self
- Offer sedation to patient
Patients don’t know palliative sedation is an option

Doctors would want it for themselves, but rarely offer it to patients

When patients ask for “terminal sedation”, the question may be construed by doctors as a request for euthanasia
A Gap

- Doctors wait for patients to ask about their condition
- Patients wait for doctors to tell them what they need to know, when they need to know it
- Patients **should** give their doctors permission to tell the truth
- Doctors should ask their patients how much they want to know
What about stopping eating and drinking?

- It is often done surreptitiously.
- It should be done with medical supervision to control unpleasant symptoms.
- It compares favorably with AID when used by hospice patients.
Hospice Nurses: Quality of Death
(Rated on scales of 0-9) (Ganzini et al 2003)

<table>
<thead>
<tr>
<th>Variable</th>
<th>VRFF (N=102) (median time to death=15 days)</th>
<th>DWDA (N=55) (waiting period=15 days)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffering (0=none)</td>
<td>3</td>
<td>4</td>
<td>0.007</td>
</tr>
<tr>
<td>Pain (0=none)</td>
<td>2</td>
<td>3</td>
<td>0.13</td>
</tr>
<tr>
<td>Peacefulness (0=peace)</td>
<td>2</td>
<td>5</td>
<td>0.04</td>
</tr>
<tr>
<td>Quality of death (0=bad death)</td>
<td>8</td>
<td>8</td>
<td>0.95</td>
</tr>
</tbody>
</table>
Advance directives

- Oregon
- Washington
POLST (Oregon)

- http://static1.squarespace.com/static/52dc687be4b032209172e33e/t/542ecc87e4b0158794be4454/1412353159011/2014.10.02+Printing+POLST+instructions.pdf
- http://www.or.polst.org/form-details
- http://www.or.polst.org/advance-directives
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- http://www.compassionandchoices.org
- http://deathwithdignity.org
- http://www.oregonhospice.org
Jackson A. Hospice care isn’t enough for all the dying. (Op Ed), Sacramento Bee, December 10, 2015 (http://www.sacbee.com/opinion/oped/soapbox/article48849635.html)


America’s Care of Serious Illness, 2015 State-By-State Report Card on Access to Palliative Care in Our Nation’s Hospitals, https://reportcard.capc.org/

References and Resources (cont)

- Clinical Practice Guidelines for Physician Aid in Dying, submitted by the Physician Aid-in-Dying Guideline Committee (Jackson A member). Compassion & Choices, September 2013.


References and Resources (cont)

- Ganzini L, Goy E, Dobscha S, Prigerson H, Mental health outcomes of family members who request physician aid in dying, J Pain Symptom Mgmt, 2009
- Hedberg K, Tolle S, Putting Oregon’s Death With Dignity Act in perspective: Characteristics of decedents who did not participate, J Clin Ethics, Volume 20, Number 2, Summer 2009 (133-135)
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- Ganzini, L., Goy, E., Miller, L., Harvath, T., Jackson, A., Delorit, M. Nurses’ experiences with hospice patients who refuse food and fluids to hasten death. NEJM, Vol. 349, No.4, July 24, 2003