Aging with Grace:
Prioritizing Your Values and Planning for Care at End of Life

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--aging--
--death and dying--
--surviving and grieving--

Loss is inevitable.

That includes loss of control.

Learning, preparing, reflecting and navigating are important practices.

Death is not principally a medical event.

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Three very good additional resources

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How we die: *Dying trajectories*

* sudden death (<15% get, >95% want)
* known terminal illness (e.g. some cancers): accelerating slope downward: *"I just can't believe the change in mom since yesterday."*
* organ failure (inc. some cancers): ever downward slope punctuated by maintained (lower) levels of functioning
* frailty, debility: low function, petering out: "*What is this old person NOT dying of?"*

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Where We (Older US Adults) Die

Hospital (many last-minute from SNFs)	41%
Skilled Nursing Facilities	22%
Home/Residence	34%
Other	3%

Most Americans are still dying in institutions, though a large majority wish to die at home.

FALLS increase the % dying in hospitals and SNFs.

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Hospice care

- Almost half of people with cancer get hospice care….
- …but are still referred very late (often just 1-7 days before death) ☹
- Non-cancer patients: increasingly being referred to hospice with months still to live, allowing optimal care of patient and caregivers (end stage heart, lung, or kidney disease, general debility, HIV, dementias & other neurological diseases)

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Going on Hospice –and early

- If on hospice: 10 times less likely to be admitted to the hospital during final month of life.
- If not on hospice: average over $27,000 more in healthcare costs than early-referred hospice patients in the last three months of life.
- ER visits are 5 times more likely for late-referred hospice patients than early-referred hospice patients in the last month of life.

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The Medicare Hospice Benefit

- You "elect" (choose) to go on hospice, generally forgoing "regular" Medicare-covered health care.
- You forgo: ER visits, visits to specialists, cure-related or non-palliative treatment of the condition that qualifies you for hospice. These could be transfusions, chemo or radiation therapy, certain procedures, for example.
- You "revoke" (sign off) hospice to resume or start such things.
- There are some exceptions (save for Q & A).

Accepting that you are dying from this condition is the key.

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What does Hospice provide?
(what do you get with hospice?)

- Team-based treatment and case management plan
- All needed medications, equipment for the condition qualifying you for hospice
- Nursing visits, health aide/bathing aide visits, chaplain, social worker, volunteer, sometimes more
- Rescue medications for emergencies
- Support to caregivers too! So often underestimated.
- Not personal caregiving. ***This is very important to know!***

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Palliative Care

- Distinct from (but included in) hospice care.
- Aims to relieve pain and other symptoms, but can be given while other health care continues.
- Helps caregivers too.
- Some insurance coverage is emerging, but not much yet.
- Pharmaceuticals, equipment, spiritual and psychological support, etc.– all may be involved.

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Caregiver issues

Over 1/4 of the US population

provides unpaid care to other adults

- Over 1/3 of such caregivers have (other) employment
- About 2/3 are female
- About 2/3 are married or living with partner
- Average length of caregiving = about 4 years, ↑ with dementia
- About 8 in 10 care recipients are female, 42% widowed

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Caregivers have higher risks

* less likely to engage in preventive health behaviors
* lowered immunity (e.g. slower wound healing)
* increased risk of serious illness and injury
* greater cardiovascular "reactivity"
* increased risk of death within 4 years if reporting "caregiver strain"

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Caregivers in cases of dementia

- Over 7 million dementia pts in USA in 2023. 1 in 10 adults older than 65 have diagnosed dementia. Predicted: 30 million by 2050.
- Caregiver stressors include duration of care, behavior problems, extreme impairment of loved one, transformations, changes in nature of relationship, conflicts with other family members, job-related difficulties, caregiving intensity, navigation of health care system
- Intensity: 50% spend over 11 hrs/day helping with Activities of Daily Living and over 35 hrs/week with "instrumental ADLs" [answering phone, making meals, driving, banking, etc.]
- 59% say they are "on" 24/7 (all day, every day)

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What do unpaid caregivers say?

* 90%: Death was a relief to the patient
* 3/4: Death was a relief to me
* 2/3: I felt prepared for the death
* 2/3: The patient was in pain "often" or "all of the time"

Interventions DO help – both patient and caregiver

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Euthanasia

= medication or procedure by a medical person who is not the patient, intended to end the patient's life to relieve or prevent suffering.

Not legal in the USA under any circumstances. (Canada, The Netherlands, Switzerland, etc. yes)

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Palliative Sedation (Total Sedation)

may be used to treat unremitting agitation or pain at the end of life

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Some different sedation approaches at the end of life

- **standard therapies used first ,** tailored to cause, clinical presentation. Intention = to reduce agitation, promote mental and physical calm.
- **respite sedation** so pt and caregiver can rest. Intention = to produce unconsciousness for a temporary period
- **total or palliative sedation** until death occurs. Intention = to produce unconsciousness until natural death occurs.

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Palliative (Total) Sedation

* **Research suggests does this not hasten death…and in fact may prolong life.**
* **It is supported by Catholic theology and bioethics.**
* **It should involve careful advance planning.**

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Medical Aid in Dying

(in Oregon, the law is the Death with Dignity Act)

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Medical Aid in Dying

- **Must be requested verbally and in writing by the person dying, with a prognosis of less than 6 months remaining to live**
- **Must be signed & submitted by an Attending Physician (physician in charge of the case or procedure)**
- **Must be accompanied by a signed affidavit by a consulting physician**
- **May require a signed affidavit by a psychiatrist or psychologist**
- **Must be reported by the pharmacy providing the medications to be use, and by the Attending Physician after the event.**

Many requirements are involved for all of these elements.

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Voluntary Stopping of Eating and Drinking

(VSED)

https://compassionandchoices.org/our-issues/vsed/

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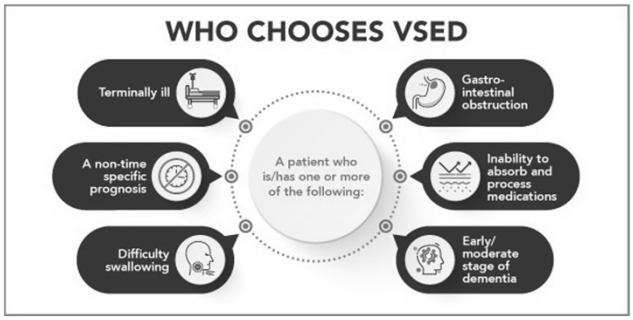

Some people with health challenges choose it just because they feel "I'm done."

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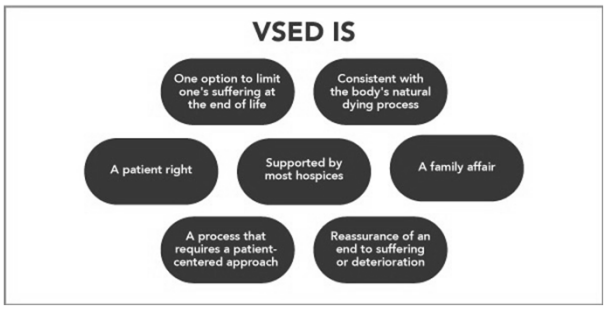

VSED is legal nationwide for mentally capable adults.

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So….given various philosophies about death and dying…facts about aging, dying and caregiving….hospice and palliative care….other options for end of life (~~euthanasia~~, palliative sedation, medical aid in dying, and VSED)…

How can you express <u>your wishes and preferences</u> for your own End of Life?

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EOLCOR End of Life Choices Oregon

Checklist for Clients

Many people postpone making arrangements for the end of life. Planning for the end of life allows individuals to spend their final days with friends and loved ones, focusing on the present. Informing family and friends of your wishes ahead of time relieves them of the possible burden of making decisions about your final arrangements.

Please consider whether the following common tasks are appropriate for you situation.

- Last will and testament or living trust
- Life insurance policies
- Advance Directive
- POLST (Physician Orders for Life-Sustaining Treatment)
- Durable Power of Attorney
- Health Care Power of Attorney
- Memorial service, Celebration of Life and /or funeral arrangements
- Detailed instruction regarding finances (bank accts., passwords, pensions, investments, property, etc.)

For further information:

website http://www.eolcoregon.org or call us at 503-922-1132

(I would add specialized Advance Directives, if appropriate.)

Starting with a general checklist (thanks to EOL Oregon)

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Appointing your Health Care Representative

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Health Care Representative

FORM FOR APPOINTING HEALTH CARE REPRESENTATIVE AND ALTERNATE HEALTH CARE REPRESENTATIVE (STATE OF OREGON)

This form may be used in Oregon to choose a person to make health care decisions for you if you become too sick to speak for yourself. The person is called a health care representative.

- If you have completed a form appointing a health care representative in the past, this new form will replace any older form.
- You must sign this form for it to be effective. You must also have it witnessed by two witnesses or a notary. Your appointment of a health care representative is not effective until the health care representative accepts the appointment.
- If you become too sick to speak for yourself and do not have an effective health care representative appointment, a health care representative will be appointed for you in the order of priority set forth in ORS 127.635(2).

1. ABOUT ME.

Name:_____ Date of Birth: _____

Telephone numbers: (Home)_____(Work)_____(Cell) _____

Address: _____

E-mail: _____

2. MY HEALTH CARE REPRESENTATIVE.

I choose the following person as my health care representative to make health care decisions for me if I can't speak for myself.

Name:_____ Relationship: _____

Telephone numbers: (Home)_____(Work)_____(Cell)_____

Address: _____

E-mail: _____

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OFFICE OF THE DIRECTOR
Office of the State Public Health Director

Oregon Health Authority

Oregon Advance Directive for Health Care

This Advance Directive form allows you to:

- Share your values, beliefs, goals and wishes for health care if you are not able to express them yourself.
- Name a person to make your health care decisions if you could not make them for yourself. This person is called your health care representative and they must agree to act in this role.

Be sure to discuss your Advance Directive and your wishes with your health care representative. This will allow them to make decisions that reflect your wishes. It is recommended that you complete this entire form.

The Oregon Advance Directive for Health Care form and Your Guide to the Oregon Advance Directive are available on the Oregon Health Authority's website.

- In sections 1, 2, 5, 6 and 7 you appoint a health care representative.
- In sections 3 and 4 you provide instructions about your care.

The Advance Directive form allows you to express your preferences for health care. It is not the same as Portable Orders for Life Sustaining Treatment (POLST) as defined in ORS 127.663. You can find more information about the POLST in Your Guide to the Oregon Advance Directive.

This form may be used in Oregon to choose a person to make health care decisions for you if you become too sick to speak for yourself or are unable to make your own medical decisions. The person is called a health care representative. If you do not have an effective health care representative appointment and you become too sick to speak for yourself, a health care representative will be appointed for you in the order of priority set forth in ORS 127.635 (2) and this person can only decide to withhold or withdraw life sustaining treatments if you meet one of the conditions set forth in ORS 127.635 (1).

This form also allows you to express your values and beliefs with respect to health care decisions and your preferences for health care.

If you have completed an advance directive in the past, this new advance directive will replace any older directive.

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Advance Directive for Health Care

(Oregon's standard/ official)

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Initial one option only	
____	I want to try all available treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis and breathing machines.
____	I want to try to sustain my life with artificial feeding and hydration with feeding tubes and IV fluids. I do not want other treatments to sustain my life, such as kidney dialysis and breathing machines.
____	I do not want treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis or breathing machines. I want to be kept comfortable and be allowed to die naturally.
____	I want my health care representative to decide for me, after talking with my health care providers and taking into account the things that matter to me. I have expressed what matters to me in section B below.

c. **Permanently unconscious**
This is what I want if:

- I am not conscious.
  AND
- If my health care providers believe it is very unlikely that I will ever become conscious again.

Initial one option only	
____	I want to try all available treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis and breathing machines.
____	I want to try to sustain my life with artificial feeding and hydration with feeding tubes and IV fluids. I do not want other treatments to sustain my life, such as kidney dialysis and breathing machines.
____	I do not want treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis or breathing machines. I want to be kept comfortable and be allowed to die naturally.

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The POLST Form (Portable Orders for Life-Sustaining Treatment)

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HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT

Oregon POLST®

Portable Orders for Life-Sustaining Treatment®

Follow these medical orders until orders change. Any section not completed implies full treatment for that section.

Patient's Last Name:	Suffix:	Patient's First Name:	Patient's Middle Name:
Preferred Name:	Date of Birth: (mm/dd/yyyy) ____/____/____	Gender: ☐M ☐F ☐X	MRN (optional):

Address (street / city / state / zip):

A Check One — **CARDIOPULMONARY RESUSCITATION (CPR):** *Unresponsive, pulseless & not breathing*

☐ **Attempt Resuscitation/CPR** — Must check Full Treatment in Section B.

☐ **Do Not Attempt Resuscitation/DNR** — If patient not in cardiopulmonary arrest, follow orders in B.

B Check One — **MEDICAL INTERVENTIONS:** *When patient has a pulse and is breathing.*

☐ **Comfort Measures Only.** Provide treatments to relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. ***Patient prefers no transfer to hospital*** *for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.*
Treatment Plan: Provide treatments for comfort through symptom management.

☐ **Selective Treatment.** In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). ***Transfer to hospital if indicated.*** *Generally avoid the intensive care unit.*
Treatment Plan: Provide basic medical treatments.

☐ **Full Treatment.** In addition to care described in Comfort Measures Only and Selective Treatment, use intubation, advanced airway interventions and mechanical ventilation as indicated. ***Transfer to hospital*** *and/or intensive care unit, if indicated.*
Treatment Plan: All treatments including breathing machine.

Additional Orders:

C Check All That Apply — **DISCUSSED WITH: (REQUIRED)**

☐ Patient ☐ Parent of minor ☐ Relative, friend or other support person (without written appointment) - See reverse side for additional requirements for completion in persons with intellectual or developmental disabilities.
☐ Person appointed on advance directive
☐ Court-appointed guardian

List all names and relationship: _____

D **PATIENT ACKNOWLEDGEMENT (RECOMMENDED BUT NOT REQUIRED)**

Signature: | Name (print): | Relationship (write "self" if patient):

This form will be sent to the POLST Registry unless the patient wishes to opt out. To opt out, check here. ☐

E **ATTESTATION OF MD / DO / NP / PA / ND (REQUIRED)**

By signing below, I attest that these medical orders are, to the best of my knowledge, consistent with the patient's **current** medical condition and preferences.

Print Signing MD / DO / NP / PA / ND Name: ***required*** | Signer's Phone Number: | Signer's License Number: (optional)

MD / DO / NP / PA / ND Signature: ***required*** | Date: ***required*** | "Signed" means a physical signature, electronic signature or verbal order documented per standard medical practice. Refer to OAR 333-270-0030.

Must Print Name, Sign & Date

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED
SUBMIT COPY OF BOTH SIDES OF FORM TO REGISTRY IF PATIENT DID NOT OPT OUT IN SECTION D

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Some specialized Advance Directives

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Dementia/ Mental Health Advance Directives

There are two I recommend.
Links are in your handouts.

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VSED Advance Directives

A link to one is in your handouts.

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Medical Aid in Dying (Death with Dignity) forms and resources

We can look at these in the Q & A if desired.
Also in your handouts.

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It's important to know:

- Advance Directives are just that. They do not have the legal strength of a medical order. They express preferences and wishes only, but can make all the difference in cases of controversy.
- Appointment of a Healthcare Representative has legal standing.
- A POLST is a legal medical order. It must be followed unless the patient, with capacity to revoke or change their mind, refuses that order. It is very unusual that a Healthcare Representative is allowed to refuse a POLST order.
- Dementia, or any condition you may have that impairs your capacity to express your healthcare decision, makes things tricky, especially regarding MAD/DWD or VSED.

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