Overview of Oregon's New Advance Directive Form

Developed by the Oregon State Legislature's
Advance Directive Advisory Committee
Spring 2022

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Objectives

1. Ability to show someone where to find the new Oregon Advance Directive and its User's Guide, in one of 13 translations
2. Ability to explain who the Oregon Advance Directive is for, why it is structured the way it is, and how it is different from the POLST
3. Understanding of the guiding principles the Advance Directive Adoption/Advisory Committee utilized to generate the new AD and User's Guide
4. Ability to get additional information and stay up to date with the revised Oregon Advance Directive

Disclosures

- Both presenters have no financial relationships or disclosures
- Woody English, MD, is currently serving on the Advance Directive Advisory Committee (ADAC) as a health care provider with expertise in palliative or hospice care; employed by hospital or health care facility
- Jennifer Hopping, LCSW, is currently serving on the ADAC as the Hospital Representative.

Advance Directive Adoption Committee 2019-2021 Membership

Name	ADAC Role
Stephanie E. Carter, JD	Member of Oregon State Bar with extensive experience in estate planning and end of life decisions
Woody English, II, MD	Health care provider with expertise in palliative or hospice care NOT employed by hospital or health care facility
Bill F. Hamilton	Health care consumer representative
Christopher D. Hamilton, JD	Member of Oregon State Bar with extensive experience in advance directive
Barb Hansen, RN, MA	Health care provider with expertise in palliative or hospice care
Jennifer Hopping, MSW, LCSW	Hospital representative
Nick Kockler, PhD, MS	Clinical Ethicist
Kellie Lapp	Expertise in advising or assisting consumers with end-of-life decisions
Eriko Onishi, MD	Primary health care provider representative
Mike Schmidt, JD	Member of Oregon State Bar with extensive experience in health law
Fred B Steele, Jr., JD	Long Term Care Ombudsman
Katrina Hedberg, MD MPH	State Health Officer (Ret.), Ex Officio
Cara Biddlecom	OHA Staff
Under recruitment	Represents individuals with disabilities

- Public process—news release to solicit applications
- Governor appointed
- Difficulty recruiting representative from disability community

- Committee selected Stephanie Carter, JD, as Chair; and Woodruff English, MD, as vice-Chair
- Staffed by Katrina Hedberg, MD, MPH

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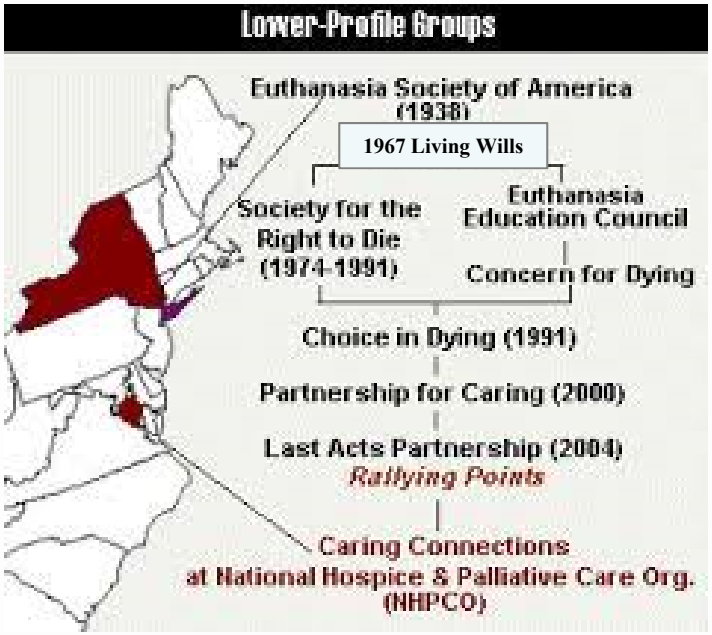
Background - It All Started in the 1970's



Caring Connections
a program of the
National Hospice and Palliative Care Organization

1. The first advance directive was proposed by the Euthanasia Society of America in 1967.
2. A 1969 article written by the human rights lawyer, Luis Kutner, proposed a "living will".
   a) Based on legal ground: "the law provides that a patient may not be subjected to treatment without his (sic) consent."
3. A "living will" would allow for "a testament permitting death". In other words, a person could decline life-saving treatment and establish their decision in advance. First state to enact this was California in 1976. (Karen Ann Quinlan trial was in 1975).
4. In 1991, New Jersey was first state to add the provision to appoint a health care "surrogate".

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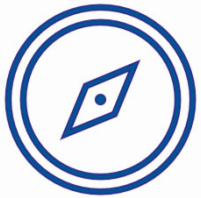
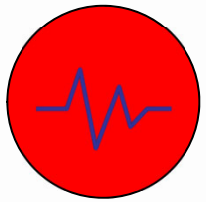
The Advance Directive Has Had Two Functions



1. It provides a way to guide medical care and outline a medical care plan when a person does not have capacity for medical decision making.

   For the most part, these care plans can be put in place following a conference with medical care givers.



2. It also addresses life prolonging measures such as withholding nutrition, antibiotics, and cardiopulmonary-resuscitation (CPR).

   But the decision to do CPR is urgent and does not allow time for a conference, highlighting the need for a Do Not Resuscitate (DNR) request before hospitalization.

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History of the Advance Directive in Oregon

Created in 1993, it was among the early Advance Directives in the United States that permitted "out-of-hospital DNR orders".

- It was established by Legislative action.
  - The intent was to provide a safe harbor for medical actions which followed the Advance Directive instructions.
- The entire directive is still written in Statute (30 of the 50 states have this).
  - We are one of six states requiring that it must be "substantially" in the same form, which effectively prohibits any other form of Advance Directive to be legally valid in Oregon.
  - Essentially, this means it cannot be updated except by act of the legislature.
    - Until recently, there has been no group or lobby accountable for managing it.

There were no changes for a Quarter Century!

- Other states have allowed a more flexible approach to Advance Directives.
  - Theirs are rarely locked so tightly into Statute and are easier to keep current with practice.
- The Oregon Advance Directive fell seriously out of date.
  - The Oregon POLST, which has gained attention and is more current with medical practice, has sometimes been used in lieu of the Advance Directive.
  - In some clinical settings, the POLST is an inappropriate substitute for the Advance Directive.
    - This has created a potential harm.

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Medical Imperatives for the Revision

- Current medical practice requires flexibility
  - The uncertainty factor: many possible medical scenarios
  - Increasing variability of options for treatment and care
  - Just listing specific treatment options no longer sufficient
- Role of Health Care Representative is invaluable
  - Emphasis on outcomes and less on specific medical procedures
  - A need "for the patient's voice" in the "Goals of Care" conversations
  - Importance for understanding the person's values, functional abilities, meaning, and purpose in life

Then

Now

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Oregon's Advance Directive Statute: 2019 Legislative Session

2019 Legislative session: The Oregon legislature made changes to Oregon's Advance Directive law

ORS 127.532: Established the Advance Directive Adoption* Committee (ADAC) within the Public Health Division of the Oregon Health Authority

Specified representation of 13 committee members, length of term, committee rules

ADAC Charge:

- Make recommendations to update Oregon's Advance Directive form
- Review the form at least every four years
- Submit the form to Legislature for ratification
- * Currently the Advance Directive *Advisory* Committee

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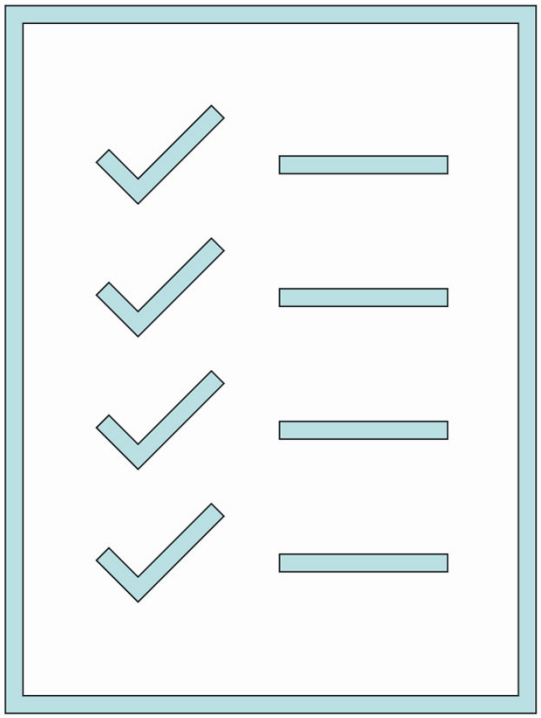
Oregon's Advance Directive Statute: 2019 Legislative Session (2)

The 2019 Advance Directive Statute (ORS 127.533)

- Required form to include designation of a health care representative
- Specified elements that must be included in the form
- Required use of plain language



ADAC Meeting Process & Design

Seven meetings from June 2019 to August 2020

External facilitator – Diana Bianco, Artemis Consulting

In-person and remote options available

Followed public meeting law (posted on website, press release)

- All meetings open to public
- Public comment accepted at meeting and in writing

Steering committee (Ms. Carter, Drs. English and Hedberg, and Ms. Bianco)

- Developed agenda, materials
- Incorporated feedback from committee and public into draft materials

Decision-making based on consensus

Committee Focus

Reviewed current form in statute

Several sections were codified in statute and outside of the ADAC's purview

Agreed that the form needed to:

- Be more flexible than current form
- Focus not just on specific treatments
- Include information about person's values and what makes their life meaningful

Reviewed final draft form

- News release to solicit broad feedback from community and experts
- Reviewed by health literacy expert to ensure plain language

Developed a "User's Guide" to assist in filling out the form

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ADAC Guiding Principles

The Oregon Advance Directive should:

- Provide guidance to the health care representative
- Avoid unintended consequences
- Preserve provider integrity
- Ensure a patient's right to self-determination, to the furthest possible extent
- Be readable, clear and understandable
- Be short and simple (language should be simple; form should be easy to complete)
- Meet legislative requirements

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Oregon's Advance Directive Statute: 2021 Legislative Session

The ADAC presented the draft revised form to the legislature for consideration during the 2021 Regular Session

The 2021 Oregon legislature passed SB 199, which made changes to Oregon's Advance Directive law

The updated Advance Directive form, based on ADAC recommendations with extensive input from the public, was codified in statute

The form was made available for widespread use and download in multiple languages on OHA's website in late 2021

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Oregon's Advance Directive Sections

Preamble

Directions

1. About Me
2. Names of Health Care Representatives
3. Medical Care Preferences
4. Additional Information
5. Signature of Principal
6. Witness or Notarization
7. Signatures of Health Care Representative(s) to accept appointment

Section 1: About Me
Section 2: My Health Care Representative

About Me:	My Health Care Representative:
• Name • Date of Birth • Contact Information	Name, relationship, and contact information for primary, first and second alternative health care representatives

Section 3-A. Medical Care Preferences

A. My Health Care Decisions (Choice of Options)

Three Scenarios:

Four Possible Choices for each Scenario:

- ❑ All Available Treatments
- ❑ Artificial Feeding and Fluids Only
- ❑ No Life-Sustaining Treatments
- ❑ Health Care Representative to Decide

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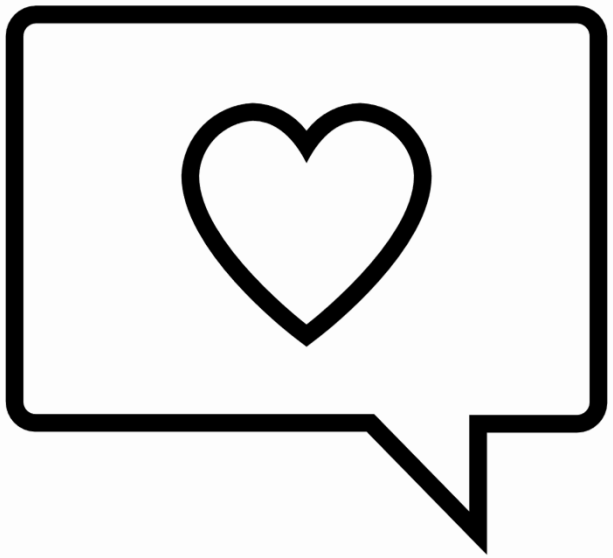
Section 3-B. What Matters to/for Me



This is what is important **to** me about my life

- A place for a narrative about what I value, what is worth living for, etc.
- Also provides multiple choice options to stimulate thinking on this subject

This is what is important **for** me as I live my life

- A place for a narrative about what I need or want to be able to live the life that I value.
- This section was created to aid persons with disabilities to communicate special needs and preferences unique to them

Section 3-C. My Belief System

This option is provided in recognition that serious illness and death are existential threats and a time when people find strength in their belief systems.

This is a completely narrative section for those persons who would want to use it.

Open-ended question about spiritual, personal, or religious beliefs, including topics that may be particularly important (e.g. rituals, sacraments, declination of a blood product transfusion, etc).

Section 4. Additional Information

A. Life and Values

- Provides an open-ended question, which allows for you to answer in a narrative form or to attach documents

B. Place of Care

- Allows you to state where you would want/not want to receive care if there is a choice

C. Space for Adding other Documents

- Allows other documents to be recognized

D. Inform Others

- Allows your Health Care Representative to authorize your health care providers to discuss status with persons you name (includes their contact information)

Sections 5-7: Signature, Witnesses, Acceptance by Health Care Representative

For the form to be valid, it must be signed, dated, and witnessed by either a Notary or two witnesses other than the health care representative or health care provider

Health Care Representatives can accept in any mode that indicates acceptance. As soon as one Health Care Representative has signed, the appointment is valid.

Let's Look at This Again: What Needs to be Completed and Why

"It is hard for people to talk about what is important if they don't know where they are headed."

Tony Back, MD
University of Washington
Founder of *Vital Talk*

The reality is that you usually do not know enough about where you are headed until you get close. So, until then be flexible.

Preamble

Directions

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Option to Walk Through the AD

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What is the Advance Directive, Really?

Most often a Dress Rehearsal waiting for the Diagnosis and Prognosis to show up

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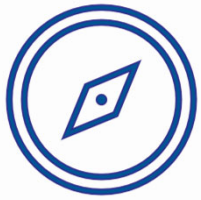
What is Its Purpose, Then?

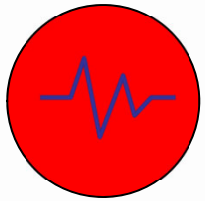
To practice
with the
Understudy
just in case the
Principal (patient)
forgets their lines
on opening night

From the Top:
How has the "Living Will" Evolved?
Advance Directive and the POLST



1. The AD continues to provide a way to guide medical care and outline a medical care plan when a person does not have capacity for medical decision making.

   These care plans can be put in place following a conference with medical caregivers and utilizing the insight of the appointed Health Care Representative.



2. The POLST addresses the Immediate decision as to whether to do CPR and urgent life saving measures such as admission to an Intensive Care Unit

In addition to providing instructions, the new User's Guide:

- Emphasizes having continued conversations with the Health Care Representative
- Gives suggestions for people with disabilities
- Has a table on the differences between the Advance Directive and the POLST
- Advises when to review and update the Advance Directive and what do to after the Advance Directive is completed
- Identifies the kinds of people who can assist with filling out the Advance Directive
- Provides a wallet card for the Advance Directive and name of the Health Care Representative

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Walk-Through of User's Guide

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Current Work of the ADAC is to:

Ensure the AD form and Users Guide are accessible to the general public by using understandable format, plain language, and appropriate translations.

Educate providers and the public about the new Advance Directive form.

Support a process to make this form widely available.

Solicit feedback to uncover weaknesses in the current form to improve the next version.

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Advance Directive and Users Guide Can be Downloaded from the Website in the Following Languages:

English	.docx .pdf	User guide
Spanish	.docx .pdf	User guide
Arabic	.docx .pdf	User guide
Chinese Simplified	.docx .pdf	User guide
Chinese Traditional	.docx .pdf	User guide
Chuukese	.docx .pdf	User guide
Hmong	.docx .pdf	User guide
Japanese	.docx .pdf	User guide
Korean	.docx .pdf	User guide
Marshellese	.docx .pdf	User guide
Portuguese	.docx .pdf	User guide
Russian	.docx .pdf	User guide
Somali	.docx pdf	User guide
Vietnamese	.docx .pdf	User guide

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For More Information:

OHA website:

- Advance Directive Advisory Committee (ADAC): https://www.oregon.gov/oha/PH/ABOUT/Pages/AdvanceDirectiveAdoptionCommittee.aspx
- Form (English and translations): https://www.oregon.gov/oha/PH/ABOUT/Pages/ADAC-Forms.aspx

OHA contact:

Charina Walker Charina.walker@dhsoha.state.or.us, 503-314-8605

Send your feedback and suggestions from this presentation to: woodyenglish@hotmail.com

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Comparing Models of Surrogate Decision-Making

Model	Instructions to Decision-Maker or Health Care Representative
Written or Oral Directive	Interpret the patient's previously written text or serious oral declaration and apply it to the current clinical circumstances.
Substituted Judgment	Choose what the patient would have chosen in the current clinical circumstances.
Best Interests	Choose what you believe would be best for the patient in the current clinical circumstances.
Substituted Interests	Choose what you judge would best promote the good of this patient as a unique person, in the context of their relationships, applying understanding of their authentic values, known wishes, and real interests to the current clinical circumstances.

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"Substituted Interests" & "Best Judgments"

Key Concept

- What the surrogate "substitutes" here are the authentic values of the patient
- The "best judgment" is the best decision for this patient, as a unique person, in these clinical circumstances:
  - Given the patient's authentic values
  - Given the patient's real interests
  - Given physician recommendations based on clinical experience

Goal of the New AD: Better Prepare Surrogates for the Role of Understudy

Not "Substituted Judgments" vs. "Best Interests"

but

"Substituted Interests" & "Best Judgments"

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