
Advance Directive Adoption Committee Update

Katrina Hedberg, MD, MPH
Senior Public Health Physician
Oregon State Health Officer, retired

Stephanie Carter, JD, MPA
Chair, Advance Directive Adoption Committee

Woodruff English, MD, MMM
Vice-Chair, Advance Directive Adoption Committee



Oregon's Advance Directive Statute

- ORS 127.532: Establishes The Advance Directive Adoption Committee within the Public Health Division of OHA
- Charge:
 - Adopt the form to be used in Oregon
 - Review the form at least every four years
- Specifies representation of the 13 committee members, length of term, committee rules
- ORS127.533: Specifies elements that must be included in the form
- Requires use of plain language
- Requires form to include designation of a health care representative

Advance Directive Adoption Committee membership

| Name | ADAC Role | |
|-------------------------|--|--|
| Stephanie E. Carter | 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 | Member of Oregon State Bar with extensive experience in advance directive | |
| Barb Hansen | Health care provider with expertise in palliative or hospice care | |
| Jen Hopping-Winn | Hospital representative | |
| Nick Kockler, PhD, MS | Clinical Ethicist | |
| Kellie Lapp | Expertise in advising or assisting consumers with end-of-life decisions | |
| Eriko Onishi | Primary health care provider representative | |
| Mike Schmidt | Member of Oregon State Bar with extensive experience in health law | |
| Fred B Steele, Jr. | 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
- 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

ADAC Meeting Process

- Seven meetings from June 2019 to August 2020
- External facilitator
- 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
- Final draft form
 - News release to solicit broad feedback from community and experts
 - Reviewed by health literacy expert to ensure plain language

ADAC Guiding Principles

The Advanced 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

Focus of Committee Work

- Review current form in statute
- Several sections codified in statute, and were outside of scope of the committee's work
- Agreement that the form
 - Needs 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
- Develop a "User's Guide" for assistance in filling out the form
- Include a "parking lot" of issues that would be helpful to clarify

Oregon's Advance Directive Sections

| Section of the Advance Directive | Source | Format for Responses on Advance Directive form |
|--|---------|--|
| | | |
| Preamble | ADAC | N/A |
| Directions | Statute | N/A |
| 1. About Me | Statute | Demographic Information |
| 2. Names of Health Care Representatives (HCR) | Statute | Demographic Information |
| 3. Medical Care Preferences | ADAC | Choice Selection & Narrative |
| 4. Additional Information | ADAC | Narrative & Demographic |
| 5. Signature of Principal | Statute | Signature |
| 6. Witness or Notarization | Statute | Signature |
| 7. Signatures of HCR Acceptance | Statute | Signature |

Purpose of a Revised Advance Directive

- Allows more flexibility
 - Uncertainty of events and variability of future options for treatment and care
 - No longer adequate to list specific treatment options
- Special role of the Healthcare Representative
 - Focus on outcomes
 - Incorporate the principles of the “Goals of Care” conversations
 - Emphasis on a person’s sense of their meaning, purpose in life, and their values



Section 3. Instructions: Medical Care Preferences (1)

- My Health Care Decisions (Choice of Options)
 - Three Scenarios
 - Terminal Condition
 - Advanced Progressive Illness
 - Permanently Unconscious
 - Four Possible Choices
 - All Available Treatments
 - Artificial Feeding and Fluids Only
 - No Life-sustaining Treatments
 - Health Care Representative to Decide

Section 3. Instructions: Medical Care Preferences (2)

- My Quality of Life (Guided Choices, Narrative)
 - What is really important for your quality of life?
 - What gives meaning to your life?
- My Spiritual Beliefs (Narrative)
 - Suggested topics

Section 4. Additional Information

- Value Statement (Narrative)
 - May share about your life and values
- Preference for Location of Care (Narrative)
 - Where would you want/not want to receive care
- Space for Adding Supplemental Documents
 - Allows other documents to be recognized
- How to Share Medical Information with Others
 - Accommodates burden created by HIPAA
 - Name persons and contact information

User's Guide to Oregon's Advance Directive

- Purpose of the Advance Directive
- Who is form for?
- What is a health care representative? What is their role?
- Organization of the form
 - Appointment of a health care representative (HCR)
 - Information for the HCR: your wishes and values; options for specific treatments
- Legal requirements
- What is the Advance Directive is NOT
- Differences between the Advance Directive and the POLST
- When to update your Advance Directive
- What do to after Advance Directive is completed
- Other helpful information and links

Additional Issues Identified

- Review sections of form currently in statute, outside the ADAC scope, viewed as confusing, internally inconsistent, and needing clarification
- Clarify forms of verification for the health care representative acceptance of their role
- Clarify which forms of an Advance Directive are valid in Oregon
- Move information about differences between the POLST and an Advance Directive from the form to the User's Guide
- Clarify whether the health care representative discussing the principal's medical condition with others is in violation of HIPAA

Next Steps

- ADAC unanimously recommends that the legislature ratify the proposed Advance Directive form.
- After approval, the ADAC recommends:
 - Conduct a plain language review of the final form before codifying it in statute
 - Reconvene the ADAC to finalize the User's Guide, including plain language review
 - Ensure that form is formatted to be as understandable as possible
 - Translate the form and User's Guide into Spanish, with other languages available upon request
 - Support a process to make form widely available, including education about new form