

Advance Directive Adoption Committee

December 16, 2019

8:30-11:30

Portland State Office Building

800 NE Oregon, Room 177

Goals

- Finalize first draft of Advance Directive form
- Discuss FAQs to accompany form

Agenda

- **Welcome, introductions, agenda review** - Katrina Hedberg, State Epidemiologist and State Health Officer; Diana Bianco, Principal, Artemis Consulting
- **Review revised timeline** - Diana
- **Review draft form** - All
 - Discussion
- **Review FAQs** - All
 - Is this the right content? What are we missing? Anything we should omit?
- **Public comment** (approximately 11:15)
- **Next steps and summary** - Diana
 - Have 3-5 people complete the draft form before next meeting
 - Rescheduling January meeting for early February; scheduling April meeting
 - Mileage reimbursement



Meeting Summary: Advance Directive Adoption Committee

Monday, November 4, 2019
9:00 am-12:00 pm

BACKGROUND, CONTEXT AND SCOPE

The Advance Directive Adoption Committee (ADAC) held its second meeting on November 4th, beginning with a review of the project timeline, and examining the work that was accomplished since the June meeting.

The planning team shared draft documents for discussion that were developed over the summer: guiding principles, value statements, and initial thoughts on a preamble/introductory statement to accompany the Advance Directive (AD).

TIMELINE REVIEW

We reviewed the timeline for our work. The group made several additions to the draft, including confirming our meeting schedule and making sure we create talking points for the Committee. We will revise the timeline and utilize it moving forward.

DIFFERENTIATING THE POLST FROM THE ADVANCE DIRECTIVE

We discussed the difference between a POLST and an AD to ensure everyone had a shared understanding. A POLST is a set of explicit instructions, specific to a critically ill patient. It tells emergency medical attendants what they should do in the event of a medical emergency.

The AD is intended to provide guidance in advance of a hypothetical situation and outlines the general wishes of a patient to their appointed health care representative. Everyone over the age of 18 should have an AD.

PRINCIPLES UNDERLYING THE AD

We discussed draft principles that the AD should meet in its final form and made several suggestions for additions. 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

POTENTIAL QUESTIONS FOR INCLUSION IN THE AD

We reviewed a draft of potential questions for the AD. We reviewed the broad categories for inclusion as well as specific language. Highlights from the discussion are outlined below:

- We should include a section for autobiographical information (e.g. "tell your representative something about yourself and your life"). This is important because in a number of cases, the representative may not personally know the individual who has completed the AD.

- We need to add a section with name, date of completion, etc.
 - We also want to remind people that they should revisit their AD at different times (the 5 Ds). This may be in the instructions section.
- We want individuals to be able to attach supplemental information.
- We discussed whether we should include information about what the individual wants to do with their remains, but decided against it. We may want to remind people in the instructions that they should give instructions regarding the distribution of their remains.
- We may want to consider a cross reference to the Declaration for Mental Health Treatment in the instructions, as well as other potentially relevant forms.
- We discussed the need to specifically break out dementia from other ailments, such as pain and coma.
- We may want to consider a question about placement – where people want to be/how they feel about being in a facility versus their home.
- We considered what medical conditions we might want to add/include, such as pain, dementia, brain injury, vegetative state).
- We discussed the pros and cons of using a Likert scale versus initialing statements.
- We thought it made sense to be consistent in the format of the questions. We need more discussion about the specific structure of questions.
- We decided we would review instructions/preamble in the future.

Public comment

- None

NEXT STEPS

- The planning team will meet in the next few weeks to revise documents, based on the feedback they received today. The planning team will send revised drafts to the Committee in advance of the next meeting.
- The next committee meeting is confirmed for December 16.
- We are also holding January 6th for a tentative meeting – whether we meet will depend on what we accomplish in December.

Attendees

ADAC Members

Stephanie Carter
 Woody English
 Bill Hamilton
 Christopher Hamilton
 Barb Hansen
 Jen Hopping-Winn
 Nick Kockler
 Kellie Lapp
 Eriko Onishi
 Mike Schmidt
 Fred Steele

Public Health Division Staff

Katrina Hedberg
 Nic Riley

Consultant

Diana Bianco, Artemis Consulting

ADVANCE DIRECTIVE ADOPTION COMMITTEE
TIMELINE: 2019-2021

Date	Activity/Deliverable
2019	
June	ADAC Meeting #1 (6/3/19) <ul style="list-style-type: none"> • Introductions, scope, context, charter approval, review of current form, ideas for new form
July	Planning Team* meets, plans and gathers information Committee reviews materials gathered by Planning Team and provides input
August-October	Planning Team prepares materials for discussion
November	ADAC Meeting #2 (11/4/19) <ul style="list-style-type: none"> • Review of ideas for form
November	Planning team meets and revises materials based on Committee input
December	ADAC Meeting #3 (12/16/19) <ul style="list-style-type: none"> • Review form and provide input; finalize first draft
2020	
January	Each committee member vets draft form with 3-5 people
February	ADAC Meeting #4 (TBD) <ul style="list-style-type: none"> • Review form and make changes based on testing Committee vets draft of form with stakeholders Committee available to testify and answer questions from legislature
March	Planning Team meets and revises materials based on stakeholder, Committee, and legislative input
April	ADAC Meeting #5 (TBD) <ul style="list-style-type: none"> • Review and revise form Draft talking points for Committee
May-July	ADAC Meeting #6 (TBD) Finalize form
August	Deliver final proposed form to Oregon Legislature
2021	
January-June	Develop final talking points for Committee Committee available to testify and answer questions regarding submitted form

*Planning Team: Katrina Hedberg, Public Health Division, OHA; Stephanie Carter, ADAC Chair & Woody English, ADAC Vice-chair; Diana Bianco, Artemis Consulting. Additional assistance provided by Katarina Moseley, Dawn Quituaga and Nic Riley.

DRAFT 12/3/19
Advance Directive Form
FAQs
For Discussion Purposes Only

What is the purpose of the Oregon Advance Directive?

In today's highly technical world, people might find themselves taken to a healthcare facility at a time when they may not be able to communicate or to have the capacity to make decisions for themselves.

- The Oregon Advance Directive provides an opportunity for you to influence the kind of care that you might receive under those circumstances.
 - Your care should be consistent with your wishes and values.
- **This is the only Advance Directive Form that is legally recognized in Oregon for this purpose.**
 - It is flexible and designed for all persons who can give consent, because this kind of event can happen at any age in one's life.
- If you do not have a health care representative, a decision-maker will be assigned as established by Oregon law (ORS 127.663).

How does the Oregon Advance Directive work?

The Oregon Advance Directive has three parts. Any one of these parts can stand on its own provided that it is properly validated using the Oregon Advance Directive Form. The three parts are:

1. A section to appoint a Health Care Representative (HCR).

It is recommended that you appoint at least one HCR. However, on this form you may appoint up to three HCR's: a primary HCR, a first alternate HCR, and a second alternate HCR.

- Only one HCR can represent you at a time. In case any of your HCRs are unable to serve, there is a sequence to follow from the primary HCR to the first alternate HCR to the second alternate HCR.
- It is recommended that you have a detailed discussion with each HCR. You can use your Advance Directive to structure regular conversations with your HCR and then take your discussion to a deeper level.
- Any designated HCR must sign the Oregon Advance Directive to approve and to agree to their selection.

2. A section to provide guidance to the HCR and health care team

The form contains simple questions to focus your thinking, to assist in your conversations with your HCRs, and to provide guidance to your HCR and your health care team.

- This section is the place for you to express your wishes and values.
- There are questions and places for you to write in specific thoughts.
- The questions are on topics that frequently arise in the process of designing care plans for persons undergoing medical treatments for serious conditions. They are helpful in starting conversations with your HCRs about how they can best serve you should they be asked to participate in shaping your medical care plan.
- If you do not have an HCR, these questions can help your health care team to make decisions that better fit your preferences.
- You are not required to fill out this section. You may answer all or none of these questions.

3. A section to add supplemental information

The Oregon Advance Directive provides you with the option to add any additional information to guide your care. For example, this may be an essay that you write, a form that you borrow (such as Five Wishes), or a document that expresses your values.

- Supplemental documentation must be made part of a properly completed Oregon Advance Directive to be considered valid.

What does the Oregon Advance Directive *not* cover?

The Oregon Advance Directive is not a medical order. It provides guidance for the creation of a medical care plan for you if you are unable to give guidance yourself.

- By way of contrast, the Portable Order for Life Sustaining Treatment (POLST) is a specific medical order that is completed by a medical professional upon request by the patient. You can see your provider to have a POLST written for you.
- What is the difference between the POLST and the Oregon Advance Directive?
 - The Advance Directive is for all adults regardless of health status.
 - The POLST is for those with serious illness, or frailty, or a limited prognosis.
 - The Advance Directive appoints a Health Care Representative, provides guidance for decision-making and is signed by the individual.
 - The POLST is a medical order and is signed by a health care professional.
 - The Advance Directive provides guidelines for future situations which may arise and for which a person may have preferences for a particular kind of medical care plan.
 - The POLST provides for events that are likely to happen and specific outcomes that can clearly be foreseen. Its medical orders address situations that are very likely to arise given person's health status and prognosis.

How do I complete my Oregon Advance Directive?

To be legally valid, the Oregon Advance Directive must:

- Contain the name, date of birth, address and other contact information of the individual.
- Must be accepted by signature or other applicable means by the individual.
- Must be witnessed and signed by at least two adults, or it must be notarized.
- Once completed, this Advance Directive takes the place of any previous Advance Directive.
- For each HCR to be validated, the Advance Directive must:
 - Contain the name, date of birth, address and other contact information of each HCR and the appointment must be accepted by signature or other applicable means by each HCR.

Should I review my Oregon Advance Directive on a regular basis?

Our perspectives may change over time. What a person values and expects at 25 or 35 years of age may not be the same at 65 or 75. You are encouraged to review and update your advance directive on a regular basis.

In addition, review and update your advance directive whenever any of the "Five Ds" occur:

- Decade – when you start each new decade of your life.

- Death (or Dispute) – when a loved one or a health care agent dies (or disagrees with your preferences).
- Divorce – when divorce (or annulment) happens. If your spouse or domestic partner is your agent, your Advance Directive is no longer valid. You must complete a new Advance Directive, even if you want your ex-spouse or ex-partner to remain your agent.
- Diagnosis – when you are diagnosed with a serious illness.
- Decline – when your health gets worse, especially when you are unable to live on your own.

Are there other forms I should look at that are related to the Advance Directive?

- *?Cross reference to Declaration for Mental Health Treatment if there is a mental health diagnosis.*
- *?Consider separate instructions regarding directions about your remains.*

DRAFT

DRAFT: December 3, 2019
Oregon Advance Directive Form
For Discussion Purposes Only

As you complete this form, we recommend that you discuss its contents and your wishes with your health care representative(s). The role of the health care representative is to make decisions on your behalf when you are not able to express them yourself. These decisions should be consistent with your wishes and values.

Autobiographical information

Below is some basic information I want my health care representative to know about me and my life (information might include childhood, family history, cultural background, career, social support system, leisure-time activities, etc.):

What makes life worth living:

1. Initial the statement that best reflect your feelings:

My life is always worth living, no matter how sick I am

OR

My life is only worth living if I can or am reasonably expected to be able to (initial all statements below that apply):

- Talk to family and friends
- Be free from long-term severe pain and suffering
- Know who I am and who I am with
- Feed, bathe, or take care of myself
- Live without being hooked up to machines
- Think well enough to make day-to-day decisions
- Other factors: _____

OR

I am not sure

Additionally, these are some other things that are important to me: _____

Thoughts about my living environment:

2. Initial all statements that you agree with:

- I do not want caring for me to be a physical burden on my family or friends
- I want to die in my home, if possible
- I would be okay with receiving hospice care in a hospital or nursing facility
- I want to have my family or friends with me when I am close to death

Other thoughts: _____

Importance of spirituality / faith community:

3. Initial the **one** statement that best characterizes your spiritual/faith beliefs:

Spiritual or faith concerns are not important to me

_____ My spiritual life and/or my faith is very important to me

My spiritual or faith community is: _____

Thoughts about dementia:

4. Initial the **one** statement that best expresses your belief in the case of dementia:

- I put great value in living as long as I can, even if it means living with advanced dementia
- I would not want to suffer with dementia even if that means not getting medical treatments to rescue me from dying
- I have no opinion on this issue

Thoughts about interventions:

5. Initial the **one** statement that best expresses your beliefs about health care interventions:

When evaluation of my overall state of health determines that I likely will die:

- I want all reasonably available health care, including life support, tube feeding, and transport to a hospital, necessary to preserve life, even if I am suffering.
- I want some care/ treatment -- try life support, tube feeding, and transport to a hospital, but discontinue if there is no hope for improvement; stop if there is suffering.
- I want comfort care only -- do not initiate life support, tube feeding, or transport to a hospital.
- I want my health care representative and provider to decide what to do.

Additional thoughts I have about interventions are: _____

Other wishes/ concerns:

6. Other specific wishes I have and feel strongly about:

This is a space where you can express additional wishes or beliefs that might impact a choice around your care.

The forms reviewed in preparation of this document included:

1. Health Directive for Dementia, www.dementia-directive.org
2. Your Conversation Starter Kit, the Institute for Healthcare Improvement, theconversationproject.org/wp-content/uploads/2015/09/TCP_StarterKit_Final.pdf
3. Pennsylvania Advance Health Care Directive, www.upmc.com/-/media/upmc/patients-visitors/patient-info/advance-directives/documents/pa-advanced-directive.PDF
4. Values history form, University of NM, Institute of Public Law, hscethics.unm.edu/common/pdf/values-history.pdf
5. Critical Conditions Planning Guide, Emory University Center for Ethics, http://ethics.emory.edu/pillars/health_sciences/Emory_HEC_CriticalConditionsPlanningGuide_2018.pdf