



800 NE Oregon Street, Suit 930
Portland, OR, 97232

Advance Directive Adoption Committee

February 3, 2020

2:00-5:00

Portland State Office Building
800 NE Oregon, Room 177

Goals

- Review and revise draft of Advance Directive form
- Review and revise draft of instructions and FAQs to accompany form

Agenda

- **Welcome, introductions, agenda review** - Katrina Hedberg, Senior Public Health Physician, OHA; Diana Bianco, Principal, Artemis Consulting
- **Review and revise draft form** – All
 - Feedback received and revision of form by planning team
 - Group discussion to determine additional revisions
- **Review instructions and FAQs** - All
 - Is this the right content? What are we missing? Anything we should omit?
- **Public comment** (approximately 4:45)
- **Next steps and summary** - Diana



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Meeting Summary: Advance Directive Adoption Committee

Date/Time:

Monday, December 16,
8:30 am-11:30 am

Background, Context and Scope

The Advance Directive Adoption Committee (ADAC) held its third meeting on December 16, beginning with a presentation of the latest AD format draft, and a review of the revisions to the project timeline. **January's meeting has been cancelled to allow time for committee members to test the current draft. Each committee member is tasked with sharing the form with 3-5 people before February's meeting.** The committee expects to begin receiving questions from the legislature in February, and the final version of the AD is still scheduled for release in August.

DRAFT Review

The current draft reflects the placement/order of questions as required by legislation, and includes mandatory language around life support, tube feeding and transportation to medical facilities.

The current draft has six sections:

1. *What makes life worth living:*

Individuals are asked to initial the statement that best reflects their level of willingness to live with disabling conditions.

2. *Thoughts about my living environment:*

The committee decided that providing "I want to die at home" as an option is problematic. There was also some debate about how much of the issue of placement falls within the scope of the committee's work, considering the possibilities of mental health facility placement.

It was suggested that the issue of placement could be addressed in the instructions section with a statement like, "these answers will help your doctor decide upon your best living arrangements," and that the entire section, "thoughts about my living environment" could be condensed around a question about hospice care.

3. *Importance of spirituality/faith community:*

The question has been simplified to two options: Is faith important or not? And offers the respondent an opportunity to list their spiritual or faith community.

The committee is still divided about the placement of this question. There was some debate about incorporating it into section six, but no decision was made.

4. *Thoughts about dementia:*

Some committee members asked if the term "dementia" was too broad. Should specific cognitive impairments be listed? Again, no decision was made.

5. *Thoughts about interventions:*

Asks the respondent to check one of 4 options regarding their end-of-life care and offers an opportunity to list additional thoughts.

One committee member pointed out that the AD should be designed for use in any situation where a person cannot communicate for themselves. Not necessarily limited to end-of-life situations.

6. *Other wishes/concerns*

Offers a space for respondents to express any additional wishes or beliefs that might impact their care choices.

Important Notes

The committee seems intent on producing a document that includes clear instructions, the AD form itself, and a list of frequently asked questions. The final form could also incorporate a tear-off card for individuals to carry with them.

The committee also decided that they might create a “parking lot” list of issues for the legislature to consider, to be presented along with the final version of the AD.

There was also considerable discussion around Wisconsin’s AD form, which was shared with the committee as an example.

Public Comment

Jim Patterson, retired M.D., commended the committee on their efforts and suggested that “what you need is a form that speaks to people who really don’t think about what makes life valuable to them.” He also encouraged the committee to consider ethnic minority communities and cautioned that it would be “easy to make the document more than it needs to be.”

Donna Rauth, retired R.N., commented on the problematic nature of using “worth living” as a way to describe an individual’s life. She expressed admiration for the Wisconsin AD format and recommended adding a “cultural element” to Section 3’s question about spirituality. She also cautioned the committee not to focus excessively on mental health issues, noting that AD’s are primarily used to make decisions on physical health needs.

Attendees

ADAC Members:

Woody English
Barb Hansen
Eriko Onishi
Mike Schmidt
Chris Hamilton
Jennifer Hopping-Winn
Stephanie Carter
Bill Hamilton
Kellie Lapp
Fred Steele

Public Health Division Staff

Katrina Hedberg
Nic Riley

Consultant

Diana Bianco, Artemis Consulting

DRAFT: January 22, 2020
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.

- 1. Background Information:** You have the option below to share basic information about your lifetime experiences and values that could inform health care decision-making (information might include family history, experiences with the health care system, cultural background, beliefs, career, social support system, etc.):

- 2. Initial the one statement that best reflects your overall feelings about medical care to prolong life:**

I recognize that I am mortal, but **my hope is to live as long as possible no matter how sick I am**. Therefore, I would choose any appropriate medical treatment that will help me to accomplish this goal.

OR

I do not want medical interventions to prolong my life **unless** I can: (initial all statements below that apply):

- Communicate with the people who I care about.
- Be free from long-term severe pain and suffering.
- Know who I am and who I am with.
- Live without being hooked up to machines.
- Other goals: _____

Therefore, I would choose any appropriate medical treatment that will help me to accomplish any of these goals.

OR

I am not sure at this time which of the above statements I most agree with.

Initial the one statement that best expresses your beliefs about specific medical interventions.

(For example, a machine that breathes for you; tube feeding; blood products; antibiotics; fluids given to me through an IV; transport to a hospital.)

If I am sick or injured and my health care providers believe there is little chance I will recover the ability to know who I am, who my family and friends are, or where I am, this is my choice:

- I want the generally recommended medical interventions even if I am suffering.
- I want some medical interventions, but limit them if there is no chance for improvement.
- I want comfort care only (such as pain and symptom control or hospice services).
- I want my health care representative and provider(s) to decide what to do.

3. Initial the one statement that best characterizes how your spiritual/faith beliefs inform health care decision making:

- Spiritual or faith concerns are not meaningful to me.
- Spirituality and/or my faith are somewhat meaningful to me.
- My spiritual life and/or my faith is very meaningful to me.

My spiritual or faith community is: _____.

In making health care decisions, my health care representative should consider the following spiritual and/or faith-based beliefs (e.g., avoid blood product transfusions, rituals and sacraments, etc.):

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

Below is a space where you can express additional wishes or beliefs that might inform your care and where you receive it (e.g. cultural beliefs; deeply held beliefs or wishes not covered above).

You may also attach additional documents or information to this form that you think would be helpful to your health care representative and health care providers if they need to make decisions for you.

I have attached the following documents listed below. Please consider them part of my Advance Directive.

DRAFT: 1/23/20
Instructions for completing the Advance Directive
For Discussion Purposes Only

Overview:

The Advance Directive Form is a legal document that meets the requirements for Oregon and lets you:

- **Name a person (your health care representative) to make your health care decisions if you cannot make them for yourself.** You can name alternative health care representatives if the person you named first or second cannot or is not willing to make those decisions.
- **Write down your values, beliefs, goals, and preferences for future medical care.**

The Advance Directive is meant to inform the people who are going to making decisions about your care and ensure that these decisions are as close as possible to those you would make if you could. Your health care representative(s) can provide input into the health care you receive (including medical treatments and hospice care) and where you get care (such as assisted living facility, nursing home, adult foster home, etc.).

As you complete this form, we recommend that you discuss the form and your values and wishes with your health care representative(s). Unless you talk with your representative(s), they may not know your wishes and beliefs.

The Oregon Advance Directive is divided into 3 sections

1. Appointing a health care representative
2. Guidance to the health care representative
3. Supplemental information

Completing the Advance Directive:

1. Appointment of 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. Of note:

- 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.
- If you do not have a health care representative, a decision-maker will be assigned as established by in the Oregon Advance Directive law.

2. Guidance to the HCR and health care team

The form contains questions to assist in 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, values and goals for care.
- The questions are on topics that frequently arise in the process of designing care plans for persons undergoing medical treatments for potentially life-threatening

conditions. The questions can guide conversations with your HCRs about how they can best serve you should they be asked to participate in shaping your health care.

- If you do not have an HCR, these questions can help your health care team to make decisions that better fit your preferences.

3. Supplemental information

The Oregon Advance Directive is designed to guide decisions about medical treatments that will prolong life. This form is particularly useful when a person may have serious medical conditions, but additional life-saving interventions are not wanted.

If the Oregon Advance Directive alone seems inadequate or inappropriate, individuals can attach supplemental, customized directives specifically designed for unique circumstances, such as the dementia directive (<https://dementia-directive.org>), the Declaration for Mental Health Treatment, or directives produced by individual religious communities.

Legal Requirements:

To be legally valid, the Oregon Advance Directive must:

- Contain the name, date of birth, address and other contact information of the individual completing the form.
- Be accepted by signature or other applicable means by the individual completing the form.
- Be witnessed and signed by at least two adults, or it must be notarized.
- Contain the name, address and other contact information for each HCR.
- Be accepted by each HCR by signature or other applicable means.

Once completed, this Advance Directive takes the place of any previous Advance Directive.

After you complete the form:

1. If you have not already, talk to the person(s) you named as your health care representative(s) about your goals and preferences for future medical care. Make sure they feel able to do this important job for you in the future.
2. Give your agent(s) a copy of this advance directive.
3. Talk to the rest of your family and close friends who might be involved if you have a serious illness or injury. Make sure they know who your health care representative(s) is, and what your preferences are.
4. Give a copy to your doctor and/or your health care facility. Make sure your preferences are understood.
5. Keep a copy of this advance directive where it can be easily found.
6. Our perspectives may change over time. What a person values and expects at age 25 or 35 years may not be the same at age 65 or 75 years. 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.

If your goals and preferences change: complete a new advance directive and talk to your health care representative, your doctor, and everyone who has copies of this advance directive.

DRAFT

DRAFT 1/13/20
FAQs for Oregon's Advance Directive
For Discussion Purposes Only

1. 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. It allows for you to designate a health care representative who can advocate on your behalf for care that is consistent with your wishes, values, and goals.

2. Why do I need to fill out the *official* Oregon Advance Directive form?

Oregon law (ORS 127.663) specifies that the Oregon Advance Directive Form is the only form that is legally recognized in Oregon for this purpose.

3. Who should fill out the form?

The form is designed for all persons who can give legally give consent for medical care, because this kind of event can happen at any age in one's life.

4. What are the parts of an Oregon Advance Directive?

The Oregon Advance Directive Form has three parts. While any one of these parts can stand on its own, it is most useful if all sections are completed.

I. Appointment of 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. Of note:
 - 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.
 - If you do not have a health care representative, a decision-maker will be assigned as established by in the Oregon Advance Directive law.

II. Guidance to the HCR and health care team

- The form contains questions to assist in 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.
- The questions are on topics that frequently arise in the process of designing care plans for persons undergoing medical treatments for potentially life-threatening conditions. The

questions can guide conversations with your HCRs about how they can best serve you should they be asked to participate in shaping your health care.

- If you do not have an HCR, these questions can help your health care team to make decisions that better fit your preferences.

III. Supplemental information

- The Oregon Advance Directive Form allows you to add any additional information to guide your care. This might include information you provide, a form that you borrow (such as Five Wishes), or a document that expresses your values.
- Note: This supplemental information must be made part of a properly completed Oregon Advance Directive to be considered valid.

5. What are the legal requirements for my Oregon Advance Directive to be valid?

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.

6. What does the Oregon Advance Directive *not* cover?

The Oregon Advance Directive is not a medical order. It provides guidance for health care planning if you are unable to give guidance yourself.

7. What is a POLST?

The Oregon 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.

8. What is the difference between the Oregon Advance Directive and the POLST?

- 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 specific medical care interventions.
 - 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.

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

Our perspectives may change over time. What a person values and expects at age 25 or 35 years may not be the same at age 65 or 75 years. 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.

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

- *Dementia decisions* <https://dementia-directive.org>
- *POLST* <https://oregonpolst.org/patientfamilyresources>
- *?Cross reference to Declaration for Mental Health Treatment if there is a mental health diagnosis.*
- *?Consider separate instructions regarding directions about your remains.*

DRAFT

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: _____

I choose the following people to be my alternate health care representatives if my first choice is not available to make health care decisions for me or if I cancel the first health care representative's appointment.

First alternate health care representative:

Name: _____ Relationship: _____

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

Address: _____

E-mail: _____

Second alternate health care representative:

Name: _____ Relationship: _____

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

Address: _____

E-mail: _____

3. MY SIGNATURE.

My signature: _____ Date: _____

4. WITNESS.

COMPLETE EITHER A OR B WHEN YOU SIGN.

A. NOTARY:

State of _____

County of _____

Signed or attested before me on _____, 2_____, by _____.

Notary Public - State of Oregon

B. WITNESS DECLARATION:

The person completing this form is personally known to me or has provided proof of identity, has signed or acknowledged the person's signature on the document in my presence and appears to be not under duress and to understand the purpose and effect of this form. In addition, I am not the person's health care representative or alternative health care representative, and I am not the person's attending health care provider.

Witness Name (print): _____

Signature: _____ Date: _____

Witness Name (print): _____

Signature: _____ Date: _____

5. ACCEPTANCE BY MY HEALTH CARE REPRESENTATIVE.

I accept this appointment and agree to serve as health care representative.

Health care representative:

Printed name: _____

Signature or other verification of acceptance: _____

Date: _____

First alternate health care representative:

Printed name: _____

Signature or other verification of acceptance: _____

Date: _____

Second alternate health care representative:

Printed name: _____

Signature or other verification of acceptance: _____

Date: _____

Advance Directive Adoption Committee
January 2020

Themes from feedback we received

- It was hard to complete without instructions (needed to know it was a legal document; place for signature; what to do to make it legally binding)
- Needed the link with the appointment form
- Make instructions super clear (e.g. initial one of the following)
- Autobiographical information should be tied to health care decision making
- A number of suggested language changes for clarity
- Concerns about first question
- Questions should all be related to health care decision making
- Concerns about including dementia
- Concerns about the use of the word “feasible”
- Didn’t like the option of “I have no opinion”