

Guide to Supporting Individual Preferences in Medical Decision-Making

Background

Allowing individuals to make their choices known ahead of time helps to inform the people caring for them of their wishes and can help reduce anxiety and concern over medical treatment. The information in this document from the Office of Developmental Disabilities Services (ODDS) is intended to support case managers to help guide families and caregivers in navigating difficult conversations about medical care, including end of life choices.

Knowing the Person's Rights

Individuals cannot be denied treatment or care because they have an intellectual or developmental disability (I/DD). All adults also have a legal right to make their own medical decisions unless someone else has been appointed to make these decisions, either by the person themselves, or by some other legal authority.

Even then, the appointed person must continue to take into consideration the person's preferences and wishes regarding medical care and treatment. When a person is at a medical facility or talking

with medical professionals, they have a right to have information explained in a way they understand. If they have difficulty understanding what the medical professional is saying, the person can ask them to rephrase or slow down or tell them they would like to have a caregiver, advocate, or family member present to help.

When they go to a doctor's office, hospital, or are riding in an ambulance, there are tools available to help with communication, including health care communication boards. Under Oregon law, individuals with intellectual and developmental disabilities have the right to have a support person with them in the hospital. Hospitals must allow individuals with intellectual and other disabilities to identify at least three people to support them while in the hospital. Hospitals must also ensure a designated support person is present for any discussion related to documenting a decision to withholding or withdrawing life-sustaining treatment (for example, an Advance Directive, POLST, or other form) unless the person does not want a support person there. See [Senate Bill 1606](#) passed during Oregon's 2020 special legislative session.

It is against the law for medical professionals to not treat a person when they are injured or ill, especially based on race, gender, disability, or ability to pay. If the person shares that they have experienced discrimination, consult with an advocacy group. See the related "Know Your Rights" Fact Sheet. Oregon Health Authority has also issued [guidance on non-discrimination in medical treatment](#). A hospital may not condition treatment, or suggest treatment is conditioned, on

individual having a POLST, Advance Directive, or documentation of a decision to withhold or withdraw life sustaining treatment.

When should I speak with an individual about medical decisions and end of life care preferences?

Anytime is a good time to talk with someone about their wishes for medical treatment and care. Other times to have these conversations may be after someone gets a serious diagnosis, or when they are aging and starting to have a decline in their overall health. Case managers should consider revisiting this conversation every year or two, particularly as the person gets older or as healthcare needs change.

Make sure when you talk with someone about their wishes that they are in an environment they are comfortable in and that they have some privacy, when possible. Talking around others, especially if they do not have the same wishes or beliefs can make someone feel uncomfortable and not be as open or honest as they would like to be. Sometimes it's just not the right time to talk, so if someone isn't receptive, try again at another time. People's beliefs vary, so do not judge, or try to change someone's mind if they do not have the same beliefs or do not make the same choices as you.

Often people will be open to identify a support person, or appoint a Health Care Representative, even if they do not want to consider deciding about end-of-life treatment. The person should be supported to document the preferences and decisions they are comfortable with and are ready to make an informed choice about.

What are options for documenting preferences for medical treatment?

Some people will document their preferences for treatment before seeking medical care is needed. There are online examples of tools for documenting preferences when seeking medical care. The tool may be used to document treatment or the person's support team. ODDS has a transmittal with [Senate Bill 1606 resources](#).

What are options for documenting preferences for end-of-life treatment and care?

There are two important tools to help a person communicate their end-of-life treatment preferences to medical professionals providing care. They are the Advance Directive and the POLST. Treatment or care cannot be conditioned upon completion of these tools. Also, a person can document their treatment preferences in other formats as well. Hospitals are required to ensure an individual's chosen supporter is present for any discussions about electing for hospice care or withdrawing or withholding life-sustaining treatments. See Senate Bill 1606 from 2020 short session.

Advance Directive

An Advance Directive allows a person to document their treatment preferences for medical care and life support so doctors will know what they want even if they can't communicate because they are sick or injured. It also appoints someone chosen by the person to make

decisions on their behalf if they are not able to communicate for themselves. This person is called a Health Care Representative (HCR). The HCR has a legal duty to make medical decisions for the person they represent based on the treatment preferences the person has shared with them and based on what the HCR believes they would have wanted. If the HCR does not know what the person would have wanted, then the decision must be made based on what is in the person's best interest.

If the person has not appointed an HCR, then the order of family and friends looked to in order to make a decision is listed under [Oregon Revised Statutes \(ORS\) 127.635\(2\)](#). If an HCR still cannot be identified, then life-sustaining procedures may be withheld or withdrawn upon the direction and under the supervision of the attending physician.

Life-sustaining procedures may only be withdrawn after consulting with family and close friends and, if applicable, the person's case manager. A case manager who receives notice regarding the intent to withhold life-sustaining treatment is required to provide any information in the case manager's possession that is related to the person's values, beliefs and preferences related to life-sustaining procedures.

Appointing a Health Care Representative (Alternative to Advance Directive)

This can be used if a person wants to appoint a Health Care Representative, but not necessarily complete an entire Advance Directive. It appoints someone chosen by the person to make medical

decisions on their behalf if they are not able to communicate for themselves.

[Appointing a Health Care Representative](#) (Alternative to Advance Directive).

Oregon POLST™

POLST stands for Portable (or Physician) Orders for Life-Sustaining Treatment. It is a form that turns a person's medical treatment preferences into a medical order. Filling out a POLST is always voluntary, and a doctor may bring up a POLST if someone is seriously ill and nearing the end of their life. It documents what types of medical treatments and life support a person wants to treat their serious illness and records their preferences around receiving CPR (cardiopulmonary resuscitation) if they stop breathing. A POLST is not appropriate for someone with a disability just because they have a disability. It is only for people with serious conditions like cancer or advance heart disease, who want to make sure their treatment preferences are honored at the end of their life.

Another term to be familiar with is DNR - Do Not Resuscitate. This is a personal decision someone makes so that medical professionals know how to take care of them during an emergency. Being "DNR" means if a person has a life-threatening injury or illness, medical staff will not do CPR or other invasive procedures to keep them alive. A person can have a DNR and a POLST, as they are not mutually exclusive.

The Advance Directive and the POLST are similar, but there are some

important differences:

Advance Directive	POLST
Voluntary - can't be required.	Voluntary - can't be required.
Not a medical order and can't be followed by emergency medical technicians. An Advance Directive is a legal document.	Medical order signed by a medical professional; will be followed in an emergency.
Completed anytime, regardless of health. Adults only.	Completed when nearing end-of-life.
Can be changed or revoked at any time.	Can be changed or revoked at any time, with the assistance of a medical professional.
Makes end-of-life decisions known.	Makes end-of-life decisions known.
Filled out by individual.	Filled out by medical professional (with the person's approval).
Signed by individual, witnesses, and Health Care Representative.	Signed by medical professional.
Appoints a Health Care Representative.	Does not appoint a Health Care Representative.
Copies need to be given to the doctor and HCR.	A POLST can be added to the POLST registry so a doctor in any hospital in Oregon would know a person's treatment wishes.

When deciding what choices to make for end-of-life treatment,

these are some important questions to consider:

Does the person want to be intubated?

Intubation is when a tube is inserted into a person's mouth and down their throat to help bring air down into the lungs so they can breathe. This is usually temporary until the person's body is well enough to breathe on its own again.

Does the person want to have a machine breathe for them if they cannot do it on their own?

A ventilator is a machine that is used to help a person breathe when they cannot do it on their own. This is usually temporary until the person's body is well enough to breathe on its own again.

Does the person want to have CPR?

CPR - Cardiopulmonary Resuscitation is an emergency life-saving procedure performed when the heart stops beating. CPR helps bring blood flow back to the person's organs to help keep them alive when they are not responsive and not breathing.

Does the person want to have a tube in their stomach to feed them if they cannot eat any longer?

What is tube feeding? There are several types of tubes that can be inserted either temporarily or permanently into the body to give food.

If the person's brain is injured and cannot deliver the support to

their organs, do they want to be on life support? What is life support?

Life support is used to describe when someone may need to have a combination of machines and medicine to help keep them alive when they are seriously injured or ill.

If the person is at the end of their life, where do they want to be supported – at home or at a medical facility?

People may have a choice in where they want to spend their final days. Deciding whether someone wants to be supported in their home or at a facility is an important topic to discuss.

Sharing Information with the Health Care Team

If the person has a residential provider, the provider must notify case managers when a person is admitted to the hospital. The case manager should make any information regarding the person's treatment preferences available to the health care team upon receiving notification that the person is seeking medical treatment.

Notification to ODHS and the Case Manager is Required before Withholding or Withdrawing Life-Sustaining Treatment

A Health Care Representative, attending physician, or attending health care provider statutorily appointed under ORS 127.635(2) or (3) to decide to withhold or withdraw life-sustaining treatment for a person who has an intellectual or developmental disability must notify the case

manager before life sustaining procedures may be withheld or withdrawn. See ORS 127.635(5) and Senate Bill 1606.

More information can also be found in the related fact sheet on [Required Notification to Case Manager Before Withholding or Withdrawing Life-Sustaining Treatment for Individuals with Intellectual and Developmental Disabilities](#).

If the designated person (attending physician, attending health care provider, or statutorily appointed Health Care Representative) knows who the case manager is, then they may give notice to the case manager through any reasonable means (phone call, email, etc.).

If the designated person has a reason to believe the person might have an intellectual or developmental disability, but does not know if they have a case manager or are enrolled for ODDS services, then the designated person may provide notice by sending a secure email to ODHS at: IDD.Report@odhsoha.oregon.gov.

The following information must be included in the secure email to ODHS:

- Information regarding the purpose of the email (for example, notification regarding withholding or withdrawing of life-sustaining treatment).
- The person's name, date of birth, social security number, and prime number if available (ODDS identification number).
- Contact information for responding to the designated person, health care provider, and health care team.

If there is no case manager, ODHS will respond with this information. If there is a case manager, then ODHS will respond and CC the CDDP program manager or Brokerage Director. The case management entity is responsible for responding to the hospital, health care team, or Health Care Representative with information regarding the person's preferences for treatment. Particularly information regarding the person's values and beliefs with regards to withholding or withdrawing life-sustaining treatment. The case management entity is also responsible for following up with those close to the person to gather relevant information, and then sharing that information with the health care team.

How to Send a Secure Email

All personally identifiable information must be sent securely when transmitted electronically. To obtain a secure email for submitting notification, send a blank email with no personal information to:

IDD.Report@odhsosha.oregon.gov.

You will receive an auto reply to gain access to ODHS secure servers. The email received from the email box contains a secure message, but it is not secure itself. In the original auto reply email, click on the box that says, "View Message" and reply within the secure system with the information listed above.

Appointing Others for Support

The person is the decision-maker and should be supported to make

their own health care decisions to the maximum extent possible. The person may need supporters for assistance to gather information, evaluate the information, and make their own decision. Supporters may also be needed to communicate the decisions and preferences for medical treatment to the health care team. A great resource is the [“Taking Charge of My Own Health Care Decisions Toolkit”](#) developed by the [Oregon Self-Advocacy Coalition](#), the Oregon Office on Disability and Health and the [University Center of Excellence in Developmental Disabilities](#).

Appointing supporters

A person may want to designate others to support them if they become sick and need to go to the hospital. A person has the right to identify at least three people to support them in the hospital, and always have at least one of those supporters present. The hospital must also ensure a supporter is present for any discussion that may lead to documentation of a decision to withhold or withdraw life-sustaining treatment (e.g., Advance Directive, POLST, etc.).

Appointing Health Care Representatives

The person might also want to appoint a Health Care Representative to make decisions on their behalf if they get too sick to make or communicate their own decisions. This is often done well in advance of getting sick or needing to seek health treatment.

A person can use this form to [appoint a Health Care Representative](#).

If a person also wants to document other preferences for treatment, to guide a Health Care Representative, they may want to consider completing an [Advance Directive](#).

Health Care Advocates (HCA)

The HCA can make certain medical decisions on behalf of the person they represent. The HCA is not authorized to make decisions about withdrawing or withholding life-sustaining treatments, but they do have a duty to inform the medical team of the person's values, preferences, and beliefs.

An HCA can be appointed when certain conditions are met, including:

- A physician or court has determined that the person is unable to provide informed consent.
- The individual does not object and does not have a Health Care Representative or a legal guardian with medical decision-making authority and the team agrees that the support of HCA is needed.

If you support someone who is unable to make medical decisions or self-appoint a Health Care Representative, the person may be able to benefit from the support of an Individual Support Plan (ISP) team appointed Health Care Advocate (HCA) as per [Oregon Administrative Rule 411 – 390](#).

ODDS offers [Health Care Decision Making](#) webinars for case managers and ISP team members on HCA, Advance Directive, and POLST.

Decision to withhold or with draw life-sustaining treatment

The decision to withhold or withdraw life-sustaining treatment may only be made under certain situations outlined under ORS 127.635, including when the person is medically confirmed to be in one of the following conditions:

- a. A terminal condition.
- b. Permanently unconscious.
- c. A condition in which administration of life-sustaining procedures would not benefit the person's medical condition and would cause permanent and severe pain; or
- d. An advance stage of a progressive illness that will be fatal, and the person is consistently and permanently unable to communicate by any means, to swallow food and water safely, to care for the person's self and to recognize the person's family and other people and is very unlikely that the person's condition will substantially improve.

The statute also outlines who may make this decision. This is in the following order of priority:

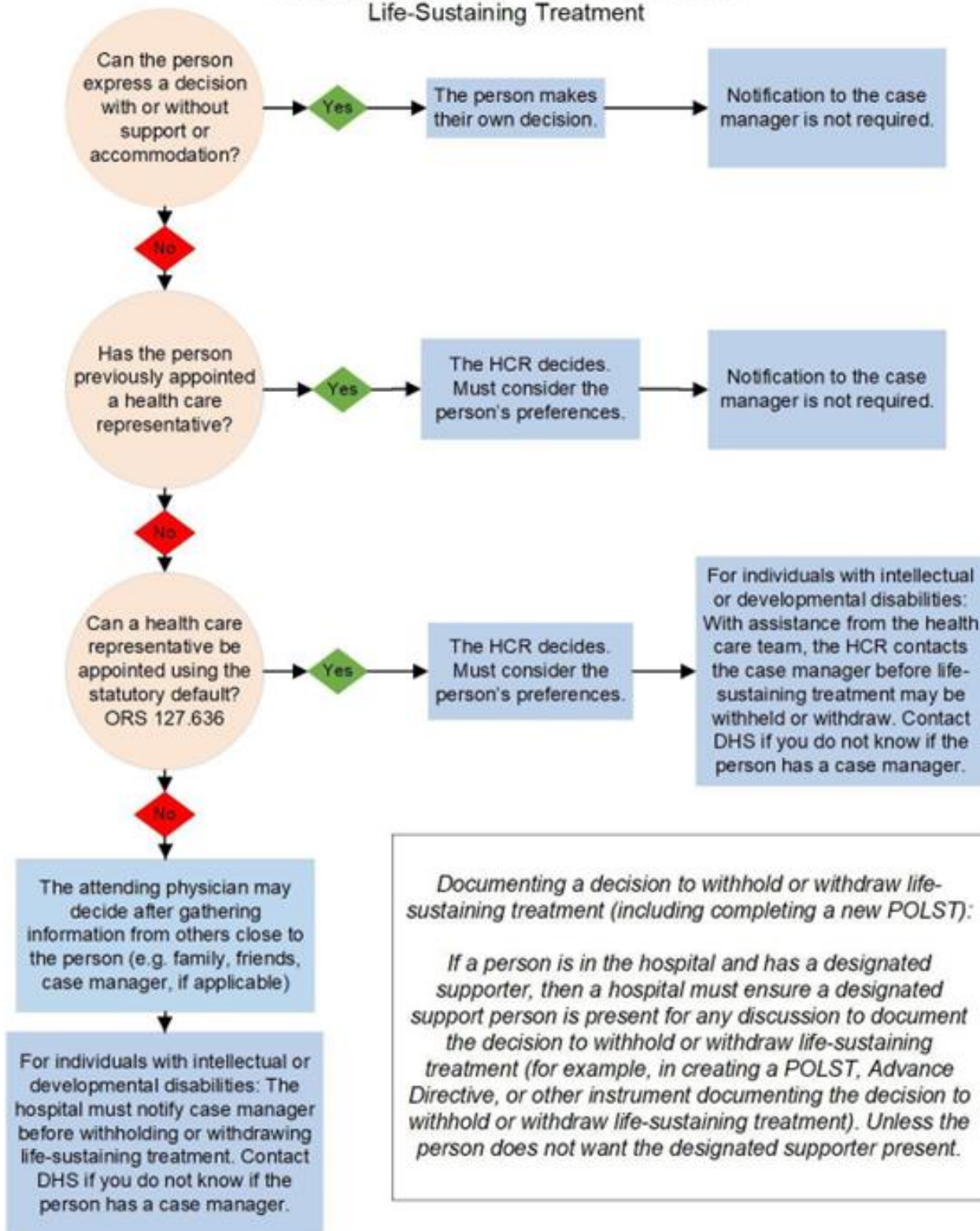
- 1. The person.
- 2. If the person cannot make the decision, then it may be made by a Health Care Representative appointed by the person (e.g., in an Advance Directive or in an appointment of a Health Care

Representative form).

3. If the person has not appointed a health care representation, and they are not able to make this decision, then the statutorily appointed Health Care Representative appointed under ORS 127.635(2), may be the first of the following: guardian (if authorized to make health care decisions); spouse; adult designated by others listed; a majority of adult children; either parent; a majority of adult siblings; and then, any adult friend.
4. Under ORS 127.635(3), the attending physician or attending health care provider may make the decision if none of those listed above can be found.

A Health Care Representative, attending physician, or attending health care provider statutorily appointed under ORS 127.635(2) or (3) to decide to withhold or withdraw life-sustaining treatment for a person who has an intellectual or developmental disability must notify the case manager before life sustaining procedures may be withheld or withdrawn. More information can be found under Section 5 and in the related fact sheet on [Required Notification to Case Manager Before Withholding or Withdrawing Life-Sustaining Treatment for Individuals with Intellectual and Developmental Disabilities](#).

Health Care Decision-Making: Making the Decision to Withhold or Withdraw Life-Sustaining Treatment



Health Care Decision Making: Making the Decision to Withhold

or Withdraw Life-Sustaining Treatment

Can the person express a decision with or without support or accommodation?

If yes, the person makes their own decision and notification to the case manager is not required.

If no, has the person previously appointed a Health Care Representative (HCR)?

If yes, the HCR must consider the person's preferences and decide. Notification to the case manager is not required.

If no, can a Health Care Representative (HCR) be appointed using the statutory default (ORS 127.636)?

If yes, the HCR must consider the person's preferences and decide. For individuals with intellectual or developmental disabilities, the HCR with the assistance from the health care team, contacts the case manager before life-sustaining treatment may be withheld or withdrawn. Contact ODHS if you do not know if the person has a case manager.

If no, the attending physician may decide after gathering information from others close to the person (e.g., family, friends, case manager, if applicable). For individuals with intellectual or developmental disabilities, the hospital must notify the case manager before withholding or withdrawing life-sustaining treatment. Contact ODHS if you do not know if the person has a case manager.

Documenting a decision to withhold or withdraw life-sustaining treatment (including completing a new POLST):

If a person is in the hospital and has a designated supporter, then a hospital must ensure a designated support person is present for any discussion to document the decision to withhold or withdraw life-sustaining treatment (for example, in creating a POLST, Advance Directive, or other instrument documenting the decision to withhold or withdraw life-sustaining treatment). Unless the person does not want the designated supporter present.

Printer-friendly Resources:

Senate Bill 1606:

<https://olis.oregonlegislature.gov/liz/2020S1/Downloads/MeasureDocument/SB1606/Enrolled>

Oregon Health Authority guidance on non-discrimination in medical treatment:

<https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le2288R.pdf>

ODDS transmittal with Senate Bill 1606 resources:

<https://www.oregon.gov/odhs/transmittals/oddstransmittals/im20093.pdf>

Oregon Revised Statutes (ORS) 127.635(2):

https://www.oregonlegislature.gov/bills_laws/lawsstatutes/2018orLaw0036.pdf

Appointing a Health Care Representative:

<https://static1.squarespace.com/static/5995c457d482e90a1ff3bd4a/t/5e34cd8a2eda975271f470f6/1580518794396/WINGS%2B-%2BHealth%2BCare%2BRep.pdf>

Notification Requirements before Withholding or Withdrawing Life-Sustaining Treatment for Individuals with Intellectual and Developmental Disabilities:

<https://www.oregon.gov/odhs/providers-partners/idd/workerguides/fact-sheet-life-sustaining-treatment-notification.pdf>

Taking Charge of My Own Health Care Decisions Toolkit:

<https://www.ohsu.edu/oregon-office-on-disability-and-health/taking-charge-my-health-care-toolkit>

Oregon Self-Advocacy Coalition: <https://www.askosac.org/>**University Center of Excellence in Developmental Disabilities:**

<https://www.ohsu.edu/university-center-excellence-development-disability>

Advance Directive:

<https://www.oregon.gov/oha/PH/ABOUT/Pages/ADAC-Forms.aspx>

Individual Support Plan (ISP) team appointed Health Care Advocate (HCA) as per Oregon Administrative Rule 411-390:

<https://www.oregon.gov/odhs/rules-policy/oddsrulesdocs/411-390.pdf>

ODDS Health Care Decision Making webinars for case managers

and ISP team members on HCA, Advance Directive, and POLST:

<https://www.oregon.gov/odhs/transmittals/oddstransmittals/22099.pdf>