

End of Life Care – Guidance for supporting people with intellectual and developmental disabilities


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 care. 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 and 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, slow down, or ask if they can have a caregiver, advocate or family member be 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. 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. Oregon Health Authority has also issued [non-discrimination guidance](#).

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.

What are the options for documenting medical decisions?

There are two important tools to help a person communicate their treatment preferences to medical professionals providing care. They are the advance directive and the POLST.

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.

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 advanced 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.

Health Care Advocate (HCA) information for case managers: 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](#).

A 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.

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. ODDS offers [webinar trainings](#) for case managers and ISP team members on HCA, advance directive and POLST.

When deciding what choices to make, 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 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.

Resources

Advance Directive: You can find an advance directive online in English and Spanish at:

<https://www.oregon.gov/oha/PH/ABOUT/Pages/AdvanceDirectiveAdoptionCommittee.aspx>


It can also be purchased for a fee from Oregon Health Decisions in English or Spanish. This version includes a helpful conversation guide and discussion questions for the individual and HCR to go over so the HCR can be fully informed of the person's care preferences and values:

<https://www.oregonhealthdecisions.org/#>

Oregon POLST™: <https://oregonpolst.org/>. On this website you will find numerous resources including a copy of a POLST form and a guidebook for the use of the POLST with persons with developmental disabilities who are near the end of their life:

<https://static1.squarespace.com/static/52dc687be4b032209172e33e/t/5dd46c490739db187dd5d056/1574202443929/POLST+for+DD+2019.11.18+final.pdf>.

POLST also has a YouTube channel, <https://www.youtube.com/user/ORPOLST> where they have videos for health care providers, patients and families and a new video about POLST and the Coronavirus.



Disability Rights Oregon, guidance on knowing your rights to medical treatment: <https://droregon.org/wp-content/uploads/DRO-KYR-COVID-19-and-Your-Right-to-Medical-Treatment-Final-1.pdf>

Oregon Health Authority Non-Discrimination Guidance: <https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le2288R.pdf>

Oregon Self-Advocacy Coalition and **OHSU's Center of Excellence in Developmental Disabilities** and created an online resource called the Taking Charge of My Health Care Toolkit. This is a toolkit featuring self-advocates that covers topics like self-advocacy in health care, signs of sickness, finding a doctor and staying healthy. <https://www.ohsu.edu/oregon-office-on-disability-and-health/taking-charge-my-health-care>

Coalition for Compassionate Care of California resources, including guide to Supporting and Improving Healthcare Decision-Making and End-Of-Life Planning for People with Intellectual and Developmental Disabilities: <https://coalitionccc.org/tools-resources/people-with-developmental-disabilities/>

Your Right to Direct Your Health Care Needs from Wisconsin's Department of Health Services: <https://www.dhs.wisconsin.gov/publications/p6/p62025.pdf>

Stony Brook University guidance on Preparing Individuals with Intellectual/Developmental Disabilities for Medical Treatment at Hospitals: <https://you.stonybrook.edu/disabilitycovid19forms/2020/04/08/preparing-individuals-with-intellectual-developmental-disabilities-for-medical-treatment-at-hospitals/>

Communication First Rights Toolkit: <https://communicationfirst.org/covid-19/>

Patient-Provider Communication Forum, with the support of the United States Society of Augmentative and Alternative Communication (USSAAC), patient communication toolkit: <https://www.patientprovidercommunication.org/supporting-communication-covid-19.htm>