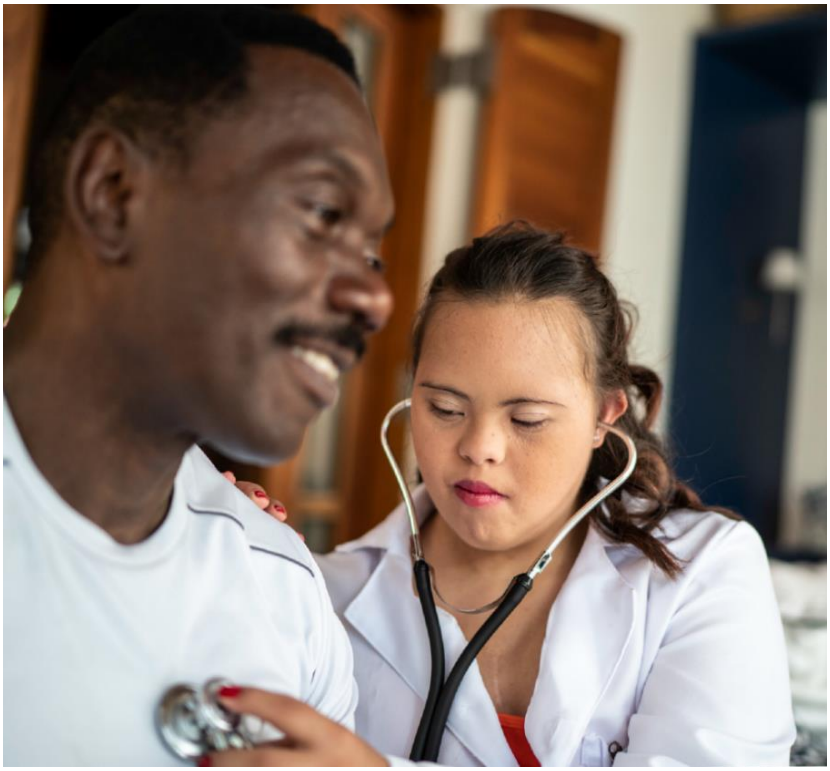
Portable Orders for Life-Sustaining Treatment (POLST®):

Guidelines on POLST Use for Persons with Significant Disabilities who are Now Near the End of Life

Developed by the Oregon POLST Coalition
and approved by its Education Committee in July 2020



Executive Summary:

The Oregon POLST Coalition strives to achieve two goals in creating these guidelines: **First**, to promote broader access to high quality end of life care for persons with significant disabilities who are nearing the end of life; **Second**, to raise awareness of the appropriate use of POLST and specifically to advise against the use of POLST in those with stable disabilities who do not have a serious illness that is in the advanced stages.

These guidelines summarize laws and best practices and have been updated to reflect changes to Oregon law by Senate Bill 1606 (hereafter SB 1606), which became effective as of July 7, 2020.

What is POLST?

POLST stands for Portable Orders for Life-Sustaining Treatment. It is a voluntary form that turns a patient's wishes for treatment into a medical order. It is meant for people with a serious illness, such as advanced heart disease, advanced lung disease, or cancer that has spread.

POLST is usually not for persons with stable long-term disabilities

These guidelines for POLST use and surrogate decision-making are applicable to persons with significant disabilities who are now nearing the end of life, including individuals with significant physical disabilities, developmental or intellectual disabilities, or a significant mental health condition. These persons generally have conditions that, while chronic, *may not be terminal* and therefore they may have many years of quality life ahead. As with other populations, POLST is only appropriate for persons who have an advanced illness or frailty, while accurate predictions cannot be made but death is likely in the foreseeable future.

When should a POLST be completed?

The POLST process begins with a health care professional offering an opportunity for a POLST discussion to a patient with advanced illness or frailty. An appropriate POLST can ensure people with a significant disability are offered timely and preferred treatment as they near the end of life. For professionals, the following questions help determine whether a patient's condition warrants a POLST discussion:

- Does the person have a disease process (not just their stable disability) that is progressive and in the advanced stages of the disease;
- Is the person experiencing a significant decline in health;
- Is the person enrolled in a hospice program; and/or
- Has this person's level of functioning become severely impaired as a result of a deteriorating health condition and intervention will not significantly impact the process of decline?

Honoring existing POLST forms

Emergency medical responders and emergency medicine health care professionals should **follow existing POLST orders** unless there is new information from the patient or appropriate surrogate/health care decision-maker to the contrary.[1] This standard is unchanged by SB 1606.

[1] See OAR 847-010-0110, issued by the Oregon Medical Board, requiring a physician or physician assistant to honor existing POLST forms. For more information and guidance, see the updated version of Oregon POLST Program's *Guidance for Oregon's Health Care Professionals*, here.

Hospitals cannot require a POLST for admission or treatment

POLST discussions with patients can occur in a variety of care settings. However, having a current POLST order may not be a condition or requirement for admission of a patient to a hospital or for treatment of a patient in an emergency department of a hospital.[2] When POLST options are discussed with a patient in a hospital, the health care team should ensure that a support person[3] designated by the patient (if any) must be present for the discussion if it may lead to a decision or medical order allowing the withholding or withdrawing of life-sustaining procedures, or admission to hospice care, unless the patient does not want a support person present for the discussion.

Health care facilities and care providers must not require a POLST

Health care facilities licensed by the Oregon Health Authority, and long-term care providers licensed by the Oregon Department of Human Services, must not require any patient, resident or other person receiving services to have a POLST form.[4] Health care facilities and long-term care providers may offer information on end-of-life planning and decision-making so a person can choose whether to have a goals of care conversation, including discussion of advance directive[5] and, when appropriate, POLST information. If applicable, a physician,[6] naturopathic physician, nurse practitioner or physician assistant may then determine if the resident's condition and expressed preferences warrant POLST orders. This conversation must be person or patient-centered and ensure the person has an opportunity to make an informed choice.

What should a caregiver do after a major change in a patient's condition?

Whenever a person has a POLST form or is enrolled in a hospice care program, all caregivers should be instructed in their responsibilities for implementing the end-of-life plan and carrying out the POLST directions. For example, new guidance from the Oregon Developmental Disabilities Services program requires direct support professionals to be aware of and follow documents that direct what medical treatment a person desires, including wishes for life-sustaining support.

---

[2] See SB 1606, Sections 1 and 2.

[3] Under SB 1606, a support person means a family member, guardian, personal care assistant or other paid or unpaid attendant selected by the patient to physically or emotionally assist the patient or ensure effective communication with the patient. The support person has a separate role from a health care advocate appointed under OAR Ch.411, Div.390.

[4] See SB 1606, ORS 127.672, OAR 411-086-0040(3) for nursing facilities and skilled nursing facilities, OAR 411-054-0034(1)(c)(D) for residential care and assisted living facilities, OAR 411-050-0750 for adult foster home rules, and OAR 411-318-0010(1)(d) for individuals receiving developmental disabilities services.

[5] A change in Oregon law in 2018 refers to these documents as either "an advance directive or a form appointing a health care representative." Documents signed prior to 2019 are still valid until superseded or revoked.

[6] A person with an MD or DO degree. See ORS 677.010(13). An Oregon-licensed MD, DO, ND, PA, or NP may sign POLST orders.

In a medical emergency, POLST orders should be followed, including when or when not to engage in cardiopulmonary resuscitation (CPR). If the person is enrolled in hospice, the hospice care team should be called immediately should a medical crisis arise. If the patient is not enrolled in hospice and help is needed, the caregiver should follow the facility policy and either contact the primary care professional or EMS in an emergency.

Individuals make their own end-of-life care decisions

All patients providing consent to healthcare treatment and end-of-life care are presumed to be competent and may make those decisions for themselves.[7] Individuals, including those with significant disabilities, must be supported to make their own decisions to the extent possible. While it has always been a best practice for any patient to make his or her own decision with any additional support or accommodation necessary to evaluate options, make decisions, and then communicate decisions to the health care team, SB 1606 now requires hospitals to ensure at least one designated support person to be present for any discussion on a decision to withhold or withdraw life-sustaining treatment.[8]

Additional guidance on how to approach end of life decision-making for a person with a significant disability is provided in the chart at the end of this document.

Statutory appointment of health care representative

If a person has not appointed a health care representative and the person does not have the capacity to appoint one, then Oregon statute allows one to be appointed to make decisions related to the POLST and withholding or withdrawing life sustaining treatment in the care setting, including making an election for hospice care. This statutory appointment (of a "default" health care representative) may be made if the patient has been medically confirmed to be in one of the following conditions[9]:

- A terminal condition;
- Permanently unconscious;
- A condition in which administration of life-sustaining procedures would not benefit the principal's medical condition and would cause permanent and severe pain; or
- An advanced stage of a progressive illness that will be fatal, and the principal is consistently and permanently unable to communicate by any means, to swallow food and water safely, to care for the principal's self and

[7] ORS 127.507.
[8] See SB 1606 Section 2(2).
[9] ORS 127.635.

to recognize the principal's family and other people, and it is very unlikely that the principal's condition will substantially improve.

Order of appointment[10]

An appointed health care representative shall be the first of the following who can be located upon reasonable effort by the health care facility and who is willing to serve as the patient's health care representative:

- A guardian authorized to make health care decisions, if any;
- The principal's spouse;
- An adult designated by the others listed in this subsection who can be so located, if no person listed in this subsection objects to the designation;
- A majority of the adult children of the principal who can be so located;
- Either parent of the principal;
- A majority of the adult siblings of the principal who can be located with reasonable effort, or
- Any adult relative or adult friend.

If no decision-maker is available

If a capable and willing health care representative cannot be identified, then life-sustaining procedures may be withheld or withdrawn upon the direction and under the supervision of the attending physician or attending health care provider. The Coalition does not recommend that an attending physician or other attending health care provider should unilaterally decide treatment without getting independent information about the patient's preferences from someone who knows the patient.

Hospital-appointed surrogate for consent to treatment, and ethics panels

In a hospital setting, where the above options do not locate a health care representative capable and willing to act, a hospital may appoint a health care provider trained in health care ethics to provide advice or consent to medically necessary health care services on behalf of the patient. A hospital may also appoint a hospital ethics committee or similar multidisciplinary committee to participate in making decisions about informed consent for life-extending treatment,[11] though these committees are not authorized to provide consent to withholding or withdrawal of life-sustaining treatment.

New duty for surrogate decision-makers for hospitalized patients

New in 2020, if a patient does not have a preexisting POLST, before life-sustaining procedures may be withheld or withdrawn for a patient

[10] ORS 127.635(2).
[11] ORS 127.760.

admitted to a hospital or who is in an emergency department and has an intellectual or developmental disability, a person statutorily-designated as a health care representative under ORS 127.635, or a member of the health care team, must contact the Oregon Department of Human Services to determine if the patient has a case manager and provide notice to the patient's case manager (if there is one) before life-sustaining procedures are withheld or withdrawn from the patient.[12] Case managers do not have authority to authorize or approve a treatment decision, but they will provide any information they have relating to the patient's values, beliefs and preferences with respect to the withholding or withdrawing of life-sustaining procedures.

Reference Tool *for "Health Care Decision-Making: Making the Decision to Withhold or Withdraw Life-Sustaining Treatment" – (See Flowchart on page 7.)*

Summary

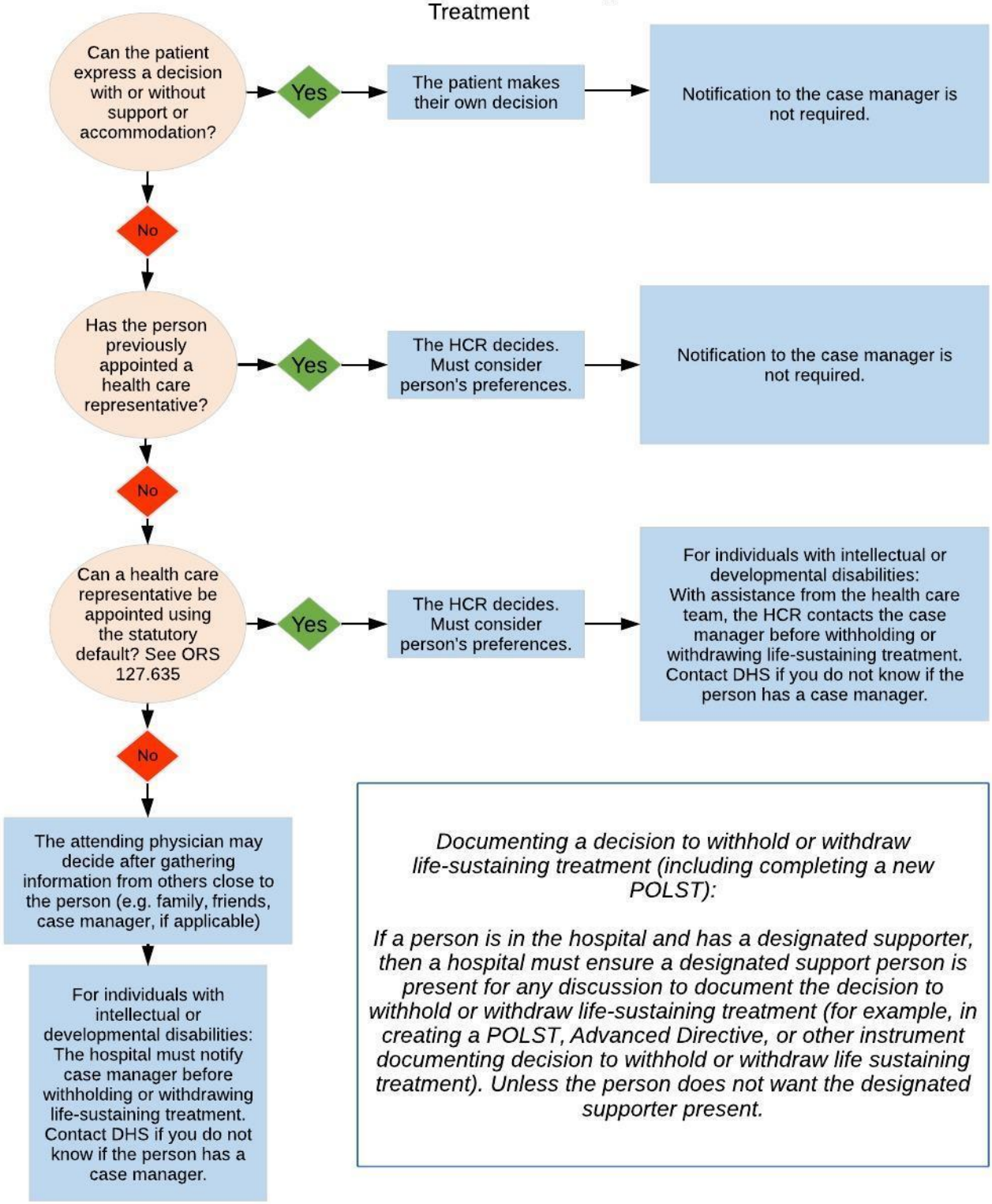
Individuals with significant disabilities have the right to access high quality end-of-life care on the same basis as people who do not have disabilities. A POLST discussion may be appropriate for any person who is nearing the end of life; POLST orders, however, are not appropriate for an individual with a stable disability who does not have a serious illness that is in the advanced stages.

If an individual is not able to make his or her own decisions, even with support or accommodations, then the surrogate appointed by the individual, or a person under statutory appointment, may make the decision for the individual to have a POLST. This decision must take into consideration the preferences the person expressed throughout life. This approach ensures that persons with significant disabilities can have their medical care and treatment wishes honored.[13]

[12] See SB 1606, Sections 4 and 5.

[13] The Coalition thanks Allison Enriquez-Buehler, J.D., and Christian Hale, J.D., of the Oregon Department of Human Services for their contributions to the development of this document.

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



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, Advanced Directive, or other instrument documenting decision to withhold or withdraw life sustaining treatment). Unless the person does not want the designated supporter present.