

Physician Orders for Life-Sustaining Treatment (POLST)

Use for Persons with Significant Physical Disabilities, Developmental Disabilities and/or Significant Mental Health Condition who are Now Near the End of Life

Developed by the Oregon POLST Task Force



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

This document was developed by the Oregon POLST Task Force and consultants experienced in the care of persons with significant physical disabilities, developmental disabilities and/or significant mental health condition who are now nearing the end of life. The Task Force invites comments about the document from interested individuals and organizations that may strengthen the document's intent.

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Purpose

The purpose of this document is to provide guidelines for POLST form use for persons with significant physical disabilities, developmental disabilities and/or 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. Also, they may or may not have capacity to make or the ability to assist in making their own health care decisions.

POLST Use for Persons with Significant Physical Disabilities, Developmental Disabilities and/or Significant Mental Health Condition who are Now Nearing the End of Life

The guidelines have been developed due to the concern that persons in these groups may not be offered timely, adequate or preferred treatment. Persons in these groups have been subject to biases resulting in under-treatment and/or had their chronic health conditions mistaken as an illnesses nearing the end of life.

With this population, the existence of a condition nearing the end of life is best determined by the physician, nurse practitioner or physician assistant asking themselves several questions to determine whether use of a POLST form is justified. These questions are:

- Does the person have a disease process (not just their stable disability) that is terminal;
- Is the person experiencing a significant decline in health (such as frequent aspiration pneumonias);
- Is the person in a palliative care or hospice program; and/or
- Has this person's level of functioning become severely impaired as a result of a *deteriorating* health condition when intervention will not significantly impact the process of decline?¹

All persons in the final months of life, without orders to the contrary, will receive life-sustaining treatments. A POLST document is written to help ensure that care provided in the last moments of life to persons with significant physical disabilities, developmental disabilities and/or significant mental health condition have their end-of-life treatment wishes respected and access to the highest quality care consistent with their treatment wishes. An appendix is included to describe terms commonly used at the end of life.

Context

The POLST program was originally designed to honor the wishes to have or to limit life-sustaining treatment of persons with end stage chronic illness. A POLST form is *not* intended for persons, including those with significant physical disabilities, developmental disabilities and/or significant mental health condition who do not have an illness nearing

¹ The “physician will not be surprised if the person dies in the next year” indicator that is used in respect to other populations is not listed because many physicians overestimate the mortality of persons with significant developmental and other disabilities, at times by decades.

the end of life, unless the person or the person's surrogate wants one in order to express treatment preferences.

Persons with significant physical disabilities, developmental disabilities and/or significant mental health condition may be cared for in a variety of settings such as a personal residence, a residential care facility, or an adult foster care or group home. In many of these settings caregivers have no immediate access to health care professionals, leaving clinically untrained caregivers to respond initially to a medical crisis. It is essential that both health care professionals and caregivers recognize changes that indicate the transition from a prior chronic health condition to one that is terminal.

Once a physician, nurse practitioner or physician assistant identifies a person as having an illness nearing the end of life, thoughtful planning can be activated. This may include:

- assessing the person's decision-making capacity,
- completing an advance directive when possible,
- identifying an appropriate surrogate,
- developing a treatment plan consistent with the person's wishes (as best known), and
- identifying comfort needs and completing a POLST form consistent with the person's wishes for end-of-life care.

These issues are complicated and require attention by the entire health care team. The following case presentation is an example of how health care decision making can become complex and result in less than optimal care if caregivers are not adequately informed.

Case Presentation

A 60-year-old woman with a history of mental illness, COPD and hypertension lived for the past 3 years in an adult foster home with the same caregiver. A psychiatric nurse practitioner prescribed medications for the mental illness and her primary care physician treated the other medical conditions. She kept appointments reluctantly because of a long-standing fear of health care professionals.

The patient has a sister who lives out of state and calls the patient on special occasions. The sister is aware that the patient prefers the least medical intervention possible, yet really values her life. The sister has never attended a medical visit. The patient has not completed an advance directive and does not have an appointed guardian.

At her last doctor's appointment the patient had worsening dyspnea and new pedal edema. Due to concern about the change in her status, the physician completed a POLST form eliciting patient wishes from the accompanying caregiver.

The physician believed the patient did not have capacity to make her health care decisions. Therefore, the physician in consultation with the caregiver completed the POLST form without the patient's direct input. The orders included:

- Do Not Attempt Resuscitation/DNR (Allow Natural Death)
- Limited Additional Interventions

- Determine use or limitation of antibiotics when infection occurs
- No artificial nutrition by tube

The next week the patient was found unresponsive in the adult foster care home. Assuming she was dead, the caregiver called the mortuary who instructed her to call EMS to inquire about what to do with the body.

Case Questions

1. Did the physician determine the patient's capacity to make health care decisions?

Not clear. The physician can determine decision-making capacity by demonstrating that the patient understands the medical information about her condition, can evaluate this information rationally and can communicate a decision back to the physician. People who know the patient well may have a better understanding of the unique communication needs of the patient and may provide valuable insight into the capacity of the patient. If the patient has decision-making capacity, then the physician should respect her wishes. Even if the patient does not have decision-making capacity, the physician should include her in the decision making process as much as her abilities will allow and determine who should make the decision on the patient's behalf. In other cases for example, a patient may have identified a health care representative through an advance directive that acts as the decision maker for the patient.

2. Has the physician used the right surrogate to help make decisions for the patient?

No. The caregiver is not the correct surrogate. If we assume that the physician is correct and that the patient does not have decision-making capacity, then the physician must determine the appropriate surrogate.

3. How should the appropriate surrogate be determined?

Physicians and other health care professionals follow a specific process to determine the appropriate surrogate. If the patient has one of four medical conditions (close to death, permanently unconscious, advanced progressive illness, extraordinary suffering), Oregon statute defines the appropriate surrogate as "the first of the following, in the following order, who can be located upon reasonable effort by the health care facility and who is willing to serve as the health care representative:

- A guardian of the patient who is authorized to make health care decisions, if any;
- The patient's spouse or reciprocal beneficiary [partner of a registered civil union];
- An adult designated by the others listed here who can be so located, if no person listed here objects to the designation;
- A majority of the adult children of the patient who can be so located;
- Either parent of the patient;
- A majority of the adult siblings of the patient who can be located with reasonable effort; or
- Any adult relative or adult friend.

- If none of the persons described in above is available, then life-sustaining procedures may be withheld or withdrawn upon the direction and under the supervision of the attending physician.”

Under statute, the operator or caregiver for a health care facility should not be the health care representative unless related to the person by blood, marriage is a reciprocal beneficiary [partner of a registered civil union] or unless the health care representative was appointed before the patient’s admission to the facility.

If the patient does not have one of the four medical conditions, Oregon statute does not provide guidance for choosing the appropriate surrogate. However, the surrogate may be determined using the above list based on the accepted standard in the medical community. Special consideration is required for persons with a developmental disability (see Question 9) and others with significant physical disabilities and/or significant mental health condition.

In the present case, the patient’s sister is the appropriate surrogate. The caregiver, however, is not the appropriate surrogate and should not be placed in this position. The caregiver is one of several others (e.g. therapist) that may have significant information regarding the patient’s preferences that can benefit the sister in helping her reach a decision consistent with the patient’s values.

4. What is the surrogate’s responsibility?

The surrogate is responsible for making health care decisions based on his/her knowledge of what the patient would have decided in the specific circumstance (substituted judgment standard). If the patient’s wishes are not known, then the surrogate makes the decision that is in the best interests of the patient (best interest standard).

The surrogate advocates for the patient. To do this, as best he/she can, the surrogate must gather information from caregivers and other parties close to the patient, and consult with the patient’s physician to understand that patient’s medical diagnosis, treatment options and prognosis.

In the present case, the sister does not know specifically the preferences of the patient, however, she has a good understanding that the patient fears health care professionals and prefers less medical intervention. The sister must gather information about the patient’s values from all sources including caregivers, and other care providers. The sister and the patient’s physician should then incorporate these values into the POLST orders and would likely determine as follows:

- Do Not Attempt Resuscitation/DNR (Allow Natural Death)
- Limited Additional Interventions
- Use antibiotics if life can be prolonged
- Defined trial period of artificial nutrition by tube

Note that the orders written with the appropriate surrogate lead to some additional treatments being provided.

5. What is the role of the caregiver and other care providers in the patient's medical decisions?

Caregivers may be family members, a hired person with a longstanding relationship with the patient or in many circumstances, a hired person having a limited relationship with the patient. At times, they may be the appropriate surrogate as described above. Family members, longstanding caregivers and other care professionals (e.g. therapist) will usually have important information about a patient's values and treatment preferences. The surrogate should seek and include this information in making the best decision for the patient.

POLST is intended for use in persons with advanced illness nearing the end of life

6. When should a POLST form be completed?

For people without a significant developmental disability, physical disability, and/or severe and persistent mental illness, a POLST form should be considered by a physician, nurse practitioner, or physician assistant when the person has expressed strong treatment preferences, especially preferences to forego certain treatments. For people with a significant developmental disability, physical disability, and/or severe and persistent mental illness, the questions listed in the Purpose section above must be asked:

- Does the person have a disease process (not just their stable disability) that is terminal;
- Is the person experiencing a significant decline in health (such as frequent aspiration pneumonias);
- Is the person in a palliative care or hospice program; and/or
- Has this person's level of functioning become severely impaired as a result of a *deteriorating* health condition when intervention will not significantly impact the process of decline?

All persons, including those with significant physical disabilities, developmental disabilities and/or significant mental health condition, will eventually die. The issue is whether their health condition has reached the end of life. Dying persons with significant physical disabilities, developmental disabilities and/or significant mental health condition, like all persons, are entitled to the highest quality of end-of-life care. The challenge is to discern whether the person has chronic stable health conditions or is now transitioning to the end of life. The distinction is critical to ensure that the person receives optimal chronic disease management or optimal end-of-life care including hospice.

In the present case, the physician does not need to complete a POLST form as a facility requirement but instead bases completion on the underlying medical condition. It is the worsening status of her COPD, not her mental illness, which determines that a POLST form is appropriate. The POLST orders are based on the patient's wishes known from the patient herself, from a prior advance directive or from the patient's sister acting as surrogate.

7. Can a health care facility *require* the completion of a POLST form?

The value of the POLST form in ensuring that patient wishes are respected has become widely accepted in Oregon. As a result of this acceptance, some health care facilities have developed policies encouraging the use of POLST forms to best honor patient preferences. For example, some hospitals developed policy requiring all patients discharged to a long-term care facility or hospice be *offered* the opportunity to have a POLST form completed.

In the present case, the adult foster care home cannot require that the physician complete a POLST form, but can require that their staff ensure that the patient and physician have the *opportunity* to complete a POLST form (e.g. by having policy requesting the physician to consider discussing the POLST form with the patient and/or surrogate). The physician must then determine if the patient's condition and expressed preferences warrant POLST orders.

8. What is the caregiver's responsibility after a major change in the patient's health condition?

Whenever a patient has a POLST form or is enrolled in a hospice or palliative care program all caregivers should be instructed in their responsibilities for implementing the end-of-life plan and carrying out the POLST directions. If the patient is enrolled, 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.

A caregiver is dedicated to supporting others. The caregiver often has little formal medical education yet is frequently confronted with clinical challenges and may not know how to respond. Caregivers and other care professionals may feel quite close to the patient and need support during the patient's transition to end-of-life care.

In the present case, the caregiver should have called 911 immediately when the patient was found unresponsive and then followed notification procedures as required by the foster home license and facility policy. The caregiver cannot be expected to make medical assessments and must get appropriate personnel to the scene immediately.

9. How would health care decisions be made if this patient had a *developmental disability* and had never had decision-making capacity?

A person with a developmental disability is defined in Oregon statute as a disability attributable to mental retardation, autism, cerebral palsy, epilepsy or other neurological disability that requires training or support similar to that required by individuals with mental retardation, and the disability:

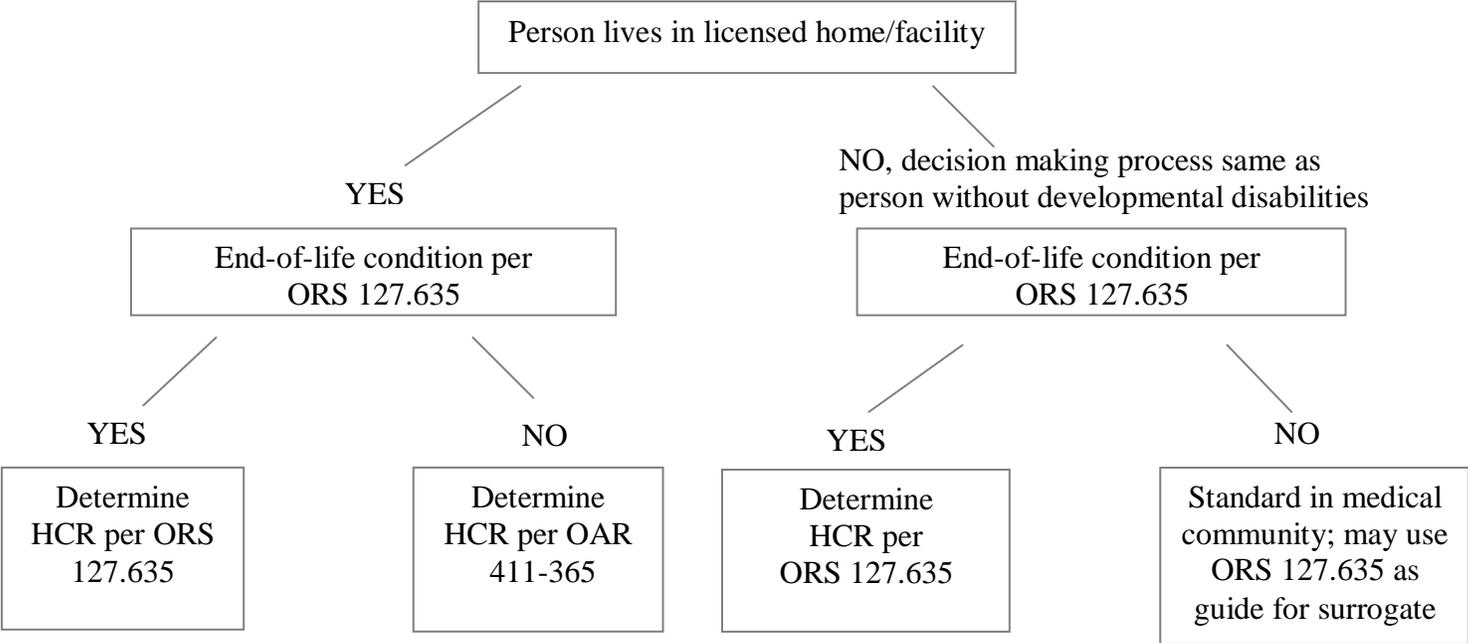
- Originates before the individual attains the age of 22 years, except that in case of mental retardation the condition must be manifested before the age of 18; and
- Has continued, or can be expected to continue, indefinitely; and
- Constitutes a substantial limitation to the ability of the person to function in society; or
- Results in significant subaverage general intellectual functioning with concurrent deficits in adaptive behavior which are manifested during the

developmental period. Individuals of borderline intelligence may be considered to have mental retardation if there is also serious impairment of adaptive behavior.

People with developmental disabilities have a wide range of abilities. Some can make simple health decisions, some can make complex ones. Many have the capacity to appoint a health care representative. All should be given the opportunity to participate as much as their capacity will allow; individuals should either appoint their own health care representative or provide input regarding who should be appointed and individuals should be asked to provide input regarding their health care as much as possible. Even those who have little capacity frequently have expressed desires or wishes that should be respected in the decision-making process. For those who have never had decision-making capacity, the process can be challenging.

Frequently, families, friends, and staff working with the person can assist in determining the person's ability to understand and to communicate the information. Health care professionals must rely on a surrogate who makes decisions in the best interest of the patient, both physician and surrogate should work to respect the patient's known wishes. Determining the appropriate surrogate is guided by Oregon law (ORS) and administrative rule (OAR) and depends on the patient's prognosis and place of residence. The figure below shows how a health care representative can be identified for a person with developmental disability.

Determination of Health Care Representative (HCR) for a Person with Developmental Disabilities



For persons with developmental disabilities, who do not have one of the four specific end-of-life circumstances mentioned above, Oregon administrative rules (OARs) determine the health care representative (see OARs 411-365-0100 to 0320). If the person does not have an end-of-life condition, lives in settings specified in the OARs (including group homes), and is determined incapable of making a health care decision under OAR 411-365-0180, the person's individual support plan (ISP) team may designate a willing person to be the health care representative. Once determined, the representative has the moral and legal duty to make decisions that are consistent with the person's wishes (substituted judgment). If wishes are not known, then representative must make decisions in the person's best interest. Thoughtful consideration of the views of those close to the patient will help the representative with this critical responsibility.

This health care representative can make most medical decisions but is not given the authority to make decisions about:

- Admission to or retention in a health care facility for care or treatment of mental illness;
- Convulsive treatment;
- Psychosurgery;
- Sterilization;
- Abortion;
- Withholding or withdrawing of a life-sustaining procedure;
- Withholding or withdrawing artificially administered nutrition and hydration, other than hyperalimentation, necessary to sustain life;
- Testing for HIV, unless testing is required to obtain treatment or care for the person;
- Assisted suicide or mercy killing; and
- Experimentation, unless the medication or medical treatment prescribed is part of a study protocol approved by a human rights committee and is determined to be in the best interests of the person.

If the patient in the present case did have a developmental disability, the physician would then need to determine if the patient has an end-of-life condition as defined in ORS 127.635 (close to death, permanently unconscious, advanced progressive illness or extraordinary suffering). If yes, then by that statute the sister is the appropriate default health care representative (see response to Question 3 above). A POLST form can be completed to have or to limit life-sustaining treatments and consistent with what the sister feels are in the best interest of the patient. If the patient is determined not to have an end-of-life condition, then OAR 411-365 details how to designate a willing person to be the health care representative. Once authorized, the representative has the moral and legal duty to make decisions that are in the patient's best interest. Thoughtful consideration of the views of those close to the patient will help the representative with this critical responsibility. Not meeting one of the four statutory end-of-life conditions, the physician should be wary about completing a POLST form unless thoughtful exploration with the health care representative and all interested parties (i.e. other family members, ISP team members, longstanding caregivers) indicates agreement that completing a form is in the patient's best interest.

Summary

Most persons with significant physical disabilities, developmental disabilities and/or significant mental health condition do *not* need a POLST form because they have chronic health conditions, not a terminal illness. It is imperative that health care professionals and caregivers work together to discern whether a person has stable chronic health conditions or is transitioning to the end of life.

All persons with an illness nearing the end of life, including those with significant physical disabilities, developmental disabilities and/or significant mental health condition, should be offered the opportunity to have their primary care professional discuss with them and, if appropriate, complete a POLST form and be assured that all comfort needs will be met. Once an end-of-life situation is recognized by appropriate health care professionals, thoughtful planning can be activated including: assessing the person's decision-making capacity; and, if the person is capable and it has not already been done, completing an advance directive and designating an appropriate surrogate; developing a treatment plan consistent with the person's wishes (as best known); and identifying comfort needs and completing a POLST form consistent with the person's present wishes for end-of-life care.

Additional consideration is required for persons with developmental disabilities. Oregon statute and administrative rule provides guidance in determining the appropriate medical decision-maker for such persons.

Caregivers are dedicated to supporting others. Unless they are otherwise authorized, they should not be the surrogate decision-maker or provide medical assessment for patients. However, they along with other care professionals may have relevant information about the patient's values to share with the surrogate. Surrogate responsibilities are defined by law and generally remain with family members. Medical assessments are the responsibility of health care professionals.

Definitions

The following definitions are intended to help health care professionals, caregivers, patients and families understand the use of the POLST form. Many of these terms have very specific legal, licensing and regulatory parameters. Therefore Oregon Revised Statutes (ORS) are noted for persons who need to understand the full import of these terms.

Advance directive. A legal document that contains a health care instruction or a power of attorney for health care. Usually this document identifies an individual's wishes related to consent, refusal of consent or withholding or withdrawal of consent to health care, decisions relating to admission to or discharge from a health care facility or decisions regarding the use, maintenance, withdrawal or withholding of life-sustaining procedures and the use, maintenance, withdrawal or withholding of artificially administered nutrition and hydration. (ORS 127).

Comfort Care or Palliative Care. The medical, nursing, environmental and psychosocial measures that must be provided to maximize the individual's quality of life, provide comfort and dignity after an individual has decided to forgo life-sustaining procedures.

Community settings. These include an individual's personal residence, unlicensed retirement homes or licensed residential care facilities, foster care or group homes. Community settings do not include hospitals or nursing homes. Most community settings utilize caregivers who have a limited range of health care skills. With rare exceptions, registered nurses are not available on-site 24 hours a day. (ORS 442 and 443)

Decision-making. Many terms are used to either describe an individual's ability to make decisions and understand the consequences of those decisions or the legal alternatives if a person can no longer make decisions for themselves. (ORS 127)

- **Capacity.** This term is used both as a legal designation i.e. the individual is 'incapable' or as an indication of his/her cognitive ability to make a decision e.g. "decision-making capacity". The legal implications of a person who is deemed "incapable" means that in the opinion of the court in a proceeding to appoint or confirm authority of a health care representative, or in the opinion of the principal's attending physician, a principal lacks the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the principal's manner of communicating if those persons are available.
- **Informed consent.** This term is used to describe a person's ability to understand, weigh and communicate a decision. The health provider has a responsibility to present the individual with information regarding their health care in a manner that is relevant and appropriate to his/her circumstance and abilities.
- **Substitute judgment standard.** In the absence of specific instructions related to a health care decision, a health care representative is expected to make health care decisions based on their knowledge of what the individual would have wanted. Substituted judgment means the health care representative is making the decision that he/she thinks the patient would have made in the same circumstance.
- **Best Interest Standard.** In the absence of specific instructions or knowledge of patient wishes related to a health care decision, a health care representative is expected to make health care decisions based on the best interests of the patient. Best interest does not mean that the patient would have made the same decision under the circumstances, but it is a judgment by the health care representative of what is best for the patient, considering the patient's known wishes, morals, ideals, etc.

Developmental Disability. A disability attributable to mental retardation, autism, cerebral palsy, epilepsy or other neurological handicapping condition which requires training or support similar to that required by individuals with mental retardation, and the disability:

- Originates before the individual attains the age of 22 years, except that in case of mental retardation the condition must be manifested before the age of 18; and
- Has continued, or can be expected to continue, indefinitely; and
- Constitutes a substantial limitation to the ability of the person to function in society; or
- Results in significant sub-average general intellectual functioning with concurrent deficits in adaptive behavior which are manifested during the

developmental period. Individuals of borderline intelligence may be considered to have mental retardation if there is also serious impairment of adaptive behavior. Definitions and classification shall be consistent with the Manual of Terminology and Classification in Mental Retardation by the American Association on Mental Deficiency, 1983 Revision. Mental retardation is synonymous with mental deficiency.

End of life. There are a variety of terms used to describe either the individuals' acuity or chronological stage of deterioration. Sometimes these terms are used interchangeably (ORS 127).

Health care representative. A person who has been appointed to make health care decisions by a patient or appointed by other legal means. If no one has been appointed and the patient meets the criteria for any of four conditions listed in the provisions of ORS 127.635 a health care representative shall be the first of the following, in the following order, who can be located upon reasonable effort by the health care facility and who is willing to serve as the health care representative:

- A guardian of the principal who is authorized to make health care decisions, if any;
- The principal's spouse or partner of a registered civil union;
- 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;
- Any adult relative or adult friend; or
- Attending physician (ORS 127.505, 127.635)

Illness nearing the end of life. In the context of persons with significant physical disabilities, developmental disabilities and/or severe and persistent mental illness, a person with such a disability has an illness nearing the end of life if the person has a disease process (not just the disability) that is terminal; the person is in a palliative or hospice program, or the person's level of functioning is severely impaired as a result of a deteriorating health condition when intervention will not significantly impact the process of decline. For people without such disabilities, the above factors apply, but there is an additional indicator that also applies: does the person have a disease process or a significant decline in health (such as frequent aspiration pneumonias) that leads their physician, nurse practitioner or physician assistant to not be surprised if the person died within the next year.

Life-sustaining procedure. Any medical procedure, pharmaceutical, medical device or medical intervention that maintains life by sustaining, restoring or supplanting a vital function. "Life-sustaining procedure" does not include routine care necessary to sustain patient cleanliness and comfort. (ORS 127.505)

Life-threatening illness. Diagnoses or behaviors, which pose a risk to continuation of life. The term "life-threatening" does not provide any indication about the imminence of death thus limiting this term's usefulness when dealing with end-of-life decisions.

Person with Developmental Disabilities. A person with a disability caused by mental retardation, autism, cerebral palsy, epilepsy, or other neurological disability that requires training or support. The condition must have originated before age 22, is expected to continue indefinitely and impacts the individual's ability to function in society. The degree of disability or severity of related health care problem is impacted by a wide variety of factors. Individuals with these conditions vary in their abilities to make informed decisions. Health related decision-making and especially end-of-life decision-making often requires the participation of a health care representative. Illnesses nearing the end of life are not usually linked to these disorders unless the causative diagnosis is a progressive disease.

Person with Significant Mental Health Condition. A person with a mental health condition that substantially limits one or more of the person's major life activities and for purposes of this document, the condition limits their ability to either make or communicate complex medical decisions.

Person with Significant Physical Disabilities. A person who have a chronic medical diagnosis, injury or congenital disorder which is restricting the individual's ability to perform activities of daily living and instrumental activities of daily living without the assistance of another person. The degree of disability or severity of related health care problems is impacted by a wide variety of factors. The ability of the individual to make informed decisions is rarely impacted. Illnesses nearing the end of life are not usually linked to these disorders unless the causative diagnoses are a progressive disease. (ORS 410)

Surrogate. A person who makes health care decisions for another person. The determination of the surrogate may be defined by ORS, OAR or the accepted standard in the medical community.

Terminal condition. A health condition in which death is imminent irrespective of treatment, and where the application of life-sustaining procedures or the artificial administration of nutrition and hydration serves only to postpone the moment of death of the principal. (ORS 127.505)

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