Frequently Asked Questions
Informed Consent Procedures – Hospice Programs

Please note that these FAQs are for informational purposes only and should not be taken as legal advice. Statutes and regulations are subject to change. You should contact your own legal counsel for advice regarding current legal requirements and how to comply with them in your particular situation.

1. What is a hospice program?

A hospice program means a coordinated program of home and inpatient care (available 24 hours a day) that utilizes an interdisciplinary team of personnel trained to provide palliative and supportive services to a patient (and the patient's family unit) who is experiencing a life threatening disease with a limited prognosis.[1] A hospice program must be licensed by the Oregon Health Authority (OHA) in order to operate in Oregon.[2] In order to be licensed, the program must comply with all applicable state and federal laws, including OHA administrative rules and CMS Conditions for Participation for hospice programs in 42 CFR Part 418.[3]

2. What is informed consent?

Physicians or physician assistants are required to obtain informed consent from a patient by following the procedure laid out in ORS 677.097, which includes explaining the medical treatment or procedure, alternative methods of treatment, and any material risks. Hospice programs must have a physician on its interdisciplinary team.[4]

3. Who can provide consent to hospice program election or services?

An adult patient with capacity has the right to consent to, refuse to consent to, or withdraw consent for a health care decision, including hospice program election or services.[5] If an adult patient does not have capacity, then a legal representative must provide that consent.[6] While some statutes allow for informal representatives to make certain end of life decisions, they do not apply in the hospice situation, particularly for Medicaid and Medicare patients.[7]

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[1] ORS 443.850(1)-(2); *see also* 42 CFR § 418.3 (federal definitions).
[2] ORS 443.860(1); OAR 333-035-0055(1).
[3] OAR 333-035-0055(8), (10).
[4] 42 CFR § 418.56(a); *see also* ORS 443.850(3).
[5] *See, e.g.,* ORS 127.507.
[6] *See* ORS chapter 125 and 127.
[7] For example, ORS 127.635(2) allows a surrogate decision-maker to be informally appointed to make decisions about life-sustaining procedures where the patient does not have a legal guardian and there are extreme, emergency conditions (*e.g.*, permanently unconscious). This would obviously not apply to hospice election or admission.

4. **Are there additional requirements for Medicaid and Medicare patients?**

An adult patient with capacity, or a *legal* representative for an incapacitated adult patient, must provide informed consent for hospice care and file a formal notice of election of hospice care, which includes identifying the hospice program selected, the patient's attending physician, acknowledgment of applicable waivers and an understanding of hospice services, and the effective date of the election.[8] A legal representative means someone who has authority to make health care decisions for the patient under state law, either by statute or pursuant to appointment by the courts.[9] Hospice election can have serious consequences for these patients because it can waive their right to obtain medical assistance payments for otherwise covered medical services to treat their terminal condition.[10]

5. How can an adult patient with capacity select a legal representative to make health care decisions for the patient in case of future incapacity?

An adult patient *with capacity* may execute an advance directive under ORS 127.505 to 127.642.[11] An advance directive allows the patient to provide health care instructions and/or appoint someone to make health care decisions for them in case the person later becomes incompetent.[12] An appointed representative can consent to an incapacitated patient being admitted to a hospice program.[13] An advance directive only comes into effect when the patient is "incapable" – *i.e.* the patient lacks the ability to make and communicate health care decisions to health care providers – by a court or the patient's treating physician.[14] The representative cannot simply declare that the patient is incapable.

Advance directive are only valid if they meet all of the formalities and requirements under state law, which includes completing specific forms. [15] Advance directives that do not comply with these statutory requirements may only constitute evidence of the patients' desires and interests, but are not effective on their own.[16] Unless the advance directive limits the duration of the authorization, it will remain in effect until: (1) the patient dies, (2) it is revoked, suspended or superseded, or (3) until the patient regains capacity if it expired while the patient was incapacitated.[17]

Patients must enter into advance directives voluntarily. State law prohibits patients from being required to execute or to refrain from executing advance directives as a criterion for insurance.[18] In addition, no health care provider can condition the provision of health care or

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[8] 42 CFR §§ 418.24, 418.104(a)(2); OAR 410-142-0080.
[9] 42 CFR § 418.3; OAR 410-142-0020(35).
[10] 42 CFR § 418.24(d)(2); OAR 410-142-0100(2)(c).
[11] ORS 127.505(2); ORS 127.510(1)-(2).
[12] ORS 127.505 (11), (21); ORS 127.510(1)-(2).
[13] ORS 127.505(9)-(10).
[14] ORS 127.505(14).
[15] ORS 127.515; ORS 127.520; ORS 127.535.
[16] ORS 127.535(6).
[17] ORS 127.510(3)-(4).
[18] ORS 127.565(2).

otherwise discriminate against patients based on whether or not the patient has executed an advance directive.[19] In other words, a hospice program or other health care provider *cannot* require an adult patient with capacity to execute an advance directive as a condition of receiving health care services.

6. How can a legal representative be appointed to make health care decisions for an adult patient without capacity when the patient does not already have one?

In cases where the adult patient lacks capacity to make health care decisions and does not already have a legal representative, a court may appoint a legal guardian, a health care representative, or issue any other protective order under ORS chapter 125.

a. Guardianships

Courts may appoint a guardian[20] for an adult patient if it determines by clear and convincing evidence that: (1) the patient is incapacitated, (2) it is necessary to provide continuing care and supervision for the patient, and (3) the proposed guardian is qualified, suitable and willing to serve.[21] Any person may file a petition with the court for the appointment of a guardian or other protective order for an adult patient.[22]

As relevant to medical treatment or admission to a health care facility, "incapacitated" means:

> [A] condition in which a person's ability to receive and evaluate information effectively or to communicate decisions is impaired to such an extent that the person presently lacks the capacity to meet the essential requirements for the person's physical health or safety. "Meeting the essential requirements for physical health and safety" means those actions necessary to provide the health care, food, shelter, clothing, personal hygiene and other care without which serious physical injury or illness is likely to occur.[23]

The guardian can make any health care decision, as defined in ORS 127.505, for the patient, including admission to a hospice program.[24] Before a guardian may place the patient in a nursing home or other residential facility, the guardian must file a statement with the court informing the court that the guardian intends to make the placement.[25] The guardian is also required to provide notice to various individuals, including the patient and, in cases where the proposed protected person resides in a licensed care facility, or the potential guardian plans to place the protected person in a licensed care facility upon establishment of the guardianship, the

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[19] *Id.*
[20] In addition to other limitations, a guardian or fiduciary may not be a person acting as the patient's health care provider. ORS 125.205(1)(b).
[21] ORS 125.305(1).
[22] ORS 125.010.
[23] ORS 125.005(5).
[24] ORS 125.315(1)(c); *see also* ORS 127.505.
[25] ORS 125.320(3).

Office of the Long Term Care Ombudsman.[26] After providing notice, the guardian may consent to the admission of the patient to the facility or program without further court order.[27] However, if there is an objection, the court must hold a hearing on the objection as soon as is practicable.[28]

b. Temporary legal representatives and other protective orders

In addition to the traditional guardianship procedure described above, courts may appoint a temporary fiduciary (with the powers of a guardian) if it determines by clear and convincing evidence that the adult patient is incapacitated, that there is an immediate and serious danger to the life or health of the patient, and that the welfare of the patient requires immediate action.[29] Temporary fiduciaries may be appointed only for a specific purpose and for a specific period of time, not to exceed 30 days without further order of the court.[30] Moreover, courts may also enter any other protective order, consistent with the powers of a guardian, without actually appointing a guardian or a fiduciary, subject to relevant statutory protections.[31] These types of limited court orders may allow a temporary fiduciary or the court to consent to a specific health care decision, including admission to a health care facility, when long-term guardianship is not necessary or available.

7. Are there any other legal routes to obtain a legal representative to make decisions for an adult patient without capacity who does not already have a legal representative?

A hospital, as defined in ORS 442.015(15),[32] may appoint a health care provider with special training to give informed consent to "medically necessary health care services" on behalf of an adult patient admitted to the hospital under certain circumstances.[33] In order for this provision to apply, the attending physician must determine that the patient lacks the ability to make and communicate health care decisions to health care providers; and the hospital has failed to locate an appropriate health care representative/surrogate or health care instructions.[34] A person appointed under this statute is not considered a health care representative under ORS 127.505, and would not be able to consent to mental health treatment or life-sustaining procedures.[35] The statute does not specifically prohibit the representative from consenting to admission to hospice programs. However, as the patient must be admitted to a hospital and the representative may only consent to medically necessary health care, this procedure would likely have limited application to hospice programs.

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[26] *Id.*
[27] ORS 125.320(3)(e).
[28] *Id.*
[29] ORS 125.600(1).
[30] ORS 125.600(3).
[31] ORS 125.650; *see also* ORS 125.010.
[32] A hospital is defined as a facility with an organized medical staff and a permanent building that is capable of providing 24-hour inpatient care to two or more individuals who have an illness or injury and that provide at least the following health services: medical, nursing, laboratory, pharmacy, and dietary; or a special inpatient care facility.
[33] ORS 127.760.
[34] ORS 127.760(3).
[35] ORS 127.760(7).