UTAH COMMISSION ON AGING

# THE PLAIN LANGUAGE PROVIDER GUIDE TO THE UTAH ADVANCE HEALTH CARE DIRECTIVE ACT

Utah Code §75-2a-100 et seq.

# Decision Making Capacity

## Definitions

"***Capacity to appoint an agent***" means that the individual understands the consequences of appointing a particular person as agent.

"***Health care decision making capacity***" means an individual's ability to make an informed decision about receiving or refusing health care, including:

1. Ability to understand the nature, extent, or probable consequences of the health care;
2. Ability to make a rational evaluation of the burdens, risks, benefits, and alternatives to the proposed health care; and
3. Ability to communicate a decision.

## Presumption of Capacity

An individual is ***presumed*** to have capacity to make a health care decision and capacity to make or revoke a health care directive.

To ***overcome the presumption of capacity***, a physician who has personally examined the individual and assessed the individual's health care decision making capacity must:

1. Find that the individual lacks health care decision making capacity;
2. Record the finding in the individual's medical chart including an indication of whether the individual is likely to regain health care decision making capacity; and
3. Make a ***reasonable effort*** to communicate the determination to:
    a. The individual;
    b. Other health care providers or health care facilities that the physician would routinely inform of such a finding; and
    c. If the individual has a surrogate, any known surrogate.

**TIP:** A provider cannot prohibit an individual from making health care choices in an advance directive, even if the provider has found that an individual lacks health care decision making capacity. The provider should document the finding in the medical record and consult an attorney about the need for legal action.

## Individual's Right to Contest Finding of Incapacity

If a physician finds that an individual lacks health care decision making capacity, the individual may challenge the finding by:

1. Submitting to a health care provider a written notice stating that the individual disagrees with the physician's finding; or
2. Orally informing the health care provider that the individual disagrees with the physician's finding.

A health care provider who is informed of a challenge shall promptly inform an individual, if any, who is serving as surrogate of the individual's challenge.

A surrogate informed of a challenge, or the individual if no surrogate is acting on the individual's behalf, shall inform the following of the challenge:

(i) any health care providers involved in the individual's care; and

(ii) the health care facility, if any, in which the individual is receiving care.

A challenge to a finding of incapacity **is binding** on a health care provider and a health care facility **unless otherwise ordered by a court**.

**PRACTICE TIP:** A health care provider or health care facility should consult an attorney regarding the emergency exception to the informed consent requirement if a patient found to lack capacity challenges the finding, and the patient's health care instructions could result in irreparable injury or death.

## Capacity to Appoint an Agent

Individuals are presumed to have the capacity to appoint a health care agent.

An individual found to lack health care decision making capacity, as described in the previous section, may still have the capacity to appoint a health care agent. To determine if the individual has the capacity to appoint an agent, a provider should consider whether:

1. The individual expresses over time an intent to appoint the same person as agent;
2. The choice of agent is consistent with past relationships and patterns of behavior between the individual and the prospective agent, or, if inconsistent, whether there is a reason for the change; and
3. The individual's expression of the intent to appoint the agent occurs at times when, or in settings where, the individual has the greatest ability to make and communicate decisions.

**PRACTICE TIP:** A provider cannot prohibit an individual from appointing an agent in an advance directive. If an individual wants to name an agent even though the provider thinks the individual lacks capacity to do so, the provider should consult an attorney about next steps.

## Surrogate Decision Making

If an individual does not challenge a finding of incapacity, a health care provider and health care facility may rely on a surrogate to make health care decisions for the individual

A health care provider or health care facility providing care to the individual that relies on a surrogate to make decisions on behalf of an individual has an **ongoing obligation** to consider whether the individual continues to lack health care decision making capacity.

If at any time a health care provider finds, based on an examination and assessment, that the individual has regained health care decision making capacity, the health care provider shall record the results of the assessment in the individual's medical record, and the individual can direct his or her health care.

**TIP:** Even if an individual lacks health care decision making capacity, the individual should be consulted and should be involved in making health care decisions, to the greatest extent possible.

## Surrogate Decision Making Standards: Substituted Judgment

Surrogate decisions made on behalf of ***a person who previously had capacity*** to make health care decisions, but who has lost health care decision making capacity should be based on the ***substituted judgment*** standard, considering:

1. Specific preferences expressed by the individual prior to the loss of health care decision making capacity;
2. The surrogate's understanding of the individual's health care preferences; and
3. The surrogate's understanding of what the individual would have wanted under the circumstances, considering past patterns of decisions, preferences, values, and beliefs.

## Surrogate Decision Making Standards: Best Interest

Surrogate decisions made on behalf of an individual who has never had health care decision making capacity or whose preferences and past history is unknown should be made on the basis of the individual's best interest.

"Best interest" means that the benefits to the individual resulting from a treatment outweigh the burdens to the individual resulting from the treatment, taking into account:

1. The effect of the treatment on the physical, emotional, and cognitive functions of the individual;
2. The degree of physical pain or discomfort caused to the individual by the treatment or the withholding or withdrawal of treatment;
3. The degree to which the individual's medical condition, the treatment, or the withholding or withdrawal of treatment, result in a severe and continuing impairment of the dignity of the individual by subjecting the individual to humiliation and dependency;
4. The effect of the treatment on the life expectancy of the individual;
5. The prognosis of the individual for recovery with and without the treatment;
6. The risks, side effects, and benefits of the treatment, or the withholding or withdrawal of treatment; and
7. The religious beliefs and basic values of the individual receiving treatment, to the extent these may assist the decision maker in determining the best interest.

## Surrogate Decision Making: Who Gets to Make Decisions?

All surrogate decision makers must meet the following minimum qualifications:

1. Over 18 years of age;
2. Has health care decision making capacity;
3. Is reasonably available; and
4. Has not been disqualified by the individual.

Priority of decision makers, in descending order:

1. Health care agent appointed by the individual
2. Court-appointed guardian
3. Default surrogate, in descending order of priority:
    a. the individual's spouse, unless:
        i. divorced or legally separated from the individual; or
        ii. a court finds that the spouse has acted in a manner that should preclude the spouse from having a priority position as a default surrogate;
    b. child;
    c. parent;
    d. sibling;
    e. grandparent; or
    f. grandchild.

**TIP:** Members of a class that lacks priority (e.g. the children when a spouse is available and willing to serve, or an adult grandchild when an adult child is available and willing to serve) has NO LEGAL AUTHORITY to override the instructions of the surrogate with the highest priority.

## Surrogate Decision Making: When Members of a Class Disagree

A health care provider shall comply with the decision of **a majority** of the members of the priority class **who have communicated their views to the provider** if:

1. More than one member of a class assumes authority to act as default surrogate;
2. The members of the class do not agree on a health care decision; and
3. The health care provider is informed of the disagreement among the members of the class.

**TIP:** The priority of decision makers should always be considered when a dispute arises among family members. A provider should follow the directions of the surrogate with priority unless the provider has reason to believe that the surrogate is not meeting his or her legal obligations. If a provider does not think the surrogate's instructions should be followed, the provider should contact an attorney or risk management for advice.

## Surrogate Decision Making: Distant Family or Unrelated Surrogate

If no agent or close family members is reasonably available to act as a surrogate decision maker and no guardian has been appointed, an individual who lacks priority may act as a surrogate if the person:

1. Is age 18 and older
2. Has health care decision making capacity;
3. Has exhibited special care and concern for the patient;
4. Is familiar with the patient's personal values; and
5. Is reasonably available to act as a surrogate.

The surrogate shall communicate the surrogate's assumption of authority as promptly as practicable to the members of a class who have an equal or higher priority and are not acting as surrogate; and can be readily contacted.

A health care provider may require the person seeking to act as a surrogate to sign an affidavit detailing how the person meets the criteria described above.

## Surrogate Decision Making: Scope of Authority

A surrogate decision maker acting under legal authority as an appointed agent or default surrogate shall make health care decisions in accordance with:

1. The individual's current preferences, to the extent possible;
2. The individual's written or oral health care directions, if any, unless the health care directive indicates that the surrogate may override the individual's health care directions; and
3. Other wishes, preferences, and beliefs, to the extent known to the surrogate.

If the surrogate does not know, and has no ability to know, the wishes or preferences of the individual, the surrogate shall make a decision based on the individual's best interest.

A surrogate decision maker acting under legal authority as an appointed agent or default surrogate:

1. May not admit the individual to a licensed health care facility for long-term custodial placement other than for assessment, rehabilitative, or respite care against the objection of the individual; and
2. May make health care decisions, including decisions to terminate life sustaining treatment for the individual.
3. A surrogate acting under authority of this section is not subject to civil or criminal liability or claims of unprofessional conduct for surrogate health care decisions made in accordance with legal guidelines and made in good faith.

## Surrogate Decision Making: Options for Provider With Concerns

If a provider has doubts regarding the status of an individual claiming the right to act as a default surrogate, the provider may:

1. Require the person to provide a sworn statement giving facts and circumstances reasonably sufficient to establish the claimed authority; or
2. Seek a ruling from the court.

A health care provider may also seek a ruling from a court if the health care provider has evidence that a surrogate is making decisions that are inconsistent with the individual's wishes or preferences.

**TIP:** No provider is obligated to blindly follow a surrogate's instructions. If instructions seem inappropriate or inconsistent with the patient's directions or wishes, a provider can assess the surrogate's understanding of the medical condition, treatment options, and the patient's preferences. A provider can also involve a social worker or other professional to help mediate disagreements between the provider and surrogate, or among surrogates in the same class. If these approaches fail, consult an attorney or risk management.

## When Surrogate's Authority Becomes Effective

An individual with health care decision making capacity retains the right to make health care decisions as long as the individual has health care decision making capacity as defined in law. The inability to communicate through speech does not mean that the individual lacks health care decision making capacity.

A surrogate's authority becomes effective only after a physician has found, after an in-person examination and assessment of the person, that an individual lacks health care decision making capacity, in accordance with the legal standard.

**TIP:** An individual's current health care decisions, however expressed or indicated, supersede the individual's prior decisions or health care directives.

## Individual's Right to Revoke Directives and Disqualify Surrogates

An individual may at any time disqualify a default surrogate, including a member of the individual's family, from acting as the individual's surrogate by:

1. A signed writing;
2. Personally informing a witness of the disqualification so long as the witness is not:
    a. Related to the individual by blood or marriage;
    b. Entitled to any portion of the individual's estate according to the laws of intestate succession of this state or under any will or codicil of the declarant;
    c. Directly financially responsible for the individual's medical care;
    d. A health care provider who is providing care to the declarant or an administrator at a health care facility in which the declarant is receiving care; or
    e. An individual who would become a default surrogate after the disqualification; or
3. Verbally informing the default surrogate of the disqualification.

Disqualification of a default surrogate is effective even if the individual has been determined to lack health care decision making capacity. Only a court can override an individual's disqualification of a surrogate.

## Advance Health Care Directive: General Principals

Utah law recognizes that individuals have the legal choice to:

1. Accept or reject health care, even if rejecting health care will result in death sooner than death would be expected to occur if rejected health care were started or continued;
2. Be spared unwanted procedures; and
3. Be permitted to die with a maximum of dignity and function and a minimum of pain.

Utah law:

1. Provides individuals with a legal tool to designate a health care agent and express preferences about health care options to go into effect only after the individual loses the ability to make or communicate health care decisions, including decisions about end-of-life care; and
2. Promotes a health care directive system that can be administered effectively within the health care system.

A health care provider who disregards a directive without cause:

1. May be liable for failure to obtain informed consent; and
2. May be found to have engaged in unprofessional conduct.

## Advance Health Care Directives

An individual may make an advance health care directive, in which the individual may, among other things:

1. Appoint a health care agent or choose not to appoint a health care agent;
2. Give directions for the care of the individual after the individual loses health care decision making capacity or chooses not to give directions;
3. State conditions that must be met before life sustaining treatment may be withheld or withdrawn;
4. Authorize an agent to consent to the individual's participation in medical research; and
5. Designate the agent's access to the individual's medical records

An advance health care directive may be oral or written, and must be witnessed by a disinterested individual, as described on page 18 of this guide.

## “Generally accepted health care standards”

Is defined to enable health care providers to interpret the statutory Advance Health Care Directive form.

The term means ***the standard of care that justifies a provider in declining to provide life sustaining or life supporting care*** because the proposed life sustaining care:

1. Will not prevent or reduce the deterioration in the health or functional status of an individual;
2. Will not prevent the impending death of an individual; or
3. will impose more burden on the individual than any expected benefit to the individual.

## Revoking a Directive

An advance directive may be revoked at any time by an individual by:

1. Writing "void" across the document;
2. Obliterating, burning, tearing, or otherwise destroying or defacing the document in any manner indicating an intent to revoke;
3. Instructing another to do one of the acts described in Subsection (1)(a) or (b);
4. A written revocation of the directive signed and dated by the individual or a person signing on behalf of the declarant and acting at the direction of the declarant;
5. An oral expression of an intent to revoke the directive in the presence of a witness who is age 18 years or older and who meets the definition of a disinterested witness;
6. A decree of annulment, divorce, dissolution of marriage, or legal separation that revokes the designation of a spouse as an agent, unless otherwise specified in the decree or the declarant has affirmed the intent to retain the agent subsequent to the annulment, divorce, or legal separation.

An advance health care directive that conflicts with an earlier advance health care directive revokes the earlier directive to the extent of the conflict.

## Witness Requirements

The witness to an advance directive, disqualification of a default surrogate, or revocation of an advance directive may not be:

1. The person who signed the directive on behalf of the individual;
2. Related to the individual by blood or marriage;
3. Entitled to any portion of the individual's estate according to the laws of intestate succession of this state or under any will or codicil of the individual;
4. Directly financially responsible for the individual's medical care;
5. A health care provider who is providing care to the declarant or an administrator at a health care facility in which the declarant is receiving care; or
6. The appointed agent.

The witness to an oral advance health care directive shall state the circumstances under which the directive was made.

## Individual/Surrogate Obligations

It is the responsibility of the individual or surrogate, to the extent that the responsibility is not assigned to a health care provider or health care facility by state or federal law, to notify or provide for notification to a health care provider and a health care facility of:

1. Existence of a health care directive;
2. Revocation of a health care directive;
3. The existence or revocation of appointment of an agent or default surrogate;
4. Disqualification of a default surrogate or agent; or
5. Appointment or revocation of appointment of a guardian.

A health care provider or health care facility is not subject to civil or criminal liability or to claims of unprofessional conduct for failing to act upon a health care directive, a revocation of a health care directive, or a disqualification of a surrogate until the health care provider or health care facility has received an oral directive from an individual or a copy of a written directive or revocation of the health care directive, or the disqualification of the surrogate.

## Provider Obligations

A health care provider that is notified of a directive **shall include in the individual's medical record**:

1. The health care directive or a copy of it, a revocation of a health care directive, or a disqualification of a surrogate; and
2. Date, time, and place in which any written or oral notice of the document is received.

Health care providers are obligated to:

1. Cooperate with a person authorized under this part to make written directives concerning health care;
2. Comply with:
    a. A health care decision of an individual; and a health care decision made by a surrogate then authorized to make health care decisions for an individual, to the same extent as if the decision had been made by the individual; and
    b. Before implementing a health care decision made by a surrogate, make a reasonable attempt to communicate to the individual the decision made and the identity of the surrogate making the decision.

## Declining to Comply with a Health Care Instruction

A health care provider or health care facility may decline to comply with a health care instruction or health care decision if, in the opinion of the health care provider:

1. The individual lacks health care decision making capacity;
2. The surrogate lacks health care decision making capacity;
3. The health care provider has evidence that the surrogate's instructions are inconsistent with the individual's health care instructions, or, for an individual who has always lacked health care decision making capacity, that the surrogate's instructions are inconsistent with the best interest of the individual; or
4. The provider has reasonable doubt regarding the status of an individual claiming the right to act as a default surrogate, in which case the provider must:
    a. Promptly inform the individual and any agent, surrogate, or guardian of the reason for refusing to comply with the health care instruction;
    b. Make a good faith attempt to resolve the conflict; and
    c. Provide continuing care to the individual until the issue is resolved or until a transfer can be made to a health care provider or health care facility that will implement the requested instruction or decision.

A health care provider or health care facility that declines to comply with a health care instruction, after meeting the obligations above may transfer the individual to a health care provider or health care facility that will carry out the requested health care decisions.

## Provider Protection Against Liability

A health care provider or health care facility acting in good faith and in accordance with generally accepted health care standards is not subject to civil or criminal liability or to discipline for unprofessional conduct for:

1. Complying with a health care decision made by a surrogate apparently having authority to make a health care decision for an individual, including a decision to withhold or withdraw health care;
2. Declining to comply with a health care decision of a surrogate based on a belief that the surrogate then lacked authority;
3. Declining to comply with a health care decision of an individual who lacks decision making capacity;
4. Seeking a judicial determination of the
    a. Validity of a health care directive;
    b. Validity of directions from a surrogate or guardian;
    c. Decision making capacity of an individual who challenges a physician's finding of incapacity;
    d. Authority of a guardian or surrogate; or

Complying with an advance health care directive and assuming that the directive was valid when made, and has not been revoked or terminated.

## Presumption of Validity of Directive

A health care directive executed under this part is presumed valid and binding.

Health care providers, in the absence of notice to the contrary, shall presume that an individual who creates a health care directive, whether or not in the presence of a health care provider, had the required decision making capacity at the time the individual signed the directive.

The fact a declarant executed a health care directive shall not be construed as an indication that the declarant was suffering from mental illness or lacked decision making capacity.

## Reciprocity

Unless otherwise provided in the health care directive, a health care provider may rely on any health care directive, power of attorney, or similar instrument:

1. Created and signed in another state; or
2. Signed in Utah prior to January 1, 2008, in compliance with the Personal Choice and Living Will Act.

## POLST
## (Physician Order for Life Sustaining Treatment)

The POLST form (Physician Order for Life-Sustaining Treatment) is a ***physician order*** not an ***advance health care directive.***

The distinction is not merely semantic. Rather, the POLST and the Advance Health Care Directive serve different, if sometimes overlapping, roles.

The POLST form is a ***transferable physician's order***. Department of Health regulations require health care facilities to follow a completed POLST form for a patient being admitted to a health care facility, unless there is reason to revise the form.

The POLST work best when a patient:

1. Suffers from an advanced progressive disease;
2. Is likely to face a life-threatening crisis in the next year; and/or
3. Has specific preferences about end-of-life care.

The POLST is likely to be neither relevant nor useful to a medically stable patient with a long life-expectancy. The POLST should not be used to terminate care in a disabled individual with a long life expectancy.

As a physician order, the POLST should be helpful in an emergency setting. The POLST is not conditional, and it requires no interpretation before it becomes relevant.

## POLST (Continued)

In contrast, Utah's Advance Health Care Directive form is conditional. The Advance Directive form may be used for healthy individuals to direct care if decision making capacity is lost. An Advance Directive may also be helpful for someone facing a life-threatening condition, whether or not the condition is deemed terminal.

Consequently, these forms may not be relevant in an emergency because of their conditional nature. For a directive to become effective and in force, a number of events must happen:

1. The patient must be found by a physician who examines the patient to lack health care decision making capacity;
2. The provider must assess the scope of authority of the appointed agent or default surrogate; and
3. A health care provider must determine whether any conditions of withdrawal or continuation of life-sustaining care have been met.

An unconditional directive may be instructive in an emergency setting. But directives that require conditions to be met before they become effective will not be useful until the patient is stable enough to determine whether the condition has been met.

A health care provider who is completing a POLST form should assure that a patient's Advance Directives and POLST forms are consistent.

## HIPAA

A surrogate or a guardian appointed in compliance with Utah law, becomes a personal representative for the individual under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) when:

1. The individual loses health care decision making capacity;
2. The individual grants current authority to the surrogate either:
    a. in writing; or
    b. by other expression before a witness who is not the surrogate or agent; or

The court appoints a guardian authorized to make health care decisions on behalf of the individual.

*The provisions of the Utah Advance Health Care Directive Act are cumulative with existing law regarding an individual's right to consent or refuse to consent to medical treatment and do not impair any existing rights or responsibilities that a health care provider, an individual, including a minor or incapacitated individual, or an individual's family or surrogate may have in regard to the provision, withholding, or withdrawal of life sustaining procedures under the common law or statutes of the state.*