

## Advance Directives for Health Care

### Q and A

States have enacted statutes to enable patients to create legal documents which direct their health care when they are unable to make these medical decisions. Over the years, such documents have been called living wills, health care proxies, and DPOAs (durable powers of attorney for health care decision making). Advanced directive (AD) is the current term used to describe these legal documents. Vermont's law governing advance directives is found at 18 V.S.A. § 9700 et seq. *See also* Vt. Code R. 13 140 066.

When enacted, Vermont's law made it easier for patients to use advance directives. For example, it created a voluntary on-line Advance Directive Registry where people can register either their advance directive or a notice that they have an advance directive. The registry makes it easier for health care providers to locate and follow advance directives.

#### **What is an advance directive?**

An advance directive is a written document, signed by a patient (the *principal*) and two witnesses, which tells people the patient's future medical treatment wishes when he or she no longer can (or wishes to) do so. It is what many people think of as a "living will."

#### **What do advance directives allow patients to do?**

Patients may, but are not required to, appoint an *agent* to speak for them. They can list people who should be informed about their care or involved in decision-making, including their primary care physician. Patients may also specify the kind of *treatment* they do or do not want if seriously ill or dying. They may also specify whether they do or do not want psychiatric medication. They may express their desires regarding *pain medication* and being treated at home, if possible, rather than in a hospital or nursing home. Patients may also state whether they want to be *organ donors*. They may specify wishes about funeral and other *arrangements after death*, including designating someone to handle these matters. There are other things that patients may express in their ADs, but these are the main ones.

#### **When does the agent's authority begin?**

The agent's authority usually begins when the person who created the AD can no longer make and communicate decisions about medical care. However, the law allows people to say in their ADs that other events or conditions may trigger when the AD becomes effective, even though a person still has the capacity to speak for himself or herself. A person may even specify that the agent's authority begins immediately upon signing the AD. However, most people choose to continue to make their own decisions for as long as possible.

**Who can serve as an agent and what are the agent's rights and responsibilities?**

An agent must be 18 years old and someone who the principal trusts to make decisions that reflect his or her values and wishes. A person's doctor or other clinician may not serve as an agent, nor may the non-family member owners or staff of a residential care facility (if the patient is in that facility). A person may appoint co-agents and alternative agents. While a person need not appoint an agent, doing so is encouraged as it makes future compliance with that person's wishes easier to achieve.

The agent has access to all necessary medical records and clinicians involved in providing care to the patient, to help in gathering information about the circumstances, diagnosis, and prognosis. The agent must follow the instructions in the AD. If the document is silent about the circumstances that the patient is in, the agent must weigh the benefits and burdens and decide the way the patient would have. If this is uncertain, the agent is expected to do what is in the patient's best interest.

**If more than one agent is named in an AD, may a provider rely on the decisions of only one?**

Only if 1) there is agreement among the agents about the pending decision, 2) all agents agree that one agent can make any decision, or 3) the other agents are not reasonably available. Such cases should be documented in the medical record.

**When does an advance directive take effect?**

An AD becomes effective when 1) the patient lacks capacity, as determined by a clinician, 2) a condition expressed in the AD is met (such as reaching a certain age or being diagnosed with a certain illness), or 3) a date specified in the AD is reached.

**What are the responsibilities of the clinician who determines that a patient lacks capacity or becomes aware that a triggering condition has been met?**

Clinicians must speak with an interested individual if one is reasonably available, such as a family member, as part of the capacity determination. Clinicians must document the cause, nature, and projected duration of the lack of capacity in the patient's medical record. A clinician must also make reasonable efforts to notify the patient's agent or guardian that the AD has taken effect.

**How is capacity defined?**

Capacity means an individual's ability to make and communicate a decision regarding an issue that must be decided. Capacity to make a health care decision means the patient has a basic understanding of the diagnosed condition, and the benefits, risks, and alternatives to the proposed health care.

Capacity to appoint an agent means the patient has a basic understanding of what it means to have another individual make health care decisions for him or her. It also means the patient is able to identify someone who would be an appropriate individual to make health care decisions for him or her.

When considering Advance Directives for patients who have been involuntarily hospitalized, it is important to remember that capacity is not the same as the "person in

need of treatment” standard. Persons that have been committed to the custody of the Commissioner of Mental Health because they are in need of involuntary psychiatric treatment may, and very often do, have capacity to make treatment related decisions.

**Who can request a re-determination of a patient’s capacity?**

The patient, agent, guardian, ombudsman, health care provider, treating clinician, or an interested individual, such as a family member, may request that the patient be reexamined to determine whether the patient has lost or regained capacity.

**What are the responsibilities of the clinician or designee, who reexamines the patient?**

The clinician must document the results of the reexamination in the patient’s medical record and make reasonable efforts to notify the patient, agent, and guardian of the results. Consistent with HIPAA’s privacy requirements, the clinician must also notify the person requesting the reexamination.

**What is the effect of a clinical finding that the patient has regained capacity?**

Generally, the AD would no longer be effective and the agent’s authority to make health care decisions would cease. But if the AD was triggered by a condition (such as reaching a certain age), the agent’s authority and provisions of the AD may remain in effect. In such cases, a patient with capacity retains concurrent decision making authority with his or her agent (similar to how a pilot and co-pilot function), and in cases of disagreement, the patient’s decision controls.

**Can a patient who does not have capacity object to care or to withholding or withdrawing care?**

Yes, patients may object to the provision of care or withholding/withdrawing care, even if they are incapacitated. **As a general rule, health care professionals may not provide or withhold treatment over a patient’s objection.** There are three exceptions to this rule. The first exception applies when the patient has a “Ulysses Clause” in his or her advance directive and the agent authorizes providing or withholding care over the patient’s objection. The second exception applies when the patient would suffer serious and irreversible bodily injury or death within 24 hours if the care is not provided. In these cases, if there is no available agent or applicable instruction in an AD or the agent agrees with the health care professional’s decision to provide care, the health care provider may provide care over the patient’s objection. The third exception applies when a patient’s guardian has a medical order from the probate court authorizing the guardian to consent to **specific** medical treatment that the patient may or may not object to.

**What is a Ulysses Clause and how does it work?**

A Ulysses Clause is a provision that is executed when an individual has capacity in anticipation of a time when he or she will lack capacity. For example, if patients know they are likely to refuse medication or other specific treatments when they are incapacitated, the Ulysses Clause could specify that the patient wants to receive the treatment even if they object at that time. If executed according to the specific provisions described below, when a patient lacks capacity, his or her agent may make health care decisions over the patient’s stated objection and the clinician is obligated to

follow the agent's instructions. The provision may refer either to providing care a patient is refusing or withholding care a patient is requesting.

**What are the required elements of a valid Ulysses Clause?**

1. The patient must name an agent for the clause to be effective.
2. The agent must accept in writing the responsibility to enforce the Ulysses Clause over the patient's objection.
3. The patient's clinician must sign the Ulysses Clause and affirm that the patient understands the risks, benefits, and alternatives to the treatment specified in the Ulysses Clause.
4. A lawyer licensed to practice in Vermont, ombudsman, clergy person, probate court designee, or hospital designee must explain the clause to the patient and affirm that the patient appeared to understand the provision and be free from duress or undue influence. (If the patient is in a hospital when the Ulysses Clause is executed, a hospital designee or other person affiliated with or employed by the hospital may not be the person who explains the clause to the patient and signs the document.)
5. The Ulysses Clause must specify the treatments that it covers and include a specific statement that the patient desires or does not desire the specified treatments, even if he or she objects in the future.
6. The clause may authorize the agent to consent to the principal's voluntary hospitalization.
7. The clause must include an acknowledgment that the principal is knowingly and voluntarily waiving the right to refuse or receive treatment at a time when he or she is incapacitated.

**When does a Ulysses Clause become effective?**

A Ulysses Clause becomes effective when both the patient's clinician and a second clinician have determined that the patient lacks capacity.

**What responsibilities do health care providers have with respect to Ulysses Clauses?**

Providers are obligated to notify the agent or guardian if a patient makes a decision which the agent appears to have authority to contradict over the objections of the patient. Providers are also required to make reasonable efforts to inform the patient of any proposal to withhold or withdraw health care.

**May health care providers refuse to honor an advance directive or the instruction of an agent or guardian?**

Yes, but **only** in limited circumstances. Providers must follow the instructions of an agent or guardian unless they are inconsistent with the AD or the statute. Providers or family members who have concerns about an AD may apply to Probate Court for clarification.

In addition, providers do not have to follow instructions of the agent, guardian, or AD if it would cause the provider to violate criminal law or professional standards of conduct.

Providers must inform the patient, agent, or guardian of the reason for refusing and document the situation fully in the medical record.

Providers may also refuse in situations in which they have moral, ethical, or other conflicts. In such cases, they must:

- inform the patient, agent or guardian;
- assist in the transfer of care to another provider;
- provide ongoing care until a new provider is found; and
- document the conflict, the steps taken to resolve it, and the final resolution.

Employees are only responsible to notify the employer of the conflict. The employer must then take the appropriate action to resolve the situation, but in the meantime, the employee must continue to provide care until another employee can be found.

Providers must make reasonable efforts to notify the patient, agent, or guardian in advance if they will not be able to follow any instructions.

**Can advance directives be executed upon admission to a facility?**

Yes. However, these ADs must be accompanied by a signed statement by an ombudsman, member of clergy, attorney licensed to practice in Vermont, a probate court designee, or an individual designated by a hospital for this purpose, that he or she has explained the nature and effect of the AD to the patient. When executed in a hospital, this person must sign the document in addition to at least two other witnesses.

**Can health care professionals witness advance directives?**

Yes. Anyone over 18 who is not an agent, spouse, or other family member may witness an AD.

**What if a patient who is subject to involuntary hospitalization asks hospital staff to assist with the creation of an advanced directive?**

Pursuant to statute (18 V.S.A. § 7626) and the Designated Hospital Manual and Standards, prior to a patient's discharge or release, a hospital shall provide information to a patient in the custody or temporary custody of the Commissioner regarding advance directives, including relevant information developed by the Vermont Ethics Network and Office of the Mental Health Care Ombudsman.

**Is there only one copy of an advance directive?**

No, there can be multiple copies. People creating an AD should make sure that the agent or agents named in the document have the original. Copies may also be provided to a hospital, nursing facility, physician, family member, pastor, neighbors, or close friends. There is also an AD registry online (go to the Vermont Department of Health website for details), where people may store advance directive documents in a secure database available to health care providers around the clock.

**How does a patient amend an advance directive?**

A patient may amend an AD by preparing a new one. The new document must be dated and signed in the presence of two adult witnesses, who cannot be relatives of the patient but may be health care professionals. If a patient amends an advance directive while in a hospital, nursing home, or residential care facility, the amendment must be accompanied by a signed statement from an attorney, clergy person, ombudsman, probate court designee, or hospital designee attesting that he or she has explained the effect of the amendment to the patient. The patient should destroy copies of the previous document, or ask people who have copies to destroy them, to avoid confusion.

**Can a patient suspend or revoke an advance directive?**

Yes, a patient can revoke or suspend all or part of an AD. A suspension makes the AD inapplicable for a specific period of time or while a specific condition exists.

**Can a patient revoke or suspend an advance directive if the patient does not have capacity?**

Yes, in general, a patient may revoke or suspend their advance directive regardless of their capacity. If a patient has executed a Ulysses Clause, they may only suspend or revoke their AD if they have capacity. *See section on Ulysses Clause above.*

**How can a patient suspend or revoke an advance directive?**

To suspend or revoke all or part of an AD, including the designation of an agent, a patient may either execute a new AD or:

- Sign a statement suspending the designation of an agent;
- Personally inform the clinician who is responsible for the patient's care;
- Burn, tear, or obliterate the AD personally; or
- Direct another person to burn, tear or obliterate the advance directive.

A patient may suspend or revoke any provision, other than the designation of an agent, orally or by any other action or statement showing an intention to suspend or revoke all or part of an advance directive.

**How can a patient suspend or revoke the designation of an agent?**

It is done much the same way as revoking or suspending an advance directive, except the patient cannot do it orally, except to a clinician.

**What are the responsibilities for health care professionals, health care facilities and residential care facilities that become aware of amendments, suspensions and revocations?**

If a clinician, hospital, nursing home, or home health agency becomes aware of an amendment, suspension, or revocation while treating an incapacitated patient, they must make reasonable efforts to:

- Confirm the suspension, amendment, or revocation;
- Record and flag the amendment, suspension, or revocation in the patient's medical record; and

- Notify the patient, agent, and guardian.

If a clinician, hospital, nursing home, or home health agency becomes aware of an amendment while treating a patient with capacity, they must make reasonable efforts to confirm and record the amendment. In addition, the health care professional, health care facility, or residential care facility must assist the patient to notify the agent, guardian, and family members if the patient requests assistance.

If a clinician, hospital, nursing home, or home health agency becomes aware of an amendment, suspension, or revocation when they are not providing care to the patient, they must record and flag the amendment, suspension, or revocation.

### **What kinds of policies are providers required to have in place?**

All health care providers, health care facilities, and residential care facilities must develop protocols to ensure that:

- Advance directives and DNR orders are available when services are provided;
- The existence of an AD or DNR order is prominently noted on the file jacket of a patient's medical record or flagged in an electronic record;
- Once an AD registry is available, the provider checks the registry before providing services to an incapacitated patient; and
- Agents and guardians have the right to access patient records, participate in discussions about treatment and decisions, and file complaints.

Health care and residential care facilities must also develop protocols to ensure that:

- Patients are asked if they have ADs before or as soon as possible after admission and periodically while at the facility;
- ADs are reviewed to determine whether the facility is able to follow their instructions;
- If the facility is unable to follow the instruction, steps are taken to notify the patient and agent, and to assist the patient to transfer to another facility that has the ability to follow the instruction;
- Patients are encouraged and helped to submit their ADs to the registry;
- The facility has a consistent process to issue, revoke, and handle DNR orders; and
- ADs and DNR orders are transferred along with the patient when the patient moves from one facility to another.

### **Are there penalties associated with these policy requirements?**

Yes, providers and facilities are subject to review and discipline by the licensing entity for 1) failure to act in accordance with a known AD or instruction of the principal, agent or guardian and 2) unauthorized accessing of the registry.

### **Can a clinician, health care facility, or residential care facility be sued or prosecuted for relying on an advance directive?**

No health care provider can be subject to criminal or civil liability for relying in good faith on the provisions of an AD, a DNR order, or the direction of an agent or guardian.

They are also immune from suit when they rely in good faith on a copy of an AD, if they are unaware that it has been suspended or revoked.

**Can employees be subjected to disciplinary action for following the provisions of an advance directive?**

No, employees may not be disciplined for relying in good faith on an AD or an AD that has been revoked.

**Can employees be disciplined for providing notice of a moral conflict to their employer?** No, as long as the employee provides ongoing health care until a new employee or health care provider has been found to provide the services.

**What law applies when a patient has an advance directive from another state?**

ADs that are validly prepared in another state are effective in Vermont and may be relied on to provide guidance to health care professionals.

**What law applies when a patient with a Vermont advance directive is being treated in another state?**

Conflict of laws doctrine will determine which law applies to patients with Vermont ADs receiving care in other states. The Vermont AD statute provides that ADs will be interpreted under Vermont law to the extent possible.

**Are the old standard Vermont documents -- terminal care documents (living wills) and durable powers of attorney for health care -- still valid?**

Yes, if the document was signed before September 1, 2005 and met the formal requirements in effect when prepared (including being signed, dated, and witnessed). Health care providers may rely on these older documents to provide guidance and to authorize agents to make health care decisions for patients.

**What issues concerning advance directives can be reviewed in Probate Court?**

Probate courts can consider whether to revoke an advance directive on grounds that at the time the patient signed the AD, he or she did not have capacity to understand its nature, was under duress, or was the subject of fraud or undue influence. Probate courts can also consider whether to reinstate an AD on the grounds that the patient was under duress or the subject of undue influence or fraud at the time of a suspension or revocation. Probate courts may construe the terms of an AD or construe the rights, legal status, or legal relationship of the parties with respect to an AD.

Patients, agents, or family members may challenge determinations that triggering conditions have been met. Patients, agents, or family members may also challenge capacity determinations, provided certain procedural steps are taken.

**Is an advance directive effective during probate court review?**

Yes, if the AD is in effect, either because a condition has been triggered or a determination of incapacity has been made, it would remain in effect until the probate court ordered otherwise. Probate judges can issue emergency orders on request when there is a risk of harm occurring before notice and a full hearing can take place.