

What Health Care Institutions Must Tell You About Whether They Will Honor Your End-of-Life Choices

The Terri Schiavo tragedy highlighted problems that can arise when patients become unable to express their choices about life-sustaining medical treatment and family members disagree about what the patient's wishes were. But even when people make their preferences known in advance, some health care institutions might not honor those choices, especially if the patient's wishes are perceived to conflict with religious doctrine.

Do people have a right to have their end-of-life choices honored?

Although exact legal protections vary from state to state, people generally have a right to have their wishes honored about forgoing (withholding or withdrawing) life-sustaining medical treatment. This right exists for any type of medical treatment, including artificially-administered nutrition and hydration (sometimes referred to as artificial feeding). People do not lose these rights when they can't express their wishes at the time a decision must be made, such as when they are unconscious or have severe dementia.

All states, through statute or case law, recognize "advance directives" as a way people can express those wishes in advance, although states define the term differently. The phrase usually refers to a written document in which people express their wishes about provision of care should they become unable to make health care decisions. Advance directives can include specific instructions (known as living wills) and/or can appoint an agent to make decisions for a patient (in documents known as health care proxies or durable powers of attorney for health care).

Usually, controversies about end-of-life care involve *forgoing* treatment, but sometimes people want to have treatment provided. For example, people generally have the right to have appropriate pain medication provided, even if that level of medication might also



Illustration: Bruce Rosch

cause death. In Oregon, certain terminally-ill patients also have a right to ask for a prescription for medication designed to end their lives.

Why are some institutions refusing to honor patients' end-of-life choices?

Some hospitals or nursing homes¹ do not want to honor legally permissible patient preferences because doing so would conflict with the institutions' religious or ethical policies. For example, according to their own religious directives, Catholic health care providers in the United States may not honor patient preferences that "are contrary to Catholic teaching."²

Can health care institutions legally refuse to honor patients' end-of-life choices?

The legal rules permitting hospitals or nursing homes to refuse to honor patients' choices depend on the state. Some states have refusal laws focused specifically on advance directives, while others apply to any health decision. In some states, institutions must give timely notification to the patient (or patient representative) and the refusing institution usually must either transfer the patient to a complying facility or take "reasonable" steps to transfer.

What must health care institutions tell patients about refusing to honor end-of-life choices?

Perhaps the most extensive institutional refusal notice requirements are found in the federal Patient Self-Determination Act (PSDA) statute and regulations, which apply to entities receiving Medicare and Medicaid payments. The PSDA rules require that these entities inform adult patients about state law regarding patients' rights to accept or reject treatment and to formulate advance directives.

The regulations require that, at minimum, written policies must: 1) include "a clear and precise statement of limitation if the [provider] cannot implement an advance directive as a matter of conscience;" 2) clarify the difference between institution-wide and individual objections; 3) identify the state legal authority permitting objections (the PSDA does not grant any federal right to refuse); and 4) describe the range of medical conditions or procedures affected by the refusals.³

A statement that the entity may not comply with advance directives that conflict with Catholic teaching,

however, might not be sufficiently clear or specific, since even experts on Catholic theology disagree about whether certain end-of-life choices would actually conflict with church doctrine.

Other national notice requirements can be found in standards of private entities that “accredit” different types of health care institutions, such as hospitals and nursing homes. Two main accrediting entities, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the National Committee for Quality Assurance (NCQA), have standards that require notice of institutional restrictions on care.⁴

States sometimes have additional notice requirements that go beyond these nationwide ones. For example, states might require notice from any state-licensed entity, not only those that get Medicare/Medicaid payments and are accredited.

What can you do to try to make sure your end-of-life choices are honored?

Before you select a health care facility for treatment:

- Complete written advance directives spelling out your wishes. You can use the forms specifically approved in your state’s advance directive statutes (usually available from state health departments or attorney general offices, as well as from local hospitals or the patient advocacy group Compassion & Choices.)
- Keep the original in a safe place. Give copies to your attorney, the

person(s) you appointed to make medical decisions, and even your local hospital if it will accept it.

- If you are planning to be admitted to a hospital or nursing home, receive outpatient treatment with serious risks, or are getting health insurance, ask the institutions if there are any end-of-life choices that are legal in that state, but which they will not honor. Ask to see written descriptions of their policies on the issue. Usually, the admissions, social work, or patient representative offices can help you get this information.
- Ask institutional representatives to explain anything you don’t understand about the restrictions. For example, if the policy states that the hospital will not honor any wishes that are contrary to Catholic teaching, ask what that means in specific situations about which you are concerned. Get the clarification in writing. For example, will they honor requests to have artificial feeding stopped for patients in persistent vegetative states or with severe irreversible dementia? Are there any additional restrictions for pregnant patients?

Once you’ve chosen a facility:

- Give a copy of your advance directive to the facility and ask that it be placed in a prominent place in your medical record. State law usually requires such placement.
- Register your advance directive if your state has an advance directive registry. (You can ask your state health department or attorney general’s office to find out.)
- If you have particular concerns about certain wishes being honored, discuss those issues with your doctor to identify any possible problems.

If a problem arises once you are receiving treatment at the facility:

- Try first to resolve the problem within the facility (through your doctors or hospital representatives).
- Use resources from advocacy organizations (see “Resources” below).
- Report the problem to governmental (Medicare/Medicaid offices, state health departments, state attorneys general) and accrediting authorities.

Work with advocacy groups for stronger protections of end-of-life choices in your state. Options to consider include:

- Seeking better enforcement of existing laws governing patients’ rights.
- Advocating for stronger state laws, such as: better notice provisions for institutions with objections to honoring legally permissible end-of-life choices; harsher penalties for failure to comply with the advance directive statutes (including provisions explicitly authorizing patients or their representatives to sue and awarding attorney fees); provisions requiring prompt transfer to a complying facility or honoring wishes at the non-complying facility if the patient isn’t transferred.

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Resources

Compassion & Choices (Compassion in Dying and End-of-Life Choices)
www.compassionandchoices.org
800-247-7421

MergerWatch
www.mergerwatch.org
212-261-4314

National Women’s Law Center
www.nwlc.org
202-588-5180

1. This fact sheet focuses on refusals by hospitals and nursing homes, but there are also rules about other health care entities, such as HMOs, and individual health care practitioners, who are governed by somewhat different rules.

2. U.S. Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services* (4th ed. 2001), available at www.usccb.org/bishops/directives.shtml (especially Directives 24, 59, Part Five, Introduction, 60). For more information about Catholic and other religious/ethical restrictions, see generally the websites for the U.S. Conference of Catholic Bishops (www.usccb.org), Catholic Health Association (www.chausa.org/), and the National Right to Life (www.nrlc.org).

3. See, e.g., 42 CFR §§ 417.436(d), 489.100, 489.102.

4. For more information on, JCAHO, see www.jcaho.org, (800) 994-6610. For complaints, e-mail complaint@jcaho.org or call (800) 994-6610. For more information on NCQA, see www.ncqa.org, (202) 955-3500.



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