

RELIGIOUS HEALTH RESTRICTIONS

How Religious Conservatives Are Trying To Legislate Away Your End-of-Life Choices

The highly-publicized struggle over the fate of Terri Schiavo demonstrated the extent to which conservative religious leaders and politicians are willing to interfere with private family medical decision-making to further a moral agenda. Florida's governor and legislature, as well as Congress and the President, all acted to try to prevent Schiavo's husband, Michael, from having her artificial feeding removed, even though he said that would have been her wish.

While ultimately unsuccessful in the Terri Schiavo case, religious conservatives immediately began campaigning for legislation that would make it more difficult for family members to honor an incapacitated patient's expressed, but not fully documented, wish to forgo life-sustaining treatment. In 2005 and early 2006, a wave of at least 50 such proposed laws were introduced in 23 state legislatures, according to research commissioned by the MergerWatch Project.¹

Who is behind these proposed restrictive state laws?

Many of the proposed restrictive state laws are based on model legislation developed by the National Right to Life Committee (NRLC), the same organization that has for years campaigned to overturn the U.S. Supreme Court's *Roe v. Wade* decision legalizing abortion in this country.² The NRLC has given its proposed bill a title intended to invoke a misleading image of patients such as Terri Schiavo: "The Starvation and Dehydration of Persons with Disabilities Act." In fact, Schiavo's autopsy confirmed that "the condition of her brain was "consistent with a persistent vegetative state" from which she would not recover.³

In the states in which the NRLC model legislation has been introduced, supporters often include state chapters of NRLC, state Catholic Conferences and Americans United for Life.

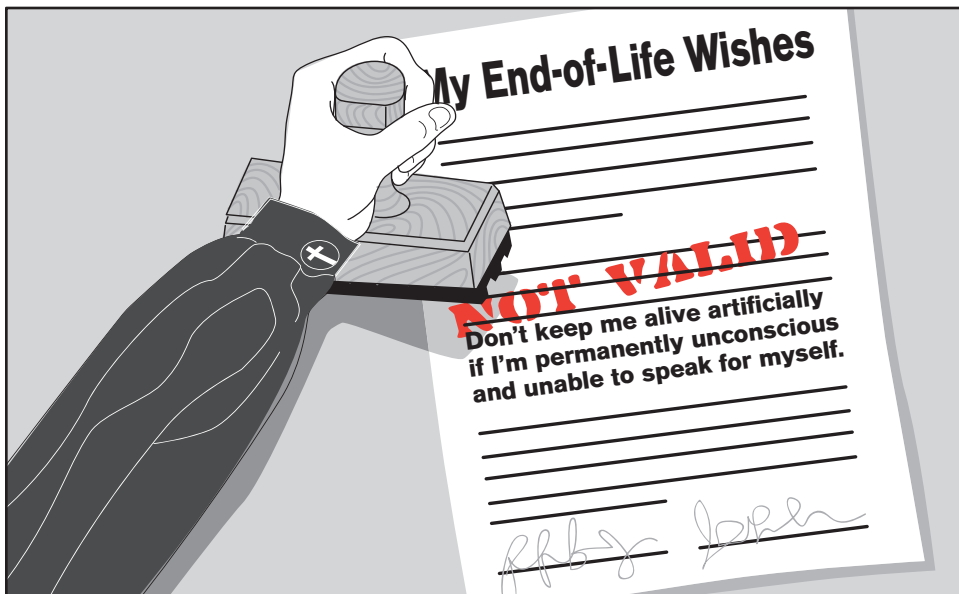


Illustration: Bruce Rosch

"This legislative push in the states demonstrates that some conservative religious leaders and politicians do not plan to stop with the Terri Schiavo case," said Lois Uttley, Director of the MergerWatch Project. "They are trying to interfere with private medical decisions that should be made by patients and their families, based on sound medical advice and patients' own religious and moral values."

What would these proposed restrictive state laws do?

The 2005 model NRLC bill (on which many of the current state bills are modeled) would make it a state law to presume that every person "legally incapable" of making health care decisions would want to be kept alive by artificially administered nutrition and hydration (ANH). For example, doctors could not withhold or withdraw ANH for patients who did not explicitly mention ANH even if the patients: i) had completed living wills explicitly stating that they did not want any life-sustaining treatment if they were in a persistent vegetative state, ii) had appointed a health care agent with broad authority to make all treatment decisions, includ-

ing forgoing all life-sustaining treatment, and iii) had repeatedly told their doctors that they never would want their lives artificially prolonged if they were in a persistent vegetative state.

The recently released 2006 NRLC model bill actually removed some language from the 2005 bill to make the language even more restrictive by eliminating the ability to provide any oral evidence of a patient's preference regarding ANH treatment at the end of life. The 2006 bill, which could influence future state legislation, again starts with the presumption that all persons would want to be kept alive by ANH except under only two circumstances i) when based on reasonable medical judgment the ANH would not contribute to sustaining life or comfort and ii) if an advance directive was executed specifically authorizing the withholding or withdrawal of ANH. As a result, regardless of whether that patient had orally expressed to a loved one or health professional what he/she may have wanted, legally no one would be allowed to withhold or withdraw ANH.

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What's the problem with this type of legislation?

This type of legislation attempts to interfere with private medical decisions that should be made by patients and their families, based on sound medical advice and patients' own religious and moral values. It puts into law an assumption that patients would want to sustain their lives indefinitely by artificially administered nutrition and hydration, unless they have specifically stated otherwise in an advance directive. Enacting a law that contains this assumption opens the door for third parties to interfere on behalf of what they believe are the patient's best interests, even if family members and physicians say that is not what the patient would have wanted.

"These proposed laws would authorize an army of vigilantes to challenge a family's decision to remove a feeding tube," explains Barbara Coombs Lee, President of Compassion & Choices, a national organization dedicated to protecting end-of-life choices. "Religious institutions, politicians and right to life groups could intrude in a family's most intimate and difficult decision, tying them up in court for years."

Does the American public approve of such proposed measures?

No. Such measures go directly against what the majority of Americans believe. According to the Pew Research Center for The People and The Press, 74% of those polled believe that close family members should be able to decide medical treatment for a terminally ill family member who cannot communicate his or her own wishes.⁴

Under these proposed laws, family members would be unable to honor the wish of a spouse, parent or other family member that may have been expressed vocally, or in written form that is not in accordance with the state advance directive statute. Although an advance directive may seem like an easy solution to directing end-of-life care choices, only 29% of Americans actually have a living will.⁵

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

Work with advocacy groups for stronger protections of end-of-life choices in your state:

- Ask your representatives to oppose legislation that would restrict end-of-life choices and allow unprecedented outside interference in individual and family medical decisions.
- Advocate for stronger state policies (such as creation of a state advance directive registry and documentation of advance directives on drivers licenses) that would make it easier for health facilities to quickly obtain documentation of your end-of-life wishes.
- Call for better enforcement of existing requirements that hospitals and nursing homes notify patients of any institutional objections to honoring legally permissible end-of-life choices, and for harsher penalties for facilities that fail to comply with advance directive statutes.

Before selecting a health care facility for treatment:

- Complete written advance directives spelling out your wishes — specifically addressing your wishes about withholding or withdrawing artificially administered nutrition and hydration. State-specific forms are available through state health departments, attorney general offices, local hospitals or advocacy groups like Compassion & Choices.
- Keep the original. Give copies to family members, physicians or an attorney.
- Ask to see written descriptions of end-of-life policies at your hospital or nursing home.
- If you check into a facility, give the document to the nurse or physician and make sure it is displayed prominently in your medical records.
- Register your advance directive if your state has an advance directive registry.

Resources

MergerWatch
www.mergerwatch.org
212-261-4314

Compassion & Choices
www.compassionandchoices.org
800-247-7421



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1. Research prepared in March 2006 for MergerWatch by Elena N. Cohen and Theresa Connor with assistance from Kathy Cerminara of Nova Southeastern University Shepard Broad Law Center and Kathryn Tucker of Compassion & Choices. Research posted at MergerWatch.org
2. The state legislation research commissioned by MergerWatch found most state bills to be based on the NRLC's 2005 model legislation, "The Starvation and Dehydration of Persons with Disabilities Prevention Act." The NRLC recently released a revised 2006 version of the bill.
3. Brown, David and Murray, Shailagh. "Schiavo Autopsy Released" *Washington Post*. 16 June 2005.
4. "More Americans Discussing and Planning End-of-Life Treatment." The Pew Research Center For the People and The Press. 5 January 2006.
5. Ibid.