**Health Care Decision Making**

**Survey of States’ Health Care Decision-Making Standards**

By Abigail Petersen

When a patient lacks the capacity to make a health care decision, someone else takes on that responsibility. That person may be an appointed agent under a durable power of attorney for health care, a default surrogate—usually a family member—recognized under state law or simply by custom and practice, or a guardian appointed by the courts. Regardless of who that person is, he or she has a difficult job. How does that person go about making decisions that could determine the patient’s life or death? What guidance does the law provide? What limitations does it impose?

This paper examines the standards for health care decision making that state law prescribes for health care decision makers. The statutes of all 50 states and the District of Columbia are reviewed, as well as relevant case law discussing evidentiary standards when health care decisions are reviewed by the courts.

The research is limited to general health care decision-making statutes, and does not address more narrowly focused statutes concerning such matters as do-not-resuscitate orders or decision making for experimental treatments. Nor does this inquiry examine state provisions or requirements for advance directive forms.

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Abigail Petersen joined the staff of the Commission in 2006 as the first-ever Nancy Coleman Summer Intern. She assisted ABA Commission Director Charles P. Sabatino with developing a database of surrogate decision-making standards across the 50 states. This article is the product of that research. Currently, Ms. Petersen is a third-year law student at St. Louis University School of Law, where she is pursuing a health law certificate from the school’s top-ranked health law program. In addition, she has been involved in leadership positions in the Public Interest Law Group, the Health Law Association, and the Women Law Students’ Association.

**Medicaid Estate Recovery**

**Protections in Medicaid Estate Recovery: Findings, Promising Practices, and Model Notices**

By Erica Wood and Ellen VanCleave Klem

ABA Commission on Law and Aging for the AARP Public Policy Institute

More than 55 million Americans rely on the joint federal-state Medicaid program for their health care and long-term care. Medicaid, the country’s largest public health insurance program, pays for almost half of all spending on long-term care.

In 1993, Congress sought to recoup the costs of long-term care and other related Medicaid expenses by requiring that states implement estate recovery programs. The Centers for Medicare and Medicaid Services issued guidelines that afford states considerable flexibility in implementation. In

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Medicaid Estate Recovery

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response, states have initiated laws, regulations, and programs to recover funds from the estates of institutionalized Medicaid recipients and those who were age 55 and older when they received Medicaid.

Estate recovery makes the Medicaid program very different from most federal benefit programs; to the extent possible, the amount of the benefit is eventually returned to the government. This fact is critical for applicants, beneficiaries, and survivors to understand, and is important to communicate to them clearly at multiple points and through multiple channels, from consideration of an initial application to the actual collection of funds.

In 2005, the ABA Commission on Law and Aging completed a national survey for the AARP Public Policy Institute assessing state estate recovery programs. Then, in 2006, the AARP Public Policy Institute asked the ABA Commission to conduct another national survey of estate recovery programs, this time focusing specifically on protections for those most affected by estate recovery—frail residents of long-term care facilities whose homes are subject to liens; surviving spouses; and other family members or potential heirs of deceased Medicaid recipients. States may face a challenge in balancing the competing social goals of protecting these populations and maximizing collections to replenish state budgets. The study identifies promising practices in estate recovery that might be replicated by other states.

The study examines state practices and protections in five aspects of estate recovery: (1) notice; (2) public information; (3) hardship waivers; (4) procedures for direct collection of funds from banks and other entities; and (5) data collection.

Among the report’s findings are:

1. While increases in amounts collected through estate recovery are modest, they may cause hardship and, thus, signal the need for solid protections.
2. Early information and notice can best protect beneficiaries and heirs.
3. Public information, pre-death lien notices, and claim notices vary widely in content and clarity, as well as the timing in which they are given.

The report concludes with a set of recommendations to protect beneficiaries and their survivors affected by estate recovery, urging that:

1. States review and consider the promising practices identified in the report.
2. States emphasize early notice of recovery.
3. States that send notice of recovery directly following the death of Medicaid recipients (before the probate process has begun) reexamine this approach.
4. The Centers for Medicare and Medicaid Services review the report’s descriptions of promising practices and model notice forms and consider offering guidance to states.
5. The Centers for Medicare and Medicaid Services consider establishing basic data elements for estate recovery, recommending formats for reporting, and making those results available to the public.


Erica Wood is assistant director and Ellen VanCleave Klem is associate director of the ABA Commission on Law and Aging in Washington.
Inside the Commission/Voting Rights

Facilitating Voting As People Age: Implications of Cognitive Impairment

By Charles P. Sabatino

On March 21-24, 2007, the Capital Government Center on Law and Policy at Pacific McGeorge School of Law in Sacramento hosted an on-campus working symposium of approximately 50 invited national experts in law and aging, medicine, long-term care, voting technology, and elections administration entitled Facilitating Voting As People Age: Implications of Cognitive Impairment.

Organized by a planning committee headed by Distinguished Visiting Professor of Law and holder of the Gordon D. Schaber Chair in Health Law and Policy Edward D. Spurgeon and Charles P. Sabatino, director of the American Bar Association’s Commission on Law and Aging in Washington, the symposium addressed critical issues of growing importance in light of the country’s exploding population of elderly citizens and the increased incidence of dementia and other cognitive impairments. Subjects addressed included how aging and cognitive impairments fit into broader issues of access to voting, absentee balloting, voting in long-term care settings, defining and assessing capacity to vote, and the implications of voter technology.

The group of experts fashioned a number of recommendations intended to protect voting rights of people with legal capacity and provide necessary assistance in voting, while protecting the integrity of the voting process. Among other things, the recommendations call for:

- Retention of the right to vote until and unless an individual is specifically determined to lack capacity to vote by a judge in a proceeding with due process protections;
- Requiring election officials to conduct mobile polling at long-term care facilities for those residents unable to travel to polling locations; and
- Movement toward the goal of well-tested universal design in voting technology so that all voters at a given polling place, including those with cognitive and intellectual impairments, can easily and accurately cast votes on the same type of system.

All the conference recommendations, along with the six working papers that formed the basis of the group’s deliberations, and the keynote address of Vermont Secretary of State and head of the National Association of Secretaries of State, Deborah Markowitz, will be published this summer in a special symposium issue of the Pacific McGeorge Law Review.

Charles P. Sabatino is director of the ABA Commission on Law and Aging in Washington.
**State Elder Bar Activities/Pro Bono**

**Pro Bono—A Win-Win Endeavor**

By Lynne Lloyd

The statistics in Oregon are staggering. As of the latest report, less than 20 percent of low-income Oregonians received assistance for their legal needs.¹ Yet many attorneys familiar with this statistic choose not to do *pro bono* legal work. Some believe that *pro bono* work is not beneficial to “the bottom line” in their practice, so that it will not benefit them professionally. So the question becomes: why do it?

**It’s Good for the Community**

For some, giving back to the community is enough. Karen Knauerhase, who was awarded the Senior Law Project Volunteer of the Year Award in 2006 says, “*Pro bono* is using your powers for good. It is a hands-on, tangible way to make a difference in someone’s life.” Many attorneys interviewed for this article expressed the notion that they were fortunate to be attorneys, and that *pro bono* work is a way to give back to the community. Others discussed how tough it is to be a member of this profession, and that doing *pro bono* work added a bright spot to their day. “It’s a hard way to make a living,” says attorney Brett Carson, “and you try to do what’s right.” Often, said one attorney, *pro bono* clients have simple legal issues, and a simple explanation of the law or process makes them more comfortable. Elderly *pro bono* clients are often exceptionally appreciative, and it’s rewarding to “make their day better.”

**It’s Good for Your Practice**

Other lawyers need some more tangible benefits. How can *pro bono* legal work benefit your practice?

First, *pro bono* work is a great way to gain substantive experience in an area of law without having to answer to a paying client. Consider how many hours it took you to write your first will versus how long it takes now. Most likely, there is a big difference in hours spent. *Pro bono* clients generally do not have complex assets or multiple properties.

Second, *pro bono* work may be a non-threatening way to refine your skills and to work with a diverse client base. Many volunteers use *pro bono* cases to develop trial skills, interviewing skills, or just general problem-solving skills. Many *pro bono* opportunities provide direct client contact, or litigation experience, and involve research and training in a variety of practice areas.

Third, your state bar may have a program to help you begin your *pro bono* legal work. The Oregon State Bar provides an “active *pro bono*” status to attorneys who wish to limit their practice to *pro bono* work. For a fraction of the usual bar dues, attorneys may maintain an active status and a caseload of *pro bono* clients, while committing to 40 hours of *pro bono* work per year for a certified *pro bono* provider. In addition, Oregon State Bar-certified providers offer Professional Liability Fund coverage to volunteers and a variety of *pro bono* opportunities, and many offer training and mentoring. About 50 attorneys in Oregon are on active *pro bono* status, including those moving toward retirement and those on parental leave.

Some attorneys use *pro bono* work as a way to develop their referral network. The Senior Law Project, operated by Legal Aid Services of Oregon, Multnomah County Office (LASO), offers free 30-minute appointments to all Multnomah County elders, regardless of their income. Some clients have the ability to pay an attorney for services, but do not know who to go to. Clients who exceed LASO’s financial eligibility guidelines often enter into fee agreements for continuing legal work with the attorneys they meet through the Senior Law Project. Many attorneys also receive paying referrals from their *pro bono* clients or even from the staff they work with at the senior centers.

*Pro bono* work can be a great way to network and make a name in the legal community. Working with clients necessarily involves working with other attorneys and often involves working with the judiciary. Additionally, there are numerous forms of recognition for *pro bono* attorneys—named publications in bar journals, awards for time donated, discounts on CLE seminars, and more.

**Get Involved**

*Pro bono* work is a win-win endeavor. Not only can it help increase an attorney’s referral network, professional reputation, and litigation experience, it is an invaluable way to give back to the community.


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Lynne Lloyd is the Pro Bono Coordinator and a staff attorney for Legal Aid Services of Oregon, Multnomah County Office. This article was originally published in the April 2007 issue of Elder Law Newsletter, a publication of the Elder Law Section of the Oregon State Bar.
**State Emeritus Attorney Pro Bono Rules Gain Momentum**

By Holly Robinson, Associate Director
ABA Commission on Law and Aging

State emeritus attorney *pro bono* rules and programs have tremendous potential to expand legal services delivery and advocacy for low- and moderate-income individuals and seniors, and to provide meaningful volunteer experience for transitioning, retired, and non-practicing attorneys.

The Indiana *Pro Bono* Commission and the Colorado Access to Justice Commission recently submitted draft emeritus attorney *pro bono* rules to their respective Supreme Courts for consideration.

In the April 17, 2007, cover memo to the Indiana Supreme Court, Judge William Lee, chair of the Indiana *Pro Bono* Commission, noted:

This “emeritus rule” recommendation follows the American Bar Association’s adoption of policy in support of limited practice rules that allow qualified retired or otherwise inactive lawyers to provide *pro bono* legal services under the auspices of experienced *pro bono* programs.

Also, a bill was introduced in the North Carolina general assembly on April 16, 2007, to establish a bar membership status for *pro bono* emeritus attorneys.

The ABA Commission on Law and Aging encourages you to contact the entity in your state to support efforts to adopt emeritus attorney rules or to strengthen existing attorney *pro bono* participation programs. The staff of the ABA Commission is ready to provide technical and other assistance to help you with these efforts. **Contact Holly Robinson, associate staff director, ABA Commission on Law and Aging, at Robinsonh@staff.abanet.org.**

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**BIFOCAL Readers’ Query**


**Kenneth Kirk**, chair of the Alaska Bar Association Elder Law Section, e-mailed that he would reach for a book that would “explain, in clear and simple language, what a special needs trustee can and can’t pay for.”

**Ann H. Britton**, professor of law at Delaware’s Widener University School of Law, e-mailed that she would reach for the “ACLU series of *The Rights of . . .* in its nice Q&A format.”

**Mary Joy Quinn**, director of the Probate Court of San Francisco Superior Court and an ABA Commissioner, e-mailed that she wishes for a book that “has all the surrogate decision-making tools and also outlines the strengths and weaknesses of each.”

**Renée Colwill Lovelace**, of the Lovelace Law Firm in Austin, Dallas, and Dripping Springs, Texas, wrote “In Texas we are blessed to have *Financing Long-Term Care in Texas*, by H. Clyde Farrell, which is a current and comprehensive guide to Texas and federal laws, regulations, cases, and strategies. If we did not have that book, it would be the book that I wish I had; most states do not have a comparable guide.”

**Sally Ramm**, an elder rights attorney and the legal services developer for Nevada, as well as chair of the National Association of Legal Services Developers, wrote that she would reach for “an annotated, updated version of the Older Americans Act prepared by the Administration on Aging.”

And **K. Gabriel Heiser**, of the Law Office of K. Gabriel Heiser, Medicaid Eligibility Planning & Estate Planning, of Boulder, Colorado, e-mailed to say “I already wrote one of those books! It’s called *How to Protect Your Family’s Assets from Devastating Nursing Home Costs: Medicaid Secrets*, and it’s a great resource (I’ve actually reached for it myself, during client meetings!). Basically, it covers the rules and planning techniques for Medicaid coverage of long-term nursing home care.”

Thank you all for responding to the April query!
Resources/Health Care Decision Making

Steal This Book!

Adapt the Health Care Proxy Guide for Your State—We’ll Help!

In commemoration of the one-year anniversary of Terri Schiavo’s death, the ABA Commission on Law and Aging and the Maryland Office of the Attorney General published two self-help guides for adults in Maryland acting as a health care proxy. A health care proxy is anyone serving as a substitute decision maker—as an agent under a durable power of attorney for health care, as a family member or close friend, or as a guardian appointed by the court.


The second guide is a more detailed, Web-based document called Making Medical Decisions for Someone Else: A Maryland Handbook. It includes steps for making health care decisions and resources for resolving disputes and getting additional help, as well as information addressing specific situations—such as dealing with grief, pain, emergencies, DNR orders, surgery, artificial nutrition and hydration, and medical research. It also includes hyperlinks to yet more detailed information.

Adapting these guides for your state would be an excellent project for bar association sections or committees on aging, in collaboration with other state groups. To date, two states—North Dakota (see http://www.nd.gov/humanservices/info/pubs/docs/aging-srv-making-medical-decisions-for-others.pdf) and New Hampshire (see www.courts.state.nh.us/probate)—have adapted the proxy guides. It is hoped that more will follow and develop these guides for use for their own states.

Contact Erica Wood at ericawood@staff.abanet.org if you are interested in developing these guides for use in your state.

The Maryland versions of these guides are on the ABA Commission Web site at http://www.abanet.org/aging, as well as on the Web site of the Maryland attorney general at www.oag.state.md (select “Health Policy”). The guides were funded by the Morton K. and Jane Blaustein Foundation.

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Lawyerly Conceits

Making the Stories of Our Clients and Our Lives Accessible Through Poetry and Prose

Lawyers are more than the sum of their academic degrees and professional experiences. Between a demanding work load and a plurality of professional obligations, many lawyers nevertheless have found an outlet in creative writing.

This Bifocal column showcases the often unseen talents of those who work in the field of law and have found a creative outlet in writing. If you have written a poem or a prose piece, or have penned a book or movie review, or simply have an inspired observation, Bifocal welcomes the opportunity to share your work. For consideration, e-mail Jamie Philpotts at philpotj@staff.abanet.org.

This month, we feature a poem by Greg Chaimov. After serving as the Oregon Legislative Assembly’s chief counsel, Greg Chaimov became an attorney in private practice in Portland, Oregon. He is a graduate of Carleton College and the Northwestern School of Law at Lewis and Clark College. He studied poetry at the University of Iowa and the Fine Arts Work Center in Provincetown, Massachusetts. His poetry and short fiction has appeared in journals in the United States and Canada. A chapbook, The Old World, was published by the William Stafford Center in 2005. Reprinted with permission.

The Fabric of Life

By Greg Chaimov

Her mother cradles her in the Morris Chair—arms broad for nursing, bought the day before—
While a world away, an astronomer Names a shining light after a goddess
Who weaves the fabric of life.

The rose
Her left fist clutches must be red, bright white
The ribbon in her hair, and that same smile
And eyes,—eyes that have taken in far more
Than we can hope to see. Four generations
To four more. At the center of the portrait,
She assumes the seat of honor, child’s hand
In her own lap, and a yellow rose,
Surrounded like a Renaissance madonna
By lives woven from the thread she’s spun.

Practice/Consumer Resource
from the ABA Commission on
Law and Aging

Consumer’s Tool Kit for Health Care Advance Planning

Good advance planning for health care decisions is, in reality, a continuing conversation—about values, priorities, the meaning of one’s life, and quality of life. To help you in this process, the ABA Commission on Law and Aging has created a tool kit that contains a variety of self-help worksheets, suggestions, and resources. The tool kit does not create a formal advance directive for you. Instead, it helps you do the much harder job of discovering, clarifying, and communicating what is important to you in the face of serious illness.

Download a free copy of the ABA Commission on Law and Aging’s Consumer’s Tool Kit from: http://www.abanet.org/aging/publications/docs/consumer_tool_kit_bk.pdf; or e-mail to order a print copy for $5 (S&H included) to the Commission at: abaaging@abanet.org.

Consumer’s Tool Kit
for Health Care Advance Planning

Second Edition
States’ Health Care Decision-Making Standards

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The focus of this review is on surrogates and agents. Health care decision-making standards articulated for agents and surrogates in state advance directive laws are presented in the corresponding online chart (see http://www.abanet.org/aging/publications/bifocal). Although the chart includes standards applicable to guardians, it cannot be considered complete, since guardianship laws were not included in this review. Guardians are regarded differently than surrogates and agents, because they are appointed and supervised by the court and their duties are often addressed in separate statutory sections. Courts also have authority to narrow or expand a guardian’s authority. Thus, while the same decision-making standards often apply to guardians as to agents and surrogates, they are not the primary focus of the paper.

Some terms require definition for purposes of this review. An agent, as used in this article, is any person appointed by an individual under any form of advance directive to make health care decisions for the person once the person becomes incapable of making health care decisions. A surrogate is the default decision maker for the individual where the individual has lost the ability to make health care decisions and has not executed an advance directive appointing an agent. Statutes often set up a priority order of people who may act as surrogate, starting with spouse, then parents, then children, etc. States use a variety of different terms for these two roles, but regardless of the terms used by individual states, this analysis will consistently refer to them as agent and surrogate as defined above. A guardian is any court-appointed decision maker for purposes of health and personal decisions. Finally, any references to withholding or withdrawing any kind of treatment will be shortened to foregoing such treatment.

Standards for Surrogate Decision Making

All states but two—Louisiana and Utah—specify a decision-making standard for health care agents. Thirty-one states specify a standard for surrogates. Most states use a combination of substituted judgment and best interests standards.

Hawaii provides an example of a typical combination substituted judgment/best interests statutory standard:

A surrogate decision maker shall make decisions for the adult patient conforming as closely as possible to what the patient would have done or intended under the circumstances, taking into account evidence that includes, but is not limited to, the patient’s personal, philosophical, religious and moral beliefs and ethical values relative to the purpose of life, sickness, medical procedures, suffering, and death. Where possible, the surrogate shall determine how the patient would have weighed the burdens and benefits of initiating or continuing life-sustaining the patient are unknown or unclear, in the patient’s best interest.

A substituted judgment standard directs the surrogate or agent to do what the patient would do in the situation, if the patient were competent. A small number of states—13 in total—have a pure substituted judgment standard, without a best interests standard as the default (eight for agents and nine for surrogates). A typical version of a pure substituted judgment standard is found in Georgia, where this standard applies to surrogates:

Any person authorized and empowered to consent … after being informed of the provisions of this Code section, act in good faith to consent to surgical or medical treatment or procedures, which the patient would have wanted had the patient understood the circumstances under which such treatment or procedures are provided.

A best interests standard is essentially a reasonable person standard, in which the surrogate or agent seeks to decide for the patient by weighing the benefits and burdens of available options as a reasonable person would do. Many states simply prescribe a best interest standard without elaboration. Arizona, for example, states:

If neither the health care directive nor the surrogate’s knowledge of the patient’s values provides a sufficient basis for making a health care decision, the surrogate shall decide based on the surrogate’s good faith belief as to what is in the patient’s best interest.

Some states itemize specific variables the agent or surrogate should take into account in applying either the substituted judgment standard or the best interests standard. Seven states itemize variables to be considered in making a substituted judgment and seven states itemize variables for the best interest standard. Illinois provides an example of itemizing variables it deems relevant to substituted judgment:

A surrogate decision maker shall make decisions for the adult patient conforming as closely as possible to what the patient would have done or intended under the circumstances, taking into account evidence that includes, but is not limited to, the patient’s personal, philosophical, religious and moral beliefs and ethical values relative to the purpose of life, sickness, medical procedures, suffering, and death. Where possible, the surrogate shall determine how the patient would have weighed the burdens and benefits of initiating or continuing life-sustaining
treatment against the burdens and benefits of that treatment.\textsuperscript{12}

A variation on the typical itemized list of substituted judgment variables or factors is a command to follow the patient’s religious beliefs. South Carolina and Virginia have statutes that prohibit health care providers and surrogates from treating a patient in a way that is against the religious beliefs or basic values of the patient. South Carolina requires the health care provider to have actual knowledge of the patient’s beliefs,\textsuperscript{13} while Virginia applies to a provider or surrogate who knows or ought to know the religious beliefs of the patient. Virginia goes on to prohibit a physician from providing, continuing, or withdrawing treatment if the health care provider knows that the action is against the values of the patient.\textsuperscript{14}

With respect to the best interest standard, Maryland provides an example of a fairly detailed itemization of seven factors it deems relevant:

(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 the 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 a condition of extreme 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 the 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 best interest.\textsuperscript{15}

**Major Limitations on Authority**

In addition to prescribing a general standard for health care decision making for either an agent or surrogate, several states also enumerate specific substantive or procedural limitations on the authority of agents or surrogates. At least five kinds of limitations were evident in this statutory review.

**Diagnostic Preconditions**

It is somewhat common for states to require that an incompetent patient have a diagnostic precondition, usually a terminal illness, before forgoing life-sustaining procedures from that patient. Sometimes a state will define its preconditions as a “qualifying condition,” which typically include permanent unconsciousness or terminal illness. Also noteworthy is the variation of definitions of these terms. Although the definitional language is not included in the corresponding online table (see http://www.abanet.org/aging/publications/bifocal), many states define permanent unconsciousness or persistent vegetative state as something different from terminal condition,\textsuperscript{16} while others define terminal condition to include permanent unconsciousness.\textsuperscript{17} Diagnostic and other limitations specific to artificial nutrition and hydration will be discussed separately, since ANH is singled out in several states for special treatment.

With respect to agents, 12 states\textsuperscript{18} specifically articulate a diagnostic precondition requirement before an agent may forgo life-sustaining procedures. With respect to surrogates, 18 states\textsuperscript{19} specifically articulate a diagnostic precondition requirement before a surrogate may do so.

Maine provides an example of language typical in the statutes that specifically limit authority to diagnostic preconditions:

In order to make decisions to withhold or withdraw life-sustaining treatment, patient must lack capacity and must be deemed by a physician to be terminally ill or in a persistent vegetative state.\textsuperscript{20}

A significant addition among the statutes is the inclusion of a third diagnostic category—“end-stage condition”—as an appropriate medical precondition for a surrogate decision regarding forgoing life-sustaining procedures. This category is more inclusive than a terminal condition and includes conditions such as advanced Alzheimer’s disease that may not necessarily be considered terminal. For example, Maryland defines end-stage condition as:

an advanced, progressive, irreversible condition caused by injury, disease, or illness:

(1) That has caused severe and permanent deterioration indicated by incompetency and complete physical dependency; and

(2) For which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective.\textsuperscript{21}

Oregon includes a condition, similar to end-stage condition, but defined as follows:

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States’ Health Care Decision-Making Standards

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... a condition in which administration of life-sustaining procedures would not benefit the principal’s medical condition and would cause permanent and severe pain or has a progressive, debilitating illness that will be fatal and is in its advanced stages, and the principal is consistently and permanently unable to communicate, swallow food and water safely, care for the principal, and recognize the principal’s family and other people, and there is no reasonable chance that the principal’s underlying condition will improve.23

Pregnancy Limitation

A majority of states24 have articulated a limitation that prohibits forgoing life-sustaining procedures when the patient is pregnant. The most restrictive nullify the advance directive outright in the case of pregnancy in which the fetus may be viable, such as this statute from Iowa:

The declaration of a qualified patient known to the attending physician to be pregnant shall not be in effect as long as the fetus could develop to the point of live birth with continued application of life-sustaining procedures.25

Less restrictive are those laws that permit forgoing treatment, but only if the principal made her wishes explicit in an advance directive, such as the Minnesota statute:

This presumption [that all pregnant patients would authorize all life-sustaining treatment if fetus could survive to point of live birth] is negated by health care directive provisions ... that are to the contrary, or, in the absence of such provisions, by clear and convincing evidence that the patient’s wishes, while competent, were to the contrary.26

Extraordinary Treatment Limitations

Twelve states include explicit limitations that prohibit a surrogate from consenting on behalf of the patient to medical interventions that are especially controversial or extraordinary, such as sterilization or abortion.27 Often included in this section is a prohibition of consent to psycho-surgery or other mental health services.28

Procedural Requirements

A variety of limitations take the form of procedural requirements that must be met before a withholding or withdrawal of treatment.

Mandatory Consultation. A few states29 encourage or require family consultation. In Delaware, consultation with the family is listed within the factors that the agents and surrogates should use in making a substituted judgment decision for the patient. In Illinois, family consultation is listed in the factors to be used in determining the patient’s best interests. Oregon differs a little in that family consultation is made mandatory. Before a surrogate may consent to forgoing life-sustaining procedures, the surrogate must consult with concerned family and close friends of the patient.30 Pennsylvania requires the agent or surrogate to “gather information on the principal’s prognosis and acceptable medical alternatives regarding diagnosis, treatments, and supportive care...” and goes on to provide certain specifications for that information.31

Presence of Witness. Two states32 require a witness to be present for certain decisions. The District of Columbia requires a witness anytime a surrogate or guardian “grants, refuses, or withdraws consent on behalf of the patient.” Iowa requires a witness to be present only when a surrogate makes a decision to forgo life-sustaining procedures.

Waiting Period. One lone state, South Carolina, requires that a patient is actively treated for at least six hours following a diagnosis of terminal illness or permanent unconsciousness before an advance directive may be followed.

Artificial Nutrition and Hydration—Special Limitations

Thirty-five33 states have special limitations on consent to forgoing artificial nutrition or hydration. Each uses some combination of the following restrictions:

Absolute Bar

In Arizona and Minnesota, a surrogate who is not the patient’s agent or guardian shall not make decisions to forgo ANH. In North Dakota, this same surrogate bar may be given by implication, because the state authorizes surrogates to consent to health care, but does not specifically give authorization for surrogates to forgo ANH.

Artificial Nutrition or Hydration Futility

A handful of states34 require that ANH be deemed essentially futile in the patient’s individual situation before a surrogate
can consent to forgo ANH. None use the term “futile,” but instead each describes circumstances in which the provision of ANH medically would have no impact on the course of illness or potentially harm the patient. Hawaii, Colorado, New Jersey, and Tennessee require that ANH is “merely prolonging the act of dying and the patient is highly unlikely to have any neurological response in the future.” Oklahoma expresses the same idea with a prohibition of withdrawal of ANH unless the patient will die from the underlying disease rather than starvation. Kentucky permits withdrawal “when the provision of artificial nutrition cannot be physically assimilated by the person.”

Comfort Care/Pain Relief Mandate

Conflicting views exist about the effects of ANH. Some view ANH as providing comfort to the patient and relieving pain, while others view ANH as causing pain.

Thirty-one states overall address comfort care and pain alleviation associated with life-sustaining procedures, including ANH. Twenty-nine states require or at least allow life-sustaining procedures to be given for the comfort of the patient, and two states prohibit ANH in circumstances where it will cause pain.

Eight states specifically require ANH to be given and prohibit the forgoing of ANH if it is needed for comfort care or the relief of pain. Fifteen states have provisions stating that the definitions of their terms [life-sustaining procedure, life-prolonging procedure or death-prolonging procedure] do not include procedures that are needed for comfort care or alleviation of pain. Therefore, any authority given to agents or surrogates or even guardians regarding health care consent would not reach any procedure that is deemed necessary for comfort care or pain alleviation. Six other states impose a disclaimer that all decisions are subject to medical responsibility, which includes caring for patient’s comfort and pain. The typical language for this type of limitation states:

this chapter does not affect the responsibility of the attending physician, attending advanced practice registered nurse, or other health care provider to provide treatment, including nutrition and hydration, for a patient’s comfort care or alleviation of pain.

Finally, two states take a completely different approach stating that ANH may not be commenced if the ANH “will itself cause severe, intractable, and long-lasting pain to the incompetent patient.”

Court Approval for Surrogates

In Ohio, surrogates may consent to forgoing ANH only upon the issuance of an order from the probate court.

Diagnostic Precondition

As discussed above, some states require a diagnostic precondition before a surrogate or agent may consent to the forgo-
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ing of life-sustaining treatment. However, nine states maintain that same requirement specifically for forgoing ANH. For example, the Hawaii statute provides:

artificial nutrition and hydration may be withheld or withdrawn for a patient upon a decision of the surrogate only when the primary physician and a second independent physician certify in the patient’s medical records that the provision or continuation of artificial nutrition or hydration is merely prolonging the act of dying and the patient is highly unlikely to have any neurological response in the future.43

Burdens Outweigh Benefits

Some states expressly stated that the burdens of ANH must outweigh the benefits as a precondition to forgoing ANH. This criterion can be read in essence as a restatement of the best interest standard, but is nevertheless articulated as a separate criterion in Kentucky and South Dakota. In South Dakota, the limitation is applied to agents, and in Kentucky it applies to both agents and surrogates. South Dakota states:

The attorney-in-fact or agent may not authorize the withholding or withdrawal from the principal of comfort care and nutrition or hydration. However, artificial nutrition or hydration may be withheld or withdrawn if … the burden of providing artificial nutrition or hydration outweighs its benefit, provided that the determination of burden refers to the provision of artificial nutrition or hydration itself and not to the quality of the continued life of the principal.45

Informed Consent

Oklahoma imposes a strong presumption that “every incompetent patient has directed his health care providers to provide him with hydration and nutrition to a degree that is sufficient to sustain life.” A surrogate may overcome this presumption only if:

the attending physician of the incompetent patient knows that the patient, when competent, decided on the basis of information sufficient to constitute informed consent that artificially administered hydration or artificially administered nutrition should be withheld or withdrawn from him.47 (emphasis added)

While this is just one avenue to overcoming the presumption, it should be noted that it is a nearly impossible standard to meet. Oklahoma Jury Instructions offer the following instruction on the requirements for informed consent:

It is the duty of the physician to disclose to [his/her][patient] all relevant information to enable that [patient] to make an informed decision on whether
to consent to or reject the physician’s proposed treatment or surgery.

This duty of disclosure includes advising a [patient], when a proposed treatment or surgery involves a known risk of death or serious bodily harm, of the possibility of such outcome and explaining in understandable terms the complications that might occur. The disclosure shall include any alternatives to the proposed treatment or surgery and the risks of each, including the risk in foregoing all treatment or surgery.48

Prior to facing the actual condition in which a decision to forgo treatment is presented, it is difficult to imagine how an individual could be given or could know “all the relevant information” or “the complications that might occur” or “any alternatives to the proposed treatment.” The concept of informed consent as it has evolved in the law applies well to presently proposed treatments, but not well to future medical decisions about which the precise circumstances are unknown.

Presumptions

Nearly all states expressly state that they create no presumptions concerning an individual’s desire to consent or not consent to life-sustaining procedures where they have not executed an advance directive or where they have revoked their advance directives. For example, the West Virginia law states:

This article creates no presumption concerning the intention of an individual who has not executed a living will or medical power of attorney to consent to, refuse or withdraw any and all medical treatment or diagnostic procedures, including, but not limited to, life-prolonging intervention. 49

Only eight states do not address the existence of a presumption.50 Three states—Alaska, Oklahoma, and Oregon51—apply a strong pro-treatment presumption. Alaska operates under a “presumption in favor of life,” where there is no evidence of the patient’s intent to the contrary. However, Alaska also supplements its presumption in favor of life with a stipulation that the presumption must also be consistent with the best interests of the patient. That stipulation really weakens any differences between Alaska and the other states, because in nearly all states the standard of surrogate decision-making comes down to best interest in one way or another.

Oklahoma imposes a very high burden to overcome a presumption in favor of providing nutrition and hydration, discussed above in the previous section. Oregon also stipulates a presumption in favor of providing nutrition and hydration, but provides ample grounds to overcome the presumption:

It shall be presumed that every person who is temporarily or permanently incapable has consented to artificially administered nutrition and hydration, other than hyperalimentation, that are necessary to sustain life except in one or more of the following circumstances

(a) The person while a capable adult clearly and specifically stated that the person would have refused artificially administered nutrition and hydration.

(b) Administration of such nutrition and hydration is not medically feasible or would itself cause severe, intractable, or long-lasting pain.

(c) The person has an appointed health care representative who has been given authority to make decisions on the use, maintenance, withholding or withdrawing of artificially administered nutrition and hydration.

(d) The person does not have an appointed health care representative or an advance directive that clearly states that the person did not want artificially administered nutrition and hydration, and the person is permanently unconscious.

(e) The person does not have an appointed health care representative or an advance directive that clearly states that the person did not want artificially administered nutrition and hydration, the person is incapable, and the person has a terminal condition.

(f) The person has a progressive illness that will be fatal and is in an advanced stage, the person is consistently and permanently unable to communicate by any means, swallow food and water safely, care for the person’s self and recognize the person’s family and other people, and it is very unlikely that the person’s condition will substantially improve.52

Clear and Convincing Evidence

There are no states that place a clear and convincing evidence standard upon agents by legislation. However, four states53

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require clear and convincing evidence of patient’s intent before a surrogate can give consent to forgo life-sustaining procedures.

In Alabama, clear and convincing evidence of the patient’s intentions is required before a surrogate may consent to forgoing ANH. The statute says:

any decision by a surrogate regarding the withdrawal or withholding of artificially provided nutrition and hydration from a person who is permanently unconscious shall only be made upon clear and convincing evidence of the patient’s desires. 54

Florida imposes a nearly identical requirement upon surrogates if the patient’s subjective intent can be determined. However, Florida differs from Alabama in that Florida allows the surrogate to base the decision upon the best interests standard if the patient’s subjective intent cannot be determined. The statute provides:

a proxy’s [i.e., Florida’s term for default surrogate] decision to withhold or withdraw life-prolonging procedures must be supported by clear and convincing evidence that the decision would have been the one the patient would have chosen had the patient been competent or, if there is no indication of what the patient would have chosen, that the decision is in the patient’s best interest.55

Ohio imposes a requirement similar to Alabama’s, requiring clear and convincing evidence of patient’s intentions before a surrogate may forgo ANH. However, in order to ensure that this requirement is followed, the surrogate may forgo ANH only upon an order from a probate court. Therefore, Ohio placed a number of requirements upon the court in a situation in which a surrogate seeks to forgo ANH, one of which is a finding of clear and convincing evidence that the patient would have consented in that situation. The statute provides:

The court shall issue an order that authorizes the patient’s attending physician to commence the withholding or withdrawal of nutrition and hydration in connection with the patient only if the applicants establish, by clear and convincing evidence, to a reasonable degree of medical certainty, and in accordance with reasonable medical standards, all of the following:

(a) The patient currently is, and for at least the immediately preceding twelve months has been, in a permanently unconscious state.

(b) The patient no longer is able to make informed decisions regarding the administration of life-sustaining treatment.

(c) There is no reasonable possibility that the patient will regain the capacity to make informed decisions regarding the administration of life-sustaining treatment.

(d) The conditions specified in divisions (A)(1) to (4) of this section have been satisfied.

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(e) The decision to withhold or withdraw nutrition and hydration in connection with the patient is consistent with the previously expressed intention of the patient as described in division (B)(2) of this section or is consistent with the type of informed consent decision that the patient would have made if he previously had expressed his intention with respect to the use or continuation, or the withholding or withdrawal, of nutrition and hydration should he subsequently be in a permanently unconscious state and no longer able to make informed decisions regarding the administration of nutrition and hydration as described in division (B)(3) of this section.56

Oklahoma holds a limitation somewhat similar to that of Ohio. One avenue by which a surrogate may give consent to forgo ANH is where:

A court finds by clear and convincing evidence that the patient, when competent, decided on the basis of information sufficient to constitute informed consent that artificially administered hydration or artificially administered nutrition should be withheld or withdrawn from him.57

Oklahoma has a little different statute in that it maintains a presumption that “every incompetent patient has directed his health care providers to provide him with hydration and nutrition to a degree that is sufficient to sustain life.”58 There are alternative avenues by which the surrogate may overcome this presumption, one of which is a clear and convincing finding from a court of law.

A somewhat ambiguous indirect reference to clear and convincing comes from the Arkansas living will statute, which states that:

A declaration executed by a qualified individual shall be clear and convincing evidence of his or her wishes, but clear and convincing evidence of an individual’s wishes is not limited to the declarations under this section.59

One could read this language to imply that clear and convincing evidence is needed, but no other language concerning this statement exists within the Arkansas statutes to clarify the matter. Arkansas may have used that statute as an attempt to clarify what constitutes clear and convincing evidence in the event of a judicial determination, and not necessarily in the typical clinical situation.

Because standards of evidence are most directly relevant to adjudicated cases, most of its legal treatment is found in the case law. “Clear and convincing” is an evidentiary standard for proving facts in dispute that, in the context of forgoing life-sustaining treatment, has been defined by state courts as:

proof sufficient to persuade the trier of fact that the patient held a firm and settled commitment to the termination of life supports under the circumstances like those presented . . .60

or evidence that:

produce[s] in the mind of the trier of fact a firm belief or conviction as to the truth of the allegations sought to be established, evidence so clear, direct and weighty and convincing as to enable [the fact finder] to come to a clear conviction, without hesitancy, of the truth of the precise facts in issue.61

“Clear and convincing” is somewhere between the highest burden of proof of “beyond a reasonable doubt” required in criminal cases and a “preponderance of evidence,” the norm for most civil disputes. In end-of-life decision disputes that require judicial intervention to resolve, the clear and convincing standard has become a dominant burden of proof.62

However, it is important to keep in mind that decision-making standards (such as substituted judgment and best interests) are different from an evidentiary standard (such as clear and convincing). The former tell you what evidence to look at and the latter tells you how much you need. Judges are accustomed to applying the concept of evidentiary standards or burdens of proof to disputes before them; the concept is far more alien and uncertain in its applicability to clinical settings where doctors and families are struggling with life and death decisions. That may explain the fact that only four states have actually included a clear and convincing requirement in their statutes addressing end-of-life decision making.

Conclusion

This statutory review of health care decision-making standards found that most states use a combination of substituted judgment and best interests standards for either agents or surrogates or both. Descriptions of these standards vary, and some states enumerate specific variables to be considered in applying the standards; however, they are all quite similar in concept. Only three states have no legislatively articulated standard.

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Unlike the relative uniformity of concept in the basic standard, there is a great deal of variety among the states in legislating limitations on authority. The forgoing of life-sustaining procedures in general, and artificial nutrition and hydration in particular, represents the most controversial and variable area. Many states impose diagnostic or other preconditions on forgoing such treatment or they assert other limitations on an agent’s or surrogate’s authority.

Most states expressly assert that they create no presumptions concerning an individual’s desire to consent or not consent to life-sustaining procedures where the individual has not executed an advance directive or revoked the advance directive.

A small number of states apply a statutory clear and convincing evidence standard to decisions concerning life-sustaining treatment. However, it is the dominant evidentiary standard used in disputes over end-of-life decision making that reach the courts. The variability evident in this survey of decision-making standards suggests a continuing struggle of the law to come to balance individual autonomy with the protection of patient’s interests in treatment and survival. The challenge is particularly daunting in the face of ever new advances and permutations in medical science and technology, combined with societal change in expectations. The balance reached by the collective “laboratories of the states” through their legislative policy-making will most certainly affect the experience of dying in America for each of us.

Notes


