On May 23, 1990, 86-year-old Helga Wanglie (“Mrs. Wanglie”) suffered a cardiorespiratory arrest that rendered her permanently unconscious.1 Her physicians determined she was in a persistent vegetative state and would be permanently respiratory dependent.2 Oliver Wanglie (“Mr. Wanglie”), Mrs. Wanglie’s husband and judicially-appointed guardian, and her children insisted on continued ventilatory treatment against the hospital’s recommendation that the ventilator support be discontinued because the continued course of treatment would render no hope of recovery for her irreversible state.3 After an extended period of time, when it became clear that the family would not agree to terminate Mrs. Wanglie’s treatment, the hospital filed a probate petition to end the impasse.4 The hospital pursued an indirect path towards its objective—rather than seeking an order authorizing the attending physician to turn off the ventilator, the hospital argued that Mr. Wanglie should be replaced as guardian.5 The probate court declined to do so, finding that Mrs. Wanglie’s medical decisions were better...
A Patient’s Right

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made by her husband, than by a court-appointed third party.6 Mrs. Wanglie, still connected to the ventilator, died four days after the court’s ruling.7

Although the Wanglie court only ruled on the guardianship matter, the case illustrates one aspect of conflict that exists between patients and providers: who should have authority in making the final decision when health care providers contend that a treatment requested by family members should not be carried out because it would be medically ineffective or “futile,” but family members want their loved one to receive the treatment nonetheless?

A refusal to comply with a patient’s request for treatment is a growing issue because advances in technology over the past decades stretch the way people experience the end of life.8 For instance, with the application of modern treatment modalities, physicians are faced with patients who are not going to recover, but who are not faced with imminent death if placed on life-sustaining treatment. While some states allow physicians to decline to provide treatment deemed to be medically inappropriate or futile, other practitioners grapple with the potential for legal ramifications associated with the withdrawal of medically ineffective or futile treatment, especially when medical futility is an undefined concept.

This paper discusses the extent to which a physician has a right to decline a patient’s request for treatment due to medical futility or other reason. Part II of this paper describes how patient-provider disputes regarding so-called futile care at the end-of-life has evolved. Part III examines provisions from all 50 states regarding the various reasons for which a health care provider may refuse to comply with a patient’s demand for treatment, in addition to the various obligations states impose on providers when they refuse to comply with a patient’s health care direction. Part IV discusses procedures some states have enacted when there is a patient-provider disagreement over requested care. Part V considers the Texas Advance Directive Act as a model statute for other states that want to address patient-provider disputes in a comprehensive manner. Finally, this article concludes by noting that balancing a physician’s right to decline life-sustaining treatment with a patient’s right to access treatment may be perceived by the majority of states as too much of a quagmire to tackle.

Background

The initial debate regarding patient-provider authority dates back to the 1970s and arose in the context of withholding or withdrawing life-sustaining medical treatment.9 The In re Quinlan case highlighted the typical argument during that time.10 Karen Ann Quinlan (“Quinlan”) was a woman in a persistent vegetative state whose father wanted to discontinue her life-sustaining treatment since it “present[ed] no hope of her eventual recovery.”11 The New Jersey Supreme Court held that Quinlan’s right to privacy included the right to have life-sustaining treatment withdrawn.12 In 1990, the U.S. Supreme Court in Cruzan v. Director, Missouri Department of Health, recognized that a competent patient has an implic-
Legislative Activities

National Conference of Commissioners
On Uniform State Laws Tackles
Transfer on Death Deed Legislation

By Ellen M. Klem

In February 2007, the National Conference of
Commissioners on Uniform State Laws established
a drafting committee to prepare a Uniform Real Property Transfer on Death Act.

A transfer on death (TOD) statute enables a property
owner to pass real property to a beneficiary upon the owner’s
death outside of probate by using a revocable TOD deed that
names the beneficiary.

Because the property passes by operation of law, similar
to survivorship in joint tenancy, individuals whose only sig-
nificant asset is the home they live in may find the process
simple and inexpensive.

Since 1989, ten states (Arizona, Arkansas, Colorado,
Kansas, Missouri, Montana, Nevada, New Mexico, Ohio,
and Wisconsin) have passed laws authorizing the transfer of
real property by a TOD deed.

The object of the project is to draft a uniform act that all
states will consider adopting. The drafting committee Web
site includes links to all the memos and drafts before the
committee, at http://www.nccusl.org/Update/Committee
SearchResults.aspx?committee=278.

The drafting committee met in late November 2007 to
consider the first draft of the Act (available online at
ing_draft.htm).

The draft addresses many of the formal and substantive
issues concerning TOD deeds and includes suggested statu-
tory forms. Key provisions of the draft include:

- The revocable TOD deed must be recorded in the
  county where the real property is located before
  the death of the owner.

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Ellen M. Klem is an associate staff director for the ABA
Commission on Law and Aging. She can be reached at
kleme@staff.abanet.org or at (202) 662-8689.
Transfer on Death Deed

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- Delivery of the revocable TOD deed to the beneficiary is not necessary.
- A revocable TOD deed is not effective until the transferor’s death and the transferor retains full ownership rights until death.
- The beneficiary has no rights in the property until the transferor’s death.
- The transferor has the right to revoke the TOD deed at any time before death, and a new revocable TOD deed can be executed to a different beneficiary(ies).
- The rights of the transferor’s creditors to reach the property are not affected by the deed.

During the November meeting, the drafting committee addressed the following issues:

- To allow alternate beneficiaries in the event that a beneficiary fails to survive.
- In the case of more than one recorded TOD deed, the later-acknowledged deed revokes the earlier-acknowledged deed.
- In the case of liability, (1) a TOD deed does not affect the ownership rights of the transferor during his or her lifetime, (2) a beneficiary who receives the transferor’s interest at the transferor’s death does so subject to all interests affecting title to the property, and (3) transfers under the Act are subject to liability to the extent the estate is insufficient to satisfy claims and allowances.
- Declined to include: (1) a procedure for proof of death, and (2) provisions on rules of construction.
- Declined to extend the Act’s application to housing units in stock cooperatives.

The drafting committee meets next on February 1-2, 2007, in Portland, Ore. If you would like to submit comments, receive additional information, or have any questions, contact NCCUSL at nccusl@nccusl.org or (312) 450-6600.

Funding Opportunity

ABA Commission, Borchard Foundation Announce Availability of Partnerships in Law and Aging Grants

The ABA Commission on Law and Aging and the Albert and Elaine Borchard Foundation Center on Law and Aging are pleased to announce the availability of grants to encourage development of new and collaborative community-based projects to enhance the legal awareness of older persons and to improve their access to the legal system.

The Partnerships in Law and Aging Program, with funding from the Borchard Foundation Center on Law and Aging and the Marie Walsh Sharpe Endowment of the ABA Fund for Justice and Education, will award up to eight grants of $10,000 each to legal services providers, bar associations, elder rights advocates, and other local non-profit organizations.

The Partnerships program has supported development of such projects as:

- outreach and services to culturally or linguistically isolated elders
- senior attorney and other volunteer legal assistance
- elder mediation
- handbooks and educational programs for lawyers and non-lawyer professionals
- senior hotlines
- state-specific editions of national materials
- law-related Web sites and other technology-based efforts
- self-help and community legal education
- holistic and other innovative delivery systems.

The grant announcement, guidelines, and additional documents are available on the Commission Web site at: http://www.abanet.org/aging/partnershipandgrants/home.shtml. Descriptions of previously funded projects are also available at that location. Please note that there is now a new electronic format for submitting applications.

Applications must be electronically submitted by March 3, 2008, and must include all items to be considered, including letters of commitment. Awards will be announced in early June 2008. Grants will run from July 1, 2008, through June 30, 2009.

Contact Holly Robinson, program manager, at robinsoh@staff.abanet.org or (202) 662-8694 with any questions regarding the process or eligibility.
Resources

Volunteer Guardianship Monitoring Programs: A Win-Win Solution

By Ellen M. Klem, ABA Commission on Law and Aging

Volunteer Guardianship Monitoring Programs: A Win-Win Solution, published this month, is a study of volunteer guardianship monitoring projects initiated by AARP in 1990. The study aimed to determine the extent to which the AARP volunteer guardianship monitoring projects are still functioning, and to examine their experiences and effectiveness in the 10 years since AARP discontinued support. The report is an insightful resource for courts and persons interested in guardianship monitoring. The study found:

- More than half of the programs are still active and volunteers are satisfied.
- Volunteers are critical to a program’s success and failure.
- Programs maximized scarce resources to successfully intervene and provide remediations for incapacitated adults at risk of abuse, neglect, or exploitation, and assisted guardians.
- Volunteers, while not free, provide an enormous value, bring a new perspective and energy to the work the court does, and often have skills and experience that paid staff does not have.
- Programs enhance the court’s capacity to monitor cases and to assist guardians without substantially increasing staff and budgets, and help the volunteers make important contributions to their own well-being.

The study urges courts interested in ensuring a program’s success do the following:

- Make room for the program.
- Have a paid program coordinator.
- Recruit volunteers.
- Form partnerships with the state and local AARP offices.
- Recognize volunteers.
- Adequately supervise volunteers.
- Conduct comprehensive training for volunteers on a regular basis.
- Track results of the program and use this information to regularly inform the court of the program’s importance.
- Integrate the volunteer program into the larger monitoring program at the court.

Volunteer Guardianship Monitoring Programs: A Win-Win Solution is available online at www.abanet.org/aging, or by calling (202) 662-8690. For a more comprehensive report on a range of guardianship monitoring practices, see Guarding the Guardians: Promising Practices for Court Monitoring, by the AARP Public Policy Institute with the collaboration of the ABA Commission on Law and Aging, available on the AARP Public Policy Institute Web site http://www.aarp.org/research/tpi/.

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Don’t delay! Join the ABA today at http://www.abanet.org/join/
In the News

At a joint press conference at the U.S. Capitol on Thursday, December 13, Sen. Gordon Smith of the Senate Aging Committee, AARP, and the ABA released a new report, Guarding the Guardians: Promising Practices for Court Monitoring. The report by Naomi Karp, of the AARP Public Policy Institute, and Erica Wood, of the ABA Commission on Law and Aging, offers help to courts around the country to ensure that the vulnerable adults under their jurisdiction receive appropriate care and financial management by their guardians.

The report identifies exemplary courts with excellent guardianship monitoring practices and provides a menu of promising practices that other courts can adapt and use to enhance their monitoring.


Key practices highlighted in the AARP/ABA report include:

- **Harnessing technology** to benefit guardians, courts, and incapacitated people. Ramsey County, Minn., implemented an e-filing system so guardians can file their annual accountings online. The system has built-in red flags to identify irregularities that bear further investigation.

- **Random audits.** Broward County, Fla., randomly selects cases and requires additional financial documentation, which serves as a sentinel effect. Arizona’s guardianship certification program performs intensive random audits of all professional guardians.

- **Visits to homes and institutional settings** by volunteer monitors and staff investigators.

- **Consistent follow-through and sanctions for malfeasance.** Maricopa County, Ariz., uses fiduciary arrest warrants when necessary.

- **A problem-solving restorative jurisprudence approach.** Suffolk County, N.Y.’s model guardianship court includes mediation, a resource coordinator, volunteer advocates, and the ability to integrate all pending cases involving the incapacitated person, including divorces, evictions, and other matters.

If you have questions about the report or guardianship in general, contact Naomi Karp at nkarp@aarp.org or Erica Wood at ericawood@staff.abanet.org.

Senator Smith, Ranking Member of the Senate Special Committee on Aging, and Senator Herb Kohl, Committee Chairman, also released a guardianship report with suggestions for federal actions to improve guardianship systems. Their report can be found at http://aging.senate.gov/minority/. Scroll to the bottom of the page to find the link.

—Naomi Karp
Strategic Policy Advisor Consumer and State Affairs Team
AARP Public Policy Institute

Worth Reading/Alzheimer’s disease/Elder care

Dancing with Rose: Finding Life in the Land Of Alzheimer’s

By Lauren Kessler
ISBN-10: 0670038598

Review by Holly Robinson
ABA Commission on Law and Aging

Lauren Kessler is many things—a writer, a wife, a university professor, a mother, a reporter, a daughter. And for four months, Ms. Kessler is a resident assistant in an Alzheimer’s unit of an assisted living facility in Oregon. Her account of her experience working as a “bottom-rung caregiver” for minimum wage is alternately heartwarming and heart-breaking. She describes the residents she cares for and the eldercare industry she works for, her co-workers and “corporate,” the residents’ families and her own experience with a parent with Alzheimer’s disease, and our own culture’s “disease” with illness, aging, and death.

You wouldn’t expect the story of a woman who leaves a writer’s life voluntarily to wake and shower, feed and toilet, dress and undress 11 adults with Alzheimer’s who may not remember her name, to be so totally compelling. Yet Ms. Kessler takes you by the arm, as she does one of her residents as she guides them towards the dining room for lunch, and gently walks with you into the world that is “Maplewood.” I didn’t want to leave her side and you won’t either.
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it right to decline life-sustaining treatment.13 A surrogate can exercise a similar right on behalf of an incompetent patient, although states can regulate the process of refusal.14

In the late 80s and early 90s, there were concerns that certain medical interventions were not always appropriate.15 Leslie Blackhall, then a medical resident, argued that physicians need not offer cardiopulmonary resuscitation as a treatment in cases where it offered no known medical benefit or where it was more likely to cause harm than good based on the patient’s physical condition.16 The American Heart Association’s Guidelines for CPR and Emergency Cardiac Care also reported that CPR was futile for patients with metastatic cancer, as several studies indicated that no patient survived to discharge.17

By the mid-90s the representative case shifted from physicians demonstrating a medical bias to treat the patient with all medical means available to physicians choosing to decline to provide treatment they deem medically futile. In 1994, the In re Baby K case provided an example of the medical futility debate.18 Baby K was born in 1992 with anencephaly, a congenital malfunction in which a major portion of the brain, skull, and scalp is missing.19 Baby K had a brain stem that allowed her to live with the aid of life-sustaining treatment, but because she lacked a cerebrum, she suffered permanent and irreversible unconsciousness.20 The attending physician recommended to the baby’s mother that aggressive life-sustaining treatment be removed because it “would serve no therapeutic or palliative purpose.”21 The mother disagreed and requested aggressive treatment.22 After about a month, Baby K was transferred to a nursing home, but was readmitted to the hospital three times with breathing difficulties.23 After the second readmission, the hospital sought declaratory relief as to whether it was obligated to provide aggressive medical treatment that it deemed “medically and ethically inappropriate.”24 The court limited its decision to statutory interpretation, and explicitly stated that “[i]t is beyond the limits of our judicial function to address the moral or ethical propriety of providing emergency stabilizing medical treatment to anencephalic infants.”25

The American Medical Association Council for Ethical and Judicial Affairs recommended that all health care institutions adopt a policy on medical futility.26 Despite attempts to identify the circumstances in which a medical intervention could be described as “futile,” medical professionals have been unable to agree on a universal, objective definition.27 The AMA Council concluded that medical futility is “inherently a value-laden determination,” and thus, “[a] fully objec-

Legislative Findings

Grounds for Provider Refusal Generally

All but five states acknowledge a provider’s right to refuse to comply with a patient’s request for treatment.32 The issue becomes whether a patient or surrogate decision maker can compel a physician or health care institution to provide treatment that the physician declines to provide. The recognized criteria for refusal vary significantly and many states have multiple criteria. Nineteen states and the District of Columbia do not establish any criteria for which providers can decline to comply with a patient’s treatment decision, yet they explicitly permit providers to decline.33 A majority of states expressly acknowledge that providers are not required to act contrary to generally accepted health care standards, although this provision is not always linked to the refusal-to-comply provision of the statute.34 Eleven states permit physicians to decline to comply with a health care decision for reasons of conscience or personal belief.35 Additionally, 14 states permit providers to withhold or withdraw medical treatment based on moral convictions or religious beliefs.36 Oregon is unique in that it also permits a health care institution or an employee or agent of the institution to decline to act in a manner contrary with “philosophical beliefs.”37

The numerous reasons for which a provider can decline to provide care reduces a patient’s ability to receive the care she needs or wants. Furthermore, a state policy that allows a provider to refuse to provide treatment without a specific reason gives more weight to physicians in the already unbalanced power ratio between patient and physician.

Provider Refusal for Medical Ineffectiveness

Fifteen states have given physicians the express authority to refuse “medically ineffective” health care.38 However, only four of the 15 states define “medically inef-
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ficient.”39 Delaware and Maryland, which have identical statutes, also have the most explicit definition. They define medically ineffective treatment as follows: “‘Medically ineffective treatment’ means that, to a reasonable degree of medical certainty, a medical procedure will not: (1) prevent or reduce the deterioration of the health of an individual; or (2) prevent the impending death of an individual.”40

Alaska and New Mexico do not specifically link medically ineffective treatment to impending death. Under Alaska's statute, “‘medically ineffective health care’ means health care that according to reasonable medical judgment cannot cure the patient’s illness, cannot diminish its progressive course, and cannot alleviate severe discomfort and distress.”41 Although New Mexico is the least explicit, stating that “medically ineffective” means that the treatment would “not offer the patient any significant benefit, as determined by the physician,” it is also the broadest in concept because “benefit” can refer to more than preventing impending death or curing a patient’s condition.42

Pennsylvania does not use the words “medically ineffective,” but the provision is treated here as substantially equivalent to medical ineffectiveness.43 Rather than providing an affirmative right to decline to provide certain health care decisions, Pennsylvania provides immunity for a health care provider who refuses to comply with a direction that is based on good faith and a reasonable degree of medical certainty that the medical care would have “no medical basis in addressing any medical need or condition of the individual.”44

Having a criteria regarding what is “medically ineffective” treatment provides a benchmark for discussion. The states that lack any definition of medical ineffectiveness deprive physicians, patients, and loved ones of a reference point for discussion in resolving differences where the provider refuses to comply with treatment demands on these grounds.

Provider Obligations Generally

A majority of states require the provider to inform the patient of her refusal to fulfill health care directions, regardless of the reason the provider refuses.45 When the patient lacks the mental competence to be informed of such refusal, then the law typically requires the provider to notify the patient’s surrogate. Sixteen states require a health care provider who refuses to comply with the patient’s health care directions to “promptly so advise” the patient,46 while a few only require that the provider make a “reasonable effort to inform the patient.”47

States that require a provider to inform the patient that certain treatment requests cannot be satisfied recognize the importance of notice and open communication between the patient and physician, akin to the reasons for informed consent. Additionally, states that request prompt notice recognize the vulnerable position that patients are in and the time a patient needs in making other arrangements to receive the health care she wants.

Transfer Requirements

All but five states impose some requirement that the patient be transferred to another physician or institution that is willing to comply when a health care provider cannot meet patient requests.48 For the majority of states, the transfer requirement is in addition to the notice requirement,49 but for some, it stands alone without any notice requirement.50 For example, Arizona and North Dakota do not require any communication between the health care provider and patient, but do impose a transfer requirement.51 Sometimes the transfer requirement is not affirmatively imposed but is imposed through an immunity provision, such that the health provider is not subject to civil or criminal liability “if the provider promptly transfers the responsibility for the patient’s care to another provider.”52

A transfer requirement is beneficial because it offers the patient some safeguard that his or her health care directions will be fulfilled by someone willing to comply. However, not all transfer provisions are created equal.
The level of effort the physician or institution must spend in transferring the patient to another physician or facility differs across the states. The transfer requirement may be as minimal as merely to refrain from being a hindrance. For example, Kentucky provides that a health care provider who refuses to comply with a health care decision “shall [not] impede the transfer of the patient to another physician or health care provider.”

In contrast, Florida imposes a time constraint, wherein a health care provider who is unwilling to comply with the health care decision of the patient because of moral or ethical beliefs “must within 7 days either: (a) Transfer the patient to another health care provider or facility . . . or (b) If the patient has not been transferred, carry out the wishes of the patient or the patient’s surrogate.” Other states provide a range of transfer obligations such that a health care provider: (a) shall reasonably cooperate to assist in the transfer; (b) make all reasonable efforts to assist or effect in the transfer; (c) shall as promptly as practicable take all reasonable steps to transfer care or immediately make all reasonable efforts to assist in the transfer; or (d) must transfer the patient.

Transfer Burden

Some states place the transfer burden on the patient herself or the surrogate. Tennessee permits physicians to do nothing when a surrogate cannot transfer the patient. Nebraska, which initially places the onus on the surrogate to pursue the transfer, places little duty on the physician, stating that the “health care provider [may] intervene” when the surrogate is unwilling or unable to effect a transfer. In New York, if a transfer cannot be effected, the hospital must either seek judicial relief or honor the surrogate’s decision.

Unlike the provisions of Tennessee or Nebraska, it is more beneficial to the patient when states place a stronger obligation on the health care provider to effect a transfer. A patient who is not transferred by the provider may then be left with truly no other gateway to receive her requested care. In effect, the provider’s interests trump that of their patients.

The patient is already in a vulnerable position, and expending energy on finding another provider may only contribute to the patient’s deteriorating condition. Unlike the patient or surrogate, the health care provider is in a better position to locate a facility to transfer the patient because of its connections with other providers and familiarity with who may be willing to comply with the health care directions of the patient. New York’s provision is worthy of Continued on page 30

State Bar/Emeritus Pro Bono Rules

South Dakota Adopts Emeritus Attorney Pro Bono Rule

On January 1, 2008, South Dakota became the 26th state with an emeritus attorney pro bono rule in effect. Lawyers or judges who are or have been active members of the State Bar of South Dakota and are or will be retiring are eligible to register for emeritus status. Emeritus status lawyers may represent, on a pro bono basis, only clients referred to the lawyer by pro bono programs approved by the State Bar of South Dakota.

For more information on South Dakota’s new rule, contact Tom Barnett, executive director, State Bar of South Dakota, at (605) 224-7554.

For more information on emeritus attorney pro bono rules and programs, contact Holly Robinson, associate staff director, ABA Commission on Law and Aging, at robinsoh@staff.abanet.org or (202) 662-8694

Resources

Tips for Making Your Printed Health Materials Senior Friendly

Making Your Printed Health Materials Senior Friendly is a new publication from the National Institute on Aging, part of the National Institutes of Health.

The tip sheet offers suggestions for how to write and design health information to accommodate cognitive and physical changes that often accompany old age. It provides specific examples and includes resources for more information.

Print copies of Making Your Printed Health Materials Senior Friendly are free and available in bulk while supplies last. It is also available online.

To preview, download, or print go to: http://www.nia.nih.gov/HealthInformation/Publications/srfriendly.htm. You can also order a free print copy by calling (800) 222-2225, or e-mailing to NIAIC@nia.nih.gov.
replication as it ensures a definitive step toward resolution where an impasse is reached.

**Institution vs. Individual Obligations**

Some states distinguish between institutional and individual provider obligations, generally in terms of when notice needs to be given. For example, some states will require that an institution inform the patient of its policy prior to or upon admission, whereas the individual health care provider will inform the patient at the time she refuses to honor the patient’s decision. Illinois requires that the health care provider only notify the administration of the health care facility, and “then assist the patient or surrogate in the transfer of the patient to another health care provider.” Additionally, some states distinguish between institutional and individual provider requirements for transfer. In Nebraska, the institution is responsible for the transfer whether the institution or the individual provider declines. When the institution declines to comply with treatment requests, the institution “may intervene to facilitate such a transfer,” but only after “the surrogate is unable or unwilling to arrange a transfer.” When the individual provider cannot comply, then the institution “shall promptly assist in the transfer.” In New Hampshire, the physician “shall, without delay, make the necessary arrangements to effect the transfer . . . .” whereas the institution “shall [allow] for the transfer.”

The distinction in transfer requirements between the institution and individual provider reveal that when the individual provider refuses to comply with treatment requests, then the transfer requirement is more forceful. This difference may reflect the ethical commitment of the individual patient-provider relationship, which fosters close interaction and communication.

**Procedures to Resolve Patient-Provider Disputes**

Given the fact that patient-provider disputes have arisen in the context of end-of-life care, some states have established a process for resolving such conflicts.

**Maryland**

Maryland has established a process for when a physician believes that an instruction to withhold or withdraw life-sustaining treatment from the patient is inconsistent with generally accepted standards of patient care. The physician shall petition the hospital’s patient advisory committee for advice concerning the withdrawal or withholding, or file a petition with the court seeking injunctive or other relief.

**West Virginia**

West Virginia provides a procedure for resolving conflict between the “surrogate and the patient’s best interests as determined by the attending physician when the person’s wishes are unknown.” The physician shall consult with a qualified physician, an ethics committee, or by some other means. If the physician cannot resolve the disagreement, she can transfer the patient to another facility.

**Texas**

The Texas Advance Directive Act, Tex. Health & Safety Code § 166.001-010, outlines a procedure for resolving disagreements about treatment both for situations in which a health care proxy requests life-sustaining treatment, and the physician declines, and when the physician wants to provide life-sustaining treatment, but the proxy refuses. When the attending physician recommends against life-sustaining treatment that the patient wishes to continue, the physician must inform the patient’s proxy of this decision. Treatment will then continue pending a review by an institutional ethics committee or medical committee (“committee” or “review board”), whereby the proxy will be given 48 hours notice of the review. Both the proxy and patient are invited to attend the committee meeting. If the review board agrees with the attending physician that “life-sustaining treatment is inappropriate,” it must provide the proxy with a written explanation of that decision. The physician must continue to provide aggressive treatment while assisting the proxy in finding a physician and facility willing to provide the requested treatment. The proxy is given contact information of health care providers who may provide the requested care, or further assist in arranging a transfer. If a health care provider is found who is willing to satisfy the patient’s requests, then the patient will be transferred. The current facility will arrange the transfer and provide the necessary services, but the patient will be responsible for the cost. However, if within 10 days, the proxy cannot find a provider willing to comply with the requested treatment, then the provider may withdraw the life-sustaining treatment. The time period may be extended with the permission of the appropriate court, provided there is a reasonable expectation that a willing facility will be found if the extension is granted.
Texas Advance Directive Act As Model Statute

There are an increasing number of patient-physician disagreements over the request to maintain life-sustaining treatment.88 There is little case law providing a definitive resolution to this debate. The Texas Act is the first state attempt to provide a clear and comprehensive process where a physician declines to honor a request for maintaining life-sustaining treatment. The Act provides a model for other states, illustrating the possibility of establishing a balance between a physician’s autonomy to provide treatment and a patient’s ability to direct her own care.

The Texas Act preserves respect for both patient requests and the medical profession by establishing an out-of-the-court process that fosters patient-physician communication and agreement. The Act requires the physician to inform the surrogate of the physician’s determination that further treatment is medically inappropriate, and the surrogate is then given the opportunity to participate in the committee meeting.89 Thus, requiring such a process recognizes that since patients do not have a right to receive their requested request for life-sustaining treatment, they do deserve a review of their request. Additionally, this gives a patient some deference by not giving a physician complete authority to make unilateral decisions.

The Act also provides a follow-up resolution where the committee supports the physician’s decision to decline life-sustaining treatment. The transfer requirement directs the current facility to assist the proxy in finding a provider willing to comply with the patient’s treatment request.90 Additionally, providing the proxy with a list of facilities and physicians who may be willing to comply with the patient’s treatment requests recognizes that the institution has networks and connections that the patient lacks. The ten-day time frame to effect a transfer encourages quick responses from both the patient and physician and also helps avoid prolonged disputes. The opportunity to extend the time frame also identifies that sometimes, even with aggressive efforts in locating another facility, a patient or proxy may need more time.

While the Texas Act provides a balanced approach in the context of patient-physician disputes, there is one concern. Even though the existing facility is responsible for assisting in the transfer, the Act requires the patient to pay for the transfer.91 A patient may not have the financial means to effect a transfer due to lack of health care coverage or even where a patient has insurance, it may not cover costs of transfers. Thus, the requirement for the patient to pay could be a hurdle that a patient may not be able to overcome, even when a willing provider is found.

Conclusion

From a state’s perspective, it must find a balance between providing a patient with the ability to direct her own health care and providing health care providers with the right to decline to provide treatment for personal or professional reasons. When a provider’s ability to decline treatment imposes obstacles for the patient to receive the health care she has chosen, the practical ramifications of the state’s statute is that it becomes a barrier to care. From a patient’s perspective, the various reasons for which a health care provider may decline to provide treatment tilts authority in favor of physicians having the final say.92

Medical ineffectiveness or futility, as a ground to decline treatment, is a topic that incites political, legal, and bedside clinical battles because it “revolves around fundamentally irresolvable moral conflicts concerning our most deeply held beliefs about the value of life, especially profoundly diminished life.”93 Perhaps this quagmire is the very reason some states remain silent on this issue, leaving patients like in Mrs. Wanglie’s condition unable to receive the treatment they seek.

Notes

2. See id. at 375-76.
3. Id. at 375-77.
4. See id. at 377.
5. See id. at 376.
6. See id.
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11. Id. at 651.
12. See id. at 671.
13. See 497 U.S. 261, 278 (1990). Writing for the majority, Chief Justice Rehnquist states that “[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred by our prior decisions.” Id.
15. See Alan Brett and Lawrence McCullough, When Patients Request Specific Interventions: Defining the Limits of Physician Obligation, 315 New Eng. J. Med. 1347, 1349 (1986) (suggesting that physicians were not obligated to provide all patient requested interventions or treatments and that there had to be a “modicum of benefit” to justify providing the desired interventions).
19. Id. at 592.
20. Id.
21. Id.
22. Id. at 593.
23. Id.
24. Id.
25. Id. at 598 (holding that based on the Emergency Medical Treatment Act such treatment must be provided).
27. Id. at 937-38 (discussing the various approaches for identifying a medically futile intervention and the criticism of each).
30. Infra note 37.
32. Five states: Idaho, Indiana, Michigan, North Carolina, and South Dakota have not addressed whether providers may decline to comply with a patient’s request for treatment for any reason.
34. Those twenty nine states are: Alaska, Arkansas, California, Delaware, District of Columbia, Hawaii, Iowa, Kansas, Maine, Maryland, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Jersey, New Mexico, Nevada, North Dakota, Ohio, Oklahoma, Pennsylvania, Rhode
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63. Id.


65. Id.

66. Id.


68. Id. at § 166.052(a).

69. Id.

70. Id.

71. Id.

72. Id.

73. Id.