The Lawyer's Role in End-of-Life Planning—Moving Beyond Advance Medical Directives

by Grant Marylander and Jean Abbott

Advance medical directives are enhanced with an inventory of a client's values regarding end of life decisions using a value-based supplement. The lawyer's role in advance care planning extends to introducing these supplements so the client's end-of-life values are respected.

Man plans and God laughs.
—Yiddish proverb

Beginning in the mid-1970s, healthcare providers, patients, families, and the public have vigorously debated the issue of patient autonomy and the right to withhold unwanted medical treatment. This debate was well summarized by the New Jersey Supreme Court in the tragic case of Karen Ann Quinlan, a young woman who suffered from a chronic persistent vegetative state.

The litigation has to do, in final analysis, with her life—its continuance or cessation—and the responsibilities, rights and duties, with regard to any fateful decision concerning it, of her family, her guardian, her doctors, the hospital, the State through its law enforcement authorities, and finally the courts of justice.

In 1990, the U.S. Supreme Court recognized competent adults have a "constitutionally protected liberty interest in refusing unwanted medical treatment..." Since then, a number of states, including Colorado, have enacted legislation affirming a patient's right to refuse medical treatment and recognizing the legal effect of advance medical directives (for purposes of this article, we use the term "advance medical directives" as that term is defined in CRS § 15-115-505(2)).

About the Authors

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Unfortunately, as we have become medically adept at prolonging death, advance medical directives often prove inadequate in providing meaningful direction to an agent or healthcare provider confronted with end-of-life decisions. Lawyers who assist clients in estate and advance care planning should consider not only appropriate advance medical directives but also the "upstream" value-based initiatives that help guide their clients in planning for end-of-life care and treatment. Clients who engage in an inventory of their values and wishes for end-of-life care as part of their planning process are more likely to provide meaningful direction to their lawyers on what values are most important to them.

Several organizations have created value-based supplements that move beyond rigid rules to capture the patient’s wishes regarding the end of life. This article discusses advance medical directives, as well as several of the more useful upstream value-based supplements that can help clients articulate their values and better allow for respect for their wishes.

Advance Medical Directives—The Legal Landscape

In Colorado, advance medical directives include: (1) the medical durable power of attorney executed pursuant to CRS § 15-14-506; (2) a declaration executed pursuant to the Colorado Medical Treatment Decision Act (sometimes referred to as a living will),
The medical durable power of attorney delegates authority to an agent to act on behalf of the patient in consenting to or refusing medical treatment.\(^5\) Notably:

1. The agent shall act in accordance with the terms, directives, conditions, or limitations stated in the medical durable power of attorney, and in conformance with the principal's wishes that are known to the agent.\(^6\)

A declaration regarding medical treatment allows a competent adult to direct that life-sustaining procedures be withheld or withdrawn if, at some future time, he is in a terminal condition and either unconscious or otherwise incompetent to decide whether any medical procedure or intervention should be accepted or rejected.\(^7\)

The declaration becomes effective forty-eight hours after two doctors certify the patient is in a terminal condition, to allow a spouse, adult child, parent, or attorney-in-fact to challenge the declaration.\(^8\)

A CPR directive allows a patient or the patient’s healthcare proxy to execute a document refusing resuscitation—that is, measures to restore cardiac function or to support breathing in the event of cardiac or respiratory arrest or malfunction.\(^9\)

A CPR directive is distinct from a Do Not Attempt Resuscitation order (commonly referred to as a DNR or DNAR order), which is used limited intervention, or full treatment; and (3) other treatment options identified by the patient.\(^11\) In contrast to a declaration regarding medical treatment, the MOST form is signed by the patient (or the authorized surrogate decision maker) and the patient’s physician, advance practice nurse, or physician assistant, and becomes a portable, standing medical order until such time as the MOST is revised or revoked.\(^12\)

When a patient lacks decisional capacity to provide informed consent and there is no known person with the legal authority to act on the patient’s behalf, Colorado allows appointment of a healthcare proxy to make medical treatment decisions for the patient.\(^13\) The healthcare proxy is selected by consensus among the patient’s “interested persons,” who are defined as “the patient’s spouse, each parent of the patient, any adult child, sibling, or grandchild of the patient, or any close friend of the patient.”\(^14\)

The person selected to act as the patient’s proxy decision-maker should be the person who has a close relationship with the patient and who is most likely to be currently informed of the patient’s wishes regarding medical treatment decisions.\(^15\)

The Appendix to this article may be helpful in distinguishing among these common advance medical directives.\(^16\)

Limitations of Advance Medical Directives

One of the common limitations of advance medical directives is their focus on specific procedures to which the patient consents or refuses. The actions articulated in advance medical directives are made in the abstract, without a specific context or circumstances that manifest in the future. These specific wishes may change over time, often in ways patients have difficulty foreseeing.

Further, values change over time. People adapt more than they would predict to some conditions that compromise the activities they loved in their prime, for example strokes or paraplegia. They may have events like a wedding or birth of a child that motivate them to accept certain treatment. And for some people, there are conditions worse than death—for example, being on a ventilator long-term, being unable to ambulate, or being unresponsive to those around them.

A number of medical professionals have called for early, meaningful discussions during advance care planning that focus on a review of values and goals. Lawyers must recognize that, when advising their clients regarding their end-of-life planning, a client’s intent may not be fully reflected in the procedure-focused elements found in advance medical directives. For example, choosing the appropriate person to act as the client’s agent often requires a thoughtful inquiry about who is most likely to understand and follow the client’s wishes. Encouraging discussions and documenting values and wishes as part of the advance medical directive process provides a safeguard against unwanted treatments or undermining patient autonomy during terminal or critical illnesses.\(^17\)
Lessons About Dying in America

The Institute of Medicine report, "Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life," highlights that "most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care." The report emphasizes the importance of advance care planning as essential to ensuring that the patient the person entrusts with medical decisions will act as consistently as possible with the patient's wishes and values. Only 30% of people have any form of advance medical directive. Even when some form exists to guide family, friends, and the healthcare team at the bedside, that directive is often difficult to interpret in light of the patient's specific circumstances. Indeed, when adopting the MOST forms, the Colorado Legislature recognized, "[c]urrent instruments for making advance medical directives are often underutilized, hampered by certain institutional barriers, and inconsistently interpreted and implemented." 

Upstream documentation and conversations about people's wishes and values—the "why" of advance medical directives—is crucial. Several upstream value-based supplements frame the advance care planning process. For the legal community, these value-based supplements provide a critical framework and launching pad that can enhance understanding of a client's desires regarding medical and end-of-life decisions. The combination of advance medical directives and value-based supplements decreases the suffering and stress that decision makers frequently encounter when they are asked to make medical choices "in the voice of" their loved one.

Five Value-Based Supplements to Advance Medical Directives

Several value-based supplements are available to assist clients identify their priorities and wishes in conjunction with preparation of advance medical directives. These documents ask the "why" behind those directives and assist clients in meaningful end-of-life planning. Further, they can be attached to the advance medical directive to help agents, families, and loved ones best discern the wishes of a client who is no longer able to participate in critical health decisions and often near the end of life.

The Conversation Project Starter Kit

The Conversation Project is an initiative started by Pulitzer Prize-winning columnist Ellen Goodman and the Institute of Healthcare Improvement. The thirteen-page "Starter Kit" is designed to encourage people to consider what is important to them regarding end-of-life decisions and to have the conversation about those values with their loved ones. The kit includes open-ended questions, such as "What matters to me most at the end of life is..." and scaled questions, such as how much information they want regarding their medical prognosis.

The questions are generally easy to follow and, in contrast to other supplements, the Starter Kit omits procedure-specific questions. The Starter Kit outlines how to engage loved ones in the conversation and encourages value-based discussions. The completed kit should be shared with healthcare providers, family, friends, and particularly any healthcare proxy, and attached to the client's advance medical directive. Further, it should be updated as the client's values and wishes change.

Five Wishes

Five Wishes is produced by Aging with Dignity, a nonprofit organization formed to promote better care for those near the end of life. This widely distributed eleven-page workbook (which is also available online) includes appointment of a healthcare proxy and detailed, multi-choice wishes about how people want to die and post-death wishes. For example:

If my doctor and another healthcare professional both decide that I am likely to die within a short period of time, and life-support treatment would only delay the moment of my death (Choose one of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

The ultimate result is a living will that is intended to operate as an advance medical directive. As is true with other forms of advance medical directives, the wishes expressed in this document may be superseded by a healthcare proxy in certain circumstances.

Prepare

Prepare was created by the University of California as an online five-step approach to expressing wishes that allows for early
underpin their advance medical directives. The program includes helpful videos of people with different decision-making styles and facilitates easy communications with the client’s healthcare provider. Clients may return to the program to change values as their lives change. Due to its online format, the program may prove intimidating to older adults unfamiliar with online materials.

**Honoring Choices and Respecting Choices**

Wisconsin-based Gundersen Health System created “Respecting Choices” to help patients with advance care planning. The program uses clinicians and nurses to facilitate conversations, create advance care planning notes, and encourage early planning, with the ultimate goal of providing evidence-based care and treatment consistent with the patient’s goals and values. This innovative program links electronically to certain hospital systems, including Kaiser in Colorado.

**ABA Consumer’s Tool Kit for Health Care Advance Planning**

The American Bar Association’s (ABA) Commission on Law and Aging created a “tool kit” that contains a variety of self-help worksheets, suggestions, and resources to help people, among other things, choose healthcare proxies, consider when the client would want to refuse medical treatment, and “after death” decisions.

The worksheet on “Are Some Conditions Worse Than Death” allows scaled responses regarding treatment when the client suffers from certain disabilities—for example, he or she is unable to think or speak clearly or recognize or interact with family and friends. Clients can also articulate priorities and spiritual beliefs in the worksheet on “Personal Priorities & Spiritual Values Important to Your Medical Decisions.” The result is value-based considerations for end-of-life treatment.

**Conclusion**

As the Institute of Medicine report stated: “For patients and their loved ones, no care decisions are more profound than those made near the end of life.” Lawyers have a unique opportunity to enhance their clients’ end-of-life process by introducing clients to value-based supplements that encourage meaningful planning and thoughtful conversations with loved ones about the values that underpin their advance medical directives.

### Notes

3. CRS § 15-14-505(2) states: “Advance medical directive” means any written instructions concerning the making of medical treatment decisions on behalf of the person who has provided the instructions. An advance medical directive includes a medical durable power of attorney executed pursuant to section 15-14-506, a declaration executed pursuant to the “Colorado Medical Treatment Decision Act,” article 18 of this title, a power of attorney granting medical treatment authority executed prior to July 1, 1992, pursuant to section 15-14-501, and a declaration executed pursuant to article 18.6 of this title.
4. Id. An advance medical directive may include a power of attorney granting medical treatment authority executed before July 1, 1992, pursuant to CRS § 15-14-501. This article does not discuss this form of power of attorney.
5. CRS § 15-14-506(1).
6. CRS § 15-14-506(2) (emphasis added).
7. CRS § 15-18-104(1).
9. CRS §§ 15-18-6-101(1) and -102.
10. CRS §§ 15-18-7-101 et seq.
11. CRS § 15-18-7-103(b).
12. CRS § 15-18-7-107.
14. CRS § 15-18-3-103(3).
15. CRS § 15-18-5-103(4) (emphasis added).
19. CRS § 15-18-7-101(c).
25. Institute of Medicine, supra note 18.

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# Appendix

<table>
<thead>
<tr>
<th>Advance Directive Type</th>
<th>Definition</th>
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<th>Cons</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical durable power of attorney (MDPOA)</td>
<td>Agent appointed by patient to make decisions when patient lacks capacity, temporarily or permanently</td>
<td>Agent has broad authority to respond to the situation according to patient values.</td>
<td>Patient must have shared values with agent; it is only for healthcare decisions; and patient can discharge agent even if s/he lacks decisional capacity.</td>
<td>Agent has latitude in making medical decisions and this is the most flexible way for patient wishes to be implemented. It cannot override declaration re medical treatment or CPR directive.</td>
</tr>
<tr>
<td>Declaration regarding medical treatment/living will</td>
<td>Person directs withdrawal of life-sustaining treatments when s/he lacks capacity and in terminal or persistent vegetative state</td>
<td>This must be honored unless an MDPOA is given express authority to override.</td>
<td>This is only in effect when patient lacks decision-making capacity and is in terminal condition or persistent vegetative state as determined by two doctors.</td>
<td>This is very narrow and inflexible.</td>
</tr>
<tr>
<td>CPR directive</td>
<td>Colorado state form documenting refusal of CPR in the event of a heart or breathing malfunction.</td>
<td>This is to be honored by all emergency medical services and facilities.</td>
<td>This does not instruct on how much to intervene on other pre-death care, like dialysis, transfusions, and intubation for respiratory distress only.</td>
<td>This is an order across settings and is only effective in cardiopulmonary arrest.</td>
</tr>
<tr>
<td>MOST form</td>
<td>Orders (not directives) signed by patient (or representative) and healthcare provider to determine treatment wishes near the end of life</td>
<td>Orders (includes copies) are to be fully honored by all providers in all settings in Colorado.</td>
<td>This is intended only for patients with chronic, serious, or advanced illness.</td>
<td>This is a new form, broader in scope than CPR directives. Wishes for wide diversity of treatments can be expressed.</td>
</tr>
<tr>
<td>Proxy decision maker for healthcare</td>
<td>Surrogate when patient lacks decisional capacity but has not designated an agent (MDPOA); selected by interested parties as person who can best speak for the patient’s wishes/best interests</td>
<td>This provides consent for non-emergent interventions or restraint by representing patient in giving informed consent.</td>
<td>Family and friends may disagree, causing significant stress. Proxy cannot withhold artificial hydration or nutrition in most instances. Many providers are unaware of the process for obtaining a proxy in Colorado.</td>
<td>This provides less freedom than agent with MDPOA to make medical decisions.</td>
</tr>
</tbody>
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