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Advance Planning and Drafting for Health Care Decisions

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Effective health care advance planning requires two things: meaningful conversation and more meaningful conversation. Having a written and executed health care advance directive is *not* the goal of legal planning for health care. Instead, the goal is to define and communicate the client's values and wishes about treatment to caregivers and surrogate decision makers in anticipation of the client's losing the capacity to make health care decisions personally.

Many people neither sign advance directives nor discuss with loved ones their wishes about health care decisions if they become incapacitated. Signing an advance directive cannot by itself accomplish the goals of health care planning, but it can provide a good starting point for the decision making process.

Research indicates that it is difficult to get people to engage in advance planning, despite a variety of educational initiatives. Although public education certainly helps, most people will never meaningfully engage in health care advance planning. There is a cultural aversion to the subject matter, but there is also a dissatisfaction with the legal tools. This article discusses some of the problems with the state advance directive laws and standardized forms, explains what advance directives can and cannot do, and suggests six steps for effective client counseling on this important but difficult-to-discuss topic.

Shortcomings of Advance Directives

Every state has one or more advance directive laws. Over the past 25 years, many layers of these laws have contributed to a great deal of confusion and complexity. A state may have separate statutory provisions for health care directives (i.e., living wills), durable powers of attorney for health care, default surrogate decision making, out-of-hospital do-not-resuscitate orders and even special mental health powers of attorney. States lack uniformity. In the last few years, states have begun to simplify and combine these separate laws, but much more needs to be done.

Generally, advance directive statutes limit the liability of health care providers. These statutes confer protection from liability or professional discipline for those who honor a directive in good faith. Mostly the statutes provide a process for making a directive but do not provide any true penalties for failing to enforce or honor such a directive. Rather, they mandate only a good faith effort to transfer the patient to a doctor or facility that will comply with the patient's directive. Enforcement is left to the courts in "wrongful life" suits, which

have met with varying results.

Many states provide sample or suggested form directives within the statute. Some statutes make these forms mandatory and discourage the use of writings that are not substantially similar. There are other forms developed by organizations—such as the Five Wishes document available from Aging with Dignity—that have been drafted to comply with the majority of state statutes.

Rigid requirements for validity make a national model advance directive virtually impossible. Many states require precise witnessing and execution formalities. Others mandate multiple medical preconditions before the directive becomes effective. These medical preconditions, such as “terminal condition” and “permanent unconsciousness,” are neither defined consistently among the states nor understood clearly. Moreover, patients may want certain treatments withheld under conditions not authorized by the statute.

Research has shown that advance directives simply do not provide much guidance to medical professionals. One study concluded that the standardized and general language of most advance directives does not address the complicated situations encountered by medical professionals. As a result, the directives fail to inform medical decision making beyond the naming of a health care proxy or surrogate. Joan Teno, et al., *Do Advance Directives Provide Instructions That Direct Care?*, 45 J. Am. Geriatric Soc. 508 (1997).

A study of the Maryland statutory advance directive form highlights another problem with statutory forms. Researchers interviewed more than 80 seniors who had completed the Maryland statutory form and then reviewed the completed forms. They found that 41% of the group gave internally inconsistent instructions within the form. When asked their wishes in different scenarios, in face-to-face interviews, up to 45% of the respondents gave answers inconsistent with their written instructions. Gender, education, occupation and race made little difference in the results. Dianne E. Hoffman, et al., *The Dangers of Directives or the False Security of Forms*, 24 J. Law, Medicine & Ethics 5 (1996). These results raise serious questions about the validity and reliability of standardized statutory forms.

Instead of focusing on an instructional directive, the appointment of an agent deserves priority in advance planning if the client has a trusted advocate on whom to rely. A health care agent can weigh all the facts and circumstances at the time an actual decision must be made and, presumably, make the decision the patient would have made. Naming an agent will succeed only if the agent knows the principal's wishes. Most lawyers who prepare advance directives for clients recommend that the client discuss the directive with the named agent and the client's physician. In practice, clients rarely follow through. Thus it is not surprising that individuals may prefer to spell out their wishes in writing.

As a practical matter, health care professionals cannot implement advance directives about which they have not been told. For the most part, the burden of notifying the health care professionals of the existence of a directive falls squarely with the client. The Patient Self-Determination Act, passed in 1990, requires certain health care professionals to ask a patient about the existence of an advance directive at the time of admission to a health care facility and to document it in the patient's record. See §§ 4206 and 4751, Omnibus Reconciliation Act of 1990, P.L. 101-508. In most instances, documentation merely re-quires a notation that a directive exists. The patient, agent or family members must provide a copy of the directive and ask that it be included in the patient's medical record. Even at that point, documentation guarantees nothing. If the patient moves to another hospital or nursing home, there is likewise no guarantee that the document will travel with the patient. The process starts again.

Proponents of advance directives suggest a variety of additional strategies, such as carrying a wallet card or filing directives with a private living will registry. Although these may help, the honoring of an incapacitated patient's wishes depends on a health care professional's immediate awareness of the directive and the initiative of the appointed agent.

What Advance Directives Cannot Do

Advance directives were designed to help clients accomplish end-of-life medical planning. Paradoxically, advance directives may help clients avoid the real task of end-of-life planning. Executing an advance directive may create a safe, legal fiction that the directive will accomplish the client's wishes regarding end-of-life care while the reality is far different.

There are at least four things advance directives **cannot** do. A directive cannot provide "cookbook" directions. Dying is just too complicated. It is individualized, personalized, sacred, profane and endlessly nuanced. A directive cannot eliminate an individual's personal ambivalence. Most clients have some level of ambivalence for themselves and for loved ones when faced with balancing the length of life versus quality of life. Goals and wishes can and do change with passage of time and with changes in a client's medical condition, level of functioning, treatment options and quality of life.

An advance directive is a poor substitute for discussions among the client, the family and the health care professional. Effective advance planning must be a continuing conversation. The relationship between principal and proxy is a covenant, not a contract. If the client perceives the execution of an advance directive as the end point, the conversation ends. There is simply no substitute for continued communication among all the parties concerned.

Finally, an advance directive can-not control health care professionals. Whether because of a disagreement with the client's wishes, professional objection or an ambiguity in the document, a health care professional may simply overrule or ignore the client's directive or object based on conscience, an option provided in almost every state's law.

What Advance Directives Can Do

Advance planning is a process of reflection and communication, and advance directives play a threefold role in the process. A directive should serve as a catalyst for thinking, discussing and clarifying values and wishes. In addition, directives can enable the client to choose a substitute decision maker. Finally, they can provide guideposts for the course of treatment to the extent the client desires, as long as the directive is a true reflection of the client's wishes and not a generic, one-size-fits-all directive.

Public Policy Implications

Public policy directly affects the options available, the choices made and the documents drafted. Legislatures must determine what the basic elements of advance planning public policy should look like. Four principles that merit explicit incorporation into advance planning legislation are as follows:

- Good health care decision making requires a meaningful, ongoing process of communication among patient, family and health care provider about present and future health care decisions, shaped primarily by the patient's needs, values and goals.
- Advance directive statutes provide a nonexclusive pathway for expressing wishes and preferences for end-of-life care. Constitutional, common law, medical and ethical principles require respect for any other authentic expression of one's wishes about care and treatment.
- Public policy and education initiatives should provide a variety of advance planning tools and forms, since no two people approach the task in exactly the same way and no one form or planning tool is ideal for everyone.
- Statutory advance directive rules require simple, flexible, user-friendly and meaningful interpretation and implementation, so that the process is tailored to meet the individual's needs as well as personal and cultural preferences.

To realize these principles, advance directive laws should be amended where necessary to:

- Avoid standardized statutory forms, since they tend to elevate form over substance.
- Permit wide latitude in both proxy instructions and authority.

- Avoid mandatory medical preconditions.
- Give priority to naming a proxy.
- Honor rather than preempt authentic instructions, regardless of the manner in which instructions are expressed.
- Address continuity across care settings by ensuring that patients' wishes follow them.
- Recognize default surrogates in the absence of a directive.

Most state advance directive laws do not contain these characteristics. The Uniform Health-Care Decisions Act comes closest to these attributes, although it, too, insists on including a suggested form and does not address the issue of continuity across care settings.

The Six Steps to Effective Counseling

Lawyers should offer clients advance planning services, not just advance directives. This does not mean spending hours discussing a client's deepest personal values and beliefs and facilitating maximum communication among client, family and providers. It does mean more than simply printing out the standard advance directive form. The "print and sign" routine is the essence of fast food advance planning. There are six steps a lawyer should take to serve clients well:

1. Incorporate advance planning as routine. Health care advance planning should be incorporated into the practice as a routine and essential part of estate planning. If the clients do not bring it up, the lawyer must.

2. Give clients homework. Do not provide form advance directives to clients. Clients can be given homework that informs them and stimulates thinking and discussion before they sign an advance directive. There are good workbooks, values histories and similar tools available to help lawyers do this. For example, the ABA recently published *The Lawyer's Tool Kit for Health Care Advance Planning*, which includes 10 worksheets that can be provided to clients to help them understand, think about and discuss advance planning, preferably before signing an advance directive. See <http://www.abanet.org/elderly>.

3. Discuss a power of attorney for health care. If the client has someone who can and will fulfill the job, give priority to creating a durable power of attorney for health care. The job of health care agent or proxy is not one with which most people are familiar. It is not an easy job, so a lawyer should counsel both the client and the health care agent. With the client's consent, the agent could attend an orientation by trained staff designed to make sure that the agent knows the job description and is willing to fulfill it. Clients should share the results of their homework with the agent. Completed worksheets or similar tools can add depth to the agent's understanding of the client's values and wishes.

Clients need to understand the importance of having open and direct discussions with the agent so the agent clearly understands his or her duties and obligations as well as the client's wishes and preferences. If the agent does not intend to carry out the client's decisions or will not be capable, emotionally or otherwise, of making the necessary decisions, then the client needs to select another to serve as the agent.

Lawyers must especially be sure that the client understands the factors to consider in selecting a proxy, such as the proxy's willingness to make decisions, to implement the client's wishes and not override the client's wishes with the proxy's personal views and to be available to health care providers when and where decisions need to be made. The attorney also needs to counsel the client about the pitfalls of naming joint agents. A client may request this because the client has more than one child and does not want to appear to be playing favorites. All co-agents must agree to a course of action unless the directive contains some provision for decision making in the event of a disagreement.

Clients need to understand that the desire to avoid the appearance of favoritism among their children might actually become an impediment to effectively implementing the client's wishes. Instead, the client could appoint one agent and singular successors but provide that

the proxy consult with the other children in the decision making process. In drafting such precatory language, a lawyer should be careful to stipulate that the agent is not bound by the opinions of the others. In one way or another, clients must resolve this issue and explain their decision to the children as part of the advance planning discussion.

4. Develop good counseling skills. Lawyers must develop good interviewing and counseling skills in discussing end-of-life planning with the client. End-of-life planning is a sensitive and emotional topic and, in some cases, painful for the client to consider, much less discuss. Legal staff should be sensitive to the issues involved in assisting clients with the matters and have appropriate training and decorum to effectively assist the clients in this planning process.

5. Customize language. Lawyers should customize the language of a directive to fit the client's needs. A potential limitation exists in states with a requirement that the form be "substantially" in the language contained in the statute. Although the form "substantially" can be quite liberally construed, the lawyer must make a professional judgment as to what will best serve the client. Even when state and local law does not require substantial conformity, practitioners have related stories of health care providers that refuse to honor customized advance directives merely because they do not look like the standard advance directive. The presumption of the health care providers is that only the suggested statutory form will provide the health care provider the immunity from liability provided in the statute. Such anecdotes should not be a deterrent to the customization of an advance directive. Unless the statutory form is truly mandatory, there is no reason for immunity to be lost in honoring a customized advance directive.

The task of customizing the directive can be approached in more than one way. Giving the client two or three significantly different types of advance directive helps bring this point home. If a client chooses to include otherwise optional instructions in a directive, the client will have a greater sense of what he or she wants to say, compared to the alternative of merely checking off a box to select a standard instruction drafted by state legislators.

The lawyer should always focus on a client's priorities. Not all information necessary to the drafting of the directive is of equal importance to the client. The lawyer may be concerned about such matters as who will serve as the agent and what limitations or conditions are to be placed on the exercise of the agent's power. The client may have other concerns, such as privacy and pain control. In gathering the information and drafting the directive, lawyers must keep sight of the client's values and vision.

6. Encourage periodic review. The lawyer should encourage periodic review and discussion of the advance directive and the client's goals for end-of-life care. Priorities change with age, experience and physical and mental condition. The need for review becomes even more important as one ages and the future is not what it used to be. Lawyers can incorporate this function in their practices by scheduling periodic advance planning reviews with their clients or by simply counseling their clients to do so periodically. The client must understand that a signed advance directive should not be thrown in a drawer and forgotten. Advising a client to provide copies of the directive to the client's physician and agent is necessary advice, but it is not enough. Talking about the directive and the thinking behind it with all of the parties who may be involved in future decision making is far more important than papering the landscape with copies. Talking is the only way to ensure that no surprises will befall the client in the form of resistance to the client's wishes. The only practical way to ensure the enforcement of an advance directive is to stress the importance of communication that occurred before the presenting health decision. Effective end-of-life planning must be an ongoing, reflective communication process.

Conclusion

Lawyers must remember that the document is just one part of the process of end-of-life planning. The lawyer's most important role is to stimulate conversation and give guidance to the process. Naming and educating a health care agent or proxy deserves priority.

Instructions, if included in an advance directive, should be tailored to the individual client's goals and wishes and drafted with clarity, so that the agent and health care professionals can implement them appropriately. Planning for end-of-life health care requires, above all, meaningful conversation.

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Guides and Workbooks

The Lawyer's Tool Kit for Health Care Advance Planning, published by the American Bar Association's Commission on Legal Problems of the Elderly. Available at www.abanet.org/elderly.

Caring Conversations Workbook, published by the Midwest Bioethics Center, 1021-1025 Jefferson St., Kansas City, MO 64105-1329 (Tel. (816) 221-1100). This is both a workbook and advance directive. It can be downloaded for free from the center's Web site: www.midbio.org. A comprehensive do-it-yourself workbook on planning for end-of-life care.

Handbook for Mortals: Guidance for People Facing Serious Illness, by Joanne Lynn, MD, and Joan Harrold, MD (NY: Oxford University Press, 1999), available through the Web site of Americans for Better Care of the Dying, www.abcd-caring.org. A most comprehensive and readable 242 page guide to dealing with serious, eventually fatal illness.

Five Wishes Advance Directive, published by Aging with Dignity. This nationally used and very popular advance directive focuses on ways of talking about health care wishes and needs. Can be purchased and downloaded from the Web site: www.agingwithdignity.org. Also available by mail order from P.O. Box 11180, Tallahassee, FL 32302-3180.

Making Health Care Decisions for Others: A Guide to Being a Health Care Proxy or Surrogate, by the Division of Bioethics, Dept. of Epidemiology and Social Medicine, Montefiore Medical Center, Albert Einstein College of Medicine, Bronx, NY. Available on its Web site: www.montefiore.org/prof/clinical/desm/progserv/bioethics/index.html.

Your Life Your Choices Planning for Future Medical Decisions: How to Prepare a Personalized Living Will, by Robert Pearlman, et al., and the Veterans Administration Medical Center, Seattle, WA. A comprehensive do-it-yourself workbook on planning for end-of-life care. (Parts of this tool kit were adapted from this publication.) Available at www.va.gov/resdev/programs/hsrd/ylyc.pdf.

The Critical Conditions Planning Guide, published by Georgia Health Decisions. Call (877) 633-2433.

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