

Bar LEADER

Issue 2

FROM THE AMERICAN BAR ASSOCIATION

TOOLKIT

Theme for August: **Advance Directives—Preparing for the Future**

Welcome

Welcome to the second issue of Bar Leader Toolkit, which brings together ABA resources on a single topic. This issue focuses on advance directives and offers information that you and other bar association leaders can share with your communities, providing a supplement to your own resources or programs.

H. L. Mencken and Bette Davis are each credited with the aphorism, "Old Age is No Place for Sissies." The same can be said of planning for what follows - one's final illness and demise.

Because many families visit with elderly relatives during the summer, this season seems an appropriate time to shine a spotlight on some of the most important issues they face: how to plan for when loved ones can no longer care for themselves, how to know that decisions reflect what family members want or how to help loved ones articulate their wishes for end-of-life care.

End-of-life planning takes resolve and a willingness to confront our own mortality. Given that only about one-quarter of Americans have any type of advance directive, it just might take an effort by lawyers to increase that percentage.

One challenge is to increase awareness of the benefits of having advance directives among all clients, especially those who are elderly. Lawyers need to communicate that the process of creating an advance directive will assure clients that their wishes will be honored.

Another challenge is to help clients and community members realize how valuable their planning can be for their loved ones. When most people realize that an end-of-life plan is a gift only they can give to their family and friends, they come to accept the responsibility of completing an advance directive. Lawyers have the duty of helping clients focus on the process, not the ultimate outcome.

This toolkit contains information and resources that help dispel some of the myths clients might have concerning advance directives. It includes an op-ed piece, a sample news release, a message you may want to use in your bar

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publication and resources on advance directives and aging. These pieces link to online resources that offer detailed background on the topics.

And, as you and your members are planning, we suggest that you may want to take a look at the resources on the **ABA Second Season of Service** Web site that includes information on a wide range of volunteer and pro bono opportunities around the country.

Please know that your thoughts on the toolkit are important. After you have a chance to review this material, can you please take a few minutes to fill out the survey linked from this page and let us know your thoughts?

We appreciate your time and the opportunity to be of service.

Sincerely,

Roseanne Lucianek
Director, Bar Services

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Op-Ed on Completing an Advance Directive

As our population ages, the problem of convincing people to make affirmative decisions about how they want to be treated at the end of their lives grows in scope and seriousness. Just as lawyers are able to help people make end-of-life decisions about their possessions through wills and trusts, they also can serve as a resource for planning for end-of-life care, and communicating these decisions to family and loved ones.

The recommended approach is a process known as advance planning. This process involves thinking about what aspects of living are most important as the end-of-life approaches, talking to loved ones and completing an advance directive, which can take several forms.

One is a living will, which outlines specific actions that caregivers should take during treatment if the person is incapacitated and unable to give instructions. Another more versatile form is a health care power of attorney or a health care proxy that names an individual to make decisions on behalf of the person. Having a legally authorized spokesperson who knows the person's wishes and values, and who can respond to medical circumstances at the time they are known is the most effective strategy to have in place. A third type of advance directive is a combination of the two, such as the *Five Wishes* document, that addresses a person's medical, personal, emotional and spiritual needs. Some states have their own forms for advance directives.

To clarify end-of-life priorities, the American Bar Association's Commission on Law and Aging has developed a consumer toolkit to help lawyers and their clients work through important planning issues and options. The kit contains ten tools that address such options as how to select a health care proxy and what to do after signing the advance directive as well as a guide for health care proxies and additional resources.

After reflection and discussion, individuals can complete an advance directive form, including naming a health care agent or proxy if there is someone they trust to serve in that role. The directive should include wishes about special treatments, such as artificial hydration or nutrition, as well as guidance about values, beliefs, quality of life or other care preferences. This guidance ensures that the individual's wishes are known and respected. It will also spare loved ones the anguish of having to make hard choices without input and will help avoid disagreements among family members.

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People are hesitant to complete advance directives because they think they will have time to do so when they are older or more ill. Or, they may feel that they are creating a reality when they express their end-of-life wishes in words. In fact, the reality is that conversations about end-of-life planning are life-affirming and should happen before the need appears on the horizon.

For a copy of the toolkit, please contact the _____ Bar Association at XXX-XXX-XXXX or download a copy at <http://www.abanet.org/aging/toolkit/home.html>.

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Helping Clients Determine Which Advance Directive is Right for Them

When you begin the discussion about end-of-life planning with your clients, you can feel comfortable recommending any or all of the following Web sites:

The Five Wishes

<http://www.agingwithdignity.org/5wishes.html>

UHCDCA Sample Short and Long Forms

http://www.hawaii.edu/uhelp/UHCDCA/UHCDCA_forms.html

State-by-state advance directives from Caring Connections, a project of the National Hospice and Palliative Care Association

<http://www.caringinfo.org/index.cfm?page=256>

The Center for Practical Bioethics, Advance Directives/Caring Conversations

<http://www.practicalbioethics.org/cpb.aspx?pgID=986>

These sites offer information on advance directives that supports thoughtful decision-making.

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ABA Resources on Law and Aging

The American Bar Association offers a variety of resources on law and aging in electronic or print form.

NEWSLETTER

The ABA Commission on Law and Aging produces a bi-monthly electronic newsletter - Bifocal - that covers issues concerning aging and the law. The newsletter is distributed without charge six times a year in pdf format. You can find the most recent issue at <http://www.abanet.org/aging/publications/bifocal.shtml>.

Bifocal invites your bar association to share news and information about programs that benefit the elderly. Other bar associations can learn from your bar association's legal assistance initiatives, such as pro bono and reduced-fee programs, multi-disciplinary partnerships, and new resources for both professionals and consumers.

Bifocal also welcomes brief or substantive articles of interest to state area agencies on aging, bar association entities, legal services projects, law schools, and others in the law and aging network. Bifocal especially is interested in e-photos.

Manuscript guidelines and deadline information are available by contacting Jamie Philpotts at philpotj@staff.abanet.org.

To subscribe to Bifocal, email your name and professional affiliation to Trisha Bullock at bullockt@staff.abanet.org and include the word "SUBSCRIBE" in the subject line.

BOOKS

Additionally, the ABA has published a number of books to equip you with information to help guide preparations for elder care.

Available titles include:

» *Advance Health Care Directives: A Handbook for Professionals*, which addresses the complex issues surrounding end-of-life health care planning

» *Estate Planning Strategies: A Lawyer's Guide to Retirement and Lifetime Planning*, a guide designed to assist lawyers in estate

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planning for their clients

» *End-of-Life Issues: A Primer on the Legal Landscape*, a book that emphasizes the need for advance planning with clients of all ages

» *Ethical Issues in Estate Planning: Avoiding Ethics Violations and Malpractice*, a review of how the Model Rules of Professional Conduct will affect your estate planning practice.

» *The American Bar Association Legal Guide for Americans Over 50*, a handbook that offers advice on everything from choosing the best pension plan to finding affordable housing and appropriate eldercare. The 320-page reference manual also walks its readers through the processes of preparing wills, getting the most out of Medicare and Medicaid, and dealing with other legal issues of caring for aging parents.

» *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers*, prepared by the ABA Commission on Law and Aging and the American Psychological Association.

The ABA Bookstore Web site offers information and pricing on these titles and more at www.ababooks.org

OTHER RESOURCES

Additional resources for the elderly and lawyers who serve them are available at <http://www.abanet.org/aging/resources/usefullinks.shtml>.

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Dear Colleague:

Many of us are finding that as our clients age, their legal needs change as well, and we must be prepared to serve them and their families in the closing chapters of their lives.

Just as they have done all their lives, our clients want to retain control over their financial, social and health care decisions as they get older. Helping clients develop strategies for maintaining their dignity, while preparing for the day when they may not be able to make choices, is an important role for each of us as lawyers.

While clients are competent, it is critical to encourage them to complete documents that outline their wishes on how they want to be cared for when they are unable to care for themselves. Even younger clients can benefit from having a set of documents to explain their wishes, as most adults will experience one or more periods of incapacity due to illness or injury during their lives.

For older adults, the chance of diminished capacity increases with age. Approximately 10 percent of the population over age 65 suffers from Alzheimer's disease or other forms of dementia. That percentage rises to nearly 50 percent of the population over age 85.

Many clients are afraid to verbalize their wishes, fearing that putting their preferences for care and treatment into writing can make the need for them a reality, or can give another party control over their person or possessions.

Our role as lawyers is to explain that planning documents ensure client wishes are carried out and conversely avoid having courts obtain decision-making authority. We need to point out to clients that they can change their minds about any one of these documents.

A brochure from the American Bar Association — Health & Financial Decisions, Legal Tools for Preserving Your Personal Autonomy — presents an overview of the rationale for planning along with brief descriptions of a durable power of attorney, a trust, a health care power of attorney and a living will. Additionally, the brochure describes the steps in the advance planning process.

Also, a list of myths and facts can help you dispel the doubts and questions your clients may express.

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Working together with them, you can help your clients maintain their dignity, autonomy and quality of life.

Sincerely,

(Your Name)

(Name) Bar Association

Health & Financial Decision Brochure
Myths and Facts about Health Care Advance Directives

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Sample News Release on Presentation

(Name) Bar Association Offers Presentation on Health-Care Planning

CITY, Date - After a fatal accident that claimed the life of their father and left their mother on life support, sisters Beverly and Claudia spent months in court in a dispute over how their mother's last wishes should be carried out. Even the closest of families can find themselves in similar legal cases involving the care of a loved one who is unable to express their end-of-life care preferences.

To help prepare you and answer any questions that you may have, the (BAR ASSOCIATION NAME HERE) is presenting "Effective Planning for Health Care Decision-Making at the End of Life" (date) at (time). This program will help individuals to learn more about end-of-life plans, or advance directives, and how having such a plan can be benefit you and your family.

"We'd like to imagine death as a peaceful process," PRESIDENT'S NAME HERE, president of the (BAR ASSOCIATION NAME HERE) said. "However, this is not always the case. Developing written advance directives can help alleviate the burden placed on your family when difficult decisions must be made."

The (NAME OF BAR ASSOCIATION) expects that this program will create awareness of the need to develop a plan. During this hour-long presentation, attendees will learn what advanced directives can and cannot do, how to make the most out of your end-of-life plan, and how to select an agent or proxy. Although death can be difficult to think about, it is something we all face. Preparation makes it easier for the loved ones we leave behind.

Although there is no charge for admission, reservations by phoning XXX-XXX-XXXX are requested.



Effective Health Care Decision-Making at the End of Life

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Four Steps to Optimize Capacity

1. Interview the client alone.

Family, friends or caretakers often accompany older or disabled individuals to the lawyer's office. Although these significant others can play an important role in providing essential background information, the ethical starting point in the client-lawyer relationship remains the individual's competent choice to retain the services of the lawyer and to decide the overall objectives of representation. From the beginning, the lawyer needs to be clear on whom the client is and the ethical implications of that relationship in terms of loyalty, confidentiality and decision-making. The initial interview should always include a time when the client and the lawyer meet alone. This time alone not only confirms representation and objectives, but also provides an opportunity, if needed, to assess capacity. This one-on-one meeting request may cause apprehension among family member and even the elderly client, but it is necessary to ensure that personal and environmental factors do not unduly influence the decision-making process.

2. Adjust the interview environment to enhance communication

Optimizing the interview environment serves all clients well. More importantly it will optimize the partially impaired client's decision-making ability. Capacity deserves to be judged under the best circumstances possible. The following are a few basic parameters. Others can be found in *Effective Counseling of Older Clients: the Attorney-Client Relationship*, American Bar Association, Commission on Legal Problems of the Elderly and *Legal Counsel for the Elderly*, 1995.

Impaired vision or hearing can result in a lack of response that can be interpreted as a lack of mental capacity. Speaking slowly, conducting the interview in a well-lit area and providing necessary audio or visual amplification will facilitate communication.

Some elderly clients need extra time to process the information regarding decisions. Although the speed of their cognitive thinking may not be as fast as that of younger persons, given enough time, partially impaired elderly will be able to understand the ramifications of each action under consideration. It is important to resist the temptation to equate speed of thought with level of capacity.

If possible, meet with a client more than once to acquire a stronger sense of the client's decision-making capacity. Multiple sessions will enhance a client's trust and comfort, leading to optimal functioning. It also allows the lawyer to see

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temporary variations in functioning. Lawyers can avoid poor functioning due to fatigue by scheduling shorter sessions when the client is most alert.

Home visits may be important to optimizing decision-making for many clients. If, for example, the lawyer needs to know whether the client can manage personal finances, the elder may be able to demonstrate her banking skills best at her own desk with her own checks.

3. Know the client's value framework

The standard against which capacity is measured is the standard set by the client's own habitual or considered standards and values, rather than against conventional standards held by others. Without knowledge of this personal frame of reference, capacity judgments have insufficient anchor and are likely to be based on someone else's judgment. For the long-time client whose functioning only recently appears to be slipping, the lawyer may already be familiar with the client's subjective frame of reference. Newer clients will require a more conscious inquiry.

4. Presume capacity

Merely raising the issue of capacity can be hurtful and damaging to the relationship. Once begun, the process could result in a major intrusion to the client's autonomy in the form of a guardianship. Therefore, the starting presumption is always one of capacity. For a formal assessment to take place, the concerned parties must offer substantiating evidence of impaired decision-making.

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Five Steps of Preliminary Assessment

If you have done everything you can to optimize the client's opportunity to act with maximum capacity, you are ready to perform a preliminary assessment. This assessment may involve most or all of the steps listed here, depending on the point at which your conclusion is clear or professional referral is needed.

1. Obtain Consent

This step does not refer to the normal questions asked to ensure the client understand options and consequences. If the lawyer proceeds to a formal screening test or makes a referral for physical or psychological testing, client consent is an ethical necessity. This consent also conveys respect for the client and a determination to protect the client's interests.

2. Physical Exam

The lawyer should provide the impetus to ensure that alternate causes of incapacity are ruled out. Deficiencies that appear cognitive often are caused by over medication, toxic combinations of medications, poor diet, vitamin deficiencies, depression, infectious diseases, head trauma, poor eyesight or other treatable conditions. By discovering and addressing medically treatable conditions first, capacity issues may be rendered moot or at least diminished.

3. Standardized Screen

After proceeding through familiarity with the client, optimizing the environment and obtaining consent, the lawyer should consider using a brief questionnaire on mental status. While these tests will not produce a firm conclusion, they can confirm the need for a formal assessment.

Two of the most used tests are the Mini-Mental Status Examination (MMSE) and the Short Portable Status Questionnaire (SPSQ).

The MMSE is a 30-item test that takes about 10 minutes to administer. It covers memory, language, spatial ability and set shifting. Scores range from 0 to 30 with scores below 24 regarded as abnormal.

The SPSQ assessment is a 10-item test that evaluates orientation to time and place. It is scored by counting errors rather than correct answers.

The greatest danger with a standardized screening test is relying on it too much. A poor score does not rule out the ability to perform some decision-making tasks.

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4. Task-Specific Assessment

The presence of some cognitive impairment does not provide information on the degree to which individuals can still use their remaining abilities to act autonomously since individuals adapt to limitations in countless and creative ways.

The lawyer, therefore, needs to consider the client's capacity for the specific legal task at hand, such as executing a power of attorney, signing a will, marrying or divorcing, agreeing to new living arrangements, donating a substantial asset, agreeing to or refusing a medical treatment, or other similar activities.

Because capacity is a shifting network of values and circumstances, it is recommended that a lawyer evaluate a client based on the following:

- » Ability to articulate reasoning behind decisions
- » Variability of state of mind; does client express the same wishes alone as when others are present; are these wishes consistent from week to week
- » Ability to appreciate consequences of decision
- » Irreversibility of decision
- » Substantive fairness
- » Consistency with lifetime convictions

For lawyers, regular and consistent documentation of capacity is essential.

5. Consultation and Referral

In borderline situations, the lawyer should seek consultation from a medical or mental health expert. Comment 5 to Model Rule 1.14 recognizes the appropriateness of such consultations in authorizing the lawyer to seek guidance from an appropriate diagnostician, even though disclosure of the client's disability could adversely affect the client's interest. The ABA's Standing Committee of Ethics and Professional Responsibility in Formal Opinion 96-404 relies on the impliedly authorized language of Rule 1.6(a) to conclude that limited disclosure to the extent necessary to act is impliedly authorized by the fact of representation.

In seeking a formal assessment, the question becomes who to use. If the client's own physician lacks special expertise, the preference would be to work with a multidisciplinary geriatric assessment team, providing members with a clear picture of the decision for which capacity is to be assessed,

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Myths and Facts about Health Care Advance Directives

Terms to Know

» **Health Care Advance Directive** - The generic term for any document that gives instructions about your health care/appoints someone to make medical treatment decisions for you if you cannot make them for yourself. Living Wills and Durable Powers of Attorney for Health Care are both types of Health Care Advance Directives.

» **Living Will** - A document in which you state your wishes about life-sustaining medical treatment of you are terminally ill, permanently unconscious or in the end-stage of a fatal illness.

» **Durable Power of Attorney for Health Care (or Health Care Proxy)** - A document in which you appoint someone else to make medical treatment decisions for you if you cannot make them for yourself. The person you name is called your agent, proxy, representative or surrogate. You can also include instructions for decision-making.

Myth — You must have a Living Will to stop treatment near the end of life.

Fact — Treatment can be stopped without a Living Will if everyone involved agrees. However, without some kind of advance directive, decisions may be more difficult and disputes more likely.

The Durable Power of Attorney for Health Care is the most useful and versatile advance directive because it applies to all health care decisions and empowers the person you name to make decisions for you in the way you want them made.

More than two-thirds of the adult population in the United States have no Living Will or other advance directive.

Myth — You have to use your state's statutory form for your advance directive to be valid.

Fact — Most states do not require a specific form, but do require witnessing or other specific signing formalities.

Even if your state requires a specific form, doctors still have a legal obligation to respect your treatment wishes, regardless of the form you use. Most official state forms are either worded too generally or include multiple choice options that may

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be too broad to guide decisions about the particular medical situation you may find yourself in near the end of life.

The critical task is to clarify your values, beliefs and particular wishes that you want others to follow if they must make decisions for you.

Myth — Advance directives are legally binding so doctors have to follow them.

Fact — Advance directive laws merely give doctors and others immunity if they follow your valid advance directive.

Doctors can always refuse to comply with your wishes if they have an objection of conscience or consider your wishes medically inappropriate. However, they may have an obligation to transfer you to another health care provider who will comply.

The only reliable strategy is to discuss your values and wishes with your health care providers ahead of time, to make sure they are clear about what you want and that they are willing to support your wishes.

Myth — An advance directive means "Do Not treat."

Fact — An advance directive can express both what you want and don't want. Never assume it simply means "Do Not treat." Even if you do not want treatment to cure you, you should always be kept relatively pain free and comfortable.

Myth — If I name a health care proxy, I give up my right to make my own decisions.

Fact — Naming a health care proxy or agent does not take away any of your authority. You always have the right, while you are still competent, to override the decision of your proxy, or to revoke the directive.

If you do not name a proxy or agent, the likelihood of needing a court-appointed guardian grows greater, especially if there is disagreement regarding your treatment among your family and doctor.

Myth — I should wait until I am sure about what I want before signing an advance directive.

Fact — No. Most of us have some ambivalence about what we would want, and that's fine, because treatment at the end of life can be complicated. We can't predict all the facts and circumstances that may face us in the future, and treatment wishes may change. You can, at least, appoint your proxy if you have someone whom you trust.

Myth — Just talking to my doctor and family about what I want is not legally effective.

Fact — Meaningful discussion with your doctor and family is actually the most important step. The question of what is "legally effective" is misleading, because even a legally effective document does not automatically carry out your wishes.

The best strategy is to use a good health decisions workbook to help you clarify your wishes; talk with your physician, health care agent and family about your wishes; put those wishes in writing in an advance directive, and make sure

everyone has a copy.

Myth — Once I give my doctor a signed copy of my directive, my task is done.

Fact — No, you have just started. First, make sure your doctor understands and supports your wishes.

Second there is no guarantee that your directive will follow you in your medical record, especially if you are transferred from one facility to another. You or your proxy should always double check to make sure your providers are aware of your directive and have a copy.

Advance planning is an on-going process. Review your wishes yearly or anytime your health or family status changes. Make appropriate changes as needed and communicate your changes to your loved ones and health care providers.

Myth — If I am living at home and do not want to be resuscitated by an EMS team if my heart or breathing stops, my advance directive must say so.

Fact — Your advance directive will usually not help in this situation. If someone dials 9-1-1, the EMS team must attempt to resuscitate you and transport you to a hospital, UNLESS you have a special out-of-hospital DNR (Do Not Resuscitate) form or bracelet used in your state. This is not the same as your health care advance directive. In most states, both the patient and the doctor must sign the special form and the patient then wears a special identification bracelet or necklace.

Myth — Advance directives are only for old people.

Fact — While it is true that more older - rather than younger - people use advance directives, every adult should have one. Younger adults actually have more at stake because, if stricken by a serious disease or accident, medical technology may keep them alive but insentient for decades. Some of the most well-know "right to die" cases arose from the experiences of young people (e.g., Karen Ann Quinlan, Nancy Cruzan) who were incapacitated by illnesses or car accidents and maintained on life support.

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Give us your feedback

Thanks for taking time to review *Bar Leader Toolkit*, an online resource for bar association leaders. Please take a couple of minutes to answer the following questions. Your answers will guide us as we plan future online materials.

This information was informative and helpful:

Yes No Somewhat

I plan to use/used the information within toolkit:

Yes No

The tools I would find most useful are:

Articles
Op-Ed pieces
Q-and-As
PowerPoint Presentations
Video news releases
Radio news releases
Other

Please cover the following topic(s):

I am affiliated with:

Local Bar Association State Bar Association

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