

ADVANCE DIRECTIVES: COUNSELING GUIDE FOR LAWYERS



Commission on Law and Aging
American Bar Association



In collaboration with:



University of California
San Francisco



AMERICAN ACADEMY OF
HOSPICE AND PALLIATIVE MEDICINE

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This publication is a collaboration of the organizations and project team members listed below:

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ADVANCE CARE PLANNING PRACTICE PRINCIPLES

These principles were developed by a multidisciplinary group of experts convened in 2017 by the American Bar Association Commission on Law and Aging in collaboration with the American Academy of Hospice and Palliative Medicine, the University of California at San Francisco Medical Center and the UCSF/UC Hastings Consortium on Law, Science & Health Policy, with funding from **The John A. Hartford Foundation** and additional support from the Borchard Foundation Center on Law and Aging.

The principles provide a conceptual framework and guideline specifically for lawyers and health care professionals to align the practice of advance care planning in legal offices with the realities of implementation in health settings. These are informed by current evidence of what makes advance care planning effective in healthcare settings as summarized in the Institute of Medicine's report on *Dying in America* and a growing body of related literature.¹ Legal and health professional organizations are encouraged to endorse these principles.²

1. **Proxy Designation:** The most important *legal* component of advance care planning is careful selection and appointment of a health care agent/proxy in a valid power of attorney for health care document. Persons who cannot or do not want to identify a proxy should delineate their wishes in an advance directive.
2. **Ongoing Process:** Advance care planning takes place over a lifetime. It changes as one's goals and priorities in life change through different stages of life and health conditions. Reflection, discussion, and communication with one's proxy and clinical professionals, along with family, friends, and advisors is essential to having one's wishes understood and honored. These discussions should occur with patients/clients of all ages at all stages of life and health.
3. **Values, Goals, and Priorities:** Discussion should focus on one's values, goals, and priorities in the event of worsening health rather than on specific treatments or clinical interventions for distant hypothetical situations.
4. **Advance Care Planning Tools:** Advance care planning tools and guides can provide structure and guidance to the process of reflection and discussion and help individuals identify their values, goals, and priorities, and ensure more authentic and useful conversations and advance directives.
5. **Advance Directive:** Instructions and guidance documented in an advance directive should result from the process of information sharing, reflection, discussion, and communication and provide enough flexibility in application to allow surrogate decision-makers to respond to new circumstances and complexities.

6. **More serious illness:** If individuals are facing serious diagnoses, such as cancer, or have been told they have a limited prognosis, the focus may then move to specific treatment preferences. In these cases, the person’s primary/key health care provider should also meet with the client and/or their closest loved ones to create a care plan that aligns with the client’s goals, values and preferences. For advanced illness, medical providers should consider introducing palliative care options and the option of providing medical orders such as Physician’s Orders for Life Sustaining Treatment (POLST)³ to ensure the individuals wishes are translated by medical professionals into actionable medical orders.

7. **Sharing Documents:** Documentation of one’s values, goals, and wishes in the form of an advance directive or other record should be shared with one’s proxy, loved ones, significant others, and primary/key health care providers, and be included in the medical record, so that they are adequately informed before a crisis arises.

8. **Coordination:** Lawyers and health care professionals should aim for greater coordination of advance care planning efforts with the healthcare system/medical providers through congruent advice and practices in accordance with the principles above, greater willingness to reach out to one another with client/patient consent to obtain information when needed, and greater collaboration in joint continuing education. programming.

References

¹ IOM (Institute of Medicine). 2015. *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press. Available at: <http://www.nationalacademies.org/hmd/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>.

² If willing to consider endorsement, contact project staff Charles Sabatino at charles.sabatino@americanbar.org, or David Godfrey at david.godfrey@americanbar.org.

³ For information about Physician Orders for Life-Sustaining Treatment, see www.polst.org.



ABA Commission on Law and Aging

UCSF Medical Center



UCSF/UC Hastings Consortium on Law, Science & Health Policy

American Academy of Hospice and Palliative Medicine



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ADVANCE CARE PLANNING CHECK LIST FOR LAWYERS

Prior to Initial meeting

- If you use an estate planning questionnaire, send along the **Advance Care Planning Resource List** with the suggestion that the client may find some of the resources helpful in thinking about advance care planning. Consider including a hard copy of the "Prepare for Your Care™ Question Guide," the PREPARE pamphlet, or the PREPARE advance directive as examples of the kinds of questions you will raise in your first meeting (www.prepareforyourcare.org).

- At intake, or in the initial estate planning questionnaire, include the following questions:
 - Does the client have an advance directive, e.g., health care power of attorney or living will?
 - Has the client ever signed an organ donor card?
 - Does the client have any significant health condition that might affect planning?

First Client Meeting

- 1. Inquire whether any communication aids may help your client to understand better, e.g. large print, visual aids, hearing support, video, etc.

- 2. Explain to your client why advance care planning is important.

- 3. Explain the key task of appointing a health care agent or proxy.

- 4. Ask client to think about a person who would make a good proxy. Discuss the candidates with client considering these key *criteria*:
 - Likely to agree with your wishes and honor them?
 - Someone you can talk to about your wishes now and when they change, and is willing to discuss your wishes with doctors and others if you were to become seriously ill?

Key messages:

- Advance care planning:
 - ▶ Helps ensure that your values, your priorities, and your preferences will be known and respected.
 - ▶ Avoids unwanted medical interventions.
 - ▶ Prevents family conflict.
 - ▶ Lifts the burden of uncertainty from loved ones.
 - ▶ Help the medical team know which person's judgement you trust.
- Your advance care planning can and should change as your goals, priorities, and health change throughout your life.

- Good at asking doctors, nurses, professional caregivers, or others, questions to find out all the facts?
- Able to advocate for you even if family or health care providers disagree?
- Emotionally-capable of fulfilling the role?
- Likely to be available when you need him/her? (Lives nearby, is in good health him/herself, etc.)

ROAD BLOCK? Absolutely No One Available to serve as Proxy/Agent? A **Living Will** type declaration is your fallback. Skip #5 and #6 and continue.

Key messages:

Proxy/Agent/Health Care Decision-maker:

- Selection of a proxy is the most important decision you will make.
- The person closest to you may or may not be the best able to carry out your wishes.
- Not everyone has traditional family members to name. It's OK to select a nonrelative. Goal is to find someone you feel comfortable talking to who will know and uphold your goals and wishes when needed.

5. Timing and Access.

- Do you want your proxy to be able to participate in decision-making NOW (if permitted by state law) or only LATER when and if you are unable to make your own decision?
- Do you want your proxy to have the ability right NOW to see your medical record and have the authority to talk to health care providers? (Include authority in advance directive or use HIPPA Right to Access Form).
- Is there someone besides your proxy whom you want to have access to your medical information even while you are healthy and making your own medical decisions. (Use HIPPA Right to Access Form)

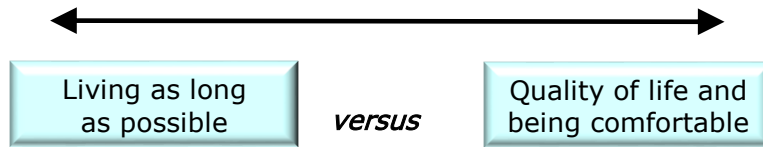
6. Explore who would be a good secondary or back-up proxy using same criteria.

If client has no primary or secondary possibilities to serve as proxy, continue below.

7. What is your understanding of your health right now?

8. **The Tough Questions: Ask and take notes of the following:**

In Your Current State of Health, How Do You Rate the Importance of:



A. If You Were So Sick That You May Die Soon:

(1) How would you then rate the importance of those two goals?

(2) Which of the following experiences, if any, would make you want to focus on comfort rather than trying to live as long as possible?

- Being in a coma & not able to wake up or talk to loved ones.
- Not being able to live without being hooked up to machines.
- Not being able to recognize loved ones, as in the case of dementia.
- Not being able to feed, bathe, or take care of yourself.
- Not being able to live on your own.
- Having constant, severe pain or discomfort.
- Something else:

OR, are you willing to live through all these for a chance of living longer?

(3) What would be most important to you? (e.g., Being with loved ones? Certain settings or experiences? Religion?)

(4) What would be most unacceptable to you?

(5) What would you prefer regarding the use of life support treatments (such as CPR or tube feeding or use of a ventilator)? [Make sure client understands these terms.]

- Try all life support treatments that your doctors think might help and stay on life support treatments even if there is little hope of getting better or living a life you value.

Acknowledgement:

The following questions are adapted from PREPARE For Your Care™ (© 2012-2018 the Regents of the University of California) as part of an evidence-based initiative to improve advance care planning. For additional assistance in asking these questions, or to refer clients for additional support, please go to PREPAREforyourcare.org.

Key messages:

- You'll never have a crystal ball to know your medical future with any certainty, but advance care planning requires knowing the likely future of any health condition you may have. That's one reason why discussion with your physician is so important.
- Advance care planning gets more specific the closer you are to a progressive, end-stage condition.
- Old Spanish proverb: *The bull looks different from inside the ring.*

- Do a trial of life support treatments that your doctors think might help. But, not stay on life support treatments if the treatments do not work and there is little hope of getting better or living a life you value.
 - Avoid all life support treatments and focus on being comfortable. Prefer to have a natural death.
- C. Have you ever documented your wishes about organ or tissue donation? If you'd like, your wishes can be included in an advance directive. Provide organ donation brochure. [See **Resource List**.]
- D. How much flexibility do you want to give your health care proxy in making medical decisions for you? Important to be clear about this.
- E. How do you prefer to make medical decisions with your doctors?
 - Prefer to make all decisions on your own, with all information available?
 - Prefer that your doctors and you share decision making equally?
 - Prefer that your doctors' recommendations be followed?
- F. How much does your family or loved ones know about your personal priorities and wishes? How much do you want them to know? (Stress importance of talking with loved ones using selected resources to assist.)
- G. Is there anyone you do NOT want involved in your medical care and decision- making, and you do not want to have access to your medical information

Key messages:

- The document is only as strong as the thought and discussion it is based on.
- See the **Resource List** for tools to help with discussions
- Even with a health care agent in place, all involved loved ones and key health care providers strongly influence the process, so they need to be informed and prepared ahead of time.
- If client has a serious, progressive illness, explain the availability of **POLST** (or term used in your state) and advise client to discuss with physician.

9. **Inquire about the health care providers involved in your client's care.**

Obtain from client:

- Names, contact information of primary health care providers and any known specialists.
- Permission to send them copies of your Advance Directive.
- Permission to share your Advance Directive with other health care providers or family members who might ask for them?

10. **Advise the client when you will send a draft of the advance directive.**

- If not already provided, give clients a tool from the **Resource List** to help them think further about the questions you raised and discuss them with loved ones. E.g., *PREPARE for Your Care™*, which is organized around the same questions discussed here.
- Advise client that they can ask questions or request changes to the draft advance directive you send them.

11. Provide Proxy Guidance.

- A. If proxy is present, with client's consent, review role of proxy and provide a proxy guide. e.g.:
 - *ABA's Making Decisions for Someone Else: A How-To Guide*
 - The Conversation Project, How to Be a Health Care Proxy
- B. If proxy is not present, offer to send proxy a copy of the advance directive along with a proxy guide. Invite client to bring proxy to the next meeting.

12. Post-Meeting Drafting:

Prepare the Advance Directive based upon the information collected.

Options:

- Draft an advance directive with appointment of a proxy, plus instructions.
- Draft only a Health Care Power of Attorney with no or few instructions. This may be an option for a client who prefers to use one of the decision tools in the **Resource List** as documentation of his/her wishes.
 - *Advantages:* Enables wishes to be changed or augmented as needed without legal formalities and in the client's own words.
 - *Disadvantages:* The decision tool, as separate documentation of your wishes, doesn't carry the status of a legal document, unless it is expressly identified and incorporated into your advance directive. If incorporated, changes require new legal formalities.
- Draft a Living Will only– if client has absolutely no one to serve as proxy.

DRAFTING TIPS:

- ▶ Avoid overly long advance directive documents. **Clinical experience suggests that the longer it is, the less likely it will be consulted.**
- ▶ Use plain language. Your audience is nonlawyers (family members, healthcare providers), who must be able to easily and quickly understand the document. If your state statute requires mandatory language, consider translating it into simple terms in the document or as a cover sheet.
- ▶ How specific should health care instructions be? For a healthy client, general. The closer to an end stage condition, the more specific one may be because more details are known.

Second Client Meeting: Signing of Advance Directive

- 1. **Review values, goals, priorities, and wishes** expressed by the client in the advance directive for accuracy. If client completed any of the decision aid tools, make sure wishes expressed in the advance directive are accurate and consistent. Make changes as required.

- 2. **Sign, witness and/or notarize per your state law requirements.**

- 3. **Actions to consider following review and signing:**
 - Provide several copies of all documents.
 - Offer registry if registries are functional in your region. Provide or refer client to a smartphone app for easy family access to the advance directive.
 - Provide a scan of the documents to client by jump drive or email.
 - With clients' permission, send documents and instructions to the named proxy. Include cover letter explaining the importance of the role and send copy of a Proxy Guide if not already provided to proxy.
 - With client's permission, send copies to other family members or loved ones.
 - With client's permission, send copy to Primary Care Physician and known specialists with cover letter. *See Sample Cover Letter to Physician.*

- 4. **Updating Plan.** Discuss trigger points for reviewing your advance care plan and documents whenever any of the **SIX D's** occur:
 - (1) You reach a new DECADE in your age.
 - (2) You experience a DEATH of a loved one.
 - (3) You experience a DIVORCE.
 - (4) You receive a DIAGNOSIS of a significant health condition.
 - (5) You experience a significant DECLINE in your functional condition.
 - (6) You change your DOMICILE or someone moves in with you.

Key Messages:

- Client should share and review the advance directive and tools already completed with family and primary health care providers. Regardless of what is said on paper, their knowledge and attitudes will still influence decisions. They need to be on board with client's wishes.

*** End of Checklist ***

SAMPLE LETTER TO PHYSICIAN

Dear Dr. Welby:

I am enclosing a document executed under [your State's Advance Directive for Health Care Act with citation]. This was signed by my client and your patient, [name of principal].

Although we started advance care planning in my office, your role in explaining [name of principal's] conditions and care and treatment options is an important element for this ongoing shared, decision-making process. At the next office visit, please consider discussing and documenting your patient's wishes as well as including your patients' Directive in the medical record.

Of note, [name] state law defines terms such as [include relevant statutory terms, e.g., terminal condition, life-sustaining treatment, permanent unconsciousness, and end-stage condition]. See [include hyperlink to relevant state law]. However, you are in a better position than legislative drafters to help your patient understand these terms as they become relevant to decision-making.

If upon further discussion you believe that the patient's wishes do not match the declaration on the Directive, please notify the patient and our office. If you complete an updated Directive with your patient, please consider forwarding a copy to our office.

I would be pleased to provide any further information that may be helpful.

Very truly yours,

(Attorney)

Fax #

Enclosure
cc: (Principal)

Adapted from H. Amos Goodall, Jr.
Steinbacher, Goodall & Yurchak, State College, PA

**SAMPLE
HIPAA RIGHT OF ACCESS FORM FOR FAMILY MEMBER/FRIEND**

I, _____, direct my health care and medical services providers and payers to disclose and release my protected health information described below to:

Name:

Relationship:

Contact information: _____

Health Information to be disclosed upon the request of the person named above --

(Check either A or B):

- A. **Disclose** my complete health record (including but not limited to diagnoses, lab tests, prognosis, treatment, and billing, for all conditions) **OR**
- B. **Disclose** my health record, as above, **BUT do not disclose** the following (check as appropriate):
 - Mental health records
 - Communicable diseases (including HIV and AIDS)
 - Alcohol/drug abuse treatment
 - Other (please specify):

Form of Disclosure (unless another format is mutually agreed upon between my provider and designee):

- An electronic record or access through an online portal
- Hard copy

This authorization shall be effective until (Check one):

- All past, present, and future periods, OR
- Date or event: _____

unless I revoke it. (NOTE: You may revoke this authorization in writing at any time by notifying your health care providers, preferably in writing.)

Name of the Individual Giving this Authorization

Date of birth

Signature of the Individual Giving this Authorization

Date

Note: HIPAA Authority for Right of Access: 45 C.F.R. § 164.524



ADVANCE CARE PLANNING RESOURCE LIST

THE TOOLS BELOW ARE FREE TO THE PUBLIC

ADVANCE CARE PLANNING TOOLS FOR CLIENTS

PREPARE for Your Care™. PREPARE is an online resource in English and Spanish that helps people learn about and prepare for medical decision making. This evidenced-based tool features video stories and examples and guides people as they explore their wishes and learn how to discuss them with family, friends, and medical providers. The result is a ‘Summary of My Wishes’ document which can be shared with family and friends, caregivers and medical providers. PREPARE also offers easy-to-read, legally-binding advance directives for all 50 states in English and Spanish. www.prepareforyourcare.org.

The Conversation Project, an initiative begun in 2010 dedicated to helping people talk about their wishes for end-of-life care. Their Conversation Starter Kit is a useful tool to help you have the conversation with a family member, friend, or other loved one about your – or their – wishes regarding end-of-life care. It is available in several languages. www.theconversationproject.org.

Consumer's Tool Kit for Health Care Advance Planning, by the American Bar Association Commission on Law and Aging is available for free download. <http://ambar.org/agingtoolkit>.

The Stanford Letter Project. This free website offers three tools available in several languages and formats with real patient videos, at <http://med.stanford.edu/letter>.

- The “What-Matters-Most” letter template. Simple letter template any one can use to write to their doctor about their care choices and preference
- The “Who-Matters-Most” letter template. Simple letter template any one can use to complete the seven tasks of life review and write to their loved ones.
- The “I-Matter-Too” tool. Allows patients to identify their life goals from six common choices

CaringInfo, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. www.caringinfo.org

The Go Wish Game, a card game for sorting out values related to end-of-life decision-making, created by the Coda Alliance. The cards help you find words to talk family or friends about what is important if you were to be living a life that may be shortened by serious illness. Although there is a charge for ordering the card decks, Go Wish can be played online for free. www.gowish.org

MyDirectives.com. MyDirectives is a free web-based service that walks you through the process of creating an “advance digital directive” which can be electronically signed. Includes a smartphone app. The directive is encrypted and stored in their secure database, available to you and your medical treatment providers 24/7.

<https://mydirectives.com>

Advance Care Planning Decisions, produces short, evidence-based videos exclusively for health care providers to assist patients and providers in decision-making in clinical settings. A limited number of videos for consumers are available free in multiple languages. Topics include: The Conversation; POLST; What is Palliative Care; Talking to Your Doctor; and A Patient Checklist. <https://acpdecisions.org/patients>.

Compassion and Choices - Tools to Plan for your Care. This web page offers a multitude of useful tools aimed at ensuring you get the care you want.

<https://www.compassionandchoices.org/eolc-tools/> .

Thinking Ahead: My Way, My Choice, My Life at the End. This workbook and video were created by California advocates with developmental disabilities and distributed by the Coalition for Compassionate Care of California. However, it is a good tool for anyone who wants a simple, easy-to-follow workbook.

<http://coalitionccc.org/tools-resources/people-with-developmental-disabilities>.

Five Wishes. An advance care planning program of Aging with Dignity. Easy to use resources include the Five Wishes advance directive (available in 29 languages and Braille), conversation guides, clinician guides and training programs. Five wishes addresses emotional, spiritual and personal aspects of care, along with appointing an agent and providing instructions. A free discussion starter is available. Other resources are available for a small fee.

www.fivewishes.org.

GUIDES FOR HEALTH CARE AGENTS

How to Choose a Health Care Proxy & How to Be a Health Care Proxy, by the Conversation Project.

<https://theconversationproject.org/wp-content/uploads/2017/03/ConversationProject-ProxyKit-English.pdf>

Making Decisions for Someone Else: A How-To Guide, published by the ABA Commission on Law and Aging, this guide is for anyone serving in the role of health care decision maker for someone else: <http://ambar.org/agingproxyguide>.

GUIDES FOR TALKING TO ONE'S PHYSICIAN

How to Talk to Your Doctor: Discussing End-of-life Care with Your Doctor, Nurse, or Other Health Care Provider. The Conversation Project.

<https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-TalkToYourDr-English.pdf>

NIH Resources for “Talking to your Doctor,” National Institutes of Health,

<https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/talking-your-doctor>

GENERAL END-OF-LIFE CARE REFERENCES *(some require purchase)*

END OF LIFE: What Are Palliative Care and Hospice Care? An online publication by the National Institutes on Aging (NIA) that explains palliative care and hospice options, with links to free related NIA articles. www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care.

Handbook for Mortals: Guidance for People Facing Serious Illness by Joanne Lynn, Joan Harrold, and Janice Lynch Schuster (2nd Ed., Oxford Univ. Press, 2011). A comprehensive and readable 320-page guide to dealing with serious, eventually fatal illness. Available for purchase from Amazon or in book stores. Individual chapters are downloadable for free at: <http://growthhouse.org/mortals/mor0.html>.

Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Measures Only and the Elderly Patient by Hank Dunn (A&A Publishers, 2016) Available for purchase at: www.hankdunn.com. A concise and helpful 80-page booklet on end-of-life decisions concerning resuscitation, food and fluids, hospitalization, and cure versus comfort care.

Fidelity, Wisdom and Love: Patients and Proxies in Partnership

by Joseph J. Fins and Barbara S. Maltby (Weill Medical College of Cornell University, March, 2003). A workbook and video designed as a step-by-step guide that provides everything you need to know about choosing, appointing, or being a healthcare proxy. It contains four medical scenarios designed to foster dialogue between patients and proxies in order to define possible choices for care and to increase patient/proxy understanding and knowledge. Available for purchase from Amazon.com.