

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)

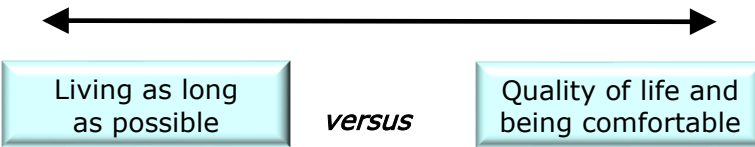
6. Explore who would be a good secondary or back-up proxy using same criteria.

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