End-of-Life Health Care: Tips from the Trenches on Getting the Care You Want

Most of us are aware that the number of people over age 65 is rising rapidly as the baby boomer generation ages. This is especially true in Marin County, which has the oldest average population of any county in California. As we age, we tend to think more about end-of-life issues, including how much medical care we want in the face of declining health. About 80% of Americans say that they would prefer to die at home but about 60% of us end up dying in hospitals. Of course, many people younger than 65 sadly face this question too and we should be prepared for it at any age.

As lawyers and allied professionals, we are better than average at making sure we have the right documents (but of course, still not perfect—when was the last time you updated your estate plan?) But do your documents do the best job they can to make sure you have the end-of-life care you want? As a mediator and attorney, I've had exposure to plenty of real-world conflicts that clients thought they had avoided. What follows are some tips for the documents themselves and for getting the most out of them.

1. Let's start with the most obvious and basic: **appoint an agent** under a durable power-of-attorney for health care ("PAHC") so that if you are incapacitated, you have someone to speak for you. (Probate Code § 4680 et seq.) One of the more common excuses for not doing this I have heard is, "I have a family" based on the false assumption that California law appoints a decision-maker for you. California law has no explicit statutory "hierarchy" of surrogate health-care decision makers. If you have not appointed an agent and are incapacitated in a hospital, the hospital gets to decide who will speak for you. Most of the time, a hospital will choose whom you expect (and under case law has certain obligations) but when there is conflict among family members about your care, the hospital may not.
2. Many PAHCs also act as a very basic "living will," setting forth whether you desire more or less care in the face of a life-threatening illness. It is highly worthwhile to **prepare a separate living will** that provides more detail about what you want (or to include it as part of the PAHC.)[1] Many of us haven't really thought about what we want (and would prefer to avoid thinking about it!) so preparing a living will may help us figure out what we actually want. And the more clearly you specify what you want, the more likely you are to get it. And you don't have to be on your own doing this. Many lawyers don't have the desire or expertise to help but some of us do and there are other ways to get help, from cards with thought-provoking questions to "Death Cafés," as aides to prompt and guide your thinking.
3. An unfortunate number of people have appointed an agent under a PAHC and never talked with their agent about what they want! **Talk with your agent** about the care you want or don't want. Better yet, prepare your living will with your agent so they are intimately involved. One of my roles as both mediator and attorney can be to facilitate these discussions and point clients to other tools that help. I listed "appoint an agent" as the number one thing to do because you can't hope to cover every conceivable situation in a living will but don't leave your agent without guidance either.

4. **Do not appoint co-agents.** This most commonly arises when a parent is reluctant to burden/privilege one child with the weight of these kind of decisions and so appoints two or more to make decisions together. Of course, the problem is that if your co-agents can't agree, you are stuck without someone to act for you. If you are concerned about this issue, you can set up a process whereby your agent must consult with/get input from others, such as siblings, but ultimately has sole decision-making authority. This does not prevent you from appointing alternate agents if your original agent is unavailable, which is always a good idea.
5. **Appoint an agent who is readily accessible and preferably nearby.** Hospitals have limited resources to try to reach your agent. If your agent isn't readily available, especially when decisions are urgent, then your agent will not be the one making decisions for you.
6. Your agent's decisions may cost money. **Make sure that your agent's decisions will be paid for.** Most lawyers prepare a separate power-of-attorney for finances (Probate Code § 4000 et seq.), often with a different person as the agent from your health-care agent. It is not uncommon for those two people (often siblings or a spouse and a child) to have different ideas about your care. Make sure any other power-of-attorney has appropriate provisions to ensure your health-care agent's decisions are respected.
7. I attended a conference on end-of-life care where a doctor said that the number one reason people do not get the end-of-life care they want is unresolved issues with their children! While this comports with my experience as a mediator, I was a little surprised it was so clear to a doctor. Of course, the advice isn't easy: **resolve disagreements or hurt feelings with your children**. What often happens is that regrets and remorse surface within a more distant (often both geographically and emotionally) child. That child may become a fierce advocate for maximum care, driven by their own needs rather than yours. Even if someone else is your agent and even if you have clearly expressed a desire not to prolong your life, withdrawing or limiting care when there is family conflict can be difficult.
8. **Talk with your primary care physician about your wishes.** Hospital care doesn't work the way it used to. Now there is someone called a "hospitalist," who is the doctor in charge of your care. He or she may never have met you before. And if you're in for a longer stay, the hospitalist will likely change over time. Especially if you don't have a PAHC, or if your family is in conflict over your care, the hospitalist will generally consult with your primary care physician about your wishes. And if you are 65 or over, Medicare now pays for your doctor to talk with you about end-of-life care planning. Of course, if you have a chronic and/or life-threatening illness, you should talk with your specialist physican(s) as well.
9. **Make sure your documents are available when and where doctors need them.** I am hopeful that as medical records become more and more electronic, the problem of access to PAHCs and living wills will go away. But for now, you should do several things to make your documents accessible. The first is to make sure that your agent has them. The second is to make sure that at least your primary care physician has them and if you have an ongoing illness, any specialty doctors. It is also a good idea to have them on file with your local hospital (try contacting the hospital's ethics committee for the best way

to do this.) You should **carry a card in your wallet** with contact information for your agent, who can then provide any doctor or facility with your documents if they don't already have them. Some people, especially those who travel a lot, pay a service that stores the documents and provides them 24/7 upon request, with its contact information on a wallet card. I know one person who keeps his documents on a flash drive on his keychain but the problem with that is that most institutions have strict policies against plugging in any external device to their systems.

10. If you check into a hospital without your documents and are conscious and your agent isn't available (or you don't have an agent), **appoint a "surrogate,"** a form of temporary agent. California law allows you to appoint a "surrogate" (orally or in writing) to make your health care decisions if you are incapacitated. (Probate Code § 4711) This is not a perfect solution because the appointment is only temporary, lasting 60 days or until you check out, *whichever is shorter*. If you have a PAHC, the surrogate takes precedence—useful if you're doing this because your regular agent is on a trek in Bhutan.
11. If you have a life-threatening illness, **consider filling out a POLST** with your doctor. A POLST is not a legal document but an actual order for medical treatment ("Physician Order for Life-Sustaining Treatment"). A POLST tells medical personnel what to do in case of an emergency as agreed upon by you and your doctor. A POLST can, for example, tell medical personnel not to resuscitate you from a heart attack. You can learn more at www.polst.org.

Medical decisions can be difficult under the best of circumstances and under the worst can be traumatic for your loved ones. No amount of preparation can guarantee that you will get exactly the treatment that you want but adequate preparation can go a long way towards achieving that end and easing the burden on your loved ones.

---

[1] You will often hear living wills referred to as "advance directives." But in California, the terminology is confusing: "Advance Directive" is defined to include a PAHC and/or an "individual health care instruction," the latter being defined as "direction concerning a health care decision…." (Probate Code §§ 4605, 4623, 4629)

Rob Rosborough is a mediator, teacher and attorney. His mediation practice focuses on disputes where an ongoing relationship is at stake, particularly elder/adult-family conflict such as disagreement over caring for an aging parent. He teaches conflict resolution skills for use in everyday life to older adults at USF's Fromm Institute. And he maintains a general advisory and transactional law practice focusing on personal and small business issues, including end-of-life planning. He also helps lawyers cope with the stresses of practice and life by teaching them meditation skills as a certified iRest® meditation teacher. He can be reached at rrosborough@montywhitelaw.com.