

Taking Charge at the End of your Life

By Tim Prosch, Author of AARP's *The Other Talk: A Guide to Talking with Your Adult Children About the Rest of Your Life* | April 15, 2014

Tim Prosch is author of AARP's [The Other Talk: A Guide to Talking with Your Adult Children About the Rest of Your Life](#), a book that helps parents and their children create a partnership to plan for the years to come, guiding them through important conversations and decisions about finances, medical care, and day-to-day living—before a crisis happens.

What can happen if you put off your end-of-life health care decisions until “the time is right?”

The Terri Schiavo case, which culminated in 2005, can put the answer to this question in stark relief.

Fifteen years earlier, Terri had collapsed at home, suffered severe brain damage and was put on a feeding tube to keep her alive. For the next decade and a half, she was yanked back and forth in a virulent tug-of-war between her husband and her parents about how she would want to be treated. Ultimately the courts got involved, pulling her off her feeding tube for 3 days in 2001, again for 6 days in 2003, and finally for 13 days in 2005, when she finally expired.

All of this drama and heartache could have been avoided if her wishes had been put in writing *and* had been thoroughly discussed by all interested parties.

While none of us will ever know what Terri wanted done at the end of her life, it is safe to say that her on-again, off-again existence and her increasingly toxic family dynamic are not what she or anyone else would wish for.

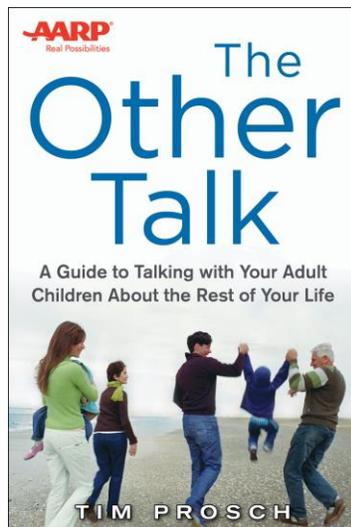
How can you avoid Terri's fate?

To begin with, it's important that you understand that health care at your end of life will be a family affair, not just a personal decision. In most cases, it is not about *you*



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personally taking charge. It is about you preparing and empowering *your family* to take charge as you approach that final stage.



The reason for this collaborative approach is that it is highly likely that you won't be physically, emotionally, or mentally able to direct the final proceedings. Collaboration addresses the challenge for someone acting on your behalf to weigh the options and make decisions and to articulate what should be done in a way that reflects your thoughts about the end of your life.

As a result, it is critical that you start these conversations *now* while you are mentally sharp. Quite simply, the longer you wait, the less effective these discussions with your family will be, due to the natural deterioration of the aging brain.

In preparing for the end game discussion, you'll want to take steps in two critical areas: guiding principles and parameters for medical treatment.

Step 1. Establish Your Guiding Principles

The first step in making your family confident and empowered in taking charge when the time comes is for you to confront and define what "being alive" means to you as you near the end.

For some people, it is fighting for every last breath. "Even one more day would be important to me. I would do everything I could to hold on to life."

For others, it is living intensely, yet comfortably, in the time remaining. "I would rather be able to do what I want, to be with my kids, to enjoy life, even if it's for a shorter time."

Of course, neither one is the better approach because it is such a personal choice. But if you start now to build a clear understanding of your preferences with your family *and* your doctors, you can dramatically increase your odds of getting what you want.

Step 2. Set Parameters for Your Medical Treatment

Step 2 in taking charge of your life (versus abdicating it to the medical community) is to put your preferences in writing. Equally important is to distribute and discuss your

wishes with your family members and your doctors to ensure that your goals are clearly understood.

An effective and relatively inexpensive way to accomplish this is to consult with your legal advisor, then draw up a health care power of attorney. This document establishes your designated agent who will make health care decisions for you if you are not able to do so.

If you are in the “do not prolong life at any cost” camp, you will also want to explore two health care directives: the living will and the do-not-resuscitate (DNR) order:

1. The living will establishes that you do not want your death to be artificially postponed. It states that if your attending physician determines that you have an incurable injury, disease or illness, procedures that only prolong the dying process should be withheld and the medical focus should shift to comfort care. This document must be signed by two witnesses who will not benefit from your death.
2. The do-not-resuscitate (DNR) order is different from the health care power of attorney and the living will in that neither your health care agent nor you can prepare it. Rather, it is a written order signed by your physician that instructs other health care providers not to attempt CPR if your heart has stopped beating and if you have stopped breathing during cardiac or respiratory arrest.

Once you have shared your “what being alive means to me” documents (the health care power of attorney and, if relevant, the living will and the DNR order) and thoroughly discussed them with family and doctors, you all should acknowledge the possibility of revisions. Every time your health status changes in some significant way, you should have another discussion to clarify your views and expectations.

It’s okay for you to move the goalposts on issues pertaining to the end of your life. You just need to make certain that the people in your world know that you moved them.

Do you have a living will or DNR? What did you learn through the process that you’d like for others to know?

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