

How to talk about End of Life

When someone you love is dying, here's how to avoid a lot of stress, fear and family battles

Jane Martin is a respiratory therapist and author who has been teaching classes on advance directives and end of life issues for many years. Here is her advice to Alphas, their families, and just about everyone else.

I suggest that family members approach the topic like this:

“Mom, I know it’s not fun to think about this, but if you’re ever unable to speak for yourself regarding what you want for health care, it’s important that your wishes be carried out. Let’s talk about what you want, not what I want or my brother wants, your lawyer wants – or anybody else. Just what you want. When you decide, write it down so everybody knows, then we can just forget about it, never need to think about it again.”

I tell patients much the same. It’s basically the same thing that I’ve been telling them in many years of teaching an advance directives class to people with severe lung disease.

It’s about choice and dignity.

Choice – deciding what you want for yourself. Not leaving it up to others to decide, guess or speculate, what you would have wanted or what they think is best for you.

And dignity – not losing control of everything that happens to you at a very important time in your life, when you are near death. You don’t want a doc-



Jane Martin

tor, or your most aggressive family member, your lawyer or a judge deciding for you.

I tell patients that even the closest, most loving families can have intense emotional battles when they talk about decisions that must be made when a parent is clearly near death. I see it all the time. So I always say, “You must have an advocate who will agree to

follow your wishes, even if they are very different from the wishes of the advocate. You might have a son who says, ‘No, Mom, I could never pull the plug on you. I couldn’t live with myself if I did that.’ He’d never sign the paperwork; he’d never be willing to do what you want. That’s OK; the son’s feelings must be accepted and honored. But you must get a different person to be your advocate who can, in good conscience, do what you wish.”

BE SURE TO TALK TO YOUR DOCTOR

And talk to your doctor about it! Bring it up at your next appointment, or make a special appointment to discuss it. Doctors might have no idea what their patients want when end of life decisions are being made.

Everybody has their own idea of what living is. And this is your chance to make your own choices about what you consider life to be, and have everybody respect that. No matter how sick you become, you’ll still have control over your own life.

When someone you love is dying, think about care and comfort. Think about that, and it covers a lot.

The subject of morphine is huge. Doctors and nurses are nervous because morphine can suppress breathing. But so what? If the patient is dying, what are we trying to accomplish? If the patient is

near death, morphine, painkillers, comfort is what he or she needs. That's why getting all these things written down when the patient is lucid and comfortable is so important.

Every adult, even those who are young and healthy, should have a living will. It makes your wishes known about life-prolonging medical treatments. Among other documents I always recommend highly are an Advance Directive and a Durable Power of Attorney for Health Care – this names your Patient Advocate, the person or persons legally empowered to speak for you when you are no longer able to speak for yourself.

This is a terrible time for families. It's always a very sad time. Why add to that by letting these decisions become so stressful? When everything is decided in advance, a family can grieve together and comfort each other without the unnecessary stress and even emotional battles.

Jane Martin tells more about end of life issue in her blogs like this one on Health Central:
<http://tinyurl.com/encdcpd>

End of life: What to do, where to find the documents you need

Here is a “To Do List” suggested by Tom Petty, MD:

- Discuss your hopes, fears, and anxieties about end-of-life issues openly and honestly with your loved ones.
- Prepare legal documents such as a living will, advance resuscitation directive, and durable medical power of attorney.
- Share your spiritual beliefs with your doctor and healthcare professionals. Surveys show that up to 80 percent of all patients employ prayer to help them reach medical decisions.

DOCUMENTS, GUIDANCE

You may want to talk to a lawyer about preparing documents concerning your wishes at the end of your life, especially if you already have a personal attorney.

Here are some places to find essential legal documents such as a living will and durable medical power of attorney, recommended by Petty and other experts. The best are written in language intended to be clear to average people. Be sure the documents meet the specific legal requirements in your state. Many are offered free.

Caring Connections offers a wide variety of free documents and downloadable brochures. They include a legal guide for the seriously ill and advance directives that are specific to your state.

<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>

The Center for Practical Bioethics offers free downloadable information on end of life, including helpful guides to families on how to talk about it.

Their website is at <http://www.practicalbioethics.org/cpb.aspx?pgID=886>

Full Circle of Care, a program of the Triangle J Area Agency on Aging of North Carolina, has extensive information for caregivers, families and patients. Their website:

<http://www.fullcirclecare.org/index.shtml>

Nolo, a 40-year-old company whose motto is “law for all,” offers free and low-cost legal forms and information, as well as a lawyer directory at www.nolo.com.