Living Will Is The Best Revenge

September 1, 2001 By Martin Downs

Drunk at 4 a.m. and weeping over the Clancy Brothers' rendition of "The Parting Glass," I like to thumb through my diary where I've scribbled notes on how I want to pass my final days, on the disposal of my sad carcass and so forth. But were I to become incapacitated and my dearly beloved to find the diary, they'd likely have a good guffaw and do whatever they please -- to the last, the scoundrels!

Given that hospitals and courts can be even more callous to HIVers than can friends and family, you would be well advised to transfer your last wishes from cocktail napkin to legal parchment, in the form of a living will and a durable power of attorney for final measures, a.k.a. a health-care proxy.

A living will lets you choose what kind of medical treatment you do and do *not* want when your candle flickers and your wits have flown. For instance, do you want to be put on a mechanical ventilator, or breathing tube, if you can't breathe on your own? Or do you want cardiac resuscitation -- a jump start for your heart if it stops?

Do-it-yourself forms are usually available at your local AIDS service organization, which may have an easy-to-use combined living will/health care proxy document. Most forms let you check boxes to state your general preferences, but you can add specific mandates, too. You can also set conditions for being kept alive artificially -- until your partner reaches your bedside, for example, or if temporary life-support is likely to lead to a meaningful recovery. Just remember that the more specific your requests, the better.

Case in point: In 1999, a Maryland court ruled that the Johns Hopkins Medical Center was not liable for having resuscitated HIVer Robert Wright Jr., even though his living will generally refused all artificial means of prolonging his life. The court ruled that the medical emergency -- a heart attack in reaction to a blood transfusion -- was not specified in his living will.

Because so many unforeseeable circumstances lie ahead as you write a living will, be sure to name an agent, or proxy, to carry out your decisions. This proxy should be someone you trust unconditionally to abide by your wishes without introducing his or her own personal agenda. "That's an easy choice for me because I have a life partner," says HIV positive songwriter Steve Schalchlin, who lives in Los Angeles. "I have been sick to the point of almost dying on three different occasions, and he has always been there for me." Nevertheless, Schalchlin admits that he -- like the vast majority of HIVers in the U.S. -- has not filled out the forms.

And don’t even dream that you can just say, “Congratulations, you’re my proxy!” and leave it at that. It’s time to sit down for a nice, long talk about life, death and your personal preferences. Long-term survivor Wes Nyberg of Austin, Texas says that he and his partner got everything hammered out by visiting an attorney. “We were doing major life stuff at the time,” he says, which made the emotional intensity easier to handle. “It was difficult, but I tried to make it as fun as possible.”

For state-specific forms and detailed instructions, contact the Partnership for Caring at www.partnershipforcaring.org, or by calling 800.989.9455.

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