Patients Aren’t Stupid!

February 8, 2009 By Richard Ferri, PhD, ANP

About ten years ago I brought a tee-shirt with Patients Aren’t Stupid! in large bold type on the face of it. I literally could not wear it out of my house unless I wanted to be stopped by tons of strangers who came up and hugged me, shouted words of support, or for those who knew they would simply say “You got that fucking right!”

The few times I did wear it in public I was always startled and unprepared for these reactions. If anyone said anything negative about the saying on the shirt it would have most likely has been my fellow “doctors” if I had to guess. But I never heard a word.

The reason this tee shirt popped into my head over the last few days is my new AIDS doc (typically I much prefer NPs to do my HIV care but none, but myself, were to be found) made it clear in a gentle but firm way she knew I wasn’t stupid, was NOT going to treat me like I was, and even when she disagreed with me she was going to make her case and allow me to make mine and we would go from there.

I also felt that I wasn’t being given any special consideration because of my background and knowledge. In fact, I was very up front that I was more than nervous about trying this clinic since the medical director and I has publically butted head on more than one occasion, and I frequently get his patients into my own clinical practice because of how his stilted bedside manner. But my new doc didn’t really care about any of that she only cared about how I felt, how I was handling my recent major bump in the ART road with developing classic hypersensitivity warning signs to Abacavir despite doing all the right pre-testing. It was a perfect first visit in my mind. I felt at ease and hopeful that I was going to be afforded respect, dignity, and get good care.

Then we hit a little snag. She looked through my chart and noted that I had signed the form that clearly and explicitly stated that I did not want to be resuscitated under any circumstance what so ever. No matter what happen all I wanted was someone to hold my hand and provided me with “comfort care.”

She looked up from the chart and said: “Aren?t you a little young to be a complete DNR?”

“Maybe to you, but I am 53 and in ’gay years? I am consider ’technically dead’ anyway.”

She laughed. I laughed. Then she said, “No, really? You do not want any resuscitation efforts even if the condition is most likely reversible?”

“Not a one,” I replied. I knew what she was getting at and I couldn’t blame her. Her job was to save lives. Here I was an extremely healthy middle age man who took good care of himself and it showed yet I did not want anyone pumping on my chest when my time comes. She just couldn’t make sense of it, but then again she didn’t really have to. I had to, and I DID.

Since the terrorist attacks I have been to hell and back so many times I get automatically upgraded without asking. I was walking by the Twin Towers when the first plan stuck and my world went black. As ashes and body parts rained down on me I distinctly heard the onslaught of the second plane. (The full story - which is hardly really full - can be read on my website www.richardferrri.com at http://www.richardferri.com/?p=16)

Soon after that life machine gunned me down with multiple collapsed lungs, the deaths of my three wonderful parents, a little cancer, my partner/husband dropping dead, and a whole bunch of other stuff that seems rather trivial when I try to add them in those events. Also, drinking and drugging were totally set free and I flung myself onto the third rail of alcohol and drug addiction. Yet I lived.

Okay, the term “lived” might be a major stretch of my truth but I was still kicking around. As time passed my life did indeed get better. My health greatly improved, I surrendered to the fact that I was an addict and AA saved (and continues to do so on a daily basis) my life, I muscled like (fuck I was even considered “hot”), and I met a new man, a new partner, who will bring me joy and love for the rest of my life. But I am still a DNR.

Why? My first instinct is to tell you fuck off and that it is none of your business, but I do realize I am the one bringing it up. So here it goes.

When you go through that many hard losses in less than six months life becomes very different. Nothing you thought is ever what it was. Your sense of reality becomes real for the first time in your life. I finally knew my life was a gift from God that I did not understand. I also knew the physical and psychological pain that I went through I could never tolerated again. I had been in the playground of Hell and I wasn’t going back.

Being a DNR is my decision. I am not stupid. I have talked to my partner, my priest, my family, and myself. I have made up my mind. I am comfortable with the decision. There isn’t any way anyone is going to change my mind.

However, standing by my decision to be a DNR does not mean I want to die. Far from it. That is where the sticking point always is. People somehow think because I want control what happens to me if disaster strikes again I am simply giving up. Bullshit. I could have given up a long time ago by just continuing to drink or drug. Or even more recently when I had the allergic reaction to the HIV medication I could have kept my mouth shut and waited for it to bottom me out. But I didn’t.

I don’t want to die, but I will not live with tubes, pains, drips, and agony again. It is as simple as that. I found out the hard way we treat the dying like shit in health care for the most part. I will not be treated that way again. Period.
I am a middle age man, I know what I am doing, and I have no illusions about my being on “borrowed time”. I also do not have any illusions that I am in charge. God is. So, as I said thousands of times in my hard days of trying to get sober, it is time to “let go, and let God.”

So there you have it in a nutshell. I know my new doc is going to ask me at every visit if I still want to be a full DNR and that is okay. She is following her heart. But I am the patient, and I am not stupid. I need to follow mine.

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