

002 Midlife Woman Radio Commentary – 4/25/10

I may not know Jack, but he knows me.

By Susan Bilheimer

Last night, I watched a stunning movie on HBO called “You don’t Know Jack” about Jack Kevorkian. In case you aren’t familiar with the man known as Dr. Death, in the 1990’s, he assisted well over 100 people in ending their lives. Obviously, the subject of euthanasia is a hot topic on both sides. But what disturbed me most, left me most haunted, was the story of Marjorie Wantz. Marjorie, from MI, was 58. Her desperate plea to be put out of her misery was due to unrelenting suffering that can be summed up in two simple words - pelvic pain. That’s right. Pelvic pain.

Her story was barely a sidenote in the movie. Her death came in tandem with a wheelchairbound woman with multiple sclerosis. They called Marjorie patient #3. Both women died at a rented state park cabin near a lake. Marjorie elected to end her misery by carbon monoxide inhaled through a face mask.

An autopsy found no physical evidence of illness or disease in the pelvic area.

She had also reportedly been taking large doses of medication that impairs judgement.

She had been hospitalized for psychiatric care previously.

This was in 1991. Nearly 20 years later, we are still debating whether pelvic pain is “all in your head.” Are you kidding me? I feel sick inside about this, but not because of what some may judge the “right” reason. I’m not enraged at Dr. Kevorkian for allowing a woman to take her life who had no physical evidence of illness and who may have taken medication that impaired her judgement.

I’m disturbed and frightened that we still as a society are so blind that we don’t understand that pain is not always visible. And that women with pelvic pain are too often shuffled off to the psychiatrist and told we’re depressed, when what we are is frustrated and demoralized by devastating pain and a system that refuses to hear us. And we’re told over and over that it’s in our heads and here, take this pill to shut you up and stop from feeling the emotions surrounding the pain. Maybe, yes, we are depressed, but who wouldn’t be when the very core of your pleasure center constantly throbs, not with spasms of ecstasy, but with agony and makes your life a living hell, and maybe destroys or precludes sexual intimacy with a partner.

It’s not just pelvic pain, but all of these intertwined chronic illnesses that come from whatever still unknown or vague causes, where the nervous system is sending out signals that are haywire alerting the body to pain that isn’t there or is, but may really have started somewhere else.

I remember seeing a doctor, a rheumatologist who shows up on the web on the lists of doctors who understand fibromyalgia. This doctor looked at my crying face, hearing my pleas for help with the fatigue and brain fog and yes, the pelvic pain too, and said with a slightly condescending tone that I was severely depressed and needed medication. Well, the psychiatrist didn’t think so, and I watched and

listened to him talk to this upstanding rheumatologist, while the psychiatrist asserted that this was not in my head and it was not depression.

In fact, the psychiatrist told me later that when doctors know you have had any anxiety or other psychiatric treatment, they will most often just think of you as a psychiatric patient and you can forget about them taking a serious look at physical causes for your illness.

Shame on that rheumatologist. Shame on all the doctors who refuse to hear our cries that we are physically sick, not mentally disturbed.

I remember vividly the call from the 77 year old woman when I first began writing *Secret Suffering*. Her son found my website. Her son. She was crying. She was lucid. She was desperate. She said she'd been to doctor after doctor about the horrifying pelvic and vaginal pain she experienced. Every one said there was nothing wrong with her. But the pain was unbearable and she said she couldn't go on. Please, she pleaded, could I help her? What was I to do? I did some research with her on the phone to find some doctors on the lists from various websites. There was nothing I could do.

A few months ago, I saw another rheumatologist a few times. He, too, came highly recommended for fibromyalgia, which for me is all connected with my pelvic pain. At the third visit, he looked at me with that withering look I've come to know all too well and said, "well, you aren't in that much pain." How the hell can he possibly know my level of pain.

Shame on him. And shame on all the doctors who play God just enough to get you in the door, but not enough to show the compassion, mercy, and kindness that a loving God would give when the answer isn't so simple.

We are learning so much more about pelvic pain now. About all these illnesses. But because medical schools train doctors to treat acute illness, not chronic, many just cannot wrap their brains around the fact that just because you don't see pain doesn't mean it isn't there.

Do you want to know the real problem with our healthcare system? Well, public option, private option, it doesn't matter for those of us with chronic illness, such as pelvic pain, whose lives and bodies have been abused, sometimes decimated by the doctors who can't find it in their hearts to deal with us anymore or do what it takes to treat us, to behave according to the Hippocratic oath, which says "Do no harm." That's the healthcare reform we really need. For doctors to take seriously the plight of the millions of people with chronic illness that cannot be seen under by the naked eye or a microscope ... yet. And for many of those millions, there are partners whose lives are destroyed as well when no help and no help are offered.

It's time to speak up. To see that one of Dr. Kevorkian's few patients was a woman with pelvic pain, who suffered so severely that she couldn't go on is bad enough. To know that there are still millions of women and men who suffer with pelvic pain and who may be undiagnosed or misdiagnosed, to know that there are too many women and men who feel the same way as Marjorie Wantz, because of their unrelenting pain nearly 20 years later is absolutely unacceptable. Thank God for the good doctors,

those who are willing to learn about pelvic pain, those who don't operate when its unnecessary because they don't want to spend more time investigating, those who are willing to research, those who don't shove off the problem patients to the psychiatrist because it's inconvenient.

There is hope, but you can't stop seeking it. If you leave your doctor's office feeling worse than when you went in, if you aren't taken seriously that you have a physical illness – keep looking. There are new treatments and doctors who are willing to spend the time to help you and who will believe you. There are more and more physical therapists available to help, and because of the Internet, you can educate yourself and find the support you need from others who suffer. We need to shout to the rooftops that doctors **MUST** learn more about chronic illnesses like pelvic pain. Medical schools need to train new doctors in diagnosing and treating this epidemic. If the family practitioner had a modicum of knowledge, just knew what questions to ask, a simple set of questions such as the eight or so that comprise the PUF Scale, like how often do you have to pee – questions that could change the life of a young woman if asked early enough – the course of history would forever be altered for all of us who suffer.