I’m not a doctor; I just play one in life

October 10, 2006 By Mark de Solla Price

I’m not a doctor. The only medical training I’ve had has been from The Red Cross (which is great and I strongly suggest everyone get CPR and first aid training). The only credentials I have are from writing about HIV for 15 years, leading support groups and being a peer counselor for GMHC.

I like to joke with some newbie medical receptionist who asks me who my primary care physician is. I tell them “I am, but my insurance company thinks it’s Dr. Paul Chambliss.”

In terms of patient-empowerment, it’s a very powerful idea to think of yourself as your primary care physician. And each of us has lots of advantages over some hired doctor. All of us have a much lighter case load (one patient, maybe two or more if you’re a family) and a much narrower field of study (whatever diseases and conditions we have).

I know I certainly feel and know what’s going on in my body better than anyone else could. Of course, not being a medical specialist does have it’s disadvantages, which is why I rely so heavily on “consulting physicians” to help me. And I sometimes need to do a little extra internet research to get up to speed.

Over the years, I’ve gotten the doctors that Vinny and I work with to treat me almost like a colleague. I always got faxes of all my labs, faxed in (and later e-mailed) my questions and problems to make the most of face-to-face time. The HIPAA privacy laws have made some of this information flow more difficult.

It was now a full week after my annual physical, and I was becoming a very impatient patient. Why hadn’t my lab results been sent over to me as they came in? Hadn’t my labs come back yet?

“Yes they had, but the doctor needs to speak with you first” - that was the sort of answer civilians get. I dashed off a quick, somewhat grumpy e-mail to my doctor to resolve this clerical mistake, so I’d once again be granted the medical equivalent of VIP access.

It was NOT a clerical mistake. Dr. Paul really did want to talk with me before I read my reports. I was negative for all those exotic pathogens, but I had hepatitis C. I had been vaccinated against hepatitis A and hepatitis B, but what I had was unmistakably, verifiably hepatitis C. WOW, that was a surprise!

My first phone call would always be to my husband Vinny, but he and his sister Maria and our friend Michael were heading off to see Barbra Streisand live at Madison Square Garden. At $375 a

ticket, my medical news could wait until he got home.

I know a lot about HIV, and a good bit about hepatitis B (which is what Vinny has been battling). But surprisingly, I knew almost nothing about hepatitis C, and I needed a crash course. Well, our own website, HepMag.com, just happens to have one of the very best hepatitis C tutorials. I did more research and started my list of questions.

When Vinny got home, I heard all about the best concert ever and all the celebrities he ran into. He even stayed awake for the whole thing, which, if you know Vinny's health these days, NEVER happens. When he was done glowing and gushing, I told him that I had some not so great news and sat him down. That was a hard conversation to have. Vinny had always been the patient and I was the caregiver. I wasn't supposed to get sick. We talked for a while, but I just couldn't stay awake anymore.

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