A Mind of Her Own

Dementia doesn't disorient Lisa Yingling's sense of service, style or self

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Hi, I'm looking for Lisa Yingling.

So am I, says Yingling, laughing at herself and at her condition.

I play NTN trivia on-line -- the National something-or-other Network. Sometimes I have trouble remembering words." The 38-year-old ex-nurse who was occupationally infected by a needle prick lights up a cigarette, recalling how she "clued in" to her dementia. "Anyway, I started not being able to remember things during NTN. I was really frustrated. My husband, Rob, he only gets things like the mythology questions, while I get all of the literature, medical and everything else. Suddenly he was winning. I knew something was wrong." In April of 1995, during an MRI brain scan, the doctors found "demylinating areas" on Yingling's brain, indicating AIDS-related dementia.

Further neuropsychological testing was conducted to verify her diagnosis. "You know," says Yingling, "they do things like read you a list of words that you have to repeat back to them. That's where the dementia really shows up. You can tell me something, and then two seconds later I don't remember what you said." She takes a drag of her cigarette. "Who are you, again? Just kidding."

This is not a long-term memory problem. It's different from something like Alzheimer's, which my grandfather has. He stares at MTV because he loves all of the colors, whereas I can barely watch TV at all because there's too much stimulation." Yingling used to sit on the computer, watch the television and listen to her husband all at the same time. Now it's too frustrating. "At least one of them gets yelled at."

Her condition was worsening until Yingling entered a clinical trial of thioctic acid, a nutritional supplement, and the anti-Parkinson's drug Deprenyl. She also upped her AZT intake to twice the normal dosage -- 1,500 mg daily. "It helps the dementia, but it certainly doesn't help the old T-cells." says Yingling, who, when forced to choose, opts for brain over body. "If you don't have your mind, you don't have a personality."

Following a recent article about her in the Baltimore Sun, the ex-nurse has been inundated with speaking engagements for Maryland hospital and hospice caregivers. Her specialty? How not to

make an AIDS patient feel like a pariah while avoiding your own risk of infection. “There are still caregivers who treat PWAs so poorly, and then there are others who try so hard to show they’re not afraid that they put themselves at risk, trying to be lackadaisical about the whole thing.”

Then there is the rural life in Manchester, Maryland. It’s not always easy for Yingling and her husband, a financial-management administrator for the state of Maryland. “When it comes to AIDS, it wouldn’t surprise me if some of my neighbors bust their butts cleaning their homes after I visit,” says Yingling with a broad cackle.

But they’re not the only ones who irritate her. The overly sympathetic, including PWAs, who say “they feel sorry for me because I am an innocent victim” really tick her off. “It’s like we don’t condemn people who get colon cancer from eating fried food all of their lives, but we condemn people for the very act that keeps us all going: Making love.”

The thing that concerns me the most, Yingling says, “is when you tell someone that you have dementia. They look at you like ’Oh my God, what is the poor thing going to do?’ So instead I say I’ve got HIV encephalopathy, which is the same thing. It’s just a nicer word for dementia, and usually no one knows what I’m talking about.”

But Yingling’s not trying to hide her disease. On the contrary, she’s done all but beg the Carroll County Health Department to give her name out to anyone who has HIV or AIDS in her area. She wants to share experiences and treatments. Besides, “having dementia makes for really interesting conversation.” And then there are those who might refuse to accept that Yingling is not, as she says, in an “ocean of [emotional] pain. It’s not like I have the Ebola virus or something. On the other hand, I do have a lot of physical pain.” Yingling lowers her voice conspiratorially. “But then I take my Marinol,” she says with a wink. “My mother says the problem with me is that you won’t be able to tell when I really get dementia.”

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