Life: Good Pill Hunting

A survivor meditates on kinder, gentler medications

May 1, 1998 By Dennis DeLeon

Once a month I used to sit at home and slowly, methodically put my pills into Dow Ziploc Snack Bags, preparing packets for the next four weeks. This pill-packet assembly line was for me a kind of highly organized meditation on repetition. Over time I varied my style and methodology with the thoughtfulness of a craftsman. In my novice stage, I would first sort and insert all the gelatin capsules, then all the tablets. Later it seemed more meaningful for the antiretrovirals to go in first (they radiated importance), followed by the related meds (bacterium, zovirax, etc.). These duller pills were the foot soldiers to the anti-HIV samurai.

The little packets of 10-plus pills and vitamins were like emotional Energizer batteries in my pocket, furnishing a steady current of faith. I knew that even if many of my meds were experimental, way off label and of dubious efficacy, still I could say I was “taking control of my treatment.”

But now that the number of meds I take has tripled, the process is a half-day event, disrupting the Zen rock garden-like spread of pills on my table. I sort nearly once a week. The sheer complexity of the task has made it about as meditative as cleaning the oven. More important than my ritual losing its magic, though, is a change in my feelings about the drugs. Yes, I’m better off today because of the zippered plastic bags. But like a consumer product with a hidden defect and no warning, the things I’m packaging and shoving down my throat no longer seem like trusted friends. This is not just because of the strange mass of fat growing on top of my shoulders, the newly diagnosed diabetes or my astronomical triglyceride and cholesterol levels.

Why do I endure these effects when I’m burning bridges that could someday be crossed by as-yet-undiscovered better drugs? I lie in bed at night and visualize the little resistance buds popping up on my gene material and wagging numbers like a roulette wheel -- 90, 42, 81. All the esoteric phenotyping or genotyping tests are, from what I can tell, not very helpful. I wonder whether I would have started on these therapies if each prescription bore a warning: “Use of this drug will cause nasty side effects and eventually result in virus resistant not only to this drug but to future ones.”

This sense of betrayal is particularly stinging because I was raised to trust pills. My family’s medicine cabinets were bursting with something for everyone -- the ill and hypochondriac alike. An asthmatic in a family with more ailments than a village, I fit right in. My great grandmother was a

curandera (village herbalist) in Mexico and then in the United States, assuaging sick campesinos (farm workers) with remedies and potions. My grandmother, Mama Mila, kept a steady flow of medicinal supplements going to the whole family.

These past years when there was no hope, meds were like life rafts on the Titanic. But after being sweet-talked into believing that protease combos are a path to the future, I have come to learn that this new car may break down in the middle of a desert. In the midst of the new enthusiasm for a longer life, I begin to feel as if I'm packing little time bombs in my Dow (they brought us napalm for the Vietnam war, remember?) baggies each month, ready to cripple my immune system yet again with some new viral mutation. Like a double-crossed lover, I'm anxious and pissed off.

Still my rational side fights this letdown. The clear-minded Dennis knows that we're at the iron-lung stage of HIV, subjecting our bodies to heavy-handed therapies while awaiting a Jonas Salk. The good, grateful, nonwhiny Dennis knows that he wouldn't be around to taste his mother's *huevos rancheros* without the new treatments. Yet I remain distrustful of my old pals wrapped in colorful gelatin.

When I was a kid, every Christmas *mi abuela* would have a *piñata* for us. Someone would string a clothesline from here to there and move the neon-colored bull up and down while the littlest to the biggest child took blindfolded swings. And the cheap candies that rained over us were the best in the world. I want to strike the pharmaceutical *piñata* and catch wonderful things. I want to believe again.

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