The Defiant Ones

Kudos to PWAs who reject treatment dogmas of all stripes

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As polarization grows between dogmatists on both sides of the “Should I take protease cocktails?” debate, more and more PWAs are saying, “A pox on both your houses.” They’re standing up to doctors who harangue them to “hit early and hit hard,” while defying the shrill pharmaceutical rejectionism of some AIDS dissident groups. These free thinkers combine a healthy skepticism about conventional wisdom with a flexibility and openness to embracing whatever works. For now, they’re abstaining from the drugs in favor of carefully chosen alternative therapies. But it’s a tough road to hoe.

On the one hand, the protease abstainers must resist the pervasive siren song of AIDS docs like Marcus Conant, MD, an influential clinician in San Francisco. “I know what happens to patients when they don’t take the medication. They die,” Conant says flatly. When self-directed PWAs do well long-term on alternative therapies, and thus don’t fit the mold of straight-downhill-to-death, they are marginalized by the protease dogmatists as anomalies or even “genetically gifted.”

On the other hand, because they consider - and sometimes use - antiretrovirals, they are rejected as semi-sellouts by treatment ideologues from groups like HEAL (Health Education AIDS Liaison) and ACT UP/San Francisco. These organizations bombard and occasionally harass PWAs with the message that “the drugs will kill you; avoid them at any cost.” In their eyes, anti-HIV therapy is a misconceived - indeed, genocidal - strategy serving only corporate greed.

But many protease abstainers are less interested in conspiracies and ideologies than in results. Stanley Rebultan of Los Angeles, HIV positive for at least 10 years, has remained quite healthy on a controversial, self-developed regimen of rectal infusions with a crude extract of bitter melon. This tropical vegetable, traditionally used in Asia for antiviral and antitumor purposes, has been tried on several continents to treat HIV. “Bitter melon is a part of my culture,” says the Filipino-American activist. “Originally it was an experiment. Before I started it in ’89, my T-cells had gone down to about 400.”

Since then, his CD4-cells have stayed above 700, his recent viral-load counts have remained between 1,000 and 8,000, and he hasn’t had a single major infection.

Despite his good health, Rebultan is being pressured by his doctor to start protease inhibitors. He

readily acknowledges the drugs' benefits and even says he may use them someday if need be. But he adds, "It's unfortunate that some physicians speak glibly about the ineffectiveness of alternative treatments when they don't know shit about the subject."

Another protease abstainer who's doing well, former ACT UP/San Francisco member Casey Carlisle, has been HIV positive for 17 years. A decade ago he had a brief, nasty interlude with AZT, which he calls "toxic crap" that made his blood work "go to hell." That prompted him to do his own research. "My first doctor refused to keep seeing me unless I continued to take AZT, so I fired him," he says. By 1993, after studying and trying various alternative therapies, he began applying the photochemical DNCB - another controversial treatment - to his skin every week to elicit a red and itchy immune response

Today his CD4s have been stable at about 300 for six years and his viral load remains under 35,000. He has had only minor infections (treated with antibiotics). Carlisle still uses DNCB, but now he says: "I do it my way, once every six months. I'm doing great! I'm not going to screw it up by taking toxic drugs that may mess up my immune system." Although he resists his doctor's urging to begin protease inhibitors, Carlisle say, "If my CD4s went below 200, I would very much consider the triple combination to save my life."

People like Carlisle and Rebultan deserve the respect of the entire AIDS community for adhering to their own independent thinking despite pressure, ridicule and even abuse from opposing directions. I salute all self-empowered PWAs - those who opt for standard drugs alone, those who forge eclectic approaches, and those who defy convention and the odds.

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