Clean, Sober...and Medicated?

From painkillers to medical marijuana, HIV meds can pose a tough challenge for people in recovery.

December 1, 2000 By Richard Elovich

Elaine remembers feeling on edge as she walked into her doctor's crowded office two years ago. A statuesque hospital housing manager from the Bronx who's been HIV positive since 1989, Elaine, 47, had something to tell her doctor: "The pharmacist says my Norvir's now only in liquid. Liquid? That's nearly a spoonful of alcohol per dose." Then, after a pause: "I can't drink alcohol twice a day." Elaine's doctor reminded her that the Norvir was working, and that another drug might not be as effective. Elaine looked at him. "I am an addict," she said. "You didn't know me when I was using." Her doctor pushed. After 13 years sober, he asked, couldn't she handle two teaspoons of alcohol? "You don't understand," Elaine said. "It's like an allergy. You never get past it. I can never have just one drink because once I start, I'm off to the races."

Elaine first told me this story over the phone. She'd searched out pharmacies that might have the old, alcohol-free form of Norvir. She'd scoured the web and even used all of her doctor's capsule samples. But then it was liquid or bust. Not knowing how to help, Elaine's doctor referred her to me, since I was then running a counseling program at GMHC for substance users and in recovery myself.

I began to hear more stories like Elaine's: Some aspect of HIV treatment was threatening people's ability to stay clean. Given that 16 percent of HIVers were infected through sharing needles, once you factor in the use of alcohol, cocaine and other drugs, the proportion of people with HIV who are in recovery is undoubtedly high. And since meds for pain, wasting, depression, anxiety and even HIV itself could pull the rug out from under years of sobriety, Elaine's treatment-or-recovery dilemma can hardly be uncommon. One person spoke of feeling high from Sustiva; another of how injecting human growth hormone (Serostim) for wasting was far too reminiscent of shooting heroin. Many were struggling with whether to take painkillers for crippling neuropathy or use medical marijuana to spark the appetite. As I knew from my own painful bounces in and out of detox, recovery is a fragile victory. Taking prescribed meds that might threaten it is no joke.

Denise, 50, is an HIV positive mother of two living in the Bedford-Stuyvesant section of Brooklyn who's been in recovery for 10 years. She dreads ever having to face one of these tough treatment choices because of what she went through with a friend who's also positive and in recovery. "He was heavily sedated on morphine," she recalls, during a bad case of tuberculosis. "Even while confined to a wheelchair with terrible neuropathy, he relapsed back to heroin." Eventually, he

started his recovery process all over again, she says, and this time was able to stick with the prescribed morphine. But the episode haunts her.

“I always have to work out whether dealing with my medications is violating my sobriety,” says Tom, a 54-year-old former cab-company manager from Denver, who got HIV a decade into his 24-year recovery. He says that Alcoholics Anonymous (AA) meetings provide him with support for his ongoing effort to stay sober and help him focus on gratitude “that’s medicine for me, too.” But one of AA’s slogans, “Keep it simple,” he just can’t follow: Tom is on high doses of a potentially habit-forming painkiller, OcyContin (time-release Percocet, a mild opiate), for his neuropathy and Wellbutrin (bupropion), which has stimulant properties, to treat depression. Sometimes he wonders, “Have I slipped?”

Denise, Tom and Elaine are a few of the millions of people across the country who say that AA was the only thing that saved them when they bottomed out. For them, treading on any of its basic principles of sobriety can be terrifying. One woman, who’d tried to stop using drugs countless times on her own, calls AA “my second leg,” the one thing that finally enabled her to quit.

Alcoholics Anonymous, and its sisters, Narcotics Anonymous and Cocaine Anonymous, have inspired this kind of loyalty in part because they are the only drug treatment programs organized by drug users themselves. Founded in the 1930s, when alcoholism was widely considered untreatable, AA -- the mother of all self-help groups -- is nearly as available as alcohol and drugs. Through its famous “12 steps,” AA encourages members to give up trying to control their drug use on their own, and to instead embrace spirituality and help from others, through telling their own stories at meetings, listening to others and speaking with volunteer “sponsors” they can turn to day or night. (Participants also commit to anonymity, the reason no one interviewed for this story used his or her full name.) At the moments they feel the most isolated, self-hating and helpless, many addicts have found in 12-step programs an acceptance by other recovering addicts that is like coming home.

Denise tells the story of her first day, 10 years ago, as if it were yesterday. She was leaving detox when a staffer said, “Take your bags from the hospital and go straight to a meeting. They’re going to cheer for you,” she recalls. “And I’m like, ’Yeah, right.’ I hadn’t heard anything good about myself in a very long time. But when I went into that meeting and I said, ’My name is Denise. I’m an addict. I just got out of detox and I have one day clean,’ those people jumped up in the air. It was thunderous applause.” Denise had found a roomful of people who knew what she’d been through -- and were there for her. Even better, Denise says, “I found the same acceptance around HIV as I did around being sober.”

Through such support, newcomers learn to rely on others for help and to respect the knowledge they’ve gained from their own experiences -- techniques that also help many former users to cope with an HIV diagnosis. “When I found out I was positive,” Elaine recalls, “I had the foundation of five years’ recovery. With HIV, I had a choice to ’Fuck everything and run, or face everything and recover.’ That’s a slogan straight out of NA and it sure as hell applied to my diagnosis.”

For Joe, 44, a tall, wry Midwesterner with a punk rock past, AA meetings held his life together at a time when everything was falling apart. He'd just been through the AIDS deaths of an entire circle of close friends in San Francisco, a felony drunk-driving conviction in Los Angeles and the sting of being dropped by a boyfriend when he learned Joe had HIV. Joe packed up for New York City to start a new life. "I was shell-shocked," he recalls. "I went to two meetings at noon, grabbed some lunch, then to a 4 o'clock meeting and to work at night word-processing. That's how I stayed sober and out of trouble."

This extremely structured life also gave him the grounding to handle a series of life-threatening health challenges. In the space of a month, he got CMV (cytomegalovirus)-related pneumonia and MAC (Mycobacterium avium complex). He served as his own home nurse, managing four to six hours of IV infusions of ganciclovir and foscarnet each day for the CMV, and did his own wrangling with insurance companies. "It was about putting one foot in front of the other and all these little slogans of AA," Joe says. "If I hadn't been sober, I couldn't have made it through what I did."

With recovery so essential to survival, questions emerge: Can HIVers maintain their sobriety, even while taking medications that may threaten it? And can people in this situation continue to get support from others in recovery who may see what they're doing as a relapse?

Joe's experience offers some hope. When he got sick in 1995 and started losing weight, his doctor told him he had to start eating or get on a food tube. After Megace, a hormone-derived appetite stimulant, failed to work, Joe tried Marinol, the chemical version of marijuana, a prescription drug, but it made him feel paranoid and unable to function. His doctor encouraged him to consider the real thing. "I talked to all these people in recovery because I was afraid if I started smoking pot, I would start doing other drugs again," Joe says. "But they promised they would tell me before that happened." When he tried marijuana, he says, "I was surprised. I always thought medical marijuana was an excuse to smoke pot, but it actually worked. With all these HIV drugs I take, I'm always nauseous, as if there's a hard shell around my stomach. The pot relaxes that." He got his appetite back and began to gain weight.

But, of course, the pot got Joe high, too. "It had been 12 years since I last smoked and I got stoned really easily. The first time I came down I put on Grace Jones and picked up my cat, who put his paws around my neck, and we started just dancing. I thought, 'Uh-oh, that was really nice.'" Over time, he learned to limit his doses; enough to perk up his appetite, but not so much that he got super stoned. "I learned to smoke not five hits but two or three -- and that was enough," he says.

The plot thickened in 1997, when Joe began to experience neuropathy and his doctor prescribed Percocet: How would he maintain both sobriety and functionality? "I was worried about taking painkillers every few hours each day," he says. "I was afraid this meant getting addicted." To stay on top of whether his physical dependence on this essential med had slipped into the old-style cravings he fought so long to kick, Joe used a method he developed with pot. He "bookended" at every step with his doctor, therapist and friends in recovery: "I talked everything through with people at either end -- I checked in before I did it and again afterward. The way I did drugs before, I was very secretive: I did heroin with one friend, speed with another and then went home for a

six-pack. My friends didn't even know I had a drug problem."

Then, last year, Joe's neuropathy got so painful he couldn't walk to the corner store. "I went off the Percocet and went on a fentanyl patch [a stronger opiate], but on that I couldn't even get out of my Barca lounge. When I found myself nodding off in an AA meeting, that was it." His doctor prescribed methadone, which completely killed the pain, but left him feeling depressed. After trying all three opiates, Joe says, "I decided I would rather put up with some pain in order to have a clear head." He went back on Percocet, which reduced but didn't eliminate the pain, and added a pain-management course, fatty-acid supplements and acupuncture, which helped him cope.

New York City HIV doctor Howard Grossman suggests looking at the end result -- what the prescribed medication allows each person to do. "With drug abuse," Grossman says, "the drug often reduces normal functioning. On the other hand, prescribed antidepressants, anti-anxiety drugs or, in the case of neuropathy, pain medications may allow the person to continue normal functioning -- even some things as basic as walking." Grossman says patients in recovery need to become attuned to the difference between dependence on a prescribed med for day-to-day functioning and "self-medication," that cycle of constant craving and ever higher dosing that signals abuse.

AA did publish a pamphlet on the use of mood-altering meds ("Medications and Other Drugs," available at 212.870.3400) that underscores the difficulty of managing prescription drugs, but it offers little advice. (For *POZ*'s tips, see "Between Recovery and a Hard Place," page 63.) And these tricky issues rarely come up in 12-step meetings, even in the many gatherings oriented specifically to HIVers. The half dozen people *POZ* spoke with for this story were so afraid they'd be seen as having relapsed that each of them has chosen, so far, to remain silent about their private debates over HIV-related medication -- at least inside AA.

Finding other places to talk over these negotiations has been one of Joe's greatest challenges. "I don't go to meetings as much as I used to. If I went, I'd want to tell people I'm on these pain drugs and that I smoke medical marijuana, but I don't want people pouncing on me, saying I'm not really sober," he says. "I once saw that happen to someone who talked about antidepressants in a meeting. So I go to meetings maybe once a month and I don't share. And yet I still have to find ways to break the isolation."

Once Elaine bit the bullet and went on liquid Norvir, she too, cast a wide net in search of support. While her AA attendance didn't flag, she relied instead on individual friends in recovery to keep those two daily spoonfuls of alcohol from becoming more. "When I tell my story in AA meetings," she says, "I always mention my HIV status. It's very important for women to hear my experience and know it's not a death sentence. But I don't go into my treatment questions, like the Norvir. I don't want someone in AA making my treatment decisions for me, and I don't want to set myself apart in AA. I got my foundation for managing all of this from AA, but I learned how to take the best from AA and leave the rest."

Joe has turned to a handful of friends who have a respectful take on his use of pot and painkillers.

“I’d rather see Joe slightly stoned in a life where he’s concerned with being sober than wasting away,” says Eileen, a friend of Joe’s whose been in recovery herself for 16 years, whom Joe describes as his unofficial sponsor. “What’s desirable here is to be alive, not just sober. It’s something you have to come up with yourself, but, hopefully, as your sobriety progresses, you know the difference between taking meds to avoid living in incredible pain and choosing to be high because that’s a place you’d rather be.”

Recently, after Eileen and Joe attended a meeting together, Joe told her, “This is the kind of meeting where I’d like to raise my hand and talk about my pain pills and pot smoking.” Eileen was skeptical. “You have to be selective about something as precious as your sobriety and your health,” she says carefully. “You have to pick your battles.”

Psychologist Philip Spivey, former director of an alcohol and drug treatment program in New York City, says the challenge is to stay aware that HIV-related drugs like marijuana or Percocet could actually lead to a relapse, while learning to trust yourself on tricky life choices. Spivey cautions about the very real possibility of “playing games with yourself” as you walk that tightrope “between making a sober assessment of the benefits and costs of taking a potentially lifesaving medication as a last resort, and talking yourself into an old pattern of drug abuse where you are minimizing possible danger or masking a craving.”

J. Kevin Rist, MD, a psychiatrist in HIV Services at St. Mary’s Hospital in San Francisco, says, “As a person with HIV in recovery, you need to be especially well-informed about the drugs you take -- including the potential impact of each on your sobriety. Be clear with your provider about the specifics of your drug-use history and then, when contemplating a new drug, ask specifically, ’I was addicted to X. Is this new drug in the same class?’” Some anti-anxiety and sleep meds, for example, such as Clonapin, are benzodiazapines, the same class of drug as Valium -- something you’ll want to know if Valium was one of the pills you popped. All benzodiazapines are potentially addictive, especially for people in recovery, since they give you a mild euphoria, and the body easily develops a tolerance so that you quickly need more. Safer options for sleep disorders may include Ambien and Sonata; for anxiety, it may be safer to take an antidepressant. If your doc can’t answer your questions, Rist recommends discussing your history with an addiction-med specialist or a psychiatrist who knows psychopharmacology to find out which meds are optimal for you.

Michael Lipson, formerly chief psychologist in pediatric AIDS at New York City’s Harlem Hospital, warns that fear of relapse can’t be your only guide. He knows of docs who go too far, refusing to give morphine to dying patients who are in recovery, as if they’d somehow get out of bed and resume addictive behavior. “Early recovery involves an appropriate fear of psychoactive substances,” Lipson says. “But ultimately recovery may require a conscious relationship to them.”

Even AA cofounder Bill Wilson crossed some boundaries while remaining sober. After helping launch the movement, Wilson suffered bouts of crippling depression and, to avoid returning to drink, sought alternative paths, including prayer, meditation, and even mind-altering substances such as mescaline and LSD. Though Wilson’s experiences are well documented in both his official

biography and the authorized history of AA, they are rarely discussed in 12-step rooms.

“I don’t think doctrine should govern what we talk about,” says Spivey. “The ability to talk these questions through may constitute emotional wellness and health for a person living with HIV.”

Joe, at least, has slowly gained confidence that he’s on the right track. “One thing I remember from early sobriety was people saying they became the person they always wanted to be when they got sober, and that’s what happened to me,” he says. “The question is, do I have to be in AA meetings all the time to be that person? That’s what I’m up against every day. Even if I cannot share about this in a meeting, I don’t think I’ve had a slip.” Recently, someone approached Joe, asking him to be his sponsor, a role that requires a great deal of trust and dependability. Joe says, “He said he ’liked my sobriety,’ which is what people say when they ask you to sponsor them, and when I told him about my medications, he said, ’Well, I can deal with that.’” It was a big moment.

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