Woman on the Verge

Or, You Can Have My Selective Serotonin Reuptake Inhibitors When You Pry Them From My Dead, Cold Fingers

March 1, 2000 By Emily Carter

I bear most of the responsibility for putting off my diagnosis of clinical depression. In 1996, after years in and out of HIV clinics, treatment centers and shrinks' offices -- I had my first "consultation" at age 4 -- the last thing I wanted was to set foot in yet another. I'd dropped out of school because I could not concentrate. I'd stopped going to recovery meetings because I couldn't face other people. I was taking my HIV meds inconsistently -- and then only at the urgent pleas of my husband. I spent days in bed, assaulted by thoughts of death and self-recrimination like a swarm of giant mosquitoes. In a month, I lost 15 pounds I couldn't afford to lose and was sometimes too dizzy from hunger to stand.

Still, the thought of food repulsed me. I felt I didn't deserve nourishment. Eating was an unfair use of the planet's resources -- taking the food out of the mouth of some good person and stuffing it into my own hateful face. Because I'd sometimes cry if I had to talk to another human being, I avoided talking. When I had to speak, I dissembled. I made my voice bright and cheerful, wisecracked and bantered as if everything was fine. The effort was exhausting. My husband knew something was wrong, but I hid the extent of my despair even from him. I told him I was just going through a "rough patch." The "rough patch" soon included the end of our marriage. I'd begun to hate him for not being able to make me feel better. And, of course, I hated myself for hating him.

One morning, I realized I was out of cat food. How many days had it been? I tried to summon the fortitude to go to the corner store, but kept forgetting why. A few hours later, my cat's yowling reminded me, and for the first time, I felt some kind of determination to fight. I called my clinic and made the gargantuan effort to take a taxi. If I didn't do something fast, I reasoned, my poor cat -- a far worthier creature than I -- might starve. When I got there, a shrink asked me questions as part of a "test" to see if I was depressed. I passed with flying colors.

Abandon hope"? You already did

Depression, at its worst, is -- there's no other word for it -- hell. Biochemically speaking, it's a little like dying of thirst. The levels of neurotransmitters in your brain that are responsible for keeping your mood stable -- specifically neuroepinephrine and serotonin -- sink, leaving your circuitry in a dry and drought-like state of distress. You are running out of feel-good chemicals in your brain --

and along with them, it seems, reasons to live.

What causes this chemical catastrophe is different for each person: unlucky genetics. A lousy childhood enforcing “learned helplessness.” A deficiency of testosterone -- common in many men, and a surprising number of women, with HIV. Mental pain, which stimulates the production of stress chemicals, which, in turn, further reduce these necessary neurotransmitters. Freud long ago identified depression as “melancholia,” a process that looks a lot like mourning but with no apparent loss to trigger it. Often it’s because anger at someone you love is too unbearable to experience at a conscious level, and so turns inward, appearing in the guise of self-hatred and immutable sadness. All of these factors may combine to cause a downward spiral.

To get an accurate diagnosis, it’s important to have a reference point -- something that, as Freud pointed out, distinguishes depression from the natural grief you feel, for example, at the death of a loved one or news of your own illness. (See “You’re Sad. But Are You Depressed?” for the textbook definition.) I started exhibiting symptoms at a precocious age, but no one in the early ’60s believed a child could be clinically depressed. Later on, my drug use confused and obfuscated any attempts at diagnosis or treatment. It wasn’t until my mid-30s -- after the cat-food incident -- that I’d had enough “clean” time to get an accurate take. And it still wasn’t easy because by then I was dealing with another complication -- I’d tested positive.

My MD was hard-pressed to recognize my symptoms as depression. Fatigue? Sleep disturbance? Weight loss? All signs of a physical illness. In fact, even the “cognitive impairment” and confusion of clinical depression do an excellent job of mimicking early-stage dementia. If you are experiencing any of these problems but are otherwise asymptomatic, a clinician *might* spot depression. But if your CD4 count is low or you’ve had an opportunistic infection, the diagnosis may just be, “Oh well, that comes with the territory of HIV disease.”

So you’d better be painfully honest about what kind of hell you are in. Otherwise, as in my case, the doctors may only encourage you to supplement your diet with vitamins or drink Black Cohosh root tea, and then give you more ampicillin to ward off infections. By doing this, they will assure you, you have a good chance of living a long life. Which, when you’re in hell, sounds more like a threat than a promise.

Does HIV cause depression? No

If anything, it’s the other way around -- mental pain, low self-esteem, shame and guilt only increase your risk of participating in unsafe activities and your vulnerability to infection. This doesn’t mean that we PWAs are all a miserable lot. A mere 4 to 14 percent of us are clinically depressed -- only slightly higher than the general population. About three-quarters of those were depressed *before* diagnosis. It’s two separate ball games in most cases. Early studies assumed depression was a natural reaction to having a stigmatizing, life-threatening illness. Testing positive was enough for clinicians to immediately recommend treatment.

The medical establishment no longer considers an HIV diagnosis a risk factor for depression. This is due, in large part, to the fact that the prognosis for a person with HIV is much less grim, at least in the developed world, in this “chronic, manageable disease like diabetes” age. But the absence of “depression on diagnosis” is also a result of the wonderful variety of coping strategies at the disposal of the human psyche, first and foremost a kind of healthy denial. In a 1998 paper delivered to the Minnesota Youth and AIDS Project, psychiatrist Craig Vine, MD, of Regions Hospital in Minneapolis, outlined this phenomenon succinctly: “Many people with HIV adapt psychologically to the asymptomatic state, which may last a decade or more. During this period of relatively good health, AIDS may seem fairly remote and abstract. Many may undertake a variety of self-help regimens, while others may respond with denial, refusing to accept that they personally will be affected.”

It’s the latter that’s always worked best for me. If you have an indefinite period of good health, with sickness looming on the far horizon, why *not* pick a best-case scenario as your reality? I chose to read about long-term survivors and to focus on the fact that -- today -- I was in good health. I couldn’t control tomorrow, and so I did not see the point in worrying. When people I knew began dying, I drew a strict line: They had AIDS; I was HIV positive. Of course I knew there was a good chance I would get AIDS. But, then again, I might not, what with all the research being done . . . It was this reality I lived in. Hadn’t my doctor said that the objective was for me to die of old age? It sounds a little loopy, given the odds in 1990, but, hey, it worked for me.

Of course, all good things must come to an end, and with the onset of HIV symptoms, a major depressive episode becomes a risk for any of us. Still, it’s crucial to remember that real depression is not a situational response to a bad event. In other words, you can be dying of AIDS and not be clinically depressed. Who feels better -- the terminal patient hooked up to a morphine drip in a hospice who has some kind of acceptance and peace, or someone in physically good health who stares out at a gray world with hopeless eyes and a broken heart? The answer is not what science might call *quantifiable*.

Another thing that puts a PWA at risk for clinical depression is, quite simply, lack of information. One of the worst parts of any physical or psychological illness is feeling a lack of control. Information is power. The more you know about the disease, the more you can predict its behavior and review your options for taking action. This is why so many people attacked by bad-ass diseases become experts about their own illness. The term used by psychologists is *informational support* -- usually obtained in conjunction with *social support*. So listen to Dear Abby when she tells you to “find a support group.” Do it *before* you get too depressed, since once you’re in hell, you may shrink from other people, and have a tough time finding your toothbrush, let alone a support group.

Others like you? You wish

Support groups can be a strange business. PWAS are like snow -- no two people’s experiences of this disease are exactly alike. For those who have sat in a support group with the wrong snowflakes, it can be even more alienating than being alone. My own experience was not particularly positive.

First, as I’ve said, it took me a long time to ask for help with my depression, even to say the word out loud to my doctor. I was deeply ashamed -- of having a mental illness. Drug addiction, in my silly world, still had an aura of glamour. Not for nothing does the American lexicon contain the phrase *heroin chic*. We associate drug abuse with rock stars and supermodels, but mental illness conjures up the fat lady with bad skin and a collection of unattractive facial tics, talking to herself at the bus stop. Eventually, however, I didn’t care what I looked like -- I needed help, badly. So when I was finally able to talk about my symptoms, it was suggested that I attend a women’s HIV support group. Having previously been the only woman and only IV-drug user (IDU) in other groups, I thought perhaps here I’d find a home.

But, aside from gender, I had little in common with these women. Most were overwhelmed by the task of being caregivers and working way too hard for the level of energy left to them by the virus’ attack. I was no caregiver. In fact, I was so incapacitated by depression that I could barely take care of my own feeding and personal hygiene. I got the virus by putting a needle in my own vein; not, as most of these woman had, through unwitting sex with an HIV-infected partner. In my depressed state, I compared myself to these put-upon souls and felt that while they deserved help, I didn’t. I couldn’t imagine telling them the problems of a single, college-educated person -- with no children or man to cook dinner for -- without having them stare back in incomprehension. Wouldn’t they be right to ask why an unencumbered, privileged person found herself so poor and desperate that she had to take advantage of a free, state-run support group in the first place? I left feeling more shameful, guilty and alone than ever.

It would be a very different experience if I went back to that support group today. No caregiving of my own to do? Why not offer to baby-sit for an hour to give one of these overworked broads a break? Educated? Why not offer myself as a source of information? No money in spite of all that liberal-arts education? No shame in that; such is life. But depression would not allow me to see things that way. It’s an ingeniously constructed Chinese box that turns your neural circuits into so many dead ends, each cul-de-sac with its own No Exit sign, the fine print reading “You piece of shit.”

So it took a long time, and a few failures, for me and my psychiatrist to find the right meds. What finally worked for me was a combination of Selective Serotonin Reuptake Inhibitors (SSRIs, but I take no end of pleasure in pronouncing the entire name) and other meds to stabilize my energy level. Before that, I’d tried Prozac, but it stopped working after a year. Another line of medication -- an MAO inhibitor -- lifted my depression by keeping me unconscious most of the day; I was all for it, but my employer expressed reservations. It was two years of trial and error, but sheer desperation made me tenacious, and I eventually found a regimen that brought me back from hell. (For more information about treatments for depression, see "Tricky Combination“ and ”Beat the Blues.")

The psychiatrist recommended talk therapy in conjunction with my meds. Although I was skeptical, the antidepressants made it possible for me to take my first baby steps back into life -- and a psychiatrist’s office. I’ve since learned that successful therapy requires rigorous honesty. The benefits I’ve received all come down to my decision that there is no truth too terrible to utter. After all, I’m paying for it -- why con myself out of good money by denying or minimizing issues I was going to therapy to deal with in the first place? If a coping strategy makes it harder for you to cope, you might want to get rid of it.

Now, nearing 40, I also make sure my clinic checks my hormone levels when they do my blood work, since HIVers are prone to drops in both estrogen and testosterone -- factors in depression. I have to make a special request for this, as crowded clinics tend to take a triage approach. Since not everyone has experienced depression, being at risk for it isn’t always taken as seriously as it should be. Depression is as devastating an illness as any opportunistic infection. If you find yourself in this position, be a squeaky wheel. Like a friend of mine who found Zoloft to be his guide out of clinical depression: When he, medicated like so many PWAs to almost toxic levels, was put on a “drug holiday,” he let them take away everything but his Zoloft. He told me he’d rather face a viral rebound than go another round with clinical depression. Now off his meds, when he feels sick, he makes himself some chicken soup.

Amazing to think that a little green pill can be the thread that leads out of the labyrinth; that the ability to envision hope can be made possible by a mere adjustment in your brain’s chemistry. But what about the other women in my support group? What therapy or medication can relieve them of the constant barrage of exhausting crises induced by poverty and illness working together in a series of jabs and uppercuts? Many more studies have been done on men with the double whammy of AIDS and depression than on women. What is clear is that, as in the general population, women with HIV are four times more likely than their male counterparts to be depressed, and that the stress of caregiving only makes the blues worse. Depression, by definition, interferes with your ability to function. For the women out there too debilitated by AIDS and depression to perform their role as caregivers, a weekly support group is only a start.

Drug use a risk for depression? Duh

Then, of course, there is the group at greatest risk for depression, what is sometimes oxymoronically called “the IDU community.” I’m here to tell you there is no such community. Junkies are out for themselves, and the disease of addiction is supremely and totally isolating. For an active user, other people exist either as a means to procure drugs or as an obstruction. Being a former daily user, I tend to sneer at studies that talk about IV-drug use as a “risk factor” for clinical depression. “Duh,” I want to say. Ever run out of your drug of choice? Felt your brain’s every endorphin sizzle and evaporate like drops of water on a hot frying pan? In this state of physical pain and desperate craving, you are free -- if you can spare a microsecond from your all-consuming task of finding more drugs -- to survey the wreckage of your life. The overpass you slept under last night suddenly doesn’t look so much like a lush and verdant bower. It’s very likely you missed your doctor’s appointment because you had to go and get more drugs. Adherence to your anti-HIV regimen? Forget it. You’re lucky if you remembered to take your antidepressants.

Conversely, clinical depression is also a risk factor for relapse: An addict of my acquaintance garnered an impressive rap sheet of 36 detoxes and 15 treatment centers. He would stay sober for a time, begin to isolate and finally start using again. The pain would simply become too much. The pattern seemed implacable until he dealt with his depression. As of this writing, he has been able to stay clean for two years -- much longer than ever before. We cross our fingers for him daily.

Shit happens. So do miracles

The bad news about antidepressants is that, like any medication, they don't work for everyone or forever. On a long-term basis, there's about a 70 percent success rate in "curing" depression. That leaves one out of every three or four clinically depressed people in hell for good. If that's you, you might have to look into more "aggressive" methods of treatment, like electroconvulsive therapy or hospitalization. ECT, not the ghoulish procedure it once was, involves small amounts of electric stimulation delivered under anesthetic. Many clinically depressed people swear by it. A stay in a hospital might give you the attention, care and relief you need to keep on keeping on. These options are a last resort, of course, but if existence starts to seem unendurable, you should consider them without shame or fear. You'd go in for surgery if your appendix was ruptured, wouldn't you?

The good news is that medication does work, a lot of the time. Once the drug settles into your bloodstream, you will find the gray, unrelenting nightmare of depression slowly receding like a tide of filthy dishwater, leaving you standing on a sparkling beach. You will notice that things that seemed overwhelming are not. You will be able to do what you thought you could never do again: cope. It's difficult to describe the joy I felt the first day I was able to get in my car, take my clothes to the dry cleaners and pick up a video without having to pull over to weep or smack my own face because I hated myself so much. To even get through a normal bout of errands without becoming exhausted and confused was a triumph. "Hey," I wanted to shout to the world. "Get me, I took a shower, and now I'm actually leaving the house."

You may still be fatigued from HIV, nauseated from your meds and sick from a host of weird and wily infections. But you will want to fight, because life will once again seem worth fighting for. In a sense, you will know what it's like to experience a miracle. Of course, *miracle* is not a scientific term. But to think too closely about depression is to wonder about the conjunction of science and spirit. Does a malfunction in the brain's biochemistry cause a spiritual malaise, or vice-versa? Is it just a lot of neurons and molecules in there, or is there such a thing as the soul?

"Who the hell cares?" says anyone who has ever been depressed. This is no time for such questions -- this is a crisis! To have both AIDS and depression is to be waging a war on two fronts. You're fighting for your life against the virus, while the depression is telling you it's not worth fighting for. Fight them both. Depression is a malevolent trickster -- whatever it makes you think is a lie. You are supremely worth the battle, so do whatever it takes to win it. You deserve to enjoy the good things in life -- from the big moments of sex and spiritual enlightenment to something as simple as the taste of chicken soup.

SHOPPING FOR A SHRINK

If signs of clinical depression are pointing you toward therapy (see "You're Sad. But Are You

Depressed?” on page 60), the next step is finding the right therapist. New York City psychologist Bill Auerbach, PhD—who has successfully treated many HIVers for depression—and Manhattan PWA Wil Leonard—who’s been on the couch with more than one shrink—offer these tips.

Bill: To find a therapist, ask your physician for a referral. Or if a friend or family member is in treatment ask if they’d recommend their therapist. Interview several candidates, asking about attitudes and experiences with HIV positive clients. A clinical psychologist has a PhD, while a social worker or counselor should have at least a master’s degree (MA or MSW); both specialize in psychotherapy and should be licensed by the state. A psychiatrist, who can provide therapy and prescribe meds, is an MD and board-certified in psychiatry.

Wil: You may need more than one. My psychiatrist prescribes the meds I need, while my psychologist sees me weekly for therapy.

Bill: At the first session, ask yourself if this person (1) is a good listener, (2) answers your questions clearly, (3) asks good questions that make you think, and (4) gives you a feeling of trust and confidence that s/he is knowledgeable and can help you.

Wil: This may be the only person interacting with you weekly. If you don’t have a good rapport, you’re wasting your time.

Bill: Although the therapist will have opinions, s/he should be understanding and open to your suggestions. After three or four sessions, you should feel a growing rapport. If not, that person may not be right for you. However, you might ask yourself if you’re not opening up because you’re afraid or embarrassed about what needs to be said.

Wil: My first therapist had his own agenda and tried to push me into the things he wanted, instead of what I needed. He was against medication, but I really needed it. I wasted time trying to fit myself into his agenda. I knew I’d found the right therapist when I felt I could share my darkest, deepest fears with him.
Bill: With short-term depression, it is reasonable to expect that you’ll start to feel better within eight sessions, and that within six to eight months, the depression will be cured. With long-term depression, the response may be slower or only partial; if there is a biological component, ongoing medication and psychotherapy may be needed.

Wil: Even after you find the improvement you were seeking, you may want to continue with therapy. My relationship with my psychologist is one of the most important ones in my life.

Bill: Your health insurance may cover at least some therapy; if not, feel free to negotiate the fee. Many therapists charge on a sliding scale, based on the ability to pay.

Wil: It’s worth every penny.

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