Chronic Fatigue

What's the matter with kids today? CMCLD confusion, says Emily Carter, who offers this tear-and-share.

October 1, 2001 By Emily Carter

OK, kids, let's have those glossy, dilated eyes up front. Stash those glow sticks. It's time for a word from your Auntie Em. Sit down, Dorothy, and may I suggest you're too big a girl to be wearing pigtails and whatever that tablecloth thing is? You're used to hearing me complain, often bitterly, about The Unfairness of Life. But today is different. Today I will try to give a prayer of thanks.

Blessed am I among the ill, for I am afflicted only with HIV, which, as you've been told all too many times, is a -- sing it -- chronic, manageable condition like diabetes. Or CMCLD, to save your old auntie's breath.

So why don't I *feel* blessed?

Pipe down, Dottie, I said I would *try*.

Maybe it has to do with the fact that diabetes is managed with insulin. I don't know what insulin does, but I know what it does *not* do. It does not give you a dowager's hump or a huge, swollen belly, wasting the muscle tissue until you resemble an olive-bodied stick figure with toothpicks for limbs.

Of course, that's no problem for us girls -- or for gay boys, either. In our worlds, our actions are valued over our appearances, and pretty is as pretty does, right? I, as usual, am lucky. Plus, I get to take the Kaletra/Combivir duo -- simple regimen, easy schedule. It contains only a tiny dose of ritonavir, a drug that once had me swaying with dizziness and projectile vomiting. Equally thrilling was the metallic numbness, accompanied by a series of subdural electrical sparks in my mouth and chin. It wasn't painful, but it did make me wonder what the hell they put in there -- recycled thermo-nuclear waste products perhaps?

Compared to that *Exorcist* skit, Kaletra is a walk in the park on a breezy summer Sunday. The electrical sparks are rare and confined to your legs, which twitch merrily whenever you lie down. Of course, you lie down a lot because one of the effects of almost all the medications used to manage this manageable condition is the fear of falling, which docs blithely dub "fatigue." As long as you don't have anemia, all your AIDS specialist will offer is "Get some exercise." And you will.

Why, just yesterday, home from work, I was sitting in the chair by the door that we usually throw

our coats on, but instead I had thrown myself on it. Thirsty, I longingly eyed a glass of water on the TV set, about five feet away. After breathing deeply and reassuring myself that there are many things more fearful than collapsing on the floor, useless, a pile of damp kindling sticks, I was able to both take my coat off and walk over to the glass of water. It only took 12 minutes. I know it takes 15 minutes of continuous motion to even start a cardiovascular workout, but I also lifted the glass of water to my mouth and walked another seven feet to the bed before I crashed down on it -- adding at least another three.

Oh, and previous to that, around 4 p.m., my coworkers were talking around the water cooler while I leaned against the microwave counter, hoping they wouldn't notice I'd been there since their last coffee break. One asked me if I'd seen the movie they were talking about. I was able not only to process the meaning of their sounds but also to formulate an appropriate rejoinder: "No." Always one to push the parameters, I even added, "I'll wait for the video." My sense of accomplishment gave me the necessary adrenaline to walk back to my desk. Action is my middle name.

Of course, my doctor is not especially concerned with these epic struggles of mine. She's seen some 200 patients die with fevers and wasting, terrifying dementia, agonizing pain in their joints, their last breath a dry, rattling whistle while their eyes cloud over. So I'm feeling a little funky, so what?

I don't blame my doctor for her lack of alarm. In truth, I only feel frustration at not being able to do what I'd like when I'd like. But, kids, what does fill your Auntie Em with dread is the idea that you might not understand what it really means to live with CMCLD. Have I made it clear that it sucks? Aren't you a wee bit nervous about having unprotected sex? Not that you should wrap yourself in Saran Wrap, but the flip side of crippling AIDS phobia is its equally dangerous counterpart -- a cavalier fearlessness. Of course, youth always feels invulnerable, immortal. A lot of you will need to cling to that belief in the coming years, because almost half of all new infections are among people under 25.

I'm afraid for you, truly. You see, right now, for me, CMCLD manifests itself as "fatigue." Later (or sooner), when my current drugs stop working, I'll switch to something else. After the initial period of nausea and malaise, I will even out and be ready to manage whatever side effects await. Perhaps it will be diarrhea and the intense fear of soiling myself in public, or maybe a third breast growing out of my forehead. None of this will kill me, but it will make me feel oh-so-vulnerable-and-mortal. And there is no end in sight -- that's what *chronic* means.

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