

Mentors

Fat deposits, sunken cheeks: Body-shifting side effects can break your bank and your spirit. Brian DiCrocco offers Drew Guyton a profile in courage.

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Drew: When I was diagnosed with HIV, I went to support groups. I heard horror stories about how some medications can cause symptoms that people could see. A caseworker told me some meds could cause lipodystrophy, which gives you fat deposits in certain areas and makes you lose fat in your face. As ridiculous as it sounds, that was one of my biggest fears. I don't have lipodystrophy—right now my viral load's undetectable, and I'm not taking medication—but I'm worried that I will. When did you realize this could be an issue for you?

Brian: First of all, it's not ridiculous. You're talking about a drastic change to your appearance. Sometime in 2002, five years after I was diagnosed and started treatment, I noticed my face was sinking in. Some friends had warned me about it, but I hadn't noticed it much. It freaked me out. I kept looking in the mirror and thinking, "My God, my face is gone."

Drew: I can't imagine that. I don't know what I would do if I had to start taking meds and my face started to change. I know there are surgical remedies, but I've always thought of any kind of plastic surgery as changing the way God made you. But I also worry about relationships sometimes. When I tell a prospective love interest about my HIV status, the usual response is "But you look so healthy!" In the back of my mind, I think that if I didn't look so healthy, I'd be far less desirable. Am I vain?

Brian: You're not vain or shallow for expressing your concern. A lot of us try to convince ourselves that looks don't matter, but that's not realistic. Because that's true, lipo can have a negative effect on your self-esteem. It definitely made me want to go to clubs less, and it made me less confident in approaching people. We make choices about people based on what they look like all the time. Even though you're not taking meds, as long as this is a concern of yours, you're going to worry about it, and that could affect your health.

Drew: Still, everyone says I'm so fortunate, and of course I'm happy to be healthy. They don't understand that I still have some of the same concerns that other people have. I think my family would worry if they saw any lipo effects—they'd think I'm getting sicker. How can I prepare myself?

Brian: It takes years for facial wasting to happen, and it's not inevitable. You should definitely eat as healthily as possible to minimize the body changes. Try to find a few close friends who you can ask to tell you if they start to notice any changes or calm any paranoia you might have. It's also not a bad idea to set some money aside for getting treatment one day; any reason to save money is good! Most important, you should do some research on the different options for treating lipo ahead of time. When I started treatment in 1997, a lot of the medicines were brand-new, and there wasn't much information out there. Now there's so much more. Ask around; talk to your doctor.

Drew: But how do I bring it up with my doctor? I went to one HIV specialist, and I tried to hint that I wanted to talk about it. He said that we should just focus on the "important" parts and that I could worry about that later. When someone shuts you down like that, you feel uncomfortable bringing it up again.

Brian: I think that as time goes on, you'll be a better advocate for yourself. If there's a doctor who doesn't want to address an issue you consider important, like lipo, then that's not a good doctor for you. Lipodystrophy is more than just your face not looking the same way it did—it can cause people to become really depressed. It can debilitate some people and make them not want to go out and be active, leading to a downward spiral in their health. But if you get in the right mind-set, it doesn't have to.