



PAULA PETERSON AND GRIFF BUTLER
WITH BEN

Paula Peterson and Griff Butler

PAULA PETERSON

WHEN I FIRST LEARNED that I had full-blown AIDS, I thought I was going to die the next day. I felt like my future had been cut off. That was nine or ten months ago. Time now is broken up into “before the diagnosis” and “after the diagnosis.” Every day is really weighty. Rather than months, I feel it in days. It just feels like every hour, every minute counts. It’s not that I feel that I don’t have a future exactly. It’s just very uncertain. But I no longer wake up and think I am going to die that day.

It took a long time before I was diagnosed with AIDS. I was very run-down after the baby was born. I was tired—but all new mothers are tired. Then I got very sick with sinusitis. I had very high fevers, night sweats. The doctor gave me antibiotics. But I just really didn’t get better. Then I developed a nasty ear infection. And I had an awful cough. I had lost weight. At that point I was beginning to think, there is something going on here.

I kept going back and forth to doctors and nurse practitioners at a major hospital. They even did a pulmonary function test and CT scans of my head. They did various blood tests. Nothing showed up. But they did not give me an HIV test. I remember one doctor who said, “Well, do you think you are depressed?” And I said, “Yeah, I’m really depressed because I’ve been sick for so long.” Finally four months later my doctor said, “Why don’t you take an HIV test? You don’t have anything that would lead me to think you had AIDS, but why don’t you try it to rule it out?”

I really didn’t think AIDS was a possibility, but I was still really frightened of the test. I had an appointment with my doctor two weeks after the test. I remember trying to call his office before the two weeks to find out the test results. I spoke to a nurse who said, “Oh, don’t worry about it. Just wait to see your doctor.” And so I finally saw my doctor at the scheduled appointment. I had to remind him I was waiting for the results of my HIV test. He went out of the room and came back and said, “I have some really harsh news for you.” And that’s how I found out.

My husband and my son were tested. I was very worried about my son because I breast-fed him up until the morning of my diagnosis. They showed up negative. That is a miracle! How I got AIDS remains a mystery. I have been with my husband basically since 1989. I contacted boyfriends I had before my marriage and they are fine. And I know it wasn’t drugs. It’s kind of a mystery I have to let go of.

I was such a basket case when I was first diagnosed that I really don’t know how I pulled myself out of it. I think it was taking care of my son that helped me. I realized I had to be a mother to him again and that was one thing that helped get me off the couch. And then, of course, gradually having my physical strength return and doing well on the medications that were given to me. I’ve been on the protease inhibitors and I’ve done very well on them. I’m really feeling almost like my old self.

I think I have always had some inner strength. I’ve never had to go through anything as bad as this in my life. But I haven’t fallen apart either. I love to read. I write. I’ve been going to a therapist once a week and that helps.

My husband has been really wonderful. And my parents were supportive from the beginning. At first my mother was in a state of shock, of course, especially when I didn't know if my baby was sick. That was the hardest thing to go through, the first couple of weeks before we knew my son's test results. My parents moved from the Midwest to be closer to me so they could help out. When I first got diagnosed, they were here almost every day. I was also very depressed, just out of my mind with worry. So they really were helping me. But it's hard for them to live here. It's not their hometown and they feel out of place.

Now I feel healthy again, and I am able to take care of my son myself. I've also been reaching out to people more and have started to make some friends here. Just having a baby helped. I know other women with babies. They don't have HIV, but they have all been very supportive of me. I don't have any close friends with AIDS that I can share this with. That part is missing in my life right now.

For me to dare to make plans for the future is remarkable. I had barely started dreaming and making plans about my son when I got sick. So maybe the things I am dreaming about are what every mother dreams about. My husband and I both love to hike. So we dream of the day when our son is old enough to backpack. I dream about teaching him to read and to love books. But I think that would have always been there too, illness or no illness. I've been discussing what schools are best for my son. We are making plans for a vacation. We're talking about buying a house. Just normal everyday plans. Things that families do. I just try to live like I always did live, pre-diagnosis.

When I look back on what happened to me, what caused my "downfall," it was just ignorance, thinking that someone like me couldn't get this disease. "A nice, white, middle-class girl can't get HIV!" That's why the doctors didn't suggest earlier that I

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be tested. But even if you aren't a drug user or a gay man, you can get HIV. I believe that pregnant women should be tested routinely. There are things they can do now for pregnant women with HIV. I was very lucky with Benjamin. And he got lucky. The fact that I had a C-section helped protect him, even though at the time I hated giving birth this way.

If I had known I was sick, I don't think I would have made the choice to have a child. So I feel lucky that I have a son and that he is healthy. I guess my biggest fear is that he won't know me. That I won't be alive long enough for him to really know me. And so that makes me more determined to stay well.

[FOUR YEARS LATER]

It has been five years since I was diagnosed. Although in many ways my life has remained the same, from an emotional and psychological perspective I am light-years away from the woman I was then. In those years my health has improved immensely. My T cells hover between 500 and 600, which is considered to be a normal range and puts me out of the danger zone for opportunistic infections, and my viral load has remained undetectable. I've switched to a protease inhibitor that is easier to take. Aside from that, my combination is basically the same. I'm lucky. I haven't had any serious illnesses and I live a virtually normal life, except for the fact that I have to take drugs every day and go to the doctor frequently.

The only real physical complaint I have right now is cosmetic—my body has changed in some drastic ways due to a peculiar side effect of the drugs called lipodystrophy, a condition that affects the way fat is distributed on the body. My arms and legs are much more wasted than what you see in the photograph from 1997, my face is thinner, and my waist is thicker. There's not much I can do about this, and I suppose I'm lucky because I don't have the internal correlates that often go along with this condition—high lipid and cholesterol levels, or in some cases diabetes. I feel ashamed of being

so vain, and I know I should be grateful just to be alive and healthy and forget about my looks, but I can't help it! Every time I look at that first picture I long for my fuller face and more youthful appearance—even though I'm much healthier now than I was then, appearances notwithstanding.

I've changed in other ways besides the physical. Nowadays I consider myself to be a part of mainstream life—meaning that I don't feel as isolated by my disease and I feel I can participate in almost anything that negative people can do. In fact, I'm proud of the fact that I'm in much better shape than some of my negative friends! I assume, like everybody else, that I will live to see my child grow up, and that I have work to do in the world, that I have something valuable to contribute, that I can be productive and not just a burden to society. Whether my assumptions are ill founded or not, only time will tell, but I think it is healthy to live this way.

The most essential aspect of my existence boils down to two things: raising my child and writing. And I do plenty of time on both fronts. Ben is a happy, healthy, well-adjusted six-year-old boy, very intelligent and active and curious. I've grown to love being home with him. I wouldn't have missed these years, although if you had asked me what I thought of stay-at-home mothers before he was born, I would have replied contemptuously. Being forced to stay home because of HIV helped me to see what was most meaningful for me. I don't feel at all guilty about still being on disability. I've made a lot of valuable use of my time, so I don't feel I've been wasting the government's money.

The other main part of my life is my writing. In the last five years I've become much more disciplined about my craft, much more focused on it. Again, HIV may have played a part here—I feel more of an urgency to write, more aware of death. And having a child constricts you a bit, too, forces you to keep more regular habits. So I credit Ben a lot in turning me into a “real” writer.

I just had my first book published, *Penitent, with Roses: An HIV+ Mother Reflects*

[University Press of New England, 2001], and I have a new collection of short stories about HIV positive mothers which I'm hoping to get published. I have all sorts of long-term plans as a writer. I don't intend to always write about HIV either. One of the luxuries of being healthy now is that I feel I can branch out to other topics—take my place in the literary community, in other words, as I've taken my place in the parenting community.

I've changed in other ways, too. In the last five years I've done lots of volunteer work, including working on the San Francisco AIDS Foundation hotline and lobbying in Washington, D.C. I also have just started tutoring kids to read, and I work at my son's school. It's funny. This urge to give back, to contribute, happens to a lot of people with HIV. It's not that I consider myself a “do-gooder.” I'm still mainly a selfish type—you have to be when you're a writer—but for some mysterious reason I found myself attracted to volunteering.

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I still get depressed from time to time. I can be compulsive, too, a big worrier, and I get irritated about petty things. I suffer doubly when I'm in a bad mood because I feel guilty about the depression. I feel like since I've been granted this miracle of good health, I should be grateful and make good use of my time, not waste a moment. I was talking with another HIV positive friend of mine recently about this pressure to live in an elevated or a particularly evolved way. That's part of the myth of being seriously ill, that we turn into saints somehow. And of course we don't.

Essentially, though, I'm a joyful person, and I'm ambitious, too. I don't feel like a “cursed” person like I did five years ago. When that picture was taken in 1997, I was standing precariously on the sidelines of life, waiting to see what would happen to me and trying to hold myself together. Now I feel like a full-fledged participant, and that means I fail or succeed in ways that are much like everybody else, that sometimes I'm good at living and sometimes I'm not. I like not being so “special” anymore. I like having the same chances everybody else does.

GRIFF BUTLER

I am a systems analyst for an airline. The good thing about my job is that it gives me a chance to get my mind off everything. I am sure I have kept my feelings internal.

Through the years I had been tested pretty regularly when I gave blood. I always thought, well, I'm not in the statistical group and I don't do anal sex. So I wasn't really worried. I didn't think it was possible for Paula to be sick either, so we were both in a state of shock when she got her diagnosis.

It's been very tough having Paula sick and having a baby. It's hard to rest when you have a baby. I'm up a lot in the night taking care of Ben, because Paula can't do it. Stuff really frazzles me now. Like the other day I spilled something in the fridge and I just went off. Usually I'm very easygoing. It's a combination of the sickness, taking care of Benjamin, and then having to deal with Paula's parents. It makes it rough. Dealing with these things sort of diverts me from what I should be concerned about, which is Paula's health.

Paula and I never used to bicker, but we bicker a lot now over simple stuff. Paula was saying to me, "You'd better go to a counselor. You're stressed out."

I went to a support group for caregivers and basically it was for people who are right near the end. The group I was in, everyone was gay. It was sort of scary because before going to this group I had thought, well, we have these protease inhibitors and everything is fine. She might not feel her best but everything will go on. In this support group, two people died that were on the protease inhibitors. And two others had partners who had dementia. Whoa! So actually, I didn't tell her what was going on when I went to these meetings. These people were in advanced stages of dementia and we're talking about going on vacation and I'm thinking, "This could be happening soon." I've tried not to think about that. It might be easier if Benjamin was older.

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We went to this other group and there were some gay guys in there. We asked them, “What do you do? Who do you contact?” They were surprised that we didn’t know other people with AIDS and that we didn’t know about any resources. But now Paula has found a group of heterosexuals that are HIV positive. That’s good for her. It’s sort of a singles group though. There aren’t many couples where one is positive and one is negative.

Sometimes I think if we didn’t have a child, the easy thing to do would be to say, “Hey, I can’t handle this” and forget it. But I haven’t even thought about that. I’m sort of focused on raising Benjamin, so I’m not dwelling on all these other things. I shouldn’t get mad. I just have this internal anger that I blow up over little things around the house.

Benjamin is starting to talk now. I’m looking forward to ages three to eight or so. From seeing my niece and nephew, those seem to be the fun years. I don’t know how he’s going to deal with the fact, once he learns his mother has AIDS. I don’t know if there’s a stigma anymore when your mom has AIDS—probably not in San Francisco. In Indiana there might be.

It’s been a problem for us sexually. It sort of puts a damper on the sex drive when you know that with one mistake you can get AIDS. What can you say? We still have sex but nowhere near like what we used to. Condoms can break. There are dental dams for oral sex and all that. Chances are nothing is going to happen, but if something does happen, you can get AIDS. Really the only safe way is just to abstain. I don’t know if that’s an option.

My father and grandmother died of cancer. It was a two-year process. My father was two hundred pounds and he ended up about seventy or eighty pounds when he finally died. Going through that process, you just learn to deal with it. In the AIDS support group I was telling them ways of going forward. It’s almost like numbing your mind to what is going on. Some of these people never had anyone die they were close to and they couldn’t come to grips with it.

I guess I'm just going on a day at a time. We're in a book group. In fact, I'm going tomorrow night. A few sessions ago Paula just came out and told everyone that she has AIDS. It made everyone quiet. It pretty much ended that book group meeting. This couple said they were just bummed out thinking about the stuff Paula and I are going through. So I'm not even thinking about all that stuff. I'm glad that Paula is OK. They keep coming out with new drugs, so I'm not expecting anything to happen anytime soon.