

The Pros and Cons of Living with a Terminal Illness

Category: Stories

written by Ellen Diamond | May 9, 2014

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Before I retired in 2000, I worked in a state agency as a peer counselor, or more formally, an employee assistance program (EAP) coordinator. The “coordinator” part was there because my job description wasn’t actually to do counseling; it was to assess the problem and refer the client for help.

But of course both of those processes involved counseling. We just couldn’t call it that.

In 1986, shortly after I’d begun the job, I was separately visited by two employees with HIV/AIDS. Treatments such as the antiviral drugs used so successfully today were nearly a decade away, and a diagnosis of HIV meant almost certain death. These clients were understandably upset and frightened, but they each made it clear to me that they were still feeling pretty good, though with ups and downs.

What they’d come for was to discuss what they wanted to do with their lives, now that there was something of a time limit. The question of whether/when to stop working loomed large. They were concerned about how leaving would affect their health insurance, whether they could live on their disability income and so on. They also felt undecided about whether they’d be better off using their remaining time doing things they’d always wished to do, such as cabaret singing, or whether they’d feel better and less anxious sticking to a more normal routine.

I vividly remember my private reaction. It was certainly politically incorrect and not at all EAP-like. I was thinking: *How can you fool yourselves like this? What’s the point of planning your life when you’ve got a terminal illness? Do you really think you can feel normal and truly happy ever again?*

In participating in this process, I felt hypocritical: my EAP training was all about helping people to face reality, and although I felt glad to be helping these clients with major life choices, I never completely lost the feeling that they were running away from the truth, and that I was colluding with them.

Looking back, I don’t know exactly what I thought they should be doing! Did I think they should just go home, get into bed, assume a fetal position and wait? I suppose I thought that’s exactly what I would do.

But in two years, I myself was diagnosed with leukemia. Immediately following the news, I did wish I could put a pillow over my head and shut it all out,

but I couldn't; the fear and sadness were too strong to run away from, and actually that's never been my style.

One of the hardest moments for me came a couple of days after I'd found out. I was returning to work after a lunch date with a cousin who worked nearby, and as I approached the door to the agency building, I suddenly realized that this "thing" was going to follow me in—that I couldn't leave it behind just by going through that door, the way I'd often done with events in my personal life.

A few days later, in an EAP room that was isolated for client privacy, I let out many spontaneous screams of fear. Amazingly, I felt much better afterwards. So much so that later that night I wrote out a list of advantages and disadvantages of having a terminal illness, as follows:

Advantages:

1. I can weed out stuff from my life that's not important—pare down to basics.
2. Already, expressing deep feelings is easier, especially feelings of love.
3. I don't have to sweat "time stuff," like frequent-flyer mileage.
4. Money won't have to last as long, so there's more for now.
5. I won't have to watch myself grow old, a substantial fear of mine.
6. I may learn to ask people for help.
7. I may get to feel really brave at times, a feeling I've rarely experienced.
8. I may not have to go the dentist ever again.
9. I won't have to suffer the loss of too many friends/family members.
10. I know what I'm going to die from and approximately when.
11. I can retire and do things I've postponed, like studying piano.
12. No worries about not having something interesting to talk about!

Disadvantages:

1. I won't be around for the people I love.
2. I'll miss out on the experiences, good and bad, that I'd share by seeing life through with them all the way to the end.

Amazingly, the only other disadvantage I could think of was my fear that, when faced with real sickness at a later stage, I'd give in to despair and so waste the precious time I had left. Still, these three disadvantages were significant enough that, weighed against the advantages, they would pretty much even up the balance.

Since the night I prepared that list, some of the advantages have faded. I still go to the dentist every four months and floss at night, and while I did enjoy a period of spending money more freely, thinking that I would die within five years as predicted, I have come to realize that I may continue to live a good while longer and have had to rein in my spending. I have studied piano and play it every day, and I now also write poetry. But those things are not just a breeze. Life is work, and I suspect that it will be, right to the end.

Life is a terminal illness, and we all are living with the knowledge of our

certain deaths. Yet we get up in the morning and make breakfast as if there's no tomorrow. Are we all in denial? In a way, yes.

But is that a bad thing?

I don't think so. I think it's the nature of things that are alive to be alive. All species appear to have an instinctive knowledge of death; we see it in their daily fight for survival. But it doesn't stop living things from fully experiencing the joys and pains of being alive. Finding out you're going to die a little or a lot sooner than you thought doesn't change that. The clinical process of "dying" is really quite brief, and until we enter into that process, we're living, not dying.

I'm just a person with a health problem that needs treatment. Eventually it may be the thing I die from, but for now I still have to brush my teeth and try not to forget anyone's birthday.

I still stop and smell every flower I can. But sometimes if I'm late for a piano lesson, I don't stop.

About the author:

Ellen Diamond was with the New York State Department of Labor for more than thirty years, earning an MA in counseling and later an MSW. Early in 1998, she was diagnosed with chronic lymphocytic leukemia (CLL), and in 2000 she retired to pursue her interests in music and writing. In 2004, her leukemia went into remission following treatment, and it has remained so to the present. Ellen volunteers as a reading tutor at an East Harlem elementary school. She also studies poetry at the 92nd Street Y in Manhattan, and within the month, a small chapbook of her poems will be in circulation.

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