# You Have to Be an Advocate for Yourself

HIV positive since 1996, Kevin Langeslay was diagnosed with stage 4 anal cancer in 2011.

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Kevin Langeslay and his rescue dog live in Vancouver, Washington.

In the fall of 2011 I visited my HIV doc in Portland, Oregon, and he looked at a lump on my ass. He concluded it was a hemorrhoid and I didn't pay it much attention. I had started a graduate level program that would lead me to a new career. I had previously been a classroom teacher for 12 years and was excited and focused on learning everything I could about my new career. In December the lump was bigger and it hurt when I defecated, I spent little time sitting down, and I learned to become a "one-cheek driver" by sitting on one cheek when driving.

I got my first job in my new field in February; a month later insurance kicked in and I went and saw my HIV doctor of a dozen years when I lived in the Seattle area. We did the normal blood draw for my twice yearly HIV test that would indicate how well my HIV was being managed. He was almost out of the room before I snapped to attention and said, "Oh please look at this 'mass on my ass,' it is really painful." I had told his nurse when I made the appointment with the doctor. He took a look at it and immediately referred me to an oncology surgeon.

Previously in 2000 I also had a "mass on my ass" that was also misdiagnosed at a hemorrhoid, but I insisted on a biopsy and it turned out to be cancer. It was surgically removed and nothing else was required. I met all the criteria for high risk and still I didn't get checked annually. What an oversight and lack of attention on my part. I guess I figured they had removed the cancer and it was all behind me. This time would prove to be something much, much different. What occurs to me now is I should have been having a yearly anal pap smear and that may have saved my life. But it wasn't brought up and I didn't think of it.

The following Monday I went to see this doctor and I was diagnosed with anal cancer. The oncology surgeon leaned over me and patted me on the shoulder and said there was a 60 percent chance of me having a colostomy and he would do everything he could do to save my life. I went from alert to fear in a nanosecond. The tears were sliding down my cheeks. I honestly was so focused on the start of a new career, my health got the least of my attention.

I had a few hours until I could get the CT scan and PET scan because the liquids needed to be

absorbed. I had my work iPad with me so I did some research on colostomies. I found what looked like to be a reputable sight and it was loaded with information. I was already overwhelmed with the day so far. What caused me to close the cover on the iPad was a little detail that was something like: “After a colostomy your life can pretty much say the same but you need to make some adjustments. For example you can still go to the beach and swim you just need to have a waterproof bandage to cover the stoma (the hole) and you might want to wear a high-waisted bathing suit to ensure your privacy.” I thought that this was enough new information for the day and quietly closed the cover on my iPad and stared out the window.

Within a few days the test revealed that the mass was cancerous and they diagnosed it as anal cancer and staged it at stage 4 because there was also a lesion on my liver. A treatment plan was made and I sat in a room with the doc(s) and said, First of all, I would not be having a colostomy. The number I had been quoted was 60 percent is not a compelling number; barely more than half. If this were a math problem for fifth-graders they would agree, and second of all, my asshole was not just an organ of elimination but an organ of sexual pleasure for me.

They were all scratching their heads and trying to wrap their brains around this bit of information. Those poor straight doctors with apparently no clue as to the pleasure of receptive anal sex; this seemed a stretch. They may have been recalling how much pleading and cajoling it took to have anal sex with their girlfriends or wives. Perhaps they would get lucky on their birthday or some other special occasion. But to be on the receiving end, oh heavens no. Or maybe they were lucky to have a partner who viewed anal sex as pleasurable and enjoyed it. I don’t know but it did seem to make them want to stop, drop, and roll — right out of the room. This was the beginning of losing my sense of privacy. I needed to be clear about what I wanted, whatever the reactions.

My cancer team decided to give me a full course of chemotherapy and radiation while stating several times that they didn’t usually give a full-course of treatment to someone with HIV, but that I was so “robust” they thought I could tolerate it. I later asked what assessment tool was used to decide that I was robust enough. I knew the answer but I had to hear it. I was told my T-cells were high (over 900), undetectable viral load, but mostly it was because I looked so healthy. It turned out I wasn’t as robust as presumed, but I don’t blame them. They killed the cancer; sadly, I had many side effects that were never mentioned to me. I was told I would be sterile and that was it. What they failed to mention as possible side effects: a severe case of “chemo brain” and also a disease from the radiation called chronic radiation enteritis. It is a disease, progressive and chronic. Sadly it has impacted the quality of my life to an extreme: wearing diapers 24/7, loss of bowel control, pain upon ingesting, digesting, and eliminating food, lack of appetite, loss of 60 pounds in the past nine months, so now the end of my life is near.

In hindsight I have two thoughts. One is the misdiagnosis in fall of 2011 that the mass on my ass was a hemorrhoid when it was cancerous — which got diagnosed correctly in March 2012 — may have gave the cancer time to travel to my liver. Damn. The second thought is after the cancer and its surgical removal in 2000, I should have been getting a yearly anal pap smear. I fell into the high-risk group: HIV+, unprotected receptive anal sex with multiple partners. Why didn’t it occur to me or my doctors? Damn again.

So, my brothers and sisters, this is a cautionary tale. I've learned through six years of dealing with the cancer machine that you have to be not only an advocate for yourself, you have to be demand that your health checkups with your HIV doc be more than just a blood draw and discussion about the results. If I had been more thoughtful I would have insisted on an anal pap smear, and I possibly would have lived until my 56th birthday.

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