“I’m a Retired Businesswoman Who Kept My HIV a Secret Until Now”

Eight lessons from an HIV long-term survivor diagnosed in 1991 and determined to face fear and live life with hope in her heart.

March 10, 2021 By Phyllis K.

I’m a retired businesswoman and long-term survivor who kept my HIV a secret until now.

The year was 1991, and HIV was still considered a death sentence (effective HIV medication didn’t come out until 1996).

After testing HIV positive as I approached my 50th birthday, I was shocked beyond reproach. My husband had just been diagnosed with Kaposi sarcoma, which is an AIDS-defining cancer. Because of that, I also got tested for HIV. The diagnosis that day changed the course of my life forever. The shock was immense, and the adjustment even larger. I rarely spoke about my condition, but now I’m ready to share my story and impart some of the lessons I’ve taken from my experience. Knowledge is power, and if my story helps anyone, especially the newly diagnosed, I’m sharing my experience for you.

Stigma and fear were prevalent, but I got through that period by staring fear in the face and resolving to live life with hope in my heart. I had motivation, determination and a positive attitude that wouldn’t quit. Still not an easy task!

Here are eight lessons and observations I’ve learned through the years.

Don’t Be Afraid to Seek Help

When I eventually found a psychologist to speak with, I wished I had been receptive earlier. It allowed me to deal with my feelings and get on with my life. It’s a way to move forward with dignity and acceptance.

Keep Your Medical Appointments

They can be numerous and exhausting, but they are lifesaving. They can also be scary and

worrisome, but I pushed ahead even though I was apprehensive. They offer a chance to address potential problems before they get worse. Find a doctor you can relate to.

Find Specialists for Your Care

Remember that you can't be denied care because of your medical condition. Doing so is illegal. Unfortunately, some stigma still exists. I checked out prospective offices before I made any appointments, even for my dentist.

Take Your Meds Regularly

Find out what schedule works for you, morning or night, with or without food. There is always a fear of whether the meds will agree with you and, more importantly, work for you. Be very diligent and compliant!

Realize That Your Body Might Physically Change

You might experience weight gain, weight loss or a rearrangement of body fat (though this is less common with more recent medications)! This affected my morale, self-esteem and self-confidence. I eventually dealt with this by accepting that it is what it is and then shopping for and wearing clothes that were appropriate. I found I was my worst enemy.

You Will Go Through a Range of Emotions

Your emotions can fluctuate, depending on situations. That's OK. Don't let your moods destroy your self-confidence or your will to live a productive life. Every day we can choose what attitude we'll embrace for that day. We are in charge of how we handle what we are dealt. Life isn't always fair, but it is beautiful, and I do count my blessings. Stay strong!

Romance and Love Are Possible

Dating and disclosing are not easy, but there are caring and understanding people out there. You might experience some rejections, but don't give up. I have been in several relationships over the years and am presently in the best one ever. Honesty is a foundation to thrive on.

Stay High on Positive Energy and Hope

My motto is: Be positive, and don’t be afraid. Life is meaningful and beautiful, and I have learned to enjoy each and every day. I have a lot to be grateful for.

To read about other women living with HIV, see the current print issue of POZ, which highlights HIV advocates who are women. You can read the entire March 2021 issue here. To learn more about the intersection of HIV and women, see the POZ Basics section titled HIV and Women or click on #Women. And don’t miss the opinion piece by transgender HIV advocate Tori Cooper titled “My Black Is Beautiful, Living Free of HIV Stigma and Shame.” In addition, Wednesday, March 10, marks National Women and Girls HIV/AIDS Awareness Day.

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