



JEFF'S JOURNAL.

10.01.11

I am both grateful and sad that I have been able to live more than half of my life with HIV. Being diagnosed in 1985, I have been living with this disease for 26 years and I turn 50 in ten days. Grateful that I lived longer than 35, like I thought I would die and sad and a bit guilty for all those that I have lost to the fight along the way.

There have been many great people that I have been fortunate enough to know that face horrible and crippling effects from AIDS. They were brave souls with many gifts to offer the world. Some were ready to move on because of the effects they experienced, and others held on 'til they no longer could.

The people that I have known over the years have not only helped me, but shaped who I would become today. They shaped my life to become the HIV advocate that I have evolved into. Made me see the value of life and how precious it is. And got me ready to stand up to anything that got in the way of becoming more healthy and making life better for others with the disease.

Sometimes I wake in the early morning and one of the first things that come into my mind is, am I really here? It's almost surreal at times, because back in the 80s, I would see some person at the bar one week and then several weeks later I see their name in the obituary. Another bright light put out before its time.

10.2.11

This morning was another one of those mornings when I could not sleep. I awoke at 4:00 a.m. even though my T-cells and viral load are good, with night sweats. You wake up, and everything that you have been touching in the bed is soaked with sweat. It's miserable and irritating and does not make for a great way to start your day. It also makes me more aware that the virus is alive and thriving within my body.

I get a little frustrated at times that there is not more understanding surrounding HIV. I mean, it is a disease just like any other. But because it is transmitted by sexual contact, and it has been associated with gay people it has a bad rap. The fear of someone finding out that you have it, keeps others from being tested and treated, and keeps those that have already tested positive from going back for treatment because they don't want to be seen going into a facility for fear of people judging them, maybe thinking they are gay or something similar. If we don't address this stigma, the spread of the disease will continue. Maybe the best scenario is to address it with youth, it's easier to change younger minds than those already embedded in their thought system.

10.3.11

I am made aware that my body is compromised because I can't do the things I used to do or that other people can do on a regular basis. Such as walking. Walking takes a toll on my feet and ankles, because I have neuropathy in both my legs. It is very painful, and frustrating to not be able to do what others do. It makes me feel less than adequate and I am aware of the differences between me and others more clearly. When these types of issues come up, it brings me back to a place of wishing I could do things differently in my life, make different choices and have very different outcomes. I would not have gotten into drugs that allowed me to put myself in compromising positions that ultimately steered me towards being HIV positive.

10.4.11

Depression has set in today. I don't want to take my pills, I don't want to talk to anyone. I don't want to think about anything. I am not really sure why I am still here. I have had HIV 26 years and known so many others that I felt deserved to live and didn't. Why me? What is it that I have to offer to the world that they didn't? Yes, I am an activist for HIV, yes, I do try to make a difference in my community. But is all that enough? Does that make up for the mistakes I have made in my life? Do I really matter?

It's later now and I have calmed down. Yes, I am making a difference in the world and I am worth living. I am grateful that I am still here!!!!

10.5.11

Didn't really feel like writing today. Kind of depressed and just want to go back to bed.

10.6.11

You can't ever depend on anyone else to help you with this disease. It's all up to you to handle all the ups and downs with it. By ups and downs, I mean when you are doing physically well and when you are not. Ultimately, the decisions are all up to you, so you have to be informed about what's out there and available to you. I know it's more difficult for some. But there is a wealth of knowledge out there that can help you make good choices and correct decisions regarding your health. I get frustrated by people that just do whatever a doctor tells them, without asking questions or looking into it further. They probably wouldn't do that when buying a computer from a tech, salesman, so why do it with your own health?

10.7.11

Today I am going to an outing that there are a lot of people that will be there that don't know my status. I don't ever hide my status, so I will surely be asked questions that will bring that out. There is always a part of me that is afraid that they won't like me or treat me with respect once I tell them. Maybe even say something really mean or hurtful. I'm not real good at confrontation, so it makes me nervous to even go. But I need to be there for my partner, so I will go and do my best.

Later: Well it wasn't too bad. There was an initial shock, and a couple of stupid questions like why did you get it? But overall it went well. There is always that fear of rejection and even fear that they will say something really harmful. I remember telling my brother, and he wanted to kill me because we had shared a needle years prior. He didn't want to take any responsibility for his actions, but he wanted to smash my face in because "I put him at risk!"

10.8.11

It's a beautiful day out and I have no energy to do anything. Some days are just like that. I want to be a part of things, but sometimes I just have to do what is best for me.

Sometimes I sit and wish that I could rewind time. Like go back to high school and start over. Like if I could be like "I dream of Jeannie" and wiggle my nose and change whatever I want to. I would go back to college, get a degree and probably have kids. Maybe with a man, maybe with

a woman. Who knows. But I would definitely change a lot about my life, if I could only have the knowledge that I have now. Of course, isn't that kind of something we all want?

10.9.11

Well, two days until I turn 50! Wow. What a statement. I never thought I would see 35! But now that I am here, I am ever so grateful and encouraged that people are living longer and productive lives while having this disease. It is a testament that people can overcome most anything if they put their minds to it. I remember years ago, I truly felt that I would not survive this disease. I felt that it would just take over and I would just not be around anymore. How sad to be in a place like that. Now 26 years later, here I am. Vibrant and alive, and doing really great HIV work in my own community. Who knew?

10.10.11

This day, the day before my birthday, I am happy and really looking forward to a new beginning. I figure that since I have made it this far, I might as well get with the program and do even more to bring awareness about HIV and continue with my fight to end the STIGMA and FEAR that are associated with it. I truly think that living by example will be the way to end stigma associated with HIV. By being an involved member of my community, I can show how living with HIV is not only possible, but that it can be productive and rewarding as well. I bring a lot to the table when I do my work in HIV prevention. And I think I do it pretty well. I am living proof that there is more than meets the eye! And since we are talking about fear and stigma, I wanted to share a letter written by Elton John to Ryan White, I really thought this was moving. Ryan White died being an activist for HIV. He contracted the disease from a blood transfusion and was ridiculed in school, accused of being gay, and spent the last years of his life battling STIGMA!

Letter Insert

Letter from Elton John to Ryan White

Dear Ryan,

Twenty years ago this month, you died of AIDS. I would gladly give my fame and fortune if only I could have one more conversation with you, the friend who changed my life as well as the lives of millions living with HIV. Instead, I have written you this letter.

I remember so well when we first met. A young boy with a terrible disease, you were the epitome of grace. You never blamed anyone for the illness that ravished your body or the torment and stigma you endured.

When students, parents and teachers in your community shunned you, threatened you and expelled you from school, you responded not with words of hate but with understanding beyond your years. You said they were simply afraid of what they did not know.

When the media heralded you as a "innocent victim" because you had contracted AIDS through a blood transfusion, you rejected that label and stood in solidarity with thousands of HIV – positive women and men. You reminded America that all victims of AIDS are innocent.

When you became a celebrity, you embraced the opportunity to educate the nation about the AIDS epidemic, even though your only wish was to live an ordinary life.

Ryan, I wish you could know how much the world has changed since 1990, and how much you changed it.

Young boys and girls with HIV attend school and take medicine that allows them to lead normal lives. Children in America are seldom born with the virus, and they no longer contract it through transfusions. The results and injustices you suffered are not tolerated by society.

Most important, Ryan, you inspired awareness, which helped lead to lifesaving treatments. In

1990, four months after you died, Congress passed the Ryan White Care Act, which now provides more than two billion each year for AIDS medicine and treatment for half the million Americans. Today, countless people with HIV live long, productive lives.

It breaks my heart that you are not one of them. You were 18 when you died, and you would be 38 this year, if only the current treatments existed when you were sick. I think about this every day, because America needs your message of compassion as never before.

Ryan, when you were alive, your story sparked a national conversation about AIDS. But despite all the progress in the past 20 years, the dialogue has waned. I know you would be trying to revive it if you were here today, when the epidemic continues to strike nearly every demographic group, with more than 50,000 new infections in the United States each year. I know you would be loudly calling for the national HIV/AIDS strategy that was promised by President Obama but has not yet been delivered. I know you would reach out to young people. I know you would work tirelessly to help everyone suffering from HIV, including those who live on the margins of society.

It would sadden you that today, in certain parts of the United States, some poor people with AIDS are still placed on waiting lists to receive treatment. It would anger you that your government is still not doing enough to help vulnerable people with HIV and populations that are at high risk of contracting the virus, including sexually active teenagers. It would upset you that AIDS is a leading cause of death among African Americans.

It would frustrate you that even though hundreds of thousands of HIV – positive Americans are receiving treatment in your name, more than 200,000 don't know they're HIV – positive status, largely because of a lingering stigma surrounding the disease that prevents them from being tested. It would disappoint you that many teenagers do not have access to science – based HIV – prevention programs in school, at a time when half of new infections are believed to be among people under 25.

I miss you so very much, Ryan. I was by your side when you died at Riley Hospital. You've been with me every day since. You inspired me to change my life and carried on your work. Because of you, I'm still in the struggle against AIDS, 20 years later. I pledge to not rest until we achieve the compassion for which you so bravely and beautifully fought.

Your Friend,
Elton

(Now that's a moving letter!)

10.12.11

Well, we had quite a time in Chicago for my birthday. We really did all the things that we wanted to do. Rode the subway everywhere we went. We went to a lovely dinner and then went to see Carrie Fisher in "Wishful Drinking" which was a one woman show that was a spoof of her life! Hilarious.

One of the things that came to mind around my birthday was that time when I found out I was positive. I had taken a test in Orlando while going through drug rehab. I had gotten out, decided to move to Key West to do a geographical change, which everyone said would not work! And I was getting settled in, and I called my mother and she had received the test results in the mail, and had to tell her baby son that he had AIDS! How awful that must have been for her. For a mother to have to tell her child that he had AIDS, just must have been the most horrific time for her. I just can't imagine. We have been and still remain the best of friends. She is a wonderful 80-year-old friend!

10.14.11

Life as I knew it as a child has changed in perception, perspective, and how I view the world. HIV has forever changed my life. Some for the better, some for the worse! But overall it has helped me to realize that life is short and how you really need to work on those demons that put you in a bad place. Concentrate on the present, and participate in all that life has to offer.

10.16.11

The Continued Lack Of Combined Efforts

The lack of communication in this country has really sent me over the edge lately. Whether it is political, spiritual, community minded, or anything else. Communication is the backbone of any relationship we cherish. I continue to look upon this with love to see where the lacking in the communication stems from. What I find is that it comes from a variety of different places.

In looking at these characteristics in others, I look within to see where my lack of communication skills dwell. There are many that I recognize in myself. Sometimes, I just don't feel like going into a long conversation to explain what I really want to communicate. I guess it is just too much energy to say, "Hey, I don't feel like talking right now, but this is what I would like to happen/see." Sometimes I am not quite sure how I feel about something, and need to reflect before communication. Whatever the case may be, it only takes a few seconds to express where you are in the world, what your frame of mind is, and that you will communicate later. In looking at communication, I decided that I wanted to bring up a subject in my HIV community about sharing information with others. I sit on three groups across the state. All these groups advocate for HIV related issues to help reduce disparities, disseminate access to care for all, and advocate/lobby for changes that directly affect the population that we serve. It is a great group of people who are committed to helping others, and lead by example. We all have a common theme, and work diligently and swiftly to meet the needs of the HIV population across the state of Florida. That being said, I was thinking about President Obama and his mission of having an open door policy, transparent operations, and in general asking for all government to comply with these standards. Some of that has been realized since he has been in office, some have not. By used his example, and thought, since these three groups have similar missions, why not have the group chairs of the committees come together three or four times a year to share information, network, and use each other to complete the task at hand. Sounds simple right?

No so much! It seems that along with the well-meaning intentions that come with the members of each group, also comes the old standard that nobody wants to lose their position or power in the world. That somehow, by sharing information, you no longer have a strong hold on your place or position. I get that some need to have a title/position to feel complete. I get that we all have our own unique personalities that come sometimes with a lot of baggage. But the goals remain the same. To help others who may not be in a position to help themselves. And besides the personal baggage issues, there were Florida Department of Health issues because one of the groups lobby and they are not allowed to sponsor any type of lobbying.

Good grief! All I wanted was to share information for goodness sakes. Not take their kidney and give it away for donation! Although...!

In the end, it looks like we are moving forward ever so slowly to combine efforts and generate communication between the groups. Like everything that means something to you, it is either flows easily and freely, or takes some effort to see it to fruition. So I move forward with a little more understanding, because I went within first, to see where the problem was in my own nature. It is easy to do when you take the time to remember it. It's just taking that extra time to look at yourself first, before you judge your brother!

10.18.11

Being a “positive” mother - By Jeff Allen

There have been great strides concerning women safely having a child while she is HIV positive. Some say why would you and others say why not. While there is still a risk of transmission, I understand the desire to want a child of your own. I make no judgment one way or the other...

An HIV positive woman can transmit the virus to her baby during pregnancy, labor and delivery, and through breastfeeding. If she takes no preventative drugs and breastfeeds then the chance of her baby being infected is around 20 to 45%. Moderate drugs are highly effective at preventing HIV transmission during pregnancy, labor and delivery. When combined with other interventions, including formula feeding, a complete course of treatment can cut the risk of transmission to below 2%. Even where resources are limited, a single dose of medicine given to mother and baby can cut the risk in half.

A woman who knows that she or her partner is HIV positive before she becomes pregnant is better able to plan ahead. If she does not want to have a child then she should consider effective contraception. If she decides to become pregnant, then early interventions may be able to help protect her, her partner and her baby. Doctors will be able to advise which interventions are best suited to her situation and whether she should adjust any treatment she is already receiving.

Pregnancy does not make a woman's own health worse in respect of HIV. Being pregnant may cause her CD4 count to drop slightly, but it should return to its pre-pregnancy level soon after her baby is born.

An HIV positive woman with an HIV negative partner can become pregnant without endangering her partner, by using artificial insemination (the process by which sperm is placed into a female's genital tract using artificial means rather than by natural sexual intercourse). This simple technique provides total protection for the man, but does nothing to reduce the risk of HIV transmission to the baby.

If the man has HIV, then the only effective way to prevent transmission is sperm washing. This involves separating sperm cells from seminal fluid, and then testing these for HIV before artificial insemination or in vitro fertilization. Sperm washing is a very effective way to protect both the mother and her baby, but it is only available at a few clinics and can be difficult to access, even in well-resourced countries.

When both partners are HIV positive, it might still be sensible for them not to engage in frequent unprotected sex, because there might be a small risk of one re-infecting the other with a different strain of HIV. If a couple does decide to try conceiving a child by unprotected sex, then they should seek advice on how to limit the risk to each other and to their baby. It is worth noting that someone is less likely to transmit HIV if they are receiving effective anti-retroviral treatment, and also if neither they, nor their partner, has any other sexually transmitted infections. In addition, by limiting unprotected sex to the time of ovulation, a couple can reduce the number of opportunities for HIV to be transmitted between them.

The love between a woman and her child is something we can all relate to in one way or another. If a woman wants to get pregnant while HIV positive, I feel that she should talk to a healthcare professional and get some straightforward advice and guidance prior to making the choice. If a woman becomes pregnant while HIV positive without making the choice, a healthcare professional can guide you through the process with the best possible outcome.

If any of this pertains to you, contact me and I will send you in the right direction.



WEMAKETHECHANGE.COM

