fragments of me

Reflections of HIV, Hope and Resiliency from community members in Waterloo & Wellington Regions

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Disclosure! (Revealing that you are HIV positive) for people living with HIV is a daily concern. You never know how people will receive you, will they jeer at you, reject you, gossip about you or accept you and remember that you are still the same person? These are questions that plague many of us living with HIV. Fragments of Me is an invitation from us (People Living with HIV, our family and friends) to take a look inside our lives and see beyond our HIV status. Many are the times when people are ready to judge us, label us or criminalize us without taking their time to know us. Our journeys with HIV have been challenging most of the time. We thought we would not live to see another sunset, or sunrise. However, we have dreams, we have hopes, and we have our fears. All we are asking is for our community to see that 'I'VE GOT HIV…HIV DOESN'T HAVE ME.' We are still members of the community. We are mothers, sisters, daughters, wives, fathers, brothers, sons, husbands. We are friends, lovers, business associates, employers, employees. We are members of the community and contributors to our society.

THESE ARE OUR FRAGMENTS

ACCKWA
The AIDS Committee of Cambridge, Kitchener, Waterloo & Area
Honouring 25 Years of Advocacy, Support & Education

A Little Faith Goes A Long Way

I got diagnosed when I was living in a refugee camp doing a medical exam for immigration to Australia; who was rejecting HIV positive people. When I had my last baby in Uganda I was not positive, but two years later I was diagnosed HIV positive (2003), I just asked God to hold me because when you listen to the stories about HIV, you can either go crazy or die with shock. My elder sister went to Australia and I was left behind with my younger sister. My younger sister is evil, she spread my name and status around like wild fire - forgetting that I was the one providing for her and for her family.

I left Sudan because of war; I fled to Ethiopia, then Uganda, then Kenya and finally Canada. In the process, I was abducted by soldiers raped at the age of 16 and had my first child as a result. In 1994, I lost my dad through the war; I totted my daughter from camp to camp as we ran not only from soldiers and war but from my soldier husband, who was bent on killing me. I again ended up being another soldiers wife and I had no choice in the matter again.

When people heard you cough, they decided you had TB and you were at deaths door...the way people perceive you kills you faster even than the disease. When I went to the doctor, my CD4 count was very low. I started taking HIV medications three months after my diagnosis.

My sis told everyone that I was dying. This broke my heart, left me sad and angry because people looked at me like I was going to keel over and die. However my philosophy in life is not to get overwhelmed or desperate but to have faith and find something to live for. That something is my children.

Some of my friends turned against me, every time I tried following up with my paper process to leave camp with the UN, they would hinder my process. If I had interpreters, some were not repeating the things I was saying but adding their own stuff. My sister and her family left me and my children when I became sick, people were isolating me, afraid that I will spread the disease just by association. However, I had my first breakthrough when one lady (was not even my friend) started teaching me how to be a hair dresser. I also started educating myself through the UN workshops. A lot of diseases kill people but with HIV, you have a chance. I took health workshops; I started educating other women on health issues. All this time I was taking my medications and helping those whose families had disowned them. With this disease, you have got to have FAITH and believe in yourself. I started my Canadian process and did my medicals and we got accepted to come to Canada. Australia was ready to take my children and leave me behind but I could not let my children go by themselves for as long as I was alive. Coming to Canada was not a picnic, I had my difficulties but then I saw them through.

One of my hardest moments was retrieving my eldest daughter from a different camp, she changed after coming to Canada into someone else. My daughter who I had conceived as a result of multiple rape by soldiers.

Someone from the Reception Center brought me to ACCKWA. ACCKWA stands with you regardless of whatever problem you have. They are like family; they follow up with you even when you try hard to isolate yourself. I have received a lot of support and help because I am a strong woman. Even with my language difficulties, I do not let them stop me. I got introduced to doctors who have helped and supported me.

My children have given me strength. I look at my children and will myself to carry on. I no longer suffer from depression and high blood pressure. I have accepted my status; my eldest daughters know that I am HIV positive. I talk to my children, they see me take my medication and know that's what keeps me going. My friends don't know about my status but people talk. I have noticed that because people say bad things, a person can forget who they are, that's what kills you. That's what isolates you. Stigma makes a lot of people afraid of getting tested, they hide, afraid of speaking up or seeking support which in turn makes them very sick.

When I remember my dad and his desire to have more grandkids, I have hope. I hope to someday get married and have more children. This time I want romance and not abduction...is that too much to ask? I believe in God and believe in myself, someday I have faith that this too shall come to pass. All I ask God is to spare me, I am my children's father and mother. I thank God that I have not suffered the way some people have.

Some days the medications give you crazy side effects, some days I ask God, *why me*? People have called me names; slut, promiscuous, whore. But funny, I have never even slept with any man of my own choosing.

Some days you crave for sex but you are afraid because in my community if a woman has condoms in her purse or pocket she is called a slut. People don't understand the need for protection.

I want to go back to school, get my driver's license, sponsor my boyfriend - who accepts my status and then we can live together. I hope to get an interpreters job because I know how painful it is if you cannot trust the person you expect to speak for you.

I have my voice; I live every day with a little more faith.

A Shattered Dream

I am the oldest of 3 children and I have looked out for my baby brothers from the time they were born. I was very protective of my youngest, standing by his crib with my arms extended out so that no one could even look at **MY** baby brother.

We grew up in a loving family that fell apart with the separation and divorce of our parents while I was in College and my brothers finishing grade school. This hit us all hard and the three of us handled things in very different ways. I threw myself into school, my middle brother threw himself into drugs and alcohol, and my baby brother got really involved in the medical profession. It was around this time that he decided that he wanted to become a paramedic and also came 'Out' to the family as being gay. Our family was not surprised. We had all known for a long time and were wondering when he would identify himself as gay. When he told us, everyone was very accepting of him, except for our Dad. He thought that this was a phase and that he would grow out of it and he would change. This was a really difficult time for my brother and father and changed their relationship for many, many years. Thinking about this now I feel it will never be the same again. Dad eventually understood and accepted him but the relationship between father and son was tainted. It was during these years of estrangement that my brother threw himself into the gay party scene and became very promiscuous. It was also at this time that he became a paramedic and later a palliative care nurse. His dream had always been to work in the medical profession, he even wanted to move to Arizona to live and work there.

He eventually met a great guy and settled down for 6 years and our family loved the two of them together! They even talked about marriage and having children together but they decided that they wanted different things and split up. Everyone in the family was heartbroken. Several months later he met a new man and they became serious - very quickly. They went on a vacation to meet this new man's family in South America. My mother, father, one other brother and I worried about the idea of him flying to South America - something just didn't feel right. He left...and our world changed forever.

We got a text from his partner late one night saying that my brother had collapsed

and was on life support. No mention of why or where he even was. It was the longest night of our lives. After 3 days we were able to identify his location and get some information on his medical status. All they knew for sure was that they didn't know what was wrong…not very helpful for us—so far away. After a series of tests and a long period of waiting he woke up and was finally able to communicate with us. He told us that he knew what was wrong; he told us that he had HIV. I had never before had the wind sucked out of my lungs, but that day it happened. In a matter of minutes my dreams for my little brother died. I felt like a failure that I could no longer hold out my arms and protect him from everything in the world. I was devastated.

Over a series of weeks he returned to Canada where he is still going through a series of tests as he suffers from chronic pain since his diagnosis. He also has had his driver's license taken away by the medical professionals treating him, due to brain tumors they found. The most painful of all, the thing that really is going to kill my brother is the permanent disability he has been put on from work. He will never again be able to work in the profession that he so loves. He will never be able to move to Arizona to help people in need, he will never be able to be a paramedic again, he will never be able to be with a family and console them with his compassionate soul as they watch their loved ones pass.

He will never again truly live……..

My brother is 29!

Another Perspective

I am a French Canadian and come from an average large family upbringing, three older siblings and three younger - me, the middle child.

October 1993 is when my life stopped. I was walking along the streets of Vancouver when I collapse on the ground. An ambulance was called and I was taken to the hospital. When I came to, a nurse told me that I had PCP (Pneumocystis pneumonia) which is most often a symptom of HIV. I weighed 100 lbs. and was anemic. After being released from the hospital I went to the local HIV clinic to talk with someone about my diagnosis and as they helped me get my life back on track, I started to volunteer while I received counselling on how to deal with this disease.

Being all alone in the big city was very lonely so I decided to move to Ontario in 1994 to live and be closer to my family, which was both good and bad. Unknown to me, a family member had made sure that almost everyone in the small Northern town we grew up in, knew that I was gay and had AIDS. I knew that I was going to face a lot of discrimination; I was beaten and told that I was not welcome in '*their*' community. Eventually I felt forced to leave and I went to North Bay.

In North Bay there was an AIDS Committee where I found a supportive community and others like me. I became involved in the Speakers Bureau where volunteers who are living with HIV/AIDS go into the community to share their story about living with this disease. I learned how to tell my story, to educate people about the issues of living with HIV which helped create a more compassionate response from the general public. **B**eing an active part of this movement, I was asked to sit on this agencies' Board of Directors to be a voice for not only myself but also other people living with HIV in this community.

I remained celibate for the next three years and then I met my partner. Together we moved to Waterloo Region where I started to volunteer at the AIDS Committee of Cambridge, Kitchener, Waterloo & Area (ACCKWA). I was involved at the agency to both receive support and to gain skills to further educate people about HIV. After I shared my experiences in a few articles in the local newspaper I became more involved on a different level, I became an advocate for the cause.

In 1999 my health started to fail because of complications with my medications and it nearly cost me my life. I had to go on a clinical trial to hopefully help me, the doctors said it was a 50/50 chance that the treatment would work.

After being a guinea pig for research for many years, I decided to work on an HIV and HEP C task force in 2007, HEP C work was fairly new for Waterloo Region but not for me, I was infected with both HIV and Hep C. I was also approached to sit on a National Board which was mainly made up of people living with HIV and election to the Board was by your peers. I served a two year term as the Ontario Representative. I worked hard to be active and to make important changes and with the help of others we did make a difference.

Today I'm still involved in this work having attended two International AIDS Conferences and numerous Regional Conferences. I co-facilitate groups for a local HIV/HEP C clinic. I help people like me, those who want to change their life and be healthier and productive.

It's been 15 years of receiving service and volunteering at ACCKWA and it has led me to make connections and to broaden my horizons.

ACCKWA has given me a new perspective on life I want to thank all the staff for being there.

Betrayed By A Loved One

I met a nice guy at church who was widowed, had children and seemed to want something serious so we started dating. A few months later, I found out that I was pregnant. He was very put off with me about it when I told him. He said the baby couldn't be his—he said he can't have children. I knew that I hadn't slept with anyone else and I made the decision to raise my daughter by myself.

I decided to apply for life insurance when my daughter was two months old. Around that time, I had run into the secretary of my family doctor, she exclaimed that my doctor had been trying to contact me. I had not heard anything from my doctor in quite awhile, so my sister decided to come with me. I thought about it and put it down to the life insurance because they had told me that test results would go my doctor. My sister thought it was something else though.

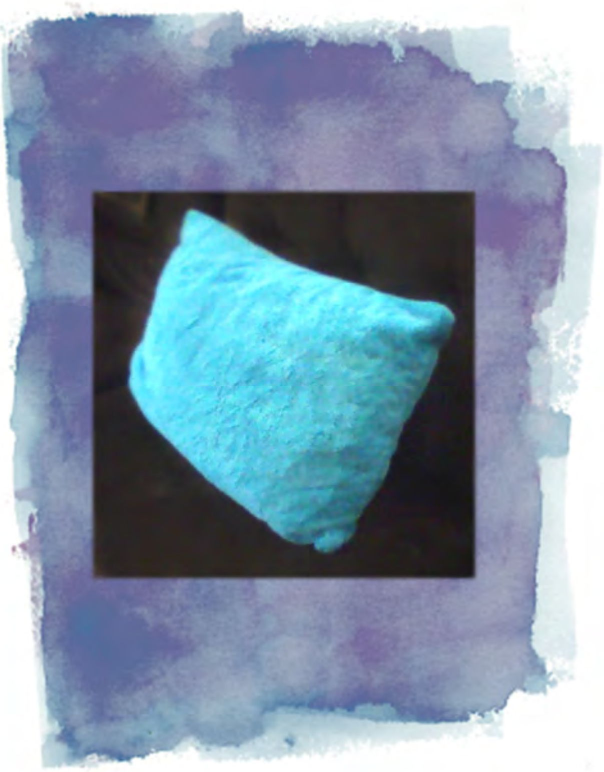
So, we went to the doctor and he told me that I had been in contact with HIV. I couldn't think straight after that. Everything went blank and I couldn't even hear him anymore. I just kept thinking about my daughter. I knew that it came from my daughter's father because I hadn't been with anyone else. So, the doctor arranged to have me and my daughter tested. He told me that the only reason they knew to contact me, was because they knew that my daughter's father was HIV Positive. A few weeks later, I got the news which confirmed that both me and my daughter were HIV Positive.

I went on to find out that my ex's late wife did not die due to a brain tumour as he and the rest of the church had told me or led me to believe. She was HIV Positive and had gotten very sick. My ex had told me that it was due to a brain tumour but the whole church knew the truth—they were both HIV Positive. Everything turned ugly once the people in church found out that I knew. I came to find out that my ex had been with a lot of women from church and once things had turned ugly—due to my revelation—they all hid away like nothing happened. Even when I called his late wife's sister, she lied to me and hung up the phone. I was really mad and disappointed. These people did nothing to help my daughter.

When I was told that I could go to the police about it, I did. He knew his status; he was in contact with the Health Board and he knew he should inform every partner that he was HIV Positive. I collected information, I tried to find out as much as I could about the girls that he was dating and brought it all to the police. It took about a year to get to court and he was sentenced to 10 years.

Now my daughter is 9 she was asking about her dad, this was difficult for a while, but after a year in counselling, I'm better equipped to deal with that. She does not tell her friends; I think that is best because she's so young. On two occasions however, she asked me to tell the parents of her friends why she takes meds so that she could stay overnight in their houses and the parents were really good and had a lot of knowledge about HIV. My daughter and I are really healthy; we don't get any side effects. She does have some problems in church, some people won't let their children get too close to her and say it is because she is sick. I explain to her that sometimes people don't understand or are just not educated about all of this and that she takes medication to stop her from getting sick.

Diagnosis Forward



It would never happen to me. That was the mindset of so many people when HIV and AIDS reared its head.

I remember when AIDS was referred to as GRID - Gay Related Infectious Disease and I also remember when people would say AIDS was the acronym for (excuse my language) Another Infected Dick Sucker.

It was 1990 and I was in a whirlwind of emotions, excited about my own wedding, but then a family member told me that he had tested positive for HIV; it was like a landslide of boulders hit me.

There were so many questions and so very few answers. There were tears that could float ships. There was much anger directed at no one in particular. I was angry and hurt and scared. We all ranted and raved, prayed and pleaded.

My Mother; always the strong one in the family cried. Seeing her cry and her reaction only made me cry more and fear more. She prayed and prayed while I, most likely at that time, cursed The Maker.

My head swam with many assumptions—*Who gave you HIV? How could you sleep with someone you hardly knew? Does he know about your test results? Does he care about your test results? Does he know his own HIV status?* So many unanswered questions; for now. The answers to these questions would come slowly but they would come with more tears and even more questions about HIV and AIDS.

I have to confess; at the time I thought it was his fault, along with others who had the virus, that they somehow deserved it. I still feel so bad about that to this day.

Now, 22 years later; I am divorced with an amazing 21 year old son and I am openly gay but back in the early 90's I fought all thoughts of myself being gay. I admit I used derogatory names for gays. I was angry-upset-pissed off that someone gave a loved one of mine HIV. I was hurt that it was "mainstream media" that added to the assumptions that HIV and AIDS were synonymous with homosexuals. That only made me more afraid and closeted about my own sexuality.

I remember the crying and blaming waned for a bit, but then I heard that my family member had been "fired" by his dentist and family physician. HOW DARE THE MEDICAL COMMUNITY BACK AWAY!!! Was HIV and AIDS even worse than they thought? Was it worse or were they just afraid and ignorant as many others at the time.

A great doctor in Cambridge; Dr. Gary Gibson took my family member on as a patient. He took on hundreds of HIV positive patients, without hesitation. My family member educated himself and us on what he had learned. He utilized the services of ACCKWA; which had started just a few years before his diagnosis.

He was on a cocktail of medications. He had bad days and he had very bad days. Fine or good days were few and far between. He inspired me; probably even more than he knows. We are a very humble family. I tried to see HIV through his eyes; but I could not. HIV invaded his body; not mine but HIV gave my heart and soul the desire to learn and hopefully touch others along the way. Now, even 22 years later, much still needs to be done. The stigma attached to HIV and AIDS can be an emotional disabler; and when one's body is weak; emotional strength is vital!

ACCKWA (The AIDS Committee of Cambridge, Kitchener, Waterloo & Area) came into my life – I didn't enter ACCKWA's. Through circumstances beyond my control I heard of and quickly wanted to learn about ACCKWA, HIV and AIDS.

I helped with Chairs for Charity, a fundraising event, did writing and continue to do so. I have written poems for those infected and affected by HIV and AIDS. I have written for positivelite.com. I have helped pack safer sex kits and have done one public speaking event. Most recently I have collected donations for the online auction for ACCKWA.

Prior to 1990; HIV and AIDS were acronyms I had only seen on CNN or in the papers; with screaming bold headlines "GAY DISEASE" I tried to pay it little mind. Now in 2012 HIV and AIDS and ACCKWA are acronyms engraved in my heart and soul.

I do this now; not only for my brother, a brother only 1 year and 360 days older than myself - my Gemini Twin. This is for everyone and their brother or sister, black or white, male or female, young or old because really HIV and AIDS does affect us all even if we are not infected.

Stigma and ignorance are not easy to deal with but they need to be dealt with.

EDUCATION CAN BE A CURE FOR MANY ISSUES.

Diagnosis: Forward 2012—My brother is having good days and some very good days. He is taking just three pills a day compared to the cocktail of many. When we cry now it is usually from laughing so hard.

ACCKWA is changing lives-prolonging lives- changing the quality of life for those infected or affected by HIV. Yet still; we have work to do. It was about that time I heard of ACCKWA and I knew I had to get involved. At the time ACCKWA was in a non-descript house on Duke Street. It had very little signage; maybe due to client privacy, fear or shame in letting others know who this office was for. I was 'like a fly on the wall' just watching and learning. I volunteered at a distance due to being shy and anxious around others. I wrote letters to officials, articles to magazines, and poems and I let everyone I knew, know about ACCKWA, HIV and AIDS.

When my son (now 21) took part alongside me at ACCKWA's live auction "Chairs for Charity" at the City Hall Rotunda in Kitchener; he shifted in his seat;

stared me down and said, “Daddy! I know something worse than AIDS.“

“You do? What’s that?” I asked. “I call it afrAID. People are afrAID of giving hugs or talking to people with AIDS.”

He was just 3 years old and had more compassion and knowledge than most grown-ups at that time. It was then and there that I wanted to be more involved. Wherever and however I could. Writing, sending letters, articles, taking part in discussion groups, writing poetry for some infected with HIV and most recently soliciting donations for ACCKWA’s online auction.

I remember when telling people I volunteer with ACCKWA, some would respond with ‘I didn’t know you were gay! or “You have AIDS? OMG!’ That was one more reason I wanted to be part of the ACCKWA family. Fight the stigma!

Looking back there are many positive changes; my family member was on a cocktail of many pills daily and now 22 years later he is on just one a day. Because of ACCKWA; safer sex education programs and materials; and antiretroviral drugs, there are fewer funerals to attend. I remember going to or hearing about 3 or more funerals in one week.

Having the knowledge is good but having the knowledge and sharing it is much more beneficial. ACCKWA has given me so much knowledge, new and amazing friends, and a voice. A voice that will always be singing the praises of ACCKWA and the great works they do. Care and compassion are why ACCKWA is making great strides in fighting HIV and AIDS.

Finally I would like to say this:

Embrace the cause because you care!
Love lives within our hearts and that love is meant to share.

I Believe In Miracles!

Ok, that may be stretching it but I've been affected by them or at least as close to them as I'll ever come. Please, allow me to explain.

I was diagnosed HIV Positive in the early '90's and began those nasty meds soon after. Back in the day, our medications often did as much harm as they did good and like so many others, I was overwhelmed with the side effects.

I'd assumed (for some 18 years now) that vertigo, nausea, dizziness, diarrhea, the inability to maintain or gain any weight, constant fatigue and the myopia were just 'my cross to bear'…that's life on the meds!

Oh, I tried a dozen or more doctors, surgery and at least one hundred old wives tales and I even invented a few temporary solutions but, inevitably I had to resign myself to the fact that HIV and those nasty meds had made me old before my time.

And then along came Peter Krupp. Peter was recommended to me by my specialist. He is a dietary wizard with the technology to develop a program specific to me (or you).

A bevy of questionnaires and tests soon pointed out how self abuse, addiction, and yes, HIV and meds (but more a lack of effort on my part to stay and be as healthy as I could) had resulted in my body breaking down over the years. I was indeed old before my time. What I had blamed on the meds were actually recognizable and treatable conditions.

For me, it was a lack of essential body fats and vegetable fibre…yuk! Dental problems made chewing properly very difficult, so my stomach was damaged from having to digest large chunks of unchewed food.

My dietary habits were atrocious to say the least. Cheap food, fast food, no food, booze, energy drinks and coffee had taken their toll. My body was ill equipped to digest and process it's fuel let alone find extra energy to fight HIV or anything else that may come down the tube. I felt that the end could not be far off.

Peter (the wizard) drew up a fairly simple plan that within weeks made a drastic difference for me. Indigestion, bowel distress and that constant fatigue began to recede the more I stuck to his advice. It's been some months now and I am amazed at how well I am feeling. I mean so often these miracles, like cures, last a few weeks and then things return to the norm.

Not this time. It's been months. Regular easy bowel movements, general health, mood, strength, sex drive have all returned. My distress for so many years is now

the exception rather than the rule.

It was difficult turning my will over to another. It was hard to spend what little money I had on Peters' recommendations because I'm so poor. Was this another pig in a poke?

One of Peters' questionnaires asks how committed are you to improving your health? 20%? 40%? 80%?

There IS some initial cost outlay and if you're anything like me that was nearly the deal breaker but I'm here to say, had I known the result beforehand, I'd have paid anything to improve my quality of life on those ugly days when I was stuck on the toilet, flowing out of both ends and praying for relief.

I've been sick for eighteen years. Every single day for 18 horrible years! Today, I feel 20 years younger, stronger, and happier.

I'm singing this guy's praises from the rooftops. If you're anything like me and have been hurting for so long with so many nagging things to gang up on you daily, anything or anyone that could remove even a couple of those things might be worth trying. AND there are some limited funds to recoup the cost of dietary aids and such, not all, but some.

The relief is worth it. I figure for all the times I've blown my money foolishly, why not splurge on something that might do me good.

I Thought I Knew It All

When I was younger, I was a typical kid but very hyper. I enjoyed sports and got away with just about everything. From around the age of 13 I wanted to be more normal and wanted to fit in because I didn't really have any friend's, just mere acquaintances.

High school was pretty average for me until I reached 15, the guys on my hockey team invited me to a party. At the party, I lost my virginity and soon after that, dating and sleeping with several women at the same time became an increasing occurrence. I knew exactly what to say to women, I had learnt to tell them anything they wanted to hear. Looking back on it now, I know that it was unacceptable but I remember how great it felt to be able to meet women so easily. But I remember that after each act, I felt horrible. But I didn't stop.

After high school I got a job and found a girl I really liked, I even saw myself spending the rest of my life with her. She worked behind a bar so I thought I'd never have a shot with her as I figured she probably knew of my reputation. But she did give me a chance, we dated and it was a different relationship from any other woman I had been with; she was good for me. We had a child together and although I was completely unprepared, we stuck by each other and we had a great family life.

The day my mother called me to tell me that I had to see my doctor was one that was particularly strange. I lived so far away now and hadn't been to that doctor in many years, 'why now?' I thought. I visited the doctor and was told I had to be tested for HIV; someone who had tested positive had put my name down along with a list of others to be tested.

The second time my mother called me was the day that everything changed. I just knew the results from her teary voice. I called the doctor regardless of my prediction from my mother's tone, and he confirmed that I was HIV positive. My life turned upside down, I didn't know what to think nor do, I felt like there was no point in anything anymore.

My wife and daughter didn't deserve this I thought, so I left them with nothing but a video to explain why. I moved away and found a support group for people living with HIV/AIDS and spent a lot of time with a girl I met there; Christine. We got a house together and we had many experiences there; learning to cook, trying new things, and going for walks. Christine had such great character, she was forever grateful for each day, even to be able to hear the birds' singing in the mornings was something she was thankful for. And every night before bed, she would always tell me that she had the greatest day of her life that day, and that she loved me. She blew me away.

When Christine started to get sick, I had no idea what I could do to help. Christine proposed marriage and I told her I'd marry her twice if that was what she wanted. The few days Christine was out of hospital were spent organizing the wedding. Her mother and step-sister came to stay and began looking at dresses and trying them on. I, of course, couldn't be in the same room when these preparations were being made. I never thought I could miss someone so much in such a short time, but I missed her sorely. What had only been a few hours had felt like days to me. That night was spent watching movies and eating pizza with Christine's mom and step-sister. Christine whispered to me that she was tired, so I carried her to bed and sure enough, she told me that it was the greatest day of her life, and that she loved me.

The next day however, she didn't wake up.

Christine inspires me and gives me strength to go out and talk to young people about HIV/AIDS. I think that the way people are being educated should change - yes, people with HIV are living longer lives and this is a good thing; but HIV is still a dangerous, incurable disease. And it is also very preventable.

I always felt that HIV/AIDS was something I didn't have to worry about, I wasn't a homosexual and I didn't use needles. I thought I knew it all, but I didn't.

I think it's important to inform people that they should get tested; it doesn't take much time or effort but it might prevent you or your loved ones from HIV.

None of us are as strong as all of us

‘I have HIV, HIV doesn't have me.’

Far too many times during the last year or so, while attending workshops or peer groups I keep hearing some of my peers say, "since I became HIV" or "I am HIV". I wait and hope to hear the word "positive" follow each of the phrases but it never comes. I'm at a loss to think of how they meant what they said or the way they said it, so I just listen and accept what I've heard.

I was at a workshop for Speaker's Bureau about a year and a half ago. We had to do a collage that showed what we were feeling about our diagnosis, who we were and our story. I couldn't find pictures in the magazines to say what I wanted to, so I drew something on the piece of paper. When it was our turn we were to hold it up and let everyone see if they could tell what we were feeling, what was going on.

I drew a picture of a very large box. It had a small square chunk cut out of the one side. Next to it was a "stick man" holding the small square chunk. As I showed it around the room, people thought it was a coffee machine and I was holding a cup of coffee. After everyone finished trying to figure it out I proceeded to tell them what it really meant. The bigger box represented HIV, I was the stick man, I had the small piece of HIV in my hand and was controlling it. If HIV had me, I would have drawn myself inside the big box.

For over 30 years I worked in a factory - and I felt I was nothing more than a factory worker, I had no desire to be anything more, I was content to have that weekly pay cheque. Other than being a father and grandfather, at times I felt I didn't have much of a life, there wasn't much to me. During the last four years I did that work, I was HIV-positive. I didn't need medications so I never worried about my health, I just went on with the life I had. Since I've been out about my HIV status and got involved with my AIDS Service Organization, I learned so much more about myself, I am doing things I only thought about before. My status has changed my life, but it isn't nor will it ever be, all there is to me.

Today, I am me, I'm a son, a brother, a cousin, a friend, a father, a grandfather and I will be a great grandfather someday. I'm a co-worker, a volunteer, a blogger, and I'm an aspiring artist/photographer - or should that read photographer/ artist? I'm an advocate for HIV, I have put my face and name out there to hopefully change the stigma we live with.

I will always try to do this as a volunteer project, I'm not going to lead the pack but I will do what I can to help in all areas I am able to. I recall a quote from Wayne Gretzky that went something like, "no one is bigger than the game". I believe that the more people who have the courage to come out, speak up and put a face to this disease, it can only help us all. I just heard a new mantra that I liked a lot, "None of us are as strong as all of us"

One By One

I was a teacher working in a school in Zimbabwe.

In 1999 when I was sexually harassed and raped by six men. Another teacher found me right after this happened, and in the hope that I wouldn't ask her what happened; told me I wouldn't want to know.

I vaguely remember what they looked like and what happened, but I was barely conscious. It was all very hard to explain to my husband what happened, but eventually, he accepted it.

I never knew I was infected with HIV until 2001. I immigrated to Canada and started to get sick, I was very ill and weak. I started getting many colds and fevers. My doctor tested me for everything, with no results. When he suggested doing an HIV test, I was so scared. But I did agree to the test.

The next day I was so sick I had to go to hospital. During my time in hospital, my HIV test results had come back...it was positive. I wanted to end my life.

I was treated at hospital initially, but then referred onto an AIDS Clinic. It took me a week to build up the courage to go see the doctor at this clinic. I met a nice man there who made me feel so positive and happy.

When I told my husband about the HIV test and that I was positive, he didn't talk to me for a month. I tried very hard to explain that this wasn't my fault and thankfully he realized that he was wrong to blame me and to not support me.

Everything is fine now and I convinced him to get an HIV test and unfortunately his test came back positive. We can support and encourage each other now; we understand what we are going through together.

I have only told my mum, daughter and father-in-law. When I told my mum, she thought I was going to die. However, she realized that this wasn't going to happen after she read up about HIV and educated herself. My mum is now a big help and she gets involved in AIDS awareness events and encourages safer sex in young people.

I had been on the same HIV medications for 7 years and had to change them twice because they were not working well for me. I was feeling so healthy with no side effects, it wasn't affecting my everyday life. I went back to school, graduated and began fulltime employment.

Unfortunately there have been some complications with my health and I am currently on a leave while the doctors figure out what is going on. I am strong and I will get through each day—one by one.

Past The Shame

I was adopted as an infant and grew up in a very loving and protective environment. My adoptive parents raised me as one of their own and never judged me. I thank my mother for teaching me to live my life with pride and dignity.

By the age of 10, I knew what I wanted to be a ballet dancer. I was a true victim of harassment and bullying because of this choice, you can imagine the struggles being the only male in my dance school.

In my teens I met my biological sisters and was able to share some good moments with them but meeting my birth father never amounted to anything and I never met my birth mother. My adoptive mothers' birth children have always been my true siblings and friends.

Upon graduating from high-school I began accepting contracts with professional dance companies and danced for 7 years. During this time I was having unprotected sex and I remember sex education in school had been about preventing pregnancy, there was no information about HIV because it didn't exist back then.

I became very tired and felt my body wasn't responding the way it should and looking back I'm not sure how I went on to dance for another couple of years. Not knowing that I had contacted HIV, I gave up dance to focus on getting better. At this time I was also settling into a serious relationship with a man who is still a part of my life today. In 1993 my partner suggested I visit the doctor as I was battling chronic fatigue and HIV seemed to primarily affect gay men. Upon hearing the test result words HIV positive for the first time, my world fell apart. I was overwhelmed with shame when my doctor stated that he couldn't do anything more for me, this was back when getting diagnosed with HIV was like getting a death sentence. I was very confused – I had been living my life with pride, as my parents taught me, but the gay community was taking the brunt and the stigma that came with it. I was angry with myself that I was not better educated about HIV.

We moved to Kitchener in 1995 and I hooked up with ACCKWA, I have been a client and volunteer since. My involvement helped me feel connected to myself and to connect more easily with others. I felt empowered - helping others to cope with day to day living which helps me not feel isolated. The Speaker's Bureau Program is for people living with HIV to tell their stories in the community and it allows me to not feel ashamed of myself when sharing and educating about HIV. I also know the importance of giving back to an agency that helps me and the community. I was so enthusiastic about my work I was trying to do too much and the agency was worried about me getting burnt out so I took some time off. During that time I broke up with my partner but we remain good friends and roommates as he continues to support me .

A few years later I met a man at an AIDS Conference in Toronto we had something in common - HIV/AIDS. During our health battles, our relationship became long-distance phone calls every night, as he lived near Kingston. Unfortunately, he passed away a few years ago.

In 2007 I was stricken with a parasitic infection that nearly killed me. I was eventually hospitalized weighing only 90 lbs. I spent many months in Freeport Hospital and to me this was where you came to die. I laid in my hospital bed and cried, I figured it was only a matter of time until I passed away. Thanks to the medical assistance and my will to live, I worked extremely hard to learn how to speak, walk and write again, as I was partially paralyzed from the infection. Aside from neuropathy in my feet I came through it fairly well.

Returning to Speakers Bureau led me to tell my story to a theatre group that was presenting RENT, a play about AIDS. The actors let me know it was inspiring for them to perform that evening after being face to face with someone who is living with HIV and hearing the human side.

Another speak that sticks out for me was to an assembly of 450 students at Eastwood Collegiate and I was scared. It was not until I arrived through the front doors that I realized it was an ARTS School and a ton of bricks was lifted off my chest. I was proud to speak at the type of school that mirrored my own inspirations. Again, students were putting a face to this disease. After I spoke, a student shared that his uncle was HIV positive and he now felt better informed to have open conversations with him. These are the things that make me no longer feel the shame and stigma that I once was absorbed with.

In 2011, I began blogging for an HIV online magazine (Positivelite.com) and my first few blogs were about my experiences acting in the Laramie Project, based on the Matthew Sheppard story, performed at SIZZLE in Cambridge. This story brings awareness to bullying and it hit home for me and what I had to contend with growing up. These encounters help my personal growth while at the same time it educates and breaks down stigma in the community. This work is so meaningful to me - I recently received my 15 year volunteer service award and the Outstanding Volunteer Education award from ACCKWA.

My biggest daily challenges would be the side effects of HIV and the medications. I try to keep motivated and rest when possible. Employer's get frustrated and the disability support program gets frustrated because the on-going struggle of our physical limitations sometimes affects productivity. HIV is a chronic but livable disease. I try to override feelings of frustration or shame that I feel about not working a fulltime job by reassuring myself that I'm a good person, I'm happy doing what I'm capable of doing on a daily basis, and will always give back to others. I have a life-long relationship with HIV.

I feel there will always be some stigma attached to HIV and there are many people that are homophobic. I'm proud to be gay and living my life of fulfillment to the best of my abilities. But I still would not like to see anyone go through what I have because of HIV.

Anyone is vulnerable to this disease if they're not taking precautions to prevent it. It's important to be educated and promote awareness. If the tests results are positive for anyone - REMEMBER - do NOT think you are a bad person, you are NOT ALONE. HIV status lives with you, you don't live with it.

PENNIES FOR AIDS

Yesterday I received a donation that to some would not be considered to sell in the on-line auction at ACCKWA. It's not just the gift he gave, or the time he gave making it. It is a gift of the simplest message of care, he knows very little of AIDS at his age. He knows the most basic…'AIDS hurts people bad' and to know that much 'little guy' delivered a message that everyone is capable of the capacity to care.

After meeting him and talking to him, I cried like a baby out of his view.

Yesterday in my blog I asked you how much 15 pennies were worth. And today I share this encounter with you...

"Hey, you are Joe right?" I turned around to see 'little guy', no older than six years, who was standing beside a tall slender man that I know I should remember, but I can't. The man stretched his hand out and shook mine as 'little guy' also reached his hand out to shake my hand. The man spoke his name and then I remembered him.

"This is my son 'little guy'. My friend has you on facebook and he suggested I check out a link to an auction page of yours dealing with AIDS. As 'little guy' and I looked at the postings he asked me what the red ribbon was for so I explained what it represented the simplest way I could.

'Little guy' looked back and forth from his Dad to me. It looked like he had something to say, "Daddy! Give it to Joe" he said, almost impatiently. "You made it 'little guy' so you give it to him", his dad said.

The 'little guy' turned shy and hid behind his dad, while Dad handed me a brown paper bag folded up. It was heavy! A piece of yarn glued to it as a handle. There was a ribbon, not made of silk or satin or cotton or denim. It was a ribbon made of pennies that 'little guy' had glued on and painted red. "I know I wrecked the pennies cuz I painted them, but now it's a picture" he said, still standing behind his dad, snuggling his leg.

Indeed it was a picture! 'Little guy' made a red ribbon work of art just because he understood and cared enough that 'AIDS hurts people bad'. "But you can't open the bag Joe," 'little guy' added. He had glued the bag shut. "If you open it you will let 'them' out and the picture bag won't work. I made wishes and put 'them' in the bag so people get better and no one will get sick from AIDS.

I had to take a huge breathe to hold in all my built up emotion as we continued to chat a bit. 'Little guy' told me that he had more pennies at home that he was gonna give to the AIDS people. Another deep breathe as I thanked him and his dad and they headed off on their way home.

Dad looking down at his son who was smiling and skipping off happily; the way little kids do. “I think Joe liked it ‘little guy’”, I heard Dad say.

I headed in the other direction, tears in the corner of my eyes, loving the red painted pennies ribbon.

I took one more deep breathe as I sat by the fountain and the tears did flow.

A simple act of care, Pennies painted, Meant to share, A young boy’s gift, Not just for me, A gift of compassion, For others to see

15 pennies painted red - far surpasses the value of fifteen cents

Thank you ‘little guy’, your "little something" means so much to me and I am sure it will to many others.

I think it also shows that a well-recognized person need not be the one to make changes, and between you and I, ‘little guy’ is affected closely by AIDS. This makes this story and him all the more sweeter.

We planned for ‘little guy’, his dad and I to have a wrap them up party! Sitting down together to wrap all the pennies he collected so they can be brought into AC-CKWA.

This is how it went -

‘Little guy’ and his dad came in with a freezer bag full of pennies and we sat down at the café. As he started counting them he reached into his Disney ‘Cars’ jacket and pulled out a few more pennies that he found on the street. "I picked these up on the way here and I gotta go to school soon Joe.” We finished counting 127 more pennies in the bag, plus the 7 he picked up on his way to the café.

Reaching Out - Helping A Community

I was a mother of two, a professional driver and married. My husband decided to have a sex change and started the change from man into a woman; he had not realized that this was what he wanted. We had separated a few times and then gotten back together and eventually we stayed apart when he figured it all out.

So I was busy raising my kids and continuing my driving job and suddenly got really sick. I thought it was flu or that I was still getting over my pregnancy as my youngest child was only two. When it got real bad, I went to hospital where they quarantined me for four days and just left me there. Then a doctor came to tell me either I had cancer, or I had AIDS, and that I was to find out the results the next day.

I was very naive back then. I thought to myself, *'people like me don't get AIDS... I'm a married woman with two kids...and I don't sleep around'* it was shock and terror; I couldn't control how I thought. I realized that my husband had passed HIV onto me. He had been experimenting with needle injections and having sex with other people. It had been three years after the separation when I tracked him down to tell him that he had HIV. If I never went to the hospital feeling so ill, I would never have known.

When I found out I had AIDS, I told my family right away. My brother and sister reacted in two completely different ways. My sister has a separate plate, knife and fork for me to use when I come over to her house. You can't talk about it to any of her friends. But that's just her way. Everyone else I know has been very supportive.

I now speak publicly and volunteer within my community. My kids are grown up and I have a grandson. I take my son every three months to get tested as he refuses to practice safer sex. None of my kids were infected with HIV and I explained it to them as they were growing up. I taught them about needles and injections, I taught them about safer sex and the use of condoms. My daughter is now an activist and is going to go on to be a nurse but my son doesn't talk about it. Lots of kids from the community come to ask me questions because others don't have it in them to answer.

One day a police officer came to the door after seeing a lot of people coming in and out of my house. I explained that my daughter had just had a baby and I also volunteer for the community by giving condoms out to teenagers. She asked me if I knew that was against the law and I thought to myself 'no it's not!' I asked a legal representative and I was right, it's not illegal. When the police officer returned at a later date she actually said to me *'Do you ever think about the kinds of people that are related to HIV and condoms? Do really want them in your home?'* I replied sternly and in shock *'I have HIV/AIDS, I live in this home, and there's nothing wrong with this home*.' She was lost for anything to say.

I am currently on all kinds of experimental medication. I have basically no immune system. When I was diagnosed fifteen years ago, they gave me six months to live and told me to find new parents for my children. Each day could be seen as a struggle; I don't have the energy for work, I barely eat, food doesn't taste the same, my fingers and toes are always numb and cold as a side effect to my meds, I get headaches, nausea, I can't sleep at night, sometimes I don't sleep at all. But I've learned to take each day as it comes. I'm lucky to have my kids to help me get on with things and to motivate me. It can be so easy for someone who doesn't have kids or close family to exclude themselves from society, get into alcoholism or drug use.

There is a summer camp in Southern Ontario that is set up for people living with HIV/AIDS and their families. It is just a calm space to get away from the stresses of everyday life and meet other people in the same situation as you. It went pretty quickly from having one community of people to becoming very multicultural. It is like a massive support group, everyone is so accepting. They offer massages, there are nurses on site and you stay for five days, it's a very positive thing.

My mum is very supportive, she understands how tired I am and really helps me out. I can't do much with my grandson so when I want to help give my daughter a break, I bring him round to my mum's house and she runs round after him.

I met my new husband here, he is also HIV positive and he is involved at ACCKWA. The support level is better than in my own home so it encourages me to volunteer more in Waterloo Region.

Rising From the Ashes

I had TB, kidney failure, uncontrollable diabetes and my CD4 count was less than 100 and I was not responding to HIV medications in 2008. A year later I was recovering but in 2010 I again became critical. My blood work kept getting worse and worse and my doctor could not give me any hope. My husband would not care for me during this time, he would cook but then leave the food downstairs for me to go and get myself, even though I was so weak. My husband told me we were done and that as soon as I get a little better I should leave. He would lie to my friends and often the only time I would get food was from the doctor or from church members. I had to make my bed in the living room so I could access the kitchen but I had to find 'a potty' to use because I could not go upstairs to use the bathroom. I received a lot of support from the AIDS Committee and I met some friends through that network and when they visited me he would tell them stories about me and eventually they stopped coming.

One time I was rushed to the hospital in just my underwear, the paramedics could not let me put on clothes because my condition was so bad. They did not admit me and I had to go back home in just the hospital gown because my husband would not pick me up, I had to call a friend. At home he did not give me food because he said I embarrassed him. For an entire year he never spoke to me or asked how I was doing, our marriage was over and we just existed for the kids. He used to call me a 'BITCH' and say things like, 'look at her, she has red lips, she is going to die, she has AIDS' in front of my kids. . I used to wonder what would happen to my children. My son was 14 and the little one was 7, their dad would tell my sons that I was cheating on him, I have AIDS and that I was going to die. My eldest hated me and only came to me when he wanted money and my youngest was scared to leave me.

I was going to church throughout this time and my pastor said they needed to pray for me. I was asking myself why do they need to pray for me? Am I dying is that the reason why? but I attended the healing service.

My husband and I did our income taxes and he took the refund money and left for vacation in Australia. I was so sick that I could not take care of my children and we had to go to the shelter. Between me and poverty I had only $75 dollars. It took a lot of courage to go to the shelter. My support worker at the AIDS Committee gave me a lot of support and encouragement. When I returned to the doctor for my blood work and my CD4 count had doubled and my doctor thought something was wrong. She compared all my counts but could not believe the numbers and she asked me to do more tests. My CD4 count was getting better and better.

My husband returned from his adventure and he wanted us to get back together but I was tired of being abused and humiliated. He was angry at me for going to the shelter and claimed that I was embarrassing him in front of friends and family. I decided to reclaim my life and registered for classes at the University of Guelph. I started with one class and eventually went full time.

Even though it took me forever to leave him, I found an apartment and I am doing good by myself with my kids. I had to start life from scratch, from zero, but it’s all good. People were awesome and I thank God that they were there to hold my hand and walk with me.

When I started going to the University of Toronto, my husband decided to go get his masters because he wanted to be above me, not in the same league.

Today, I know I have friends; I will be graduating with my social work degree. I have my children and I have my whole life ahead of me. I used to pray and ask God to just let me have the strength to see my children grow to be 18, today I know I will be around for a long time to see them get married and see their children. I survived my toughest time, but it was just a phase, church for me made the greatest difference. I never gave up, even the days I thought I would die. I knew I did not want strangers raising my children and I told God I was not ready to go, I would just call out to Jesus and pray and cling to my bible calling Jesus *help me, help me*...when things are good we forget to pray but I know where I have come from and now I can see where I am going.

My youngest son worries a lot, one day he told me that he knows I almost died once and he is scared of going anywhere, even to visit his dad because he thinks I will die. As for my teenager, it’s hard for him but we worked it out. I remember when I was in the hospital he refused to bring me my bible, he hid it, so I took comfort in my family album.

Today I am just like any single mother, working hard to see her children raised, dealing with teenage problems and coping with wrapping up my Bachelor of Arts program.

Shores of The Indian Ocean

The shores of the Indian Ocean are beautiful, covered with white sand and palm trees. A place where one watches the beautiful sunset and dreams of a lover. I grew up on the shores of the Indian Ocean enjoying the gentle breeze, riding camels and hearing a lot of laughter. It was a great paradise, one I wished to share with someone I loved.

My wife and I courted long distance for two years before we finally got married at this beautiful beach on the shores of the Indian Ocean. I loved sharing my paradise with the love of my life, hearing her laughter as we enjoyed life like two little children with not a care in the world. After we were married we continued to live separately, my wife visiting me in my home country as she proceeded to complete the necessary process to assist me to migrate to Canada.

I had disclosed my status of being HIV positive to my wife and this, according to her, was not a deal breaker. I felt so lucky, cherished and loved. It was just awesome! I was in seventh heaven! Finally, my paper work was done and in 2009, I joined my wife in Canada. The first month was out of this world. The love we shared for each other was so great...then things started slowly falling apart.

My wife started being abusive. She would kick me out of the house every so often - I was forced to seek shelter at bus stations, religious houses or shelter. I did not know where to get the bus or seek services, she was my only link to this country. My wife would take off for vacations to Mexico and leave me by myself. One time we went to Alberta for the stampede and she left with all my documentation and money, I was alone after having been in the country for only two months. I received assistance from the local police and found my way back. Sometimes she inflicted injuries on herself and called the police claiming that I had abused her.

What truly broke my heart was when she started posting my pictures on various websites and announcing to the world that I was HIV positive. With all due respect to the GLBTQ community, she stated that I was seeking men as my partners, well this went against my beliefs. She would put my name on face book and then add the words *'with AIDS'.* She would call my employers and disclose my HIV status. She truly exploited the stigma against people with HIV in order to cause me a lot of mental anguish. She would tell people that I would soon die of AIDS. She would even email the AIDS Committee pretending to be me and saying things like *'thank you I hope I can get a job and go home because I have HIV I am going to die soon'*. All this maliciousness made me feel so alone and hopeless. At some point she asked her lawyer to see if she could lay criminal charges against me—even though I told her of my HIV status.

My turning point was the support from the AIDS Committee. I received so much support and love. I was able to put my life back together, square my shoulders - literally and figuratively—in order to move on. My support worker held my hand as he assisted me to file for a divorce and start a new chapter in my life.

Today however I am afraid of looking at women, let alone approaching them to have a relationship. I never knew this disease would mess me up this bad, not only my career but also my relationship with women and other people. I am afraid of falling in love again.

However, I have learned a new trade, picked up the fragments of my life and slowly I am stitching them together. My journey has been long but along the way I have met great people. People who have chosen to nudge, push or just hold my hand so I can walk again. I look forward to the day I fall in love; the day someone will accept me for who I am; someone who will see beyond HIV; and someone who will not take advantage of the stigma and abuse me. Someday, I look forward to walking along the shores of the Indian Ocean, listening to the breeze whisper, holding hands with my lover, my love, as we softly laugh and watch the sunset.

Someday...

Since The Beginning

I've been HIV Positive for twenty-eight years and I have seen HIV in Ontario since the beginning - when it was seen as 'The Gay Disease'. There was an awful lot of discrimination at that time and not many support organizations.

When I was twenty, I was in a car accident. I got hit by a drunk driver and unfortunately my boyfriend died. I required a blood transfusion which saved my life - HIV or not - I'm alive. I'm not angry at the hospital or at the person who gave me HIV through their blood. Back then blood wasn't checked for HIV/AIDS because there was no knowledge about such things. The only reason I found out I was HIV positive was because the person who gave their blood to me died of AIDS and I was instructed to have an HIV test which turned out positive.

Along with that diagnosis I was told that I might have two years to live, if I was lucky, so I believed that I was going to die. My family doctor knew and immediately told me that it would be a good idea to find another doctor. When I told my dentist, she thought it would be better for my care if I found another dentist. My massage therapist told me bluntly that he couldn't massage me, left the room and returned wearing gloves - he removed the sheets I had been sitting on and offered them to me. No one knew anything about HIV/AIDS so I can't blame people for that back then.

I soon moved to Toronto by myself, no family or friends around me. I thought that since I'm a gay man, the gay community would welcome me, that assumption was wrong. Once I had told one person that I was HIV positive, everyone knew and they didn't like it. I had no one to talk to. Since this was labelled the 'Gay Disease'; I figured there must be at least one other person around me who was HIV positive and needed someone to talk to, just like I did. But in actual fact, anyone who was HIV Positive was trying to hide it and wouldn't associate with someone who was openly living with HIV. This was all due to the fear they had of people finding out. I got upset and this turned to anger. I began telling anyone would who listen and got a lot of awful feedback for it. I'm still not comfortable with my community because I think they should have been supportive no matter what. But it was a hard couple of years after that, as I waited for death.

I started seeing an HIV specialist who set timelines for how long someone with HIV could live. I prepared myself for death numerous times. Yet before the end of each timeline it was extended, due to research and new information. I felt lucky that I had seen it through that far but still didn't get out partying and socializing in my youth like most people around me because I was still busy waiting for death.

At the beginning I did not take the HIV medications, I didn't see the point if I didn't feel sick and I was going to die anyway, I thought I didn't need them or their awful side effects. Instead I treated myself by turning into a workaholic to avoid feelings of loneliness or thinking about HIV/AIDS. I again tried sharing my story thinking people might be ready to hear about it and hopefully educate them, that wasn't a reality but thankfully nowadays that has changed.

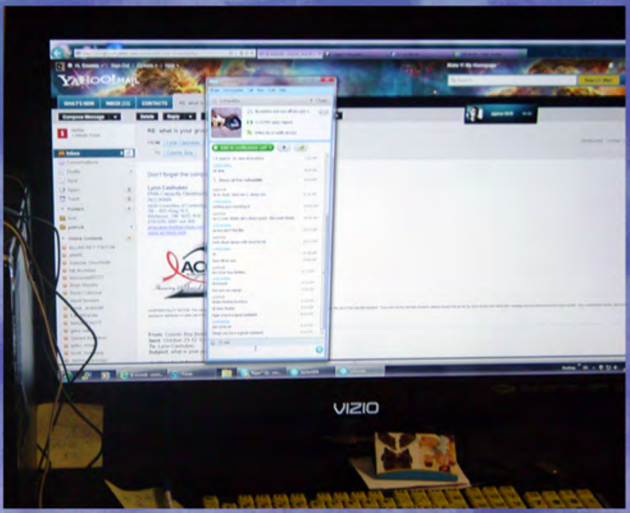
I became involved in art shows with other people who were HIV Positive, one art show called 'I love you when you're dead' had a big impact on me and strangely it was comforting. Through this community I met people whose kids were also HIV Positive which was new to me. This was a good circle of friends but slowly, people started getting sick and passing away. We had to take shifts at the hospital to make sure they got the appropriate care they needed. Some nurses didn't want to care for an HIV patient so we made sure the beds were changed and that our friends were bathed or showered. Some of us even learned to give injections, because the nurses preferred not to.

I was the youngest person of our group. Watching each person pass away was extremely difficult. They passed on in different ways and required different things and sometimes needed to be told it was okay to die. Sometimes they needed to know that God would forgive them. I'm not a religious person and I don't believe in God but I prayed with them or told them what they needed to hear at that moment.

Long term survivors don't often talk about that time in HIV/AIDS history. We learn now that we, as the living, often suffer from survivor's guilt; many of our friends are gone. We carry this burden, including things we haven't dealt with. I often pulled away from people over the years and still don't make friends easily. I guess this is my way of keeping myself protected; I've already seen too many friends die. Much stems from being tired of looking death in the face and tired of watching friends suffer.

Today I deal with that guilt, I didn't have time to mourn each death and I pushed the sorrow deep inside. Coping skills were not learned because I wasn't aware that I would later need them - the hurt and pain just began to surface in the past few years. Along with learning about emotional healing I currently take HIV medications. Unfortunately one of my drugs had the possible side effect of heart attacks in males of which I now have suffered two. The need to change that drug brought a new one which caused a large weight gain. It's trial and error to stay healthy.

Through the ups and downs and varying side effects I appreciate that right now I'm healthy and that's all that matters to me.



The Best I Can

I was born in Nova Scotia in a family of 11 (I am the 9th boy) and we grew up in poverty. I didn't like school so I played a lot of hooky; I was somewhat a happy kid and had a few close friends. But we moved to Ontario when I was 10 years old, and it was hard getting used to new places and new people.

My parents were in a car accident in Kitchener, caused by a drunk driver. My mom survived but it was really hard to lose my father at 15 years old. A year later, my mom re-married a wealthy family friend I remember him being 'always right' and argumentative but we were a big family to take care of so I guess my mom just dealt with it. When my stepfather died years later, my sister and I had to move my mom into a nursing home where I visited her often until she recently passed away.

By 16 I was having sex with guys and at that time it had to be kept to yourself. I had to be very careful about telling anyone I was gay. At the time (the 70's) I was doing drugs; LSD, pot & hash... I was working for a living, finding more gay guys and was hanging out with a group of pot smoking hippies. Me and one guy from the group started to do break & enters, I trusted the guy and I was a follower, not a leader. One night we got busted and I ended up in jail for a year - it was a hell hole. I heard stories of how you could get killed in jail; I was really freaked out and very scared thinking about a whole year in there. I met a few guys that were cool with me, some wanted sex which happened a lot but you sure didn't want to get caught! That year felt more like I lost 10 years of my life. I learned my lesson – if you can't do the time, don't do the crime. I had to stay at a halfway house for 2 years and get a job before I became a free man.

In 1973 I lived In Toronto for a year but it was too fast-paced so I moved to Kitchener. I was just living the best way I knew how to - working hard. I jumped from job to job trying to find where I fit best and I married a woman to cover up who I really was.

In 1993 I was openly looking to date guys because I came out about my sexuality, coming out of the closet at 30 meant I had a new found freedom and I know I made careless choices. I was being promiscuous at the gay bars in town and started to go to bath houses In Toronto. Not knowing anything about HIV/AIDS, I was having lots of unsafe sex. Soon after, I met a guy from Welland and dated him for about one and a half years. We had unsafe sex most of the time and one night he said he had something to tell me. As he told me he had AIDS I didn't know what to say or do but it was too late because we had unprotected sex lots of times. I think that's how I got HIV...we continued to date and have sex.

I met a guy at a bar who came up and asked me 'Is there any gay men here?' I asked what he was looking for. Well, that night with him turned into living together for five years, he was much younger than me. Four years into the relationship I became very sick and had sores all over me. I heard about ACCKWA so I went there for HIV test. The first test was negative so waited a month and got re-tested, it came back positive for HIV. I just remember taking each step I had to for my health, many struggles with medications when I started taking them. And I remember one time I was working with a man and, although I can't remember how or why I told him I was HIV positive, but his reply was 'oh, well I'm not going to work with you anymore'. That was that!

When I'm dating, I always tell the person I am HIV positive, it is very hard meeting someone and having to tell them. It's got nothing to do with liking them enough to want to tell them or knowing that the relationship may go somewhere, the law says I have to disclose that I am HIV positive. It is understandable, but sometimes you can't predict how the person will react, and that can be difficult.

In 2007, I lost my sister, Donna to suicide, I was there with her at her apartment. We were looking for papers that she wanted me to have because looking after my moms' affairs was too much for her to handle. All I remember is her calling out my name, I answered her and she said 'never mind'. I continued looking for the papers but shortly after came out to see what she was doing. I looked throughout the apartment and saw the patio door open, I went out to look and something told me to look over the balcony. I saw her on the ground, she had jumped eight floors. The paramedics tried to get her breathing again but it was too late. She's been gone five years and I still have flashbacks. I was blaming myself saying 'what if…'but I know there wasn't anything I could do. Not long after I lost one brother to bone cancer and one other brother died of a heart attack at 53. Life is hard when we lose loved ones but we know life goes on.

In 2011, I lost a very good friend Peter that I am still trying to get over. It haunts me - all these deaths, but I try to move on the best way I know how. I try my best to deal with HIV; trying to keep up to all the medications, blood work, doctor appointments, side effects, stigma, and disclosure and someday I don't feel like I want to do it all anymore and getting older makes me sad too. My friends keep me alive and I try to keep busy to ease my day. I'm just taking each day as it comes until I meet the right person. I'd like to meet someone who is HIV positive because we would share an understanding of what the other is going through and we would have each other for support. I won't let HIV control me as I live out every single day.

A Wonder

Every time I invite someone in I wonder what they will leave behind
Will today be sunshine or a mud trail...I wonder?
Today I am inviting you in...yes you, uhuh you. I wonder what you bring with you today?
They say I should be cautious who I invite in, but today I wonder if it's not time to invite you!

Come let me hold your hand, I will show you the wonder that is my life
Come, behold my soul I bare
Here I am a daughter (as beautiful as my mother), a mother, a lover, a friend
Here I am a graduate, an employee, an immigrant, a community member
Here I am positively living with HIV, I wonder what you will choose to see

My heart grows heavy, as I see you wondering,
You choose to ignore everything and pick one fragment that is part of me
You choose the fragment of 'I am HIV positive'
You turn away your face and trail your muddy boots in my soul
You wonder what you will leave with

Off you go, leaving me shivering with cold as you expose me and leave my door wide open
As I wonder if I will ever be warm again...you, yes you, uhuh you walk my way
You take your time to remove your muddy boots
But in trails SUNSHINE and the smell of a new day
My eyes open wide and I wonder what you bring

You take my hand and walk with me
You show me around my soul
I wonder what you want to see
You point out to me, my own wonders

You are a mother, a daughter, a lover, a friend
You are a graduate, an employee,
a community member
You are living positively with HIV…

All these Fragments make you who you are
I look at you, yes you, uhuh you
I wonder, should my status define me?
No, they are just a part of my fragments
I wonder no more, I am warm again

Thank you for taking my hand...

fragments
of me