



**MORE THAN FICTION**

**POZ WOMEN SHARE THEIR STORIES**

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# ACKNOWLEDGMENTS

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# PROLOGUE

In 2013 women of ELAN's social support group at ASAAP talked about how to address a lack of representation in the HIV/AIDS movement, a recurring theme. Their discussions stemmed from feelings of frustration as they participated in research studies and focus groups yet, did not see their voices as they wanted represented in larger dialogue. The result of their discussion was a stated recommendation for a project that would enable them to create and share their story; not under the umbrella of a research study with summarized findings but simply as a collection of stories that reflect how they see their struggles and their strengths. This was the impetus for 'More Than Fiction.'

The twelve authors of these brave and lucid narratives were engaged in a series of workshops that further developed their capacity for storytelling. Guided by dedicated facilitators and community advisors, creative writing, poetry, and photo voice were some of the modes that were explored over the course of a 4-month period. The authors have each chosen an alias to reflect the silencing impact of stigma and discrimination that has denied many people living with HIV/AIDS the right to live openly. Their stories capture the profound isolation that living a secret life can entail, but they also give voice to the self-compassion and resilience that such challenges engender. In reading these narratives, common themes emerge, yet we also bear witness to the uniqueness of the authors' struggles.

We hope this unique and beautiful collection will inspire thinking and understanding among both communities and service providers. But ultimately, we hope that as the women aspired to do, they have carved a visible space for themselves in HIV and AIDS narratives in Canada.

Vijaya Chikermane, Shazia Islam  
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# ‘Praise for More than Fiction’

“Bold. Honest. Powerful. Real. Everyone should read “More than Fiction: Poz Women Share their Stories,” and celebrate not only the women who contributed to the anthology, but all women living with HIV – their endurance, their resilience, their strength, their truth. Breathtaking.”

*Valérie Pierre-Pierre, Director, African and Caribbean Council on HIV/AIDS in Ontario*

“The stories and testimonials transported me, if only for a few moments, into the worlds of these strong and resilient women. They helped me to see the experiences of South Asian HIV+ woman in a whole new light and for that I am grateful.”

*Suzanne Paddock, Director of Programs and Services, Toronto People with AIDS Foundation*

“I am deeply touched by the authenticity, honesty and courage of these women’s stories; and profoundly inspired by their unwavering quest for love, meaningful lives and communities against all odds. This is an important collection of oral histories to be celebrated and shared far and wide.”

*Dr. Alan Li, HIV Primary Care Physician; Founding President, Asian Community AIDS Services*

“This beautiful collection of stories is filled with courage, astounding resilience and hope. The honesty and dignity of each woman reminds us that being positive is about more than you HIV status. Thank you for such a wonderful gift!”

*Notisha Massaquoi, Executive Director, Women’s Health in Women’s Hands Community Health Centre*

“Very inspiring and moving stories which bring out the strength, passion and resiliency of the story tellers. Although the women went through such difficult situations of oppression, ostracism, and stigma/ discrimination, they are all heroes in the way they

managed to go beyond life struggles and emerge stronger, more determined and more victorious! Everyone should and must read these stories and act!”

*Maureen Owino, Director, Committee for Accessible AIDS Treatment*

“These are beautiful stories of love and loss, faith and miracles, strength and community, and smiles and tears that speak to the strength of the story tellers. Each story stands as a powerful example of women who have thrived in the face of HIV stigma and each provides a universal lesson in resilience.”

*Shannon Ryan, Black Coalition for AIDS Prevention*

“Powerful and empowering!! Inspiring stories of compassion, resilience and collective strengths that capture the regenerative human spirit of twelve amazing women as they journeyed through the changing landscapes of HIV/AIDS.”

*Josephine Wong, RN, PhD, Associate Professor, Daphne Cockwell School of Nursing, Ryerson University*

“With generosity and tenderness, these trailblazing women share stories of sex and love, isolation and survival. They burst open our myths about who lives with HIV in Canada and remind us how critical spaces like ASAAP are to our community.”

*Mohini Datta-Ray, Manager, Provincial Women and HIV/AIDS Initiative, AIDS Committee of Toronto*



I am a mother,  
a grand-mother, and a  
great-grand-mother.

# TO WHOM IT MAY CONCERN

SAVITRI

My name is Savitri. I was born, and brought up outside of Canada. I am a mother, a grand-mother, and a great-grand-mother. My husband and I had separated long before. I came to Canada like so many others, with the hope of a better life. My immigration status was uncertain, so I went through some hard times.

I decided to talk to a trusted friend I met in Canada, and he told me not to worry, and that he would take care of me. He was a very religious person, and I loved everything about him. I felt happy knowing someone would support me. He introduced me to his family and things were going good for a while. His sister sponsored me so I could work as a housekeeper and nanny.

As days went by, I fell in love with my friend, and we started having sex. I had no idea at the time what I was getting myself into. I was lonely in this new country and needed companionship. I also wanted something better for myself other than working in other people's homes. I started looking for factory work.

About a year later, my friend got very, very sick, and was admitted to the hospital. No one knew what the problem was at the time, but the AIDS scare prompted the doctors to test my friend for the HIV virus. He not only tested positive for HIV, but he also had full-blown AIDS. He lived about a year more, and then passed away. I could not believe he had died of AIDS.

It took me some time to recover from the loss of my friend, but I also knew that I had to keep moving forward with my own life. I decided to apply for insurance. Everything seemed fine, and I complied with the requirements of the insurance application and had a blood test done. I got a call from the insurance company to check with my doctor. I had no idea what they were talking about. When I saw my doctor, he told me that I

was HIV positive. I cried out, and the tears did not stop. My doctor told me it was not the end of the world, and that he and the care team would help me maintain my health.

It's been many years since that day. I have been living with this virus, and none of my family knows that I'm living a lie. I can't tell them about my status because back home, the belief is that if someone has this illness, they will die within six months. I was very sick, and felt very isolated. I felt like there was no point in living anymore. Society looks upon you differently. You lose all your friends, and even your family, too, because you have to hide who you are. Many days I sit all by myself, crying, and asking myself, "What have I done?"

But my doctor connected me to some organizations that could offer me some support. I must thank the organization and the HIV positive community I am now a part of for supporting me in every way they could. I could count on them and reach out to them when I needed someone to listen.

Still, whenever I was with my family or friends, eating, and enjoying our time together, I felt guilty because I was afraid that I would infect them, but now after going to group support meetings for HIV positive people, and learning more about HIV, I know it's not going to spread to anyone by touching, hugging, or even sharing the same glass.

I cope with my illness one day at a time. Sometimes I am ok, sometimes I am down. I am alone a lot, wondering what each day will bring. I have a few friends and some family who come to see me every so often. HIV is one of the most serious illnesses a person has to live with. It tears me up inside knowing that I have an illness I can't even talk about with the people closest to me. I pray every day asking the Lord to take care of me.



# CHANELLING FEAR INTO SUPPORT & EDUCATION

JAIYANA

I wanted to contribute a story that would stress the importance of community support and education for people living with HIV. That support saved my life.

I was living in Canada with my husband, and we had a baby. It was a hard time for me because my husband was cheating on me and he would beat me just so the fight would give him an excuse to leave me alone in the house with the baby. I went back to my home country to live with family members. They also had children in their lives and watching them receive their father's love made me sad. Each time my husband called, our child would ask him when he'd be coming to watch the sports at school. My husband would apologize and ask me for another chance. So for the sake of keeping the family together, I decided to return to Canada.

My husband paid for my education to help me upgrade my skills, so I could find something I enjoyed doing rather than be a stay-at-home mom. But I got pregnant again, and we then decided to apply for life insurance. Shortly after we applied, we got a letter of rejection. I was really concerned, but not my husband. The insurance agency asked for my consent to release my medical information to my family doctor, so I decided to do so against my husband's wishes. My family doctor notified me that I was HIV positive and also had chlamydia. They referred me to another hospital to get counselling for the HIV diagnosis. I was a few months pregnant, so they discussed with me the question of whether I should keep the baby or not. I decided to get an abortion since I was not sure what kind of effect the treatment would have during the pregnancy. At the time of the abortion, I felt like I was going to die. It was a painful procedure, both physically and emotionally, and I had to get it done on my own since my husband was at work.

We were planning to tell our child that we both had been diagnosed with HIV at some point, but the medication that my husband was taking had been discovered, along with a pamphlet on HIV/AIDS. Our child didn't ask the father, but came directly to me, looked me in the eye and asked if their father had HIV. I told them to go speak to the father once he was back home. I called my husband and told him it was the right day to disclose. Although my husband did not want to face the confrontation, he had no choice but to be honest about our diagnosis. When they found out that their mother had also been infected, they became very upset by the news. I reached out to an old married couple who my husband and I knew well. They were the first people I disclosed my diagnosis to after my husband and I found out. They were there again for me when I asked if they could provide our child with some support.

But even though I had that support, I was still very anxious about passing on HIV to my family. The day I found out I was HIV positive, I didn't want anyone to walk near me because I didn't know how HIV was transmitted and thought that I could give it to anyone by standing near them, so I asked the old couple to take my child under their care. They reassured both my husband and I that we could not pass HIV through close contact with others. They told us they would remain supportive. I was so scared of infecting my child that I couldn't think rationally. I wanted to end my life then and there. Every single moment I was with them, I believed that they might get infected.

I then stepped up my determination to connect with the HIV community again to look for answers. My husband was against the idea of going to workshops and support groups for HIV positive people because he was afraid

of people finding out. But I wanted to confirm what my friends told me about the virus not being transmitted through touch or close proximity. I reached out to all the support I could get to learn about HIV, and to help keep my child safe.

After all of the support I received from community AIDS service organizations, healthcare providers, and our dear friends, I had a much better understanding of HIV and learned that I could not give it to anyone simply by standing near them or hugging them, and that the new advances in treatment could help prolong the lives of people living with HIV. So, I decided to have another child. I took all the precautions necessary, and had good healthcare support, as well as spiritual support. My faith helped me deliver a healthy child who tested HIV-negative.

It's been a real blessing to have my children, and now, we also have grandchildren in our lives. This wonderful family and community continue to support me and my husband with their love, care, and concern.



*I miss you.*

BONNA  
RECEIVING

TRISNA

ANGUS

INDUSTRY WEDNESDAY  
THE FIX FRIDAYS  
COBRA SATURDAY  
COBRA

AGUAVIVA  
WINN +  
GREGG

KEYS W/ T BE PICKED  
UP BY 10 PM OR  
WE'LL BE HERE TO  
HELP YOU

# LETTER TO MY MOTHER

NEEL

I hope this letter finds you well. I know you will never read this letter because I have no intention of sending it to you, but it's just my way of letting go of the need to tell you some things. I'm very happy that the beautiful relationship we have keeps evolving as the years go by. I know at times things were not the easiest for you as you struggled to raise your children in an environment far away from the home you loved. As a child, I witnessed what such displacement could do to a person as each day I felt the weight of your sadness and longing. But with faith, dignity and strength, you worked hard in this new land to provide all the things your children needed to feel whole, healthy, and happy. We are all stronger because of the sacrifices you made. Thank you.

Now it seems that you and I have become like sisters. In our frequent calls to each other, we share our stories and confide in each other about our troubles and challenges. I hear pride in your voice when I tell you what goals I've achieved so far, and the ones I plan to achieve in the future. But I know that concern you feel for me will always define you as my mom. Although there was a time when you had hoped I'd have found someone, now my happiness is all that counts with or without another. You've encouraged me in everything I wanted to do in my life. I will always remember those times when you were there on the other line as I spoke through a beaten body throbbing with the fresh pain of a punch. You kept repeating to me that this was not going to be the rest of my life, that there were happier paths to follow, and that there was always a way out.

Some days I wish I could have grown into that daughter you had hoped me to be. Wish I had done the things expected of daughters: be a good sister, find a sweet man

and settle down, have some kids, build a dream home for the family with visits from the grandparents and in-laws, and trust in god that we'll all remain happy and healthy. Whenever you talk of these things, I trick myself into dreaming that dream with you, like I could just forget for a moment that I actually adore women, that I'm gender-fluid, and...that I'm HIV positive. I know you'll understand what I mean by these new things because you read the news all the time and know a lot about how our world keeps changing. All I can say is that they've defined much of my life since leaving home.

Having fled with you and our family from a country ravaged by rape and bloodshed, and then experiencing firsthand the violence and hatred of men through the years, those memories are alive and well in the often complicated, messy, and fragile relationships I've had with the men who've loved me. They will never be part of that equation, mom, but some of them have become my closest, most trusted companions. I know all of this will hurt you. You gave birth to a daughter, who you believed would bring you happiness and contentment. And now, you have someone new, with all these confusing labels, who might seem a stranger to you. But whatever I have come to be, it will only reinforce the connection we two have without you ever having to know it. A thought, a feeling, a prayer – these are enough to know that love abides.

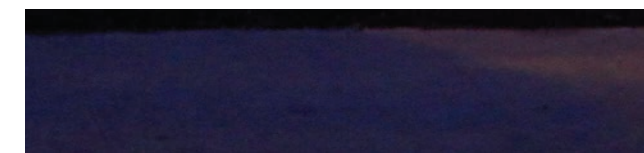
All of our life struggles, yours and mine, continue to converge in that place where love, faith, and hope have the power to revive and resurrect our sunken spirits. We have both learned as two passionate, caring, and wounded women that our dreams, our happiness, and our health matter. Thank you for encouraging me to challenge

the confines of all those norms, customs, traditions, identities, values, beliefs, and histories, so I may keep moving, with your blessings, on this (r)evolutionary path.

And if I can't share any of the above with you, I will at least share this,

I miss you.

Neel





**I AM A HUMAN  
BEING.**

# FROM HIV TO ACCEPTANCE

LAYLA

I was diagnosed HIV positive a few years ago. I don't really remember how I felt when the doctor told me that I had HIV. I've heard people say that HIV positive people shouldn't even be on this earth but I was never bothered by their ignorance. I'm a human being and I deserve to be loved, valued, and heard.

After I found out about my status, I reached out to the HIV community and made some new friends. I was happy to know that there were others like me and that we could support one another through our challenges. It makes me a little upset when I see things on T.V about HIV but then again they're trying to help people so they don't end up like me. I guess that's kind of good because sometimes it feels like nobody gets me. I know most people are trying to help me, but sometimes I just wanna be able to live a life without this illness on my shoulders...you know have a normal life and live with my kids, but I will never regret who I am and what I have. It's made me who I am and I guess that's what's important. Honestly, I really don't like the meds they give me. If I could think of one word to describe them, it's nasty. But, my mom makes me laugh about having to take them or at least she tries to make me laugh.

I had to start ARVs shortly after I was diagnosed because my CD4 count was very low and I was not feeling too great. I started taking the meds after a month and I continue to take them every day. Well, I never thought this would happen to me, but it did happen, and there's nothing I can do about it except live a positive life. My prayer is for God to keep protecting me all the days of my life.

The only problem I am facing is telling my story to others. I'm so scared that people will judge me and not want to be around me if they find out that I am HIV positive 'cuz every time I bring up the issue of HIV just to get people's

views, they say HIV positive individuals would most likely die from depression. I don't believe them, but it's hard to challenge them sometimes. I can only live my life one day at a time.

Now let me tell you how I got HIV. I was married for many years and had children. My children are my pride and joy, and they have helped and supported me through the years. Only a few years ago, my husband was admitted to the hospital because he was having a seizure. When the doctors did tests on him, they found out that he had AIDS. As soon as I sat down to help me recover from the news of my husband, the doctor told me that I should go for an HIV test. I think the blood must have drained from my face because he said, "You look very pale." Well, what did he expect me to feel after such news?

He had just told me to go for an HIV test, no information, no discussion! I sat there in silence while he wrote out instructions on a piece of paper for the hospital to do an HIV blood test on me. I remember looking at it and seeing the word HIV written on it. We got the test results back, and my children were negative, but my test came back positive. I cannot describe how I was feeling. I thought I was going to die but I knew I had to be strong for my kids. I shut down all my feelings of sadness when I was around them.

When I told my children I was HIV positive they did not know what to do. They were scared to go near me and they were scared to even touch me. We did not know one thing about HIV until doctors told us and we got counselling. I was devastated that I had HIV but I could not do anything but take care of myself and try to live my life without my kids fearing me. When I went on medication for HIV I felt weird taking the pills and I didn't like how I felt after I took them. I felt weak and helpless. I had to quit my job because HIV made me sick, but I could

not afford to live in my apartment or support my children. After quitting my job, I went on social assistance to help with all the bills and daily living expenses.

When I found out HIV and AIDS were two different things I wondered if my husband was going to have to go on pills too. But in his case it was too late for him. He could not take pills or anything. After months being in the hospital, his vital organs started to shut down and collapse. We knew this was going to be the last time we'd see him alive. I was in tears and heartbroken that I was going to lose my husband, but my children were even more devastated. They were going to lose their loving father.

After we all said out goodbyes, we had a funeral for him. We didn't know if it was a good idea to keep the casket open at his funeral for everyone to see him but we kept it open so people could say goodbye to this amazing man. Now you all must be wondering by now, how did my husband catch AIDS? I have been wondering the same and till today I do not know how my husband contracted the HIV virus that eventually led him to AIDS. I do not blame him for anything but I do wonder everyday what happened. I miss my husband a lot and I wish he were here today to see his children grow into young adulthood.

It was a difficult time for me, though one of the first things that gave me the strength to carry on was the fact my children did not have HIV and that they still were and are in my life. They have been a great source of strength for me. Either I could choose to be bitter and blame the world for infecting me with HIV, or I could make the most of whatever life I had left. I chose the latter and to this day, I appreciate each day that I am alive. I do what pleases me, within limits of course, and make absolutely no apologies for it!

It is now 2014, and it is going to be 6 years that I am living

with this illness. I am in control of it. It has no control over me. I remain happy and content with a positive attitude. Today my children are not afraid to be with me or touch me because we have all taken counselling and therapy to understand more about HIV and they know how to protect themselves from getting HIV. I have gone through a wave of emotions and feelings and it's been one hell of a ride! I am so thankful for the support I have from my friends and family and the support I can give back to them.

I would hope anyone that's reading this will understand that it will feel at first like your life has ended when you get an HIV diagnosis. You might wonder how you will function but believe me something like this makes you put life into perspective and you discover just how precious the time you have. What life deals us is what makes us stronger. Believe in yourselves and make the best of what you've got. I won't lie and say I don't have my down days, but I also have some really great days. Truthfully, not a day goes by without my status and the memory of my husband on my mind. I have the conviction and energy to carry on, though, and make my life mean something to me and to my children.



**THERE IS ONLY ONE HAPPINESS IN  
THIS LIFE: TO LOVE AND BE LOVED**





# LIVING WITH LOVE FOR 30 YEARS

NUPUR

I want to share the story about my 30th wedding anniversary. The celebration party we held to commemorate our special day included all the sights, scents, and tastes of a South Asian gathering of friends and family – sweet, salty, and spicy!

Normally, couples do something special on their 25th year of being together, but my husband and I wanted to do something different. We were visiting our home country and realized that we had been together for 30 years as a couple. We wanted to recognize our union while we were there surrounded by all of the people we grew up with and the people who were part of our extended families and helped raise us.

We thought it would be fun to organize a festive celebration, so we booked a banquet hall, and in our home country, those banquet halls can be quite big, holding up to hundreds of party guests for a single event. The event organizer wondered why we were commemorating our 30th, which seemed odd to him, but after we explained that it was just the right time, he supported our idea and congratulated us for remaining committed to each other. He went ahead and booked the hall for us, and also took care of everything else, including the entertainment and decorations.

The food included some tasty traditional dishes as part of a four-course meal, and a DJ played our favourite tunes from our younger days. The hall looked bright with warm festive colours that encouraged our guests to enjoy and celebrate our marriage, for it was a very special marriage! My husband and I had met and fallen in love. We knew that it wasn't the custom in our families to choose marriage partners based on love alone, but for us,

it was wonderful to have found each other. We decided to elope because that was the only way we could make a commitment without anyone interfering.

When we returned as a married couple, we didn't know what to expect from our families. They were naturally upset that we had made a decision without their input. But when they saw how loving we were to each other, and how compatible we were as husband and wife, they eventually gave us their blessings and realized we had done the right thing.

There's a lot of news in South Asian communities today about parents punishing their children for being in romantic relationships or for eloping. It's sad how some people react. Our families never tried to control us or dictate to us what we should do with our lives. Of course, we grew up with certain traditions and customs, which we respected and still respect, but people were still open to new things even if it took them a while to get used to them. With this story, I hope people will understand that not all South Asian families should be painted with the same brush. We all communicated openly about our feelings, and finally, people learned to accept us and our marriage.

Through our 30+ years together, supporting each other with our health challenges, and never taking each other for granted, we have come to understand that there is only one happiness in this life: to love and to be loved.



**I HAD TO  
BE STRONG**

for everyones sake

# WHAT DOESN'T KILL YOU MAKES YOU STRONGER

ADITI

I was the youngest child of a very big family, and was raised by my grandma whom I loved with all my heart. When I was in high school, I met a guy and we started dating. We eloped. I got pregnant and he left me back home with his mother. I gave birth, and got very sick and lost a lot of blood. I needed a blood transfusion, so one of my family members said that if he couldn't save my life, he could at least save my baby's, and the doctor took his blood.

A few months after giving birth, my baby passed away and I left my country to come to Canada with my husband. I got pregnant again, and that's when the family member who gave me blood called and told me that he had just found out that he was HIV positive. He told me that I needed to get tested. I prayed to God that my husband and my child would be ok. But both of them tested HIV positive. I had my child tested again after a couple of years, and I was so relieved to know that the results came back negative. It was the happiest time of my life. From then, I started taking better care of my health and my family's health.

When I found out I was HIV positive, I didn't have any emotional reaction to the news. I felt that I had to be strong. My doctor told me the news three times and he asked if I was ok. I reassured him that I was fine. When I arrived home, I told my husband that my blood work came back positive. My husband gave me a warm hug and told me not to worry because everything would be ok. He wasn't angry because he had faith in me and trusted me. He said he loved me no matter what. I was so thankful for his support. He didn't judge me. We were in this together. At the time when both my husband and child had been

diagnosed HIV positive, I felt like I wanted to die because I had infected the most innocent member of our family. But I told myself I had to be strong for everyone's sake so we could pull through the crisis. I turned to my faith to help me cope. All the prayers I recited came through for me when my child was re-tested and was diagnosed HIV-negative.

But the virus did catch up with me, and after a few years, I got really sick and had to go to emergency. After one hour, they pronounced me dead. For 45 minutes, my body was lifeless. The doctor called my husband to tell him the news. As he was doing that, two nurses came into my room and they saw me sitting up on the gurney. They ran off screaming, and called for the medical team to come and see me. The doctors asked me questions to make sure I was really ok. After a few minutes, I saw three doctors and they started asking me questions like, was I ok? I got all my vital organs checked again, and everything was normal. I didn't sleep for four days because I was so scared that I'd die again.

I don't tell anyone outside my immediate circle of family and close friends about my HIV status because I don't know how they're going to react. I keep it to myself. But it's very hard to have to hide it all the time because I get sick very often. When friends and relatives ask, I have to lie and tell them that I have cancer or another chronic illness that is more socially acceptable. If they ever found out what I really had, they would spread the news to others in the community. I've heard people say that if someone has HIV, they don't deserve to live. I don't subscribe to that way of thinking. I've come a long way through my own experience living with HIV.

My faith has kept me strong. I believe in God and whenever I have bad days, I'll go to the temple and sit there for hours until I get my fill and I feel good again. I often hear a voice in my head telling me that everything will be fine. My doctor is also a big support. She calls me her miracle patient because I always have a smile on my face no matter how bad the illness can get. I have a very strong belief in my ability to overcome. I know in my heart that God is with me, and that nothing will happen to me until my time comes.

I tell my family this all the time, and I encourage them to be happy and to enjoy their lives. I like doing my garden. I feel free from stress and I love looking at the flowers. They make me feel good about myself. Most importantly, I love spending time with my family. My family means the world to me. Every Sunday, we have family meetings where we share with each other everything that happened during the week. Sometimes we go out for dinner, or a movie, or a long drive, so we can spend some quality time in one another's company.

Twenty years ago, I was very sick and everyone thought I was going to die, but I'm still here, living, breathing, and loving all that I am, and every moment I'm alive.



