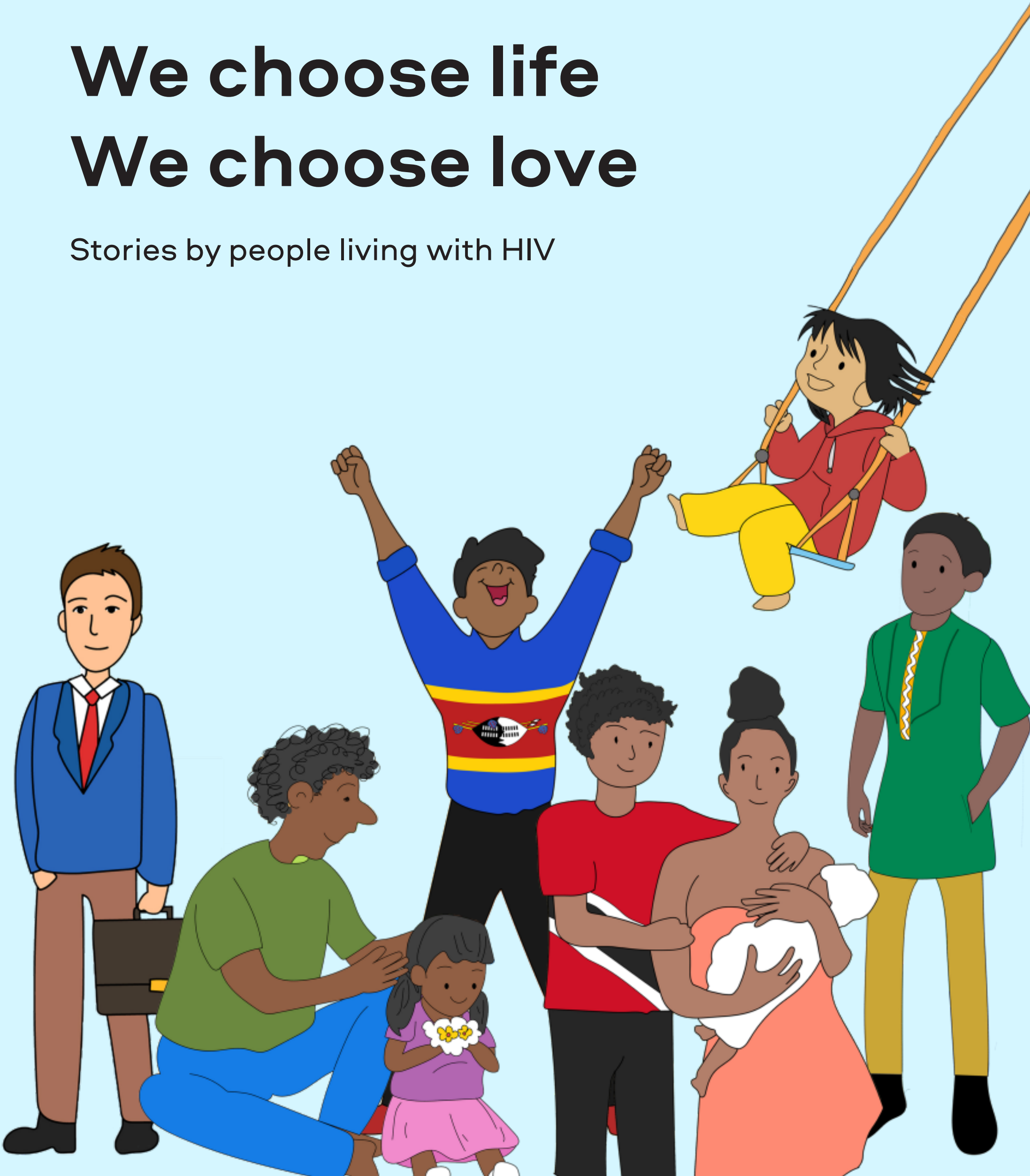
BEYOND LIVING

We choose life
We choose love

Stories by people living with HIV



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Beyond LIVING is a consultation and advocacy process led by GNP+, ICW and Y+ Global, the global networks of people living with HIV. We are guided by a diverse and creative Life Force – people from across regions with different lived experiences, helping us to connect our global advocacy to the realities of countries and communities.

We are grateful to the Life Force members of Beyond LIVING who agreed to author their own stories. For many, this was their first experience of writing their stories and we appreciate their commitment to sharing openly.

We are also grateful to Life Force member, Eva Dewamasyitha for illustrating each story and celebrate her talent.

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Introduction

From the very beginning of the HIV epidemic, people living with HIV have faced shame, blame and stigma – from family, from wider society and from themselves.

Much has happened in the past four decades. Activism, science and political commitment has changed the HIV epidemic globally. While there is still no cure, people living with HIV can live their lives like others. Almost three-quarters of people living with HIV around the world have access to treatment. Treatment options continue to improve - many people only need one pill a day. Soon even this burden will be reduced, as people will be able to get their treatment through an injection every two months. There are also medicines to protect oneself from getting HIV. A person living with HIV who is able to take their treatment regularly has an undetectable viral load. This is good for their own health and also has a prevention benefit - as the slogan goes “U=U” (undetectable=untransmittable).

Despite these advances, some things haven’t changed as much. In country after country, people living with HIV continue to identify stigma as the biggest challenge they face. All the science and all the investment has not changed our mindsets enough. Our governments continue to punish or criminalise whole communities – sex workers, LGBTI communities, people who use drugs. This drives ignorance and fear which in turn lead to blame and exclusion. We are seeing this again with COVID-19.

This book brings together a collection of six stories and visuals by people living with HIV from around the world. The stories are real. As the global networks of people living with HIV, we know that these stories are not unique. From self-stigma and rejection by loved ones to being excluded from schools and workplaces, these stories capture some of the many ways people living with HIV experience stigma.

However, these stories also highlight the resilience of people living with HIV and the support and solidarity that they have found. These are stories of overcoming rejection and discrimination. They are stories of choosing to live and choosing to love. They are stories of giving back to the community and contributing to society.

Gentil

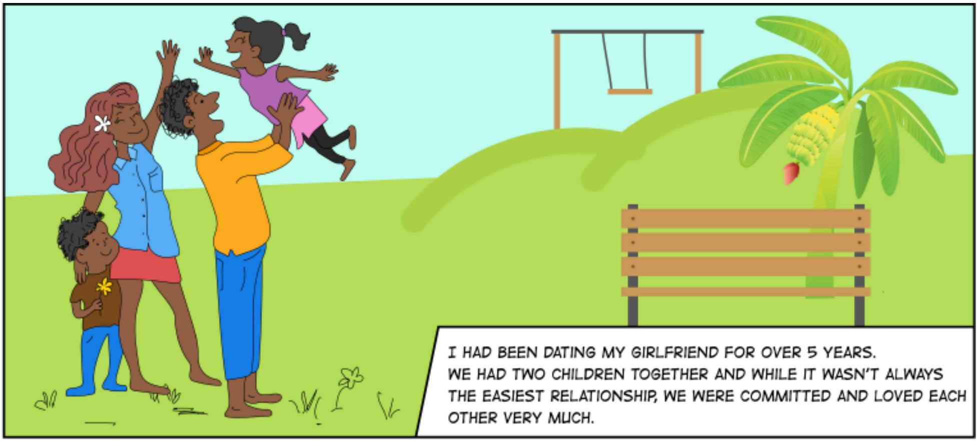
Burundi

I had been dating my girlfriend for over 5 years. We had two children together and while it wasn't always the easiest relationship, we were committed and loved each other very much. One day I came home to find my life completely changed. The woman I thought I knew and loved said to me that she did not love me anymore and she had been doing me a favour staying in the relationship because she was not HIV positive.

I was heartbroken for myself but also for our children. Years later I found out that she had been pressured by her own family and her church community to end the relationship.

For me, resilience came from my years of leading the Burundian organisation of young people living with HIV (RNJ+). The organisation's main objective was to fight against the stigma and discrimination suffered by young people. I knew I was not alone and leaned on my HIV positive community for support.

Even though their mother ended our relationship, I never stopped loving and providing for my children, as I am their father. I try to role model love, compassion and understanding. Today, I have started a new chapter, with a new family. Both my wife and I are HIV positive and everything feels fine.



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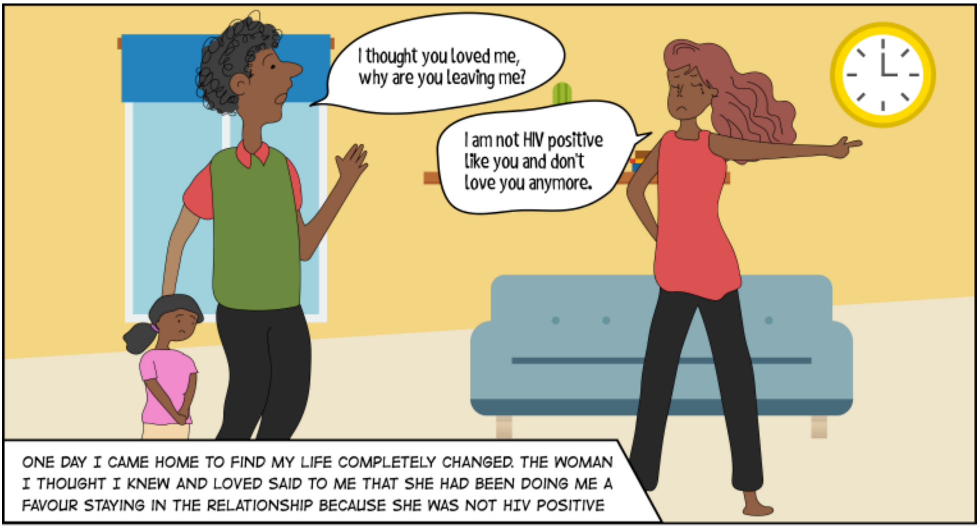

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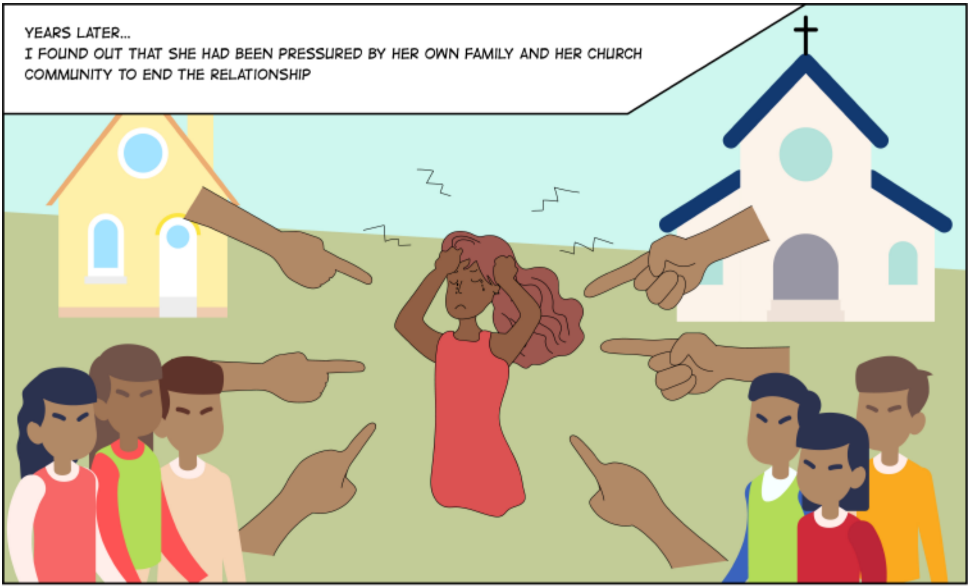
I WAS HEARTBROKEN FOR MYSELF BUT ALSO FOR OUR CHILDREN. I DON'T UNDERSTAND WHY SHE CHANGED LIKE THAT AFTER WE'VE BEEN TOGETHER ALL THIS TIME



YEARS LATER...
I FOUND OUT THAT SHE HAD BEEN PRESSURED BY HER OWN FAMILY AND HER CHURCH COMMUNITY TO END THE RELATIONSHIP

EVEN THOUGH SHE ENDED OUR RELATIONSHIP, I NEVER STOPPED LOVING AND PROVIDING MY CHILDREN, AS I AM THEIR FATHER TODAY. I TRY TO ROLE MODEL LOVE, COMPASSION AND UNDERSTANDING. TODAY, I HAVE STARTED A NEW CHAPTER, WITH A NEW FAMILY. BOTH MY WIFE AND I ARE HIV POSITIVE AND EVERYTHING FEELS FINE.

Azeez

Nigeria

Being gay in Nigeria, we all knew that we needed to test for HIV. I was 20 when I went to the neighbourhood clinic for an HIV test. But I could not believe it when the test came back positive. At that time there was no separate clinic for people with HIV and I was referred to the government military facility for a confirmatory test.

On my first day at that facility, I faced stigma for being gay and being HIV positive - from the administrative staff to the counsellor and pharmacist. They asked if I was gay. Some used abusive words. Some told me that HIV was a punishment from God. I collected the medicine but never went back. I felt traumatized and it made me not to use the medication given to me. I was still in shock that I was HIV positive and was in denial.

Few weeks later my family got to know my sexuality. They held a family meeting and I was thrown out of my home. My family shared my status with others - no one wanted to associate with me in the neighbourhood. I also lost my job because the reports reached my working place.

For a week I had to figure out where to sleep or stay. A friend I met on social media invited me to stay at his house. I told him my story including the test result which I still did not believe.

Fortunately, a few months later a new facility opened just for LGBTI people. One of my friends invited me to the clinic. I was tested again and the result still came out positive. I now felt I had to accept the result. I was encouraged to start my medication. The facility welcomed me and there was no discrimination. I was even encouraged to report any form of discrimination from any staff. We were introduced to a support group. The drugs I was prescribed had a lot of side effects which made me feel mentally down but my support group made me feel like I would not be left behind. They introduced me to a treatment partner who helped me with my adherence to my medicines.

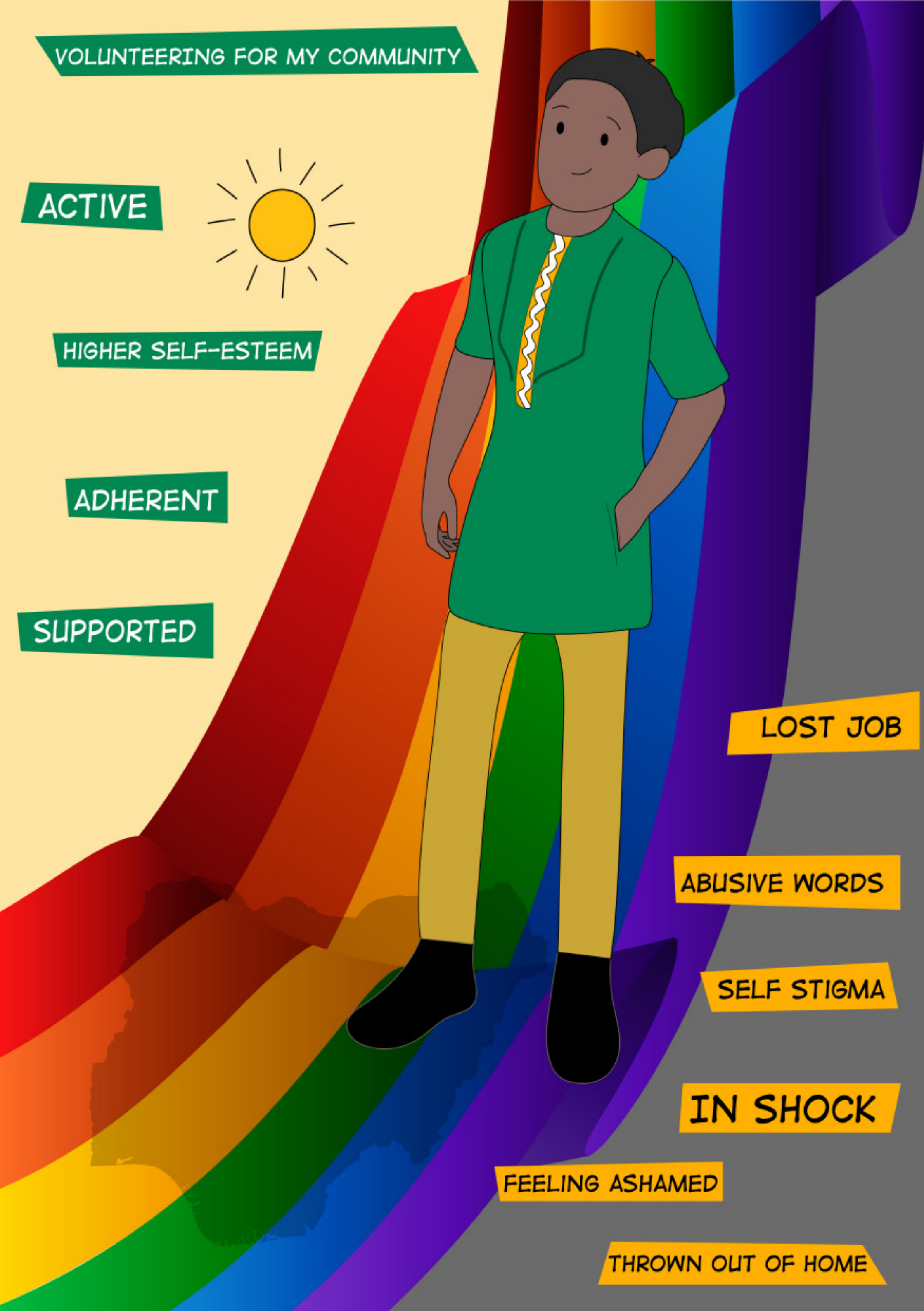
My friend who I stayed with also supported me. But I felt rejected by others. Once when I was at a party, many of my friends did not want me to sit among them and one and one said “this is not a gathering for an HIV person”.

All these problems gave me mental health issues. I was ashamed of myself and blamed myself for the infection. As a gay man living with HIV, I felt self-stigma and did not believe I could make it in life or achieve my goals. This has caused a lot of setbacks in my life. But I got help from a psychologist. And the support group of people living with HIV really boosted my confidence when I saw how people are doing well and making it.

As I remained active and responsible in taking my medication, opportunities opened up. I started volunteering as a counsellor in the HIV clinic. For the past 7 years, I have been helping people who are newly diagnosed. We are like family there.

I have built my capacity and self-esteem as a gay man living with HIV. That has led me to become an activist and I wanted to create a safe space for my community. We formed the first initiative for gay men living with HIV called Think Positive Live Positive Initiative (TPLPI) in Lagos state. We help to lower barriers between patients and health care providers; demystify HIV and its treatment; improve the quality of life for people living with HIV and foster community. We welcome those who feel excluded and help recreate ‘family’ and community networks through support groups and civic participation.
We hold trainings in developing life skills such as negotiating safe sex, relationship skills, managing HIV and side effects and dealing with discrimination.

Supporting other people living with HIV has had several measurable physical and mental health benefits for me. With the grace of God, I started a network with some gay men living with HIV and we want to change the narrative of stigma.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FEELING ASHAMED
THROWN OUT OF HOME

Sebastian

Romania

In 2015, I was offered a new job at a bank. I had applied and performed well in the interviews. I even felt relieved being offered the contract after disclosing my HIV status to the hiring manager.

On my planned start date, I woke up early, got dressed and walked to work with all the excitement that comes with a new career. When I arrived at the bank, I opened the door and told the person at the front desk that I was here to start work, showing them my freshly signed contract. To my surprise, they told me that I didn't have a contract there and that I needed to leave. I was angry, hurt and embarrassed.

I knew deep down that even though they didn't say it was because of my HIV status, I knew it was. This was later confirmed when I consulted the agency that helped me find the job. They blamed me for not mentioning my disability certificate that is given to people in Romania who are living with HIV.

After this I promised myself that I would fight for my rights and for all people living with HIV. I decided to file a human rights complaint against the bank. While I didn't win in the way that I wished, due to Romanian legislation at the time, they did apologise and gave me one month's salary. This was the first and last time in my life when I felt discrimination and stigma associated with my HIV status. I vowed to never let it happen to me again.

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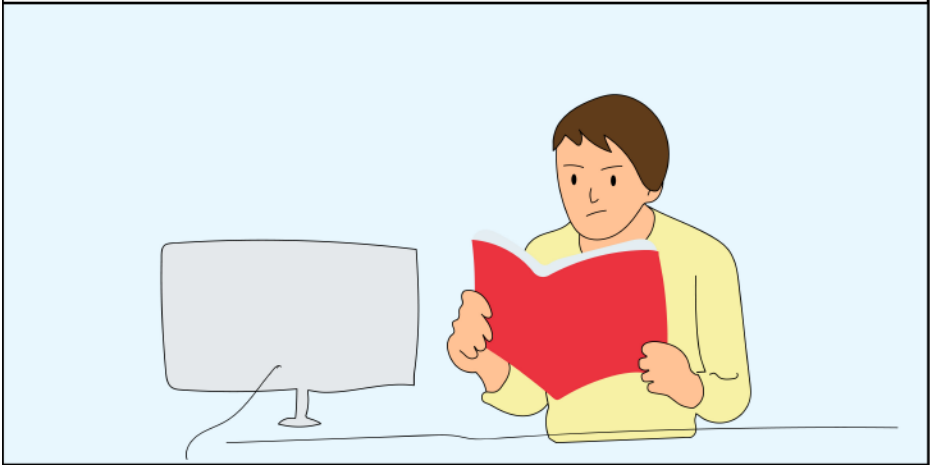


Kimberly

Trinidad & Tobago

Growing up as a child in Trinidad & Tobago, I faced a lot of hardships including abuse and trauma. I found out I was HIV positive when I was 15 but couldn't talk about it then.

It was only after I had got therapy and some medication that I was able to deal with the pain. I then went back to the clinic where I got my HIV diagnosis and spoke to a nurse called Miss Avion. I started taking ARVs and started to feel better. Whenever I needed to, I would go back to Miss Avion as I felt comfortable with her. She once told me "you have a choice – you live or you die". I chose to live.

Although I kept to myself, I was comfortable with myself. I do a lot of community work and like to help people. Soon, I met my boyfriend and I told him about my HIV status. Miss Avion had told me that if I kept taking ARVs I would be "undetectable" and this would protect my boyfriend. He continues to test negative and I don't feel worried.

However, when I got pregnant, I was scared. I went to Miss Avion immediately. I didn't want my baby to be HIV positive. She reassured me and was happy for me. She gave me literature to read so I knew that my baby had a very high chance of not getting HIV. But I felt unlucky and thought I would be in the 1% chance of my baby getting HIV. My boyfriend also reassured me "you take your medications regularly, so don't worry".

I was fine during pregnancy and kept going to the health centre. It was after I gave birth that I first faced problems.

In my country women living with HIV are provided with formula and are cautioned not to breastfeed. But for two days my daughter was not taking the formula. I walked into the nursery to feed her. The nurse there asked me to go to separate place to feed her – I was not sure why but think it was due to my HIV status. She was discreet so I brushed it off and we went home after three days.

I had a depo shot [contraceptive injection] soon after, which sounded like a good idea at the time. But it turned out to be the worst decision of my life – I had heavy bleeding for 6 months. When I went to a women's health centre an older nurse opened my file and loudly exclaimed "you are HIV positive" in a room full of people. I was horrified and upset. My boyfriend was also upset as he was aware of the stigma that HIV positive people face. I then had to sit in the same waiting room being judged by others who don't know me or my story.

I don’t share my status openly for my safety. I don’t think I have self-stigma. I have been undetectable for 10 years and my boyfriend is HIV negative. And he chooses to stay. Most of my fear was around my baby. But her result came back negative, so I am happy.

I am my strength. I had got therapy in the past so was comfortable with my reality. Now my daughter is my strength. I know that nobody can look after her or care for her better than me.

In 2020, Miss Avion introduced me to the Trinidad & Tobago Community of Women Living with HIV (TTCW) as I had more time and wanted to be active. TTCW leaders welcomed me – they introduced me to their global network ICW and gave me opportunities. One of these was an opportunity to share the traumatic story of my childhood. I have now met others who have also survived different forms of trauma like a woman who survived the Rwandan genocide. It helped me feel comfortable sharing with others who have similar experiences.

I am not the same person I was before. I can now put my passion and energy into serving my communities and learning new things.


PREGNANT WOMEN AND MOTHERS LIVING WITH HIV
HAVE THE SAME RIGHTS AS OTHER WOMEN

Eva

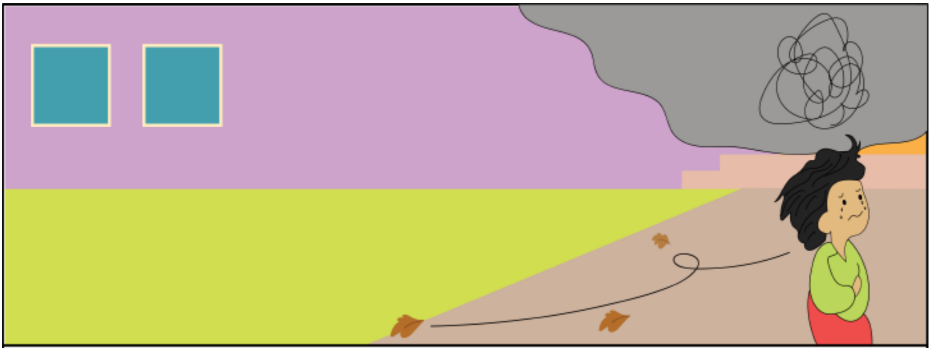
Indonesia

In 2017, I found out that I was HIV positive and a few days after that, my 2 year old son tested positive too. Words cannot express how guilty I felt for transmitting HIV to my child.

I could not overcome the grief and blame. One day I attempted to commit suicide and end my own life. It was the only way that I could think of to make the grief stop. Following my suicide attempt, my friends and family pressured me into psychiatric therapy, which I am thankful for. After a long and slow process of healing, I began to forgive myself for our HIV status.

One lesson that I learned through this process was to not disclose my child's HIV status, after he was rejected from attending school when he was 3 years old, based on him being HIV positive. Creating our own family boundaries, works in partnership with taking our treatment and focusing on our health and wellbeing. My HIV is not a barrier to my success and his HIV status will not be a barrier for him either.

My resilience in dealing with stigma and discrimination starts with me and finding and maintaining peace inside. I gain power and love from those closest around me, including my children. My quality of life is tied to their quality of life and therefore I must remember that. Even on days when I am feeling down, my children still need me, and even if I struggle, I must overcome all my fears so I can live with them for a long time.



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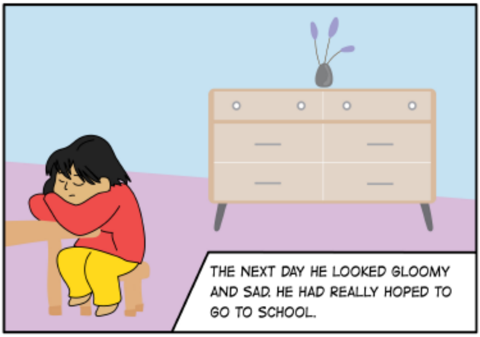
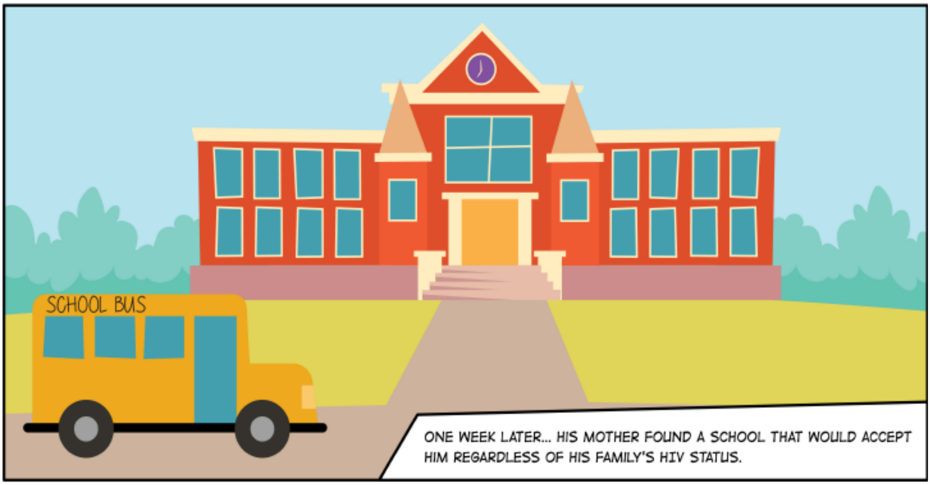
TWO YEARS LATER...
THEY REFUSED TO LET MY CHILDREN JOIN THE SCHOOL BECAUSE OF OUR FAMILY'S HIV STATUS

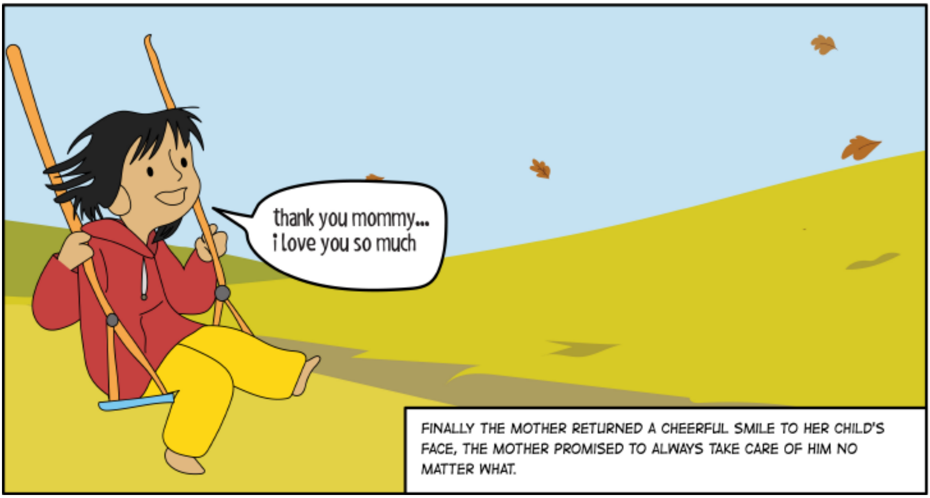
THE NEXT MORNING I TRIED TO EXPLAIN THAT WE HAD TO FIND ANOTHER SCHOOL FOR HIM. HE JUST SAT THERE HOLDING HIMSELF FROM CRYING.



THE NEXT DAY HE LOOKED GLOOMY AND SAD. HE HAD REALLY HOPED TO GO TO SCHOOL.



ONE WEEK LATER... HIS MOTHER FOUND A SCHOOL THAT WOULD ACCEPT HIM REGARDLESS OF HIS FAMILY'S HIV STATUS.



FINALLY THE MOTHER RETURNED A CHEERFUL SMILE TO HER CHILD'S FACE, THE MOTHER PROMISED TO ALWAYS TAKE CARE OF HIM NO MATTER WHAT.

Mthobisi

Eswatini

In June 2020, people in Eswatini, like in other countries, were struggling with COVID-19 and a lot of restrictions were put in place. I am a young person living with HIV and we need to take our treatment regularly to keep well.

One day I was travelling on a minibus to the health facility to collect my medicines. Suddenly the bus was stopped at a roadblock by security personnel. They requested a travel permit from all of us. I did not have a permit and the only proof that I was going to the hospital for my medication was my remaining two tablets of ARVs and my treatment card. I was afraid to show my treatment card to the security person but he harassed me and demanded it forcefully. Unfortunately, he was not able to understand what was written on it so then I was forced to disclose my HIV status in the minibus. I was upset as I know stigma against people living with HIV is high in my country.

Since then, I feared traveling during the COVID-19 pandemic even for essential trips. However, I am a volunteer advocate working with many organisations such as Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), Baylor and the Swaziland Network of Young Positives (SNYP+). They offered me psychosocial counselling as I was traumatized and developed a fear of police and soldiers.

My story was not unique – many people living with HIV struggled to collect their ARVs and keep up with their HIV treatment during COVID. In response, SNYP+ which is an affiliate of the Y+ Global network started strong advocacy with the Ministry of Health and with law enforcers to ease the travel restrictions for people living with HIV going to health facilities.

Their advocacy was successful - it was an important step for all those who might have faced a similar situation. I was lucky to get counselling and support to understand my rights including to health care. Being empowered can help overcome stigma and discrimination.

LIVING WITH HIV DURING COVID-19


TRAVEL PERMIT
DISCLOSE HIV STATUS


BEYOND
LIVING