Living with HIV personal stories and experiences

Learning that you are HIV-positive can be one of the most difficult experiences you go through in life. You may feel scared, sad or even angry – this is OK, and a completely natural part of coping with something that can be life changing.

But remember, HIV doesn’t have to stop you living a long, happy and fulfilling life. With the right treatment and support, it is possible to live as long as the average person.

There are a lot of misconceptions about what it means to be living with HIV. Ultimately, everyone’s lives are different – how you cope with your diagnosis and how you move forward will be unique.

Read these stories about some people’s experiences of being diagnosed with and living with HIV.

If you have your own story to tell, you can share it with us here and we’ll do our best to publish it. Just let us know if you’d like to remain anonymous.

*Photos are used for illustrative purposes. They do not imply the health status or behaviour on the part of the people in the photo.*

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30 June 2019

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Boris - go and get tested for HIV

Lara - I'm studying HIV/AIDS management

Lynette - diagnosed at birth

'I know you’ll hear this a lot but I’ll say it anyway: If you take your meds HIV will not kill you. It’s not the end.'

'I was constantly educated about HIV, but trying to understand it was so hard.'
Masiye – The hardest part was telling my kids

‘I still cry but I don’t allow my status to stop me working towards my goals in life.’

Makena - it didn’t seem like a big deal when I first found out

‘I was under other pressures at home and at school but my biggest fear was failing my new treatment.’

Arun – HIV treatment is free here at least

“I was very scared when the counsellor told me that I was HIV-positive and I cried.”

Raya - I was ashamed, kept asking myself, ‘How this could be?’

“To anyone reading this: I want you to know that there is no rush at all, tell people when you feel you’re ready.”

Mariana - It’s great to share what we have in our hearts

“I still worry about my responsibilities but I know that taking my medicine is the best thing I can do.”

Anna - it's okay to be scared... the important thing is to get support

“I’m the first to admit that growing up with HIV positive parents was agonising"

Karan – let’s work together to stop the discrimination

“I was ashamed to be open about my condition due to fear of embarrassment and

Benoite - finding out you and your partner are HIV-positive

“The tester was so amazing... telling me he’d known people living with HIV for 25+ years. I

Ricardo - self-stigma made me feel depressed

“Forgetting myself was the first step to starting treatment, but it was still the hardest decision for
“Humiliation.” “Latched on to those words.” “Me to make.”

Elizabeth – I’m glad I didn’t give up on love

“It was my faith that got me through. I decided this would not ruin me.”

Kain - coping with being HIV-positive

“I have learnt a lot about myself. ‘Living with HIV undoubtedly has its calm waters and turbulent storms; but it doesn’t define who you are.’

Michael – turn living with HIV into a strength

“I have become more headstrong.”

“Living with HIV undoubtedly has its calm waters and turbulent storms; but it doesn’t define who you are.’

Claire - being born with HIV

“I am still very quiet about my status to my friends. But otherwise, I don’t let my HIV affect me in any way. I am a normal teen.”

Jesse – My specialist reassured all my worries

“I’ve started treatment and although I still have sickness I feel that I will be ok.”

Israel – my HIV story

“I still go in for my routine therapy every two months but that’s the only thing that has really changed in my life.”
Esther – I learnt to accept myself

"Even today it still hurts but I am going strong no matter what."

Curt - learning you are HIV-positive

“My point to this is find some sort of positive support from the time you find out until the time you can rely on yourself.”

Dembe – I represent young people with HIV

‘Now I cope with this new life, to extent of advocating for it.’

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Harrison - testing HIV-positive in the army

“I tested HIV positive in August 2012, when I wanted to join the Nigerian Army... I was dumbfounded.”

Luthando – I gave birth to a positive baby

‘Now my daughter is 14 years old. I’m healthy and she's healthy too.’

Ryan - testing positive for HIV

"I’m happy with the love and support from my friends and family. There is always a life after an HIV-positive diagnosis."

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Bayani – My diagnosis gave me a second chance

‘I want to take care and begin to love myself.’

Mulilo - getting over a diagnosis

‘The day that I disclosed to my brother was through text message, because I didn't have"

Thadie – silence can kill, talk about it

"I speak about it… it’s how I’ve managed all these years and lived a normal life”
Rick - choosing to live, not die

“I gave up my bad habits and started having my family in my life more than ever before.”

Amaka - on treatment and never sick

“Do not be scared... You can live a healthy life if you adhere to your medication – I have never fallen sick since then.”

Karuna - I’m now a peer educator

“During my first year of work, the organisation and I faced discriminatory remarks because they employed a drug user to work.”

Krish - we just need love, care, equality and support

“I felt that if I told someone that I was positive, they would judge me and wouldn’t accept me. So I kept it a secret for more than 20 years.”

Karta - HIV stigma changed my whole life

“The hospital I was about to start working at refused to hire me after I disclosed my HIV status.”

Talent - I lost my job when my company found out my status

“At that moment I knew I had lost my job and I almost went mad, thinking what am I going to tell my wife?”
Carrie - Fear meant I kept my status a secret for 3 years.

Grace - HIV taught me to live a full life

Chris - how I overcame stigma to be healthy and in love

“I felt that if I told someone that "At age 61, I found out I was HIV" When I told him my status I thought he would run for the hills, but to my surprise he told me he didn't care.”

Ruth - I want to give hope to those still suffering

Alan - Don't be scared to tell people

Amber – have faith in yourself and continue to live your life

"My dream is to go all around the world and give hope to those still suffering." "I think if I had kept it a secret, it would have played on my mind more and probably made me quite depressed." "Thanks to the help and love I got from my man and the healthcare providers, I am positive about my disease."