

# *To our dead*

Testimonies from the living, 2016– 2019



*The testimonies in this booklet were collected in November 2019 by Coalition PLUS, an international network of associations in the fight against AIDS and viral hepatitis, from its member associations and partners in Africa.*

*These life stories, recounted by families, carers and activists, constitute the very heart of our campaign, “One million deaths, Zero plan”. One million deaths - that is the number of estimated HIV-related deaths in 2016.*

*The States committed to reducing this terrifying figure by half by 2020. Yet one year from this deadline, this target is still far from being achieved and the decline in HIV-related mortality is experiencing a worrying slowdown. Between 2017 and 2018, the number of deaths caused by HIV/AIDS fell by just 30,000. At this rate, the 2020 target to bring the number down to under 500,000 deaths per year will not be achieved until 2028. In the meantime, the death toll is mounting, yet without any concrete action being taken to avoid it.*

*Faced with this emergency, we, as activists in the fight against AIDS united within Coalition PLUS, are calling for the implementation of a specific plan to provide better care for the opportunistic infections affecting people with advanced HIV infection.*

# Outraged.

I've been living with HIV for 33 years. I was the first person in Burundi to talk about my HIV-positive status openly. Back then, dying of AIDS bore a stigma.

My baby had just died. His name was Guy Bertrand.

I simply could not accept the gratuitous condemnation. It is this outrage as a mother that has always guided my struggle against discrimination and stigmatization.

I am still outraged to this day.

Outraged to see that, more than 30 years after the discovery of HIV, universal access to treatment remains an empty hope. Outraged to see that people living with HIV, particularly those among key populations, are still treated like second-class patients. Outraged to have to endlessly count the deaths that we are supposed to collectively avoid. Outraged by the deafening silence of our governments regarding AIDS-related mortality.

As aberrational as they are, these deaths trap our communities in a vicious circle of vulnerability and put a price on the future of our countries. Those who have died leave behind them unfulfilled hopes and broken families.

Some of these deaths remain invisible. They are attributed to chronic medical conditions, like diabetes and heart disease, even though people living with HIV are more at risk of developing these problems. We are told that it is impossible to demonstrate the causality between suicide and HIV-positive status, even though, too often, HIV-positive individuals still suffer high levels of stigma, which can have a lasting effect on their mental health.

Through this booklet, our community-based associations, united within Coalition PLUS, have sought to restore the consideration and respect due to these people so recently deceased from AIDS.

We hope that it will give you an understanding of the reality of HIV-related deaths and the pain, regrets and anger that accompany them. Now is the time to act: tomorrow it will be too late.

# Pascal, 1990 • 2018

*By Hervé Antoine Yemi, psychosocial counselor at  
Humanity First — Cameroon*

— Pascal was being monitored within our community-based association. He was diagnosed HIV-positive in 2012 and began his treatment at the central hospital in Yaoundé. He came to the association to take part in support groups and educational talks on positive living. Having trained as a restaurant owner, Pascal opened a restaurant called “La Balance”. He lent us his culinary services and was even in demand among local NGOs.

It seemed that he had it all. But physically, Pascal was not well, he showed signs of fatigue and had spots across his skin. What’s more, his latest viral load was detectable. After several follow-up tests, the diagnosis was definitive: he was suffering from Kaposi sarcoma and also had tuberculosis. He was admitted to the Jamot center to treat the tuberculosis, and was also undergoing chemotherapy for the Kaposi. Unfortunately, after three weeks in hospital, Pascal succumbed to the illness.

His death came as a shock within our association and beyond, because Pascal was a model of resilience for our community, who are often outcast from families due to their sexual orientation or HIV-positive status. He had decided to fight for his life and did not give up on learning he was HIV-positive. Quite the contrary, it made him all the more determined. But he stopped the treatment and the illness took over.

# Hakima,

## 2001 • 2019

*By Soukaina Zerradi, psychologist with the Association de lutte contre le sida (ALCS) — Morocco*

— As a psychologist, I often work with people living with HIV, hospitalized at the CHU. That's where I met Hakima, just under two years ago, when she was transferred from the pediatric ward to infectious diseases. She had to leave school because of her health problems. That was a huge blow for her, and she hoped one day to go back. Hakima loved drawing. She spent her time drawing fictional characters, animals and animations from her hospital bed, and was immensely proud of them.

She didn't have an easy life. After her mother died, she fell out with her father and extended family. None of the adults in her family were willing to take her in, and she was often left wondering where she would live and if she would end up in an orphanage. It was very difficult for her. In the last months before her death, she lived with her older brother. But family conflicts and financial difficulties were a constant aspect of her life.

Hakima stopped and started her treatment several times, and her health declined. The last time she was hospitalized, she was no longer talking or walking, and found the presence of others trying. I had never seen her in such a bad state.

But we did everything we could to give her hope. We wanted to keep hold of this hope ourselves. Her death was a shock for us because we hoped to see her recover and grow up. We would have wanted her to have an easier, more stable and happier life, and to achieve her dreams. Her loss is a great sadness to all who knew her.

# B.B., 1979 • 2018

*By Pélagie Nimbona, doctor with the Bujumbura branch of the Association nationale de soutien aux séropositifs et malades du Sida (ANSS) — Burundi*

— B.B. was admitted to our care in January 2005. She had thoracic herpes zoster and was generally in very poor health. We ran a HIV test which came back positive. At the time, we had to wait for the results of the CD4 test before starting treatment. She was put on antiretroviral treatment in August 2006.

B.B. had a very complicated personal life: raped by one of her mother's colleagues, she became pregnant aged 14 and had to leave school. Rejected by her biological family, who could not accept her pregnancy, she developed psychosis and was a regular figure wandering the streets asking those she knew for money.

B.B. often had fits, and had to be hospitalized on several occasions within a neuropsychiatric center. The ANSS paid her hospital fees. In 2012, B.B. once again fell pregnant. The ANSS provided support as part of its program to prevent mother-to-child HIV-transmission. She gave birth to a HIV-negative little girl.

Our team did everything possible to ensure support for B.B., but she was badly affected by her family's rejection. She found it very difficult to keep up her treatment, leading her to develop opportunistic infections.

Severely weakened, B.B. passed away in November 2018.

# Aïcha, 2001 • 2019

*By Marhya Moussiele, member of the Association des Jeunes Positifs du Congo (AJPC) — Republic of Congo*

— I met Aïcha at a psychological support group for people living with HIV. She was a shy, quiet and studious young girl. She was born with HIV, and her parents died while she was still a baby. She lived with her grandmother, who gave her her treatment without telling her she was HIV-positive.

At the age of 7, Aïcha joined the support groups to raise awareness of HIV/AIDS among young people, as well as its treatment and nutrition. As she got older, these sessions made her curious about the treatment she took on a daily basis. She naturally wanted to know more, and spoke to a psychologist, who told her she was HIV-positive. Aïcha accepted the news well at the time.

But as she reached adulthood, everything changed. Aïcha had a busy social life. She spent most of her time with her friends and often went out, like many young women. However, her family did not approve of this lifestyle and accused her (unfoundedly) of behaving like a prostitute, and of going out to infect men. Things got out of hand: her family exposed her HIV-positive status to the entire neighborhood, and further afield! Scorned by all around her, Aïcha became so desolate that she ended her life by drinking acid.

Her death shattered me. It is not right that, in 2019, people living with HIV still suffer such discrimination, within their own families. Thanks to the treatment, Aïcha could have lived a full life, without transmitting HIV. But instead she is gone. That is my biggest regret.

# Fontaine, 1996 • 2017

*By Patrick Uwimana, peer educator and head of monitoring-evaluation at the Association nationale de soutien aux séropositifs et malades du Sida (ANSS) — Burundi*

— I joined the Maison de la Joie in 2002, a transit center for HIV-positive children. That's where I met Fontaine.

She was a sociable, courageous, cheerful young woman, and very fashionable. She was also mature and responsible - she was the one in charge at the Maison de la Joie! It was Fontaine that would speak on behalf of the other youths and children at ceremonies like Christmas. She lost both her parents to AIDS. After their death, she lived with her grandmother and sisters. She was placed at the Maison de la Joie to help her follow her antiretroviral treatment.

In 2009, she was also diagnosed with heart disease\*, which steadily weakened her. Fontaine was often hospitalized, which led her to drop out of her secondary studies. In 2017, after a decade of antiretroviral treatment and the constant support of the ANSS, she died in hospital aged just 21. Her death greatly saddened all of the young people at the ANSS, who were there for her right to the end.

*\* HIV is a risk factor in the development of heart disease. Some antiretroviral treatments are also linked to the development of cardiovascular disease.*

# A.D., 1989 • 2019

*By Diarra Zoumana, medical coordinator at the CESAC in Bamako, managed by the ARCAD-SIDA association — Mali*

— Born in Nigeria, A.D. came to Kéniéba in the Kayes region, in the west of Mali, in search of a better life for herself and her family. As a sex worker - like many women in this gold-bearing zone -, she already had advanced HIV infection and was being treated by the referring health center in this district.

When A.D. arrived at the CESAC in Bamako, her health had already deteriorated. With no family in Mali to support her, she could not afford the cost of care that would have given her access to coordinated treatment in a healthcare facility. Despite the efforts of the CESAC team, she died two weeks after her admission, aged just 30.

Her death left us distraught. All she wanted was to improve her living conditions, like anyone else, yet A.D. died without dignity in another country, far from her family. The transportation of her body for the funeral had to be organized with the support of the CESAC and community-based associations, particularly ARCAD-SIDA and the AFAS (Association Féminine d'Aide et Soutien aux Veuves et Orphelins du SIDA).

# Covilen, 1974 • 2016

*By Brigitte Michel, Coordinator at AIDES Infos Espoir et Solidarité (AILES) — Mauritius*

— As an AILES coordinator, I work in the field and support patients at methadone substitution treatment centers. It was at one of these centers that I met Covilen, who had come to thank the staff for helping get him on the treatment. We talked a little that day, and he became the association's most determined and committed volunteer.

Covilen learned he was HIV-positive when he was 20. It was all very sudden. The son of a farmer, he excelled at school and worked as a manager in the public sector. His family and friends were extremely proud of him. He was building the family home, which ended up going to his nephews. But when his family learned that he was injecting heroine, they immediately disowned him, disinherited him and stripped him of his rights. Despite all of his efforts, his family never forgave him, never supported him. He was devastated, which pushed him further down the path of other psychoactive substances.

In 2010, Covilen joined AILES as a peer educator. He quickly became one of our top people. He had an incredible drive and ability to connect with his peers. He threw himself into his work to support and assist the users of our services.

He had this fervor, this indignation against society, against his family, against the world. He saw his HIV-positive status as an injustice, and would not accept that children, women and young people could be infected by HIV. Yet he strove to transform this anger and this feeling of injustice into a desire to help his peers, and he did a lot of work on himself to get over his trauma.

Covilen was on antiretroviral treatment, but each quarrel with his family represented another obstacle to his health. It was paradoxical, because he knew precisely the effects the medication had on his system, he did everything he could to make sure his peers understood the importance of triple-combination therapy and stuck with their treatment, but for him it was a real inner struggle.

The day he fell into a coma we realized he was no longer taking his medication. We were all greatly shocked and affected by his state of health. He died after just a few weeks of intensive care. A few days before he passed, he opened his eyes and we truly believed that his fervor, his strength, his indignation could help him overcome the illness. He was 42.

Today marks three years since Covilen passed away. He is still very much in my thoughts, and those of all the team. He left behind his indignation and this feeling of injustice that guide us, that give us strength in our struggle and give us the courage to denounce the inequalities we see every day in the field.

# L.J., 1991 • 2019

*By Matbilde Affi Nouvi, nurse at the Espoir Vie Togo (EVT) association care center — Togo*

— When I first met L.J., when he arrived at the EVT care center in 2003, he was full of energy. Left motherless and fatherless and living with HIV since birth, he had nevertheless decided to take on life with confidence and had all sorts of plans for the future!

L.J. had been on antiretroviral treatment since the age of 16 and received psychosocial support at the EVT. But he had suffered discrimination and stigmatization from his guardians since the death of his mother. This lack of support affected his adherence to the treatment and the illness caught up with him: in 2017, he was diagnosed with chronic kidney disease due to HIV-related nephropathy. Despite dialysis, L.J. passed away two years later at the CHU in Lomé, following much suffering. He was just 27.

For me, L.J.'s death represented an utter failure, and plunged me into depression. I had become too attached to him: after his death, I had to take at least two months off work.

## *Acknowledgments*

The individual stories collected within this booklet testify to the diversity of the life paths and the circumstances surrounding the passing of those who have died of HIV-related causes in the last three years. They are moving, they anger, and they illustrate the powerlessness that we, as carers, activists and families feel in the face of these deaths, that are all the more unbearable since in this day they could be avoided. This booklet is also a much needed reminder of the reality of the epidemic. That is why I would like to thank everyone who contributed to its production.

First of all thank you to those who accepted to share their experiences. It is never easy to delve into your memories to talk about the death of a loved one, a patient, or a colleague. For that I would like to express my sincere thanks to them, on behalf of Coalition PLUS, for this contribution.

Thank you also to our member associations and partners, who have come together to shed light on this taboo subject and to give a voice to those too often left on the sidelines. HIV-related mortality should not be concealed: quite the opposite, we need to face up to it if we want to drastically reduce this rate.

Lastly, thank you to the health professionals, peers and activists who support people living with HIV every day to help them combat social isolation, boost their self-esteem and (re)build their lives, in order to take care of themselves and others. This community-based support, with no judgment and in complete confidentiality, is one of the keys to reducing the number of HIV-related deaths.

Unfortunately, the testimonies collected in this booklet are proof in themselves: this essential work can only do so much in the face of stigmatization, discrimination, the lack of health infrastructure and the difficulties in access to testing and to treatment.

It is only through collective action that we can act effectively on these issues. That is the mission Coalition PLUS has set itself: being a real force for change, through and for people infected with, affected by and vulnerable to HIV/AIDS. Together, we can end the epidemic and improve the quality of care for those infected.

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