



**STORIES
FROM AN
AGING
PANDEMIC**

AGING IN HIV: OUR PURPOSE

Increasingly, simple and effective HIV treatments are making it possible for People Living with HIV to grow older, changing the profile of the HIV pandemic. It is estimated that 50% of People Living with HIV are over 50 years of age.

This increased life expectancy, combined with HIV-related chronic inflammation and long-term exposure to antiretroviral drugs, creates new challenges for healthcare professionals working to provide individualized health care to patients living with multiple simultaneous medical diagnoses, the potentially conflicting treatments prescribed to address those diagnoses, and the side effects that can result from this “polypharmacy.”

Fundación Huésped (Buenos Aires, Argentina) and the Fight AIDS Foundation (Barcelona, Spain) joined forces in 2016 to launch the “Comprehensive Management of Aging in HIV” international workshop series, to be held in alternating years in Europe and South America. Our objective is to provide a platform to review current trends and explore the most appropriate comprehensive healthcare management options to improve the quality of life of people aging with HIV from a multidisciplinary perspective.

As we do this, it is critical that we keep the perspectives and life experiences of this growing population in mind. We are grateful to the participants of *The Graying of AIDS: Stories from an Aging Pandemic* project for sharing their insights.

—Barcelona, September 2018



flsida.org



huesped.org.ar



I get really surprised when people point at me and say, "That older woman." I say, "Oh! Is that me?"

I'm more than my age. See me. Ask my name. Talk to me by my name. I have an identity. I can't be defined by "that older lady." Find out who I am.

I don't want to be discarded, because any country is what it is because of those that have been there before.

Hope, age 62
Francistown, Botswana

I think that we're not a priority in the health system. They are thinking more in the young person. We are fighting for medicines, for treatment. We need to be accepted in the hospitals. That is difficult in Puerto Rico.

José, age 60
San Juan, Puerto Rico

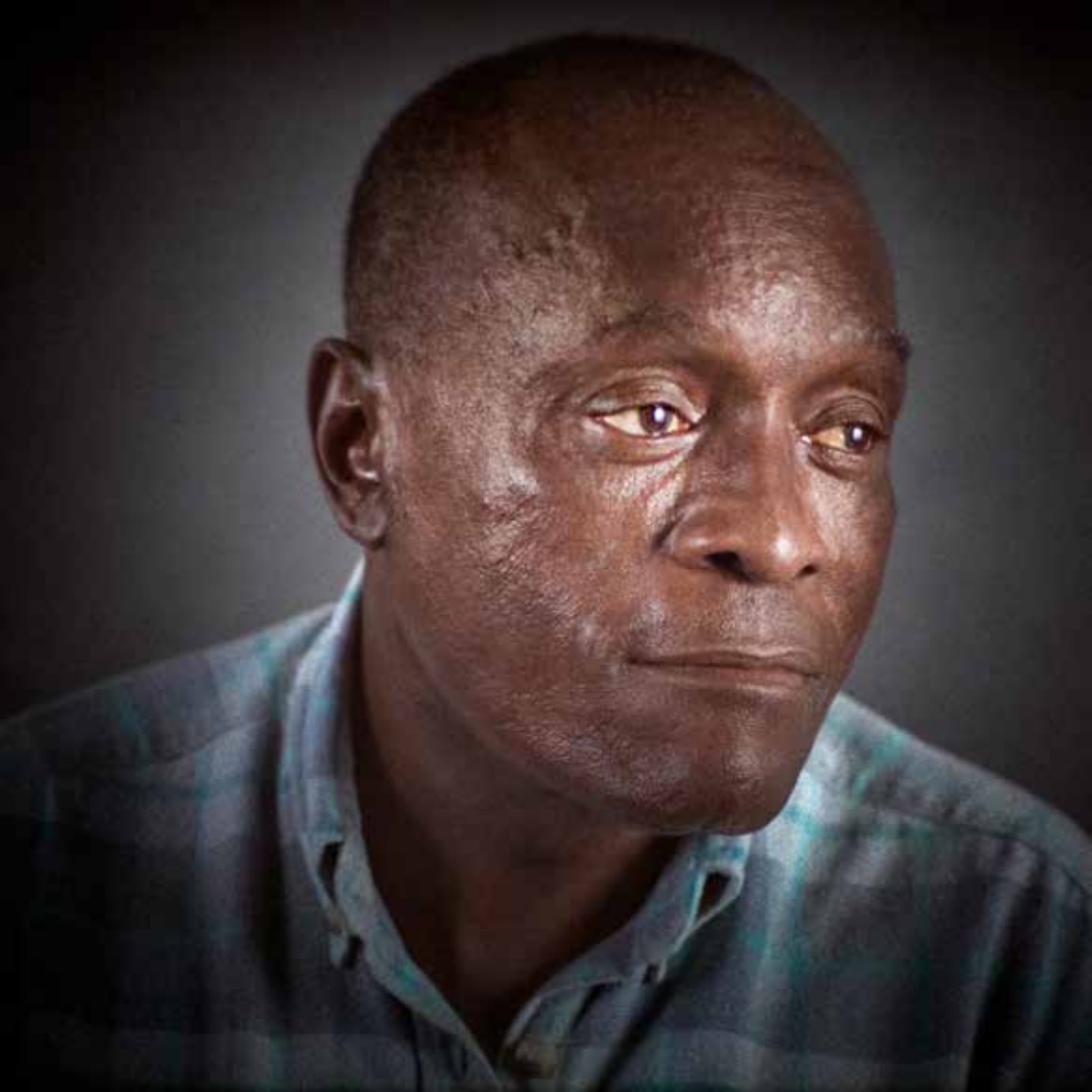


Me quité eso de que: “Porque Dios me castigó? Porque...?” De estarme martirizando. Dije: “No, ya, es el momento de quitarme todo esto. Yo creo que Dios me mandó una misión y la tengo que cumplir.” Empecé a luchar, y empecé a ser representante, ya no de los trabajadores sino de enfermos, de los pacientes de VIH.

I stopped asking myself: “Why did God punish me? Why...?” Tormenting myself. I said: “Enough, it is time to stop all this. I think God gave me a mission and I have to accomplish it.” I started to fight, and I started being – not the workers’ representative, but the representative of the sick, of the HIV patients.

Flor, age 60
Mexico City, Mexico





Some people wonder why an old man like me could be seen collecting ARVs. They think that this is a disease for young people and it's usually associated with promiscuity. In our culture, well, the elders are supposed to be role models. So that really makes me feel bad.

Sebastian, *age 65*
Harare, Zimbabwe

The most devastating part about dealing with HIV when you're over 50 is isolation. And unfortunately, people are so afraid of the stigma that they isolate themselves even further.

Robert, age 62
Medicine Hat, Canada



I'm one of the long-term survivors. I have a healthy lifestyle. And also, I love myself. Meditation is my medication.

Last year I was retired, but I don't find somebody to stand by me to take my job over. I have to keep going because people don't want to come out the closet.

Ethel, age 60
Paramaribo, Suriname



El rechazo era visto, se miraba de lejos. Primero porque soy transgénera, mujer transexual. Y luego el VIH, luego no saber el idioma y luego venir de un país “bajo.” Pienso que ahora ya están bien educados acerca del VIH.

The rejection was visible, you could see it from a distance. First of all because I am transgender, a transsexual woman. And then the HIV. Then not knowing the language. Then for coming from a “lower” country. I think now people have become better educated about HIV.

Lorena, age 53
New York, USA and Mexico





I'd rather have HIV than some cancer, right? But for others it's still... they can cope better when you say you have a cancer than this HIV thing.

When you have breast cancer, it doesn't mean you did something terrible – it just happened to you, right? But HIV, you acquire. It's an "icky" illness, because it has to do with sexuality. That's the weird difference that remains to this day.

Gabi, age 55
Munich, Germany



Edward: I walked past a place and decided to get tested. I was really hooked on drugs, and I just kinda felt I probably had it anyway. I've been positive for 25 years.

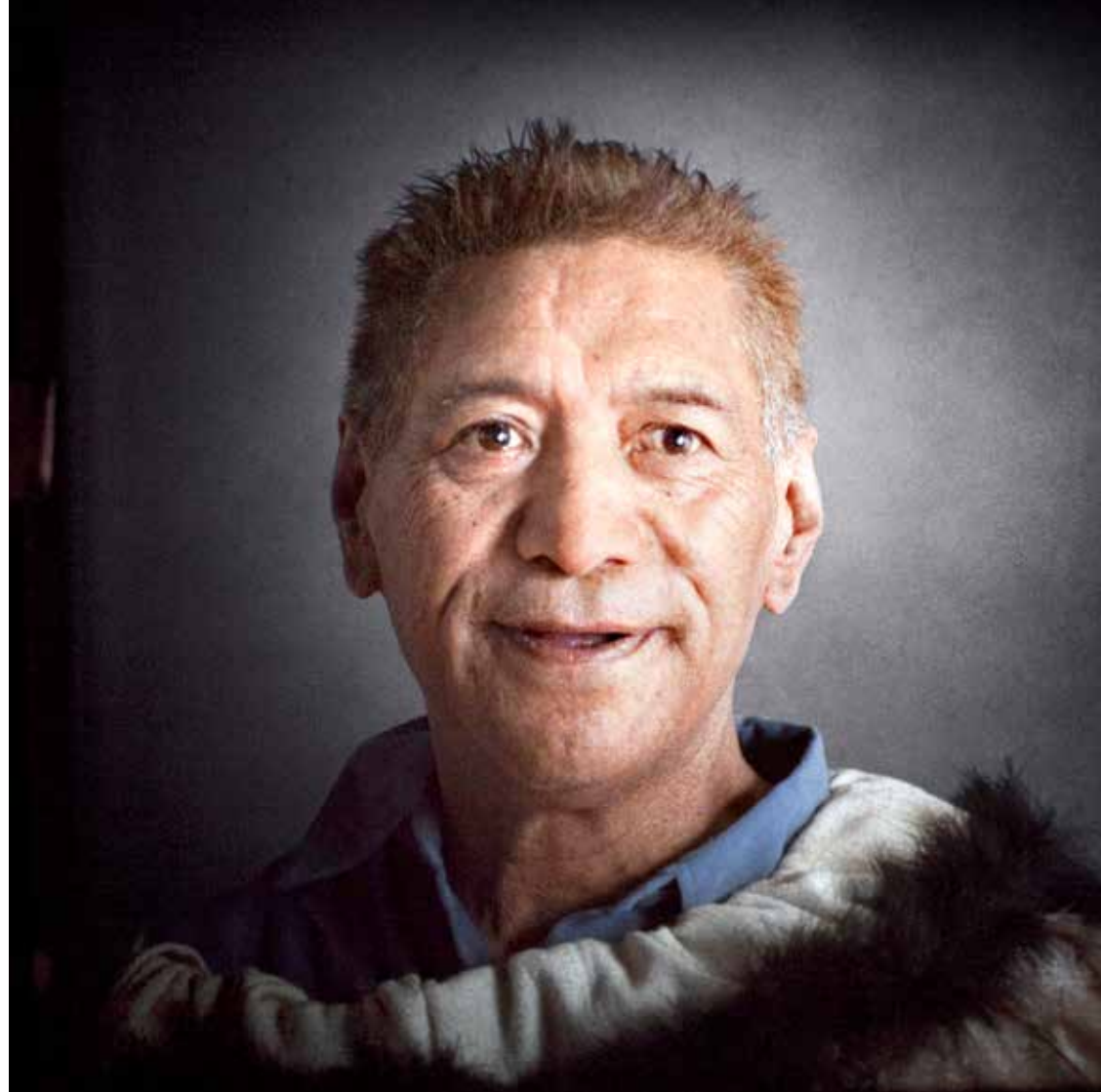
Andrea: He disclosed to me immediately. And I said, "So? Whatever I need to know, you'll teach me." I've heard comments like, "You're a better woman than me. There's no way I'd be with somebody that's HIV positive." That kinda stuff.

The one thing that I know that makes me happy is love. And I would never trade that, and I would never be afraid of the vessel that gave me that love. But I still can't wrap my head around the thought that maybe he'll leave here before me. That's really scary.

Andrea, age "51 and a half," and **Edward**, age 55
New York, USA

I've only had it 4 years. It couldn't have been much earlier than that. Because I was in a relationship, and then after that relationship finished I got promiscuous and thought to see if I still had it at my age. And yeah, then started experimenting again.

Michael, age 62
Auckland, New Zealand

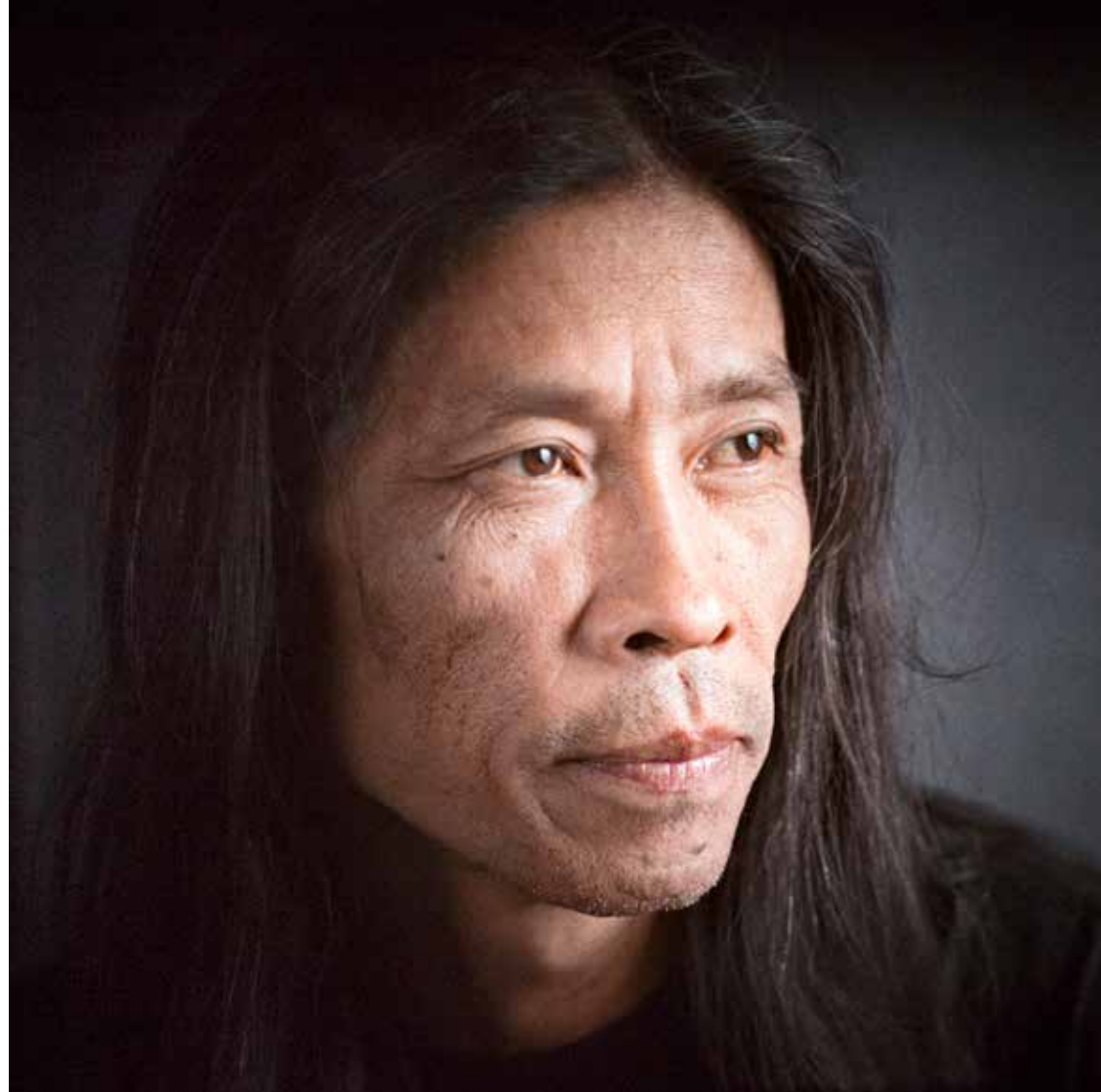


“Recover” means how many hours or how many days or how many months or how many years you have to be clean?

Or “addict” means what? Shooting every day? Or twice a day? Or once a week?

I don’t know this. I’m just a drug user. I’m not a current or ex. Once in a while I use something.

Loon, age 50
Manipur, India



People think that HIV has been finished, that the treatments are great and everyone's fantastic. Because "the drugs are working so well now." "We've solved the issues." "There's no more side effects." Um, no.

I think we put unnecessary expectations on people to be well. It's almost like blaming the victim.

Glenn, age 50
Newcastle, Australia





In 2003 I already need to be on medications, but at that time we need to pay about 1,000 Malaysian ringgit, and my salary is less than 1,000. So I stop seeing the doctor because the doctor says, "You need to be on medication."

I rather, you know, feed my children.

*Ella, age "nearly 50"
Selangor, Malaysia*

I was a single mother. When I was diagnosed with TB we had to initiate ARVs at the same time. I'm on these drugs with different side effects, all working on this weak immune system. I thought that's it, it's the end now.

I remember my kids sitting around me, and my eldest was asking me if there's anything they can do to take the pain away. I'm weak, and they have to try and manage all this, to spread out the medication. My daughter, the youngest, at the age of nine, she was my best treatment supporter.

Nomampondo, age 52
Johannesburg, South Africa



I sort of don't have a person that I can say, "Just take care of me." When I know I don't feel well I stay home, I do more internal healing. Some days when I'm irritable and changes are going on with my body, I won't get out in the public. I know to tell people, "It's not my best day."

Fredricka, age 50
California, USA





I hope to God the nursing homes are ready for us. Because there's gonna be an influx of older people living with HIV. We're coming. These nursing homes don't know what's gonna hit them.

Jan, age 64
Mataura, New Zealand

You've got all this sort of relative privilege, and okay, yeah, you haven't got the home, the car, the dogs, the boyfriend that you thought you might have had without HIV. But you're still alive, honey, and when you look at the fact that 4,000 people in other places are dying every day, what are you doing about that? What are you actually doing?

Julian, age 58
South London, United Kingdom



People are saying, "What gives you the right to be an elder?"

You just hold yourself up and say, "I have a right to be here."

"And I have a right to share my knowledge around HIV and AIDS." And find ways of helping the younger generation.

Liz, age 57
West Coast First Nations, Canada



THE GRAYING OF AIDS: STORIES FROM AN AGING PANDEMIC

The first-ever documentary project on HIV and aging around the globe invited people age 50+ from around the world who self-identify as aging with HIV or AIDS to pose for a portrait and share their story. In all, over 100 people from over 25 countries and 6 indigenous nations took part in this series of participatory installations at three successive International AIDS conferences, from 2012-2016.

The resulting collection of candid conversations and formal portraits offers insights into what it's like to age with the virus in rural, urban, and suburban communities across a diverse range of cultures. The evolving online archive challenges stereotypes and preserves critical perspectives on the global pandemic, serving as a resource for people who are living positive, and for those who care for them.

The older adults featured in this archive include both long-term survivors and people who acquired the virus only recently. Many of them are among the early generations of People Living with HIV/AIDS who have been so critical in changing the course of the pandemic. As activists and advocates working on the local, national, and international levels they have fought for changes in everything from education to media coverage to public policy to the way scientific research is conducted and new treatments are developed and made accessible to those in need of care.

Throughout the course of this pandemic, the voices of extraordinary people living with the virus have led to key innovations and positive social change. As we search for the best ways to support current and future generations aging with HIV/AIDS, we need to keep listening.

Visit the online archive: agramingpandemic.org

Interviews were edited for clarity and length.



COMPREHENSIVE MANAGEMENT ON
AGING IN HIV

aginginhiv.com



FIGHT **AIDS**
FOUNDATION

flsida.org



FUNDACIÓN
HUÉSPED
PREVENCIÓN-CIENCIA-DERECHOS

huesped.org.ar

The **Graying of AIDS**

agrayingpandemic.org