



Every Chapter Has a Meaning

Long-term survivor Roy Allen reflects on decades living with HIV.

February 20, 2026 By Roy Allen

I was diagnosed with HIV on my birthday.

I was 21 years old, lying in a hospital bed in 1996, admitted because I was dangerously dehydrated. I couldn't swallow. There was a rash inside my esophagus that burned every time I tried to drink even a sip of water. My body had already begun to betray me before anyone explained why.

The room smelled like disinfectant and stale air.

Birthdays are supposed to mark beginnings. Mine marked a fracture.

When the doctor told me, it didn't feel real. HIV. On my birthday. At 21.

Back then, HIV didn't come with reassurance. It came with fear. I didn't picture growing older. I pictured hospitals, wasting and dying alone. That fear settled into my body and quietly shaped the years that followed.

The stigma arrived immediately.

I learned to carry a secret that felt radioactive. I learned how to edit myself to survive—who I could tell, how much truth was safe, how small I could make myself. At 21, when your sense of worth is still forming, HIV becomes more than a diagnosis. It becomes a mirror you don't recognize yourself in.

Fear shaped my choices. Some were careful. Others were reckless.

When you believe your life will be short, consequences feel abstract.

I used drugs. Sometimes to escape. Sometimes to feel powerful instead of afraid. Sometimes because I didn't care whether I woke up. I treated my body like something temporary, like I wasn't planning on staying.

The medications kept me alive, but they came at a cost. Early treatments were harsh. Over time, my face changed in ways that felt premature and unforgiving. Fat disappeared. My cheeks

hollowed. My skin thinned. Even when I was stable, I looked tired. Sick.

HIV announced itself before I ever spoke.

Dating meant disclosure. Disclosure meant risk. Rejection wasn't always explicit, but it was frequent enough to teach me caution. I learned how to be close without being fully seen. The fear of rejection became a quiet companion, shaping how much of myself I offered the world.

At 40, desperate to look healthy again, I tried to fix it.

I had fat taken from my stomach and injected into my face. I hoped it would soften the hollowing, make me look less fragile, less marked. At first, it felt like relief. I looked fuller. Healthier.

But fat doesn't age gently.

Over the next decade, it stretched my skin and pulled my face downward. The thing I did out of desperation slowly made things worse.

I don't blame myself for that decision. I understand it now.

I was trying to look like someone worth saving.

And still, I lived.

I got sober. I learned how to care for myself instead of punishing my body for surviving.

But aging with HIV carries an accumulation that's hard to explain—decades of medication, inflammation, stress, vigilance. By my late 40s, my reflection told a story I no longer felt inside.

So at 50, I chose a deep-plane facelift.

Not to erase my past but to stop wearing it so visibly. Not to look young but to look aligned. To let my face catch up to the life I was still living.

I've just had the surgery.

Right now, my face is wrapped in a tight, stretchy mask. It hurts. Everything feels swollen and unfamiliar. I don't know what I'll look like yet, and that uncertainty is frightening. There's a particular vulnerability that comes with not knowing how you'll be seen.

Lying here, I think about that 21-year-old in the hospital bed, unable to swallow, convinced his life was already over.

I wish I could tell him what I know now: that fear lies, that survival isn't linear, that there will be mistakes, relapses, regret—and also moments of care that arrive later than expected.

I'm writing this because someone else might be reading from their own hospital bed. Or sitting with their own diagnosis. Or staring at a mirror that feels cruel.

Maybe you're ashamed of choices you made just to get through. Maybe your body tells a story you didn't consent to.

If that's you, I want you to know this: You don't have to be perfect to be OK. You don't have to make the "right" choices every time to deserve care. Survival is messy. Healing is uneven. And wanting to feel at home in your body isn't vanity. It's human.

I don't know what I'll look like when this mask comes off.

But I know this story matters.

Because if my fear, my mistakes and my survival help even one person feel less alone, then every chapter—even this painful, swollen one—has meaning.

This face—however it emerges—belongs to someone who stayed.

And if you're still here, so do you.

What three adjectives best describe you?

Stubborn, determined, funny.

What is your greatest achievement?

Finding true love.

What is your greatest regret?

Not reaching out for help when I knew help was available.

What keeps you up at night?

Current politics.

If you could change one thing about living with HIV, what would it be?

Removing stigma.

What is the best advice you ever received?

Keep moving forward.

What person in the HIV community do you most admire?

Myself.

What drives you to do what you do?

A deep desire for equality.