



SEVENTEEN

WinstoneZulu

The first time I met Winstone Zulu, he asked *me* the questions. How, he wanted to know, can your government, your country—you—just let us die?

“I have friends, married couples, who both have HIV and they can afford ARVs for only one of them,” he said. His gaze was fierce. “So they’re trying to figure out which one will take the drugs. Will their kids keep a mother or a father? What kind of choice is that?”

It had already been a grim day. I had met grandmothers swamped with orphans, pleading for help to buy food, and patients in an overcrowded clinic that lacked the most basic drugs. I had interviewed the minister of education, who told me about rural schools with 250 pupils and no teacher, and had a conversation with the minister of child welfare, who admitted, hushed but horrified, to an explosion in incidents of abuse of children by overstretched foster parents. Come evening, I had wound up in a plain meeting room in Lusaka, the capital of Zambia, with a dozen members of a local group of people living with HIV/AIDS. They were warm and thoughtful, and sick. They told me how they were waiting and waiting for the state to make ARVs available, but the government said it had no money—and in the meantime, another member failed to show up for each weekly meeting.

And there was Winstone, and his questions. He sat at the end of the table wearing a faded red-and-white “HIV POSITIVE” T-shirt.

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The crutches he used to walk leaned against his chair. He had strong, handsome features and the honeyed voice of a late-night DJ. He was polite and gracious, but his disgust with the injustice of their situation lay like a sheen on his skin. “What are our lives worth?” he asked.

I had no answer, and I took refuge in my job, avoiding his eyes while I scribbled his words in my notebook.

Winstone was then buying his own ARVs, just managing on his salary as director of the group; his wife, Vivian, didn’t yet need the drugs. “So my children keep both their parents. For now.”

When Winstone spoke, his words made the crisis in Zambia searingly real—in a way that even the hungry grannies and the emaciated babies couldn’t do.

I saw him often over the next few years. I sought him out whenever I returned to Zambia, and I bumped into him at AIDS conferences in different parts of the world—he is much in demand as a speaker. In bits and pieces, I learned about his astonishing life, and sometimes I felt the gentle sting of his wicked sense of humour. (“I see you’ve *also* got a sexually transmitted condition,” he said to me, deadpan, when we met up in Zambia in 2006 and I was enormously pregnant.) And through him, I have come to understand the injustice of AIDS in a newly visceral way. The virus has exacted an almost inconceivable price from his life. And it never had to be that way. Winstone knows it. And it fills him with a clear, hot anger, something he keeps cloaked in good-natured wit. Most of the time. If it were me, I wonder, could I do the same?

Winstone learned of his HIV infection by accident. He was born in 1964 in Lusaka. He survived an attack of polio when he was three

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(“Bugs love me,” he says), hence the crutches, which have etched calluses into his powerful arms. He had political ambitions and in 1990 won a scholarship for a six-month political science course in Leningrad. His visa application (much like Siphwe Hlophe’s) involved a routine medical, including an HIV test. He would never have tested otherwise, Winstone said. “I wasn’t entirely naive about what it meant.” A former girlfriend had died the year before—of AIDS, although no one said so at the time. So when he went for his test, “I was hoping against hope.”

The hope was denied. Winstone headed home from the clinic, passing garbage bins in the street emblazoned with the skull and crossbones and the words “AIDS Kills.” For the next few days he sat in the small room he was renting with his brother Shadreck and wrote—dark, despairing poems about having his life so brutally truncated. After a week holed up at home, he thought he would try to find a place to publish them before he died; he knew he was a good writer, and a collection of poems seemed as good a legacy as any other. A friend told him about a new centre for people with AIDS, called Kara Counselling, run by a Catholic priest. Winstone went there, hoping the staff might be able to help with his manuscript. They couldn’t—but they did offer support for people newly diagnosed with HIV. The first counsellor with whom Winstone sat down told him he might live as long as another six years. “I thought, ‘Well. I can use six years.’”

Four days after his test, he had his first conversation about HIV, with Shadreck. “His reaction was typical. He said, ‘I think I might have it myself—it’s no big deal.’” Alarmed, Winstone began to pester his brothers to go and test, but they resisted. Three months later, his brother Erasmus was dead at thirty-three. His wife died the next day. Then

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another brother, Christopher, died a week later, at thirty-one. All three died of tuberculosis; they were all made vulnerable by an underlying HIV infection, for which they agreed to test only in the last days of their lives.

Kara, at the time, was an offshoot of a Zambian aid agency called Family Health Trust, and took its name from the building where the first office was located. But its founder, an Irish Jesuit named Michael Kelly, wanted to turn it into a free-standing AIDS service organization, and Winstone offered to help. It was an incredibly courageous decision: in 1991, not a single person in Zambia, or anywhere else in southern Africa, was openly living with HIV. “But I had this anger that this disease was killing so many people and no one was speaking or even showing the face of this disease. I decided, Look, this thing is going to kill me but I might as well use it to help people.”

He started big: he went to *Good Morning, Zambia*, the most watched program on the national broadcaster. He sat down in the studio chair, the cameras went live, and he said he had the virus. Interviewers peppered him with questions: How did you get it? How do you feel? How did your parents and siblings react? Are you scared you're going to die? Televisions were, and are, scarce in Zambia, but news travels plenty fast by mouth, and by the time Winstone left the studio, it seemed as if everyone in the country knew he had HIV.

A few days later, Father Kelly took him to speak to a group of young seminarians. Then to a factory, where he addressed the workers. Soon he was the country's AIDS outreach effort, a campaign of one. He found it strangely comforting, despite the staring crowds and their probing questions. “I was feeling as if a burden was removed, the sense of worthlessness. One of the things that happens to you when you are HIV-positive is you lose all

esteem.” Winstone didn’t feel so bad when he spoke before the crowds. And by standing up in front of them, he shattered the myth that a person infected would be visibly wasted and ill.

Before long, he had company. A young man named Simon, a year older than he at twenty-seven, agreed to join Winstone on his rounds of workplace education. Soon a third fellow, David, came too. Many people were reluctant to have them speak—“AIDS was bad for business,” Winstone said—but they made their way through the industrial zones. Winstone began to accept invitations outside Lusaka, and spoke to groups of soldiers, teenagers and hospital patients around the country. Three more young men joined what was beginning to feel like a club, and they decided to move in together, renting a house in a poor, high-density neighbourhood on the edge of Lusaka—the kind of place where AIDS was having its worst effect, where they thought they could be most useful as activists. Before they moved, social workers they knew at the University of Zambia did a survey of the neighbours’ attitudes. It wasn’t encouraging: more than half said they would not eat with the men, and a third said they should stay away altogether. Nevertheless, Winstone and his pals moved in. And before too long, the neighbours softened—perhaps, Winstone speculated, because the men didn’t *look* sick, or maybe it was the nuns they knew through Kara. If the nuns had tea and scones with them, could the men be that bad? Soon people from the street came by to borrow sugar, and some even stayed for a meal.

Winstone and his new friends did outreach workshops all day, and in the evenings watched videos or went to the bars in town for drinks. There was no hiding that they had HIV—they had all been on TV—and now he faced the judgment and public moralizing that would become a constant in his life. People tsked when they saw him order a beer; when Simon found a girlfriend, neighbours came right out and said that these men with HIV should not be having sex. “But we refused to die before we were actually dead,” Winstone wrote about this time. “We believed in life before death and we did not want to live like monks in the mountains of Tibet.”

Then it started. George, whose HIV infection was more advanced than the others', got sick and died at thirty-nine. "The rest of the team looked at each with the question: who is next?" Winstone wrote. By this point, most of the men were troubled with diarrhea; they kept a container of oral rehydration salts in the kitchen. (Rakish Simon kept a bottle of vodka alongside it.) Lawrence was the next to die. "He got so thin that you could actually count every bone in his body." The men fell into macabre humour about who would be next. "But inside, some, and maybe all of us, were scared shitless." In the end, Arthur was next.

Winstone threw himself into work at Kara. The agency began to offer testing and counselling, and opened a hospice, called Hope House, to provide dignified care to people dying of AIDS. And in the spirit of defying death, Winstone got married. Vivian, six years younger, was one of many people who had sought Winstone out after his first TV appearance. She had tested positive in 1989, although she had not told anyone. Winstone's tough, droll demeanour softens when he talks about her, her strength and her courage. "At the time I was thinking, 'It's wrong to get married, it's wrong to have children'"—other people certainly thought so, and he had those doubts himself. But he thought, too, that if he could persuade himself that he really had a right to the life he wanted, then maybe in time others would come to see it that way as well.

Vivian desperately wanted children. "Here the stigma of not having children is horrible," Winstone explained. "If you die without having kids you are going into the ancestors' world without leaving anyone. Your life is useless." But they agreed it would not be fair to pass the virus to a baby. Instead, they adopted a boy they named Michael, after Father Kelly. The child was born to Vivian's sister, who was single and struggling to raise him. People expressed their unsolicited approval: this, they told Winstone and Vivian, was the *right* way for people with HIV to have children.

As one of the first Africans to live publicly with HIV, Winstone was welcomed into the emerging international AIDS establishment, and given a rare opportunity to have a voice in how the global response

to the pandemic unfolded. In 1994, he helped draft the Paris Declaration, which laid out the then-radical notion that people with HIV must be consulted about their care and treatment, and that they must be guaranteed legal protection from discrimination. He was part of the 1996 meeting in Como, Italy, at which UNAIDS was founded. And he helped to organize what was perhaps the most seminal AIDS gathering of the past twenty years: the 1996 conference in Vancouver where David Ho announced that he had successfully suppressed HIV using his cocktail of antiretrovirals. Winstone was in the audience when Ho presented. He didn't quite understand the implications at first—he needed to decipher the technical jargon—but when he did, he felt the first rush of hope since his diagnosis.

Except, of course, that no one in Zambia had the cocktail. The next year, Winstone came down with TB. He was treated, and recovered, but he knew he needed the new drugs. "I thought, 'If I'm thirty-three and I have TB there must be something terribly wrong with my immunity.'" He enlisted the help of friends in AIDS organizations abroad, who sent him pills donated by patients in the developed world who no longer needed them, and Winstone began ARV therapy. The drugs had side effects—nausea and numbness—but he ceased to be plagued by the rashes and infections he had had for years. Soon he felt fine.

And then a crazy thing happened. At the 1998 AIDS conference, held in Geneva, Winstone encountered a group of the so-called AIDS dissidents, who staged a hunger strike at the global gathering. They insisted that HIV did not exist and that the idea of AIDS was being peddled by Western drug companies and scientists in their pay. Winstone stopped to listen, intrigued that people of such passionate conviction were being ignored or dismissed as lunatics by everyone else at the meeting. "I was looking for an escape. For me the idea was, 'If these guys are proven to be right then I'm off the hook.' I was seduced by the promise of the idea."

He didn't feel he knew enough to judge whether the dissidents were right or wrong. But among their ranks were Nobel Prize-winning scientists such as Kary Mullis, who had won the award for chemistry in

1993. It seemed to Winstone that the dissidents were asking valid questions that no one from the world of mainstream AIDS thinking was willing to take on. “They were people questioning things. They didn’t have solutions—but these were real questions. For example, why is one child of an infected woman born with HIV and not another?” And then he heard that the dissidents had an additional supporter: Winstone had been a committed member of an African National Congress solidarity organization during the years Thabo Mbeki lived in exile in Zambia, and now he learned that Mbeki, South Africa’s new president, was also expressing doubts about the validity of mainstream thinking on HIV. “Here was Thabo Mbeki, my hero—when Thabo Mbeki questioned it, I was sold.”

Winstone resigned from his various posts with AIDS organizations, and in February 2000 he stopped taking ARVs. “I really believed them—that AZT was doing me harm.” Vivian asked him gently if he was sure this was a good idea; he was firm. “I said, ‘Yes. I met these Nobel Prize winners who said this is wrong.’”

The dissidents were thrilled: attracting one of Africa’s best-known activists to their fringe cause was a coup. By the time the next International AIDS Conference rolled around, in Durban in 2000, Winstone was firmly in their camp. Mbeki used the meeting to make clear the breadth of his skepticism about AIDS; outside the conference venue, thousands of people with HIV hurled abuse at the dissidents, accusing them of murder—it was the kind of protest Winstone usually led.

His stance caught Mbeki’s attention, and the president invited him to join the panel of experts he had struck to investigate the truth about HIV and its treatment (Winstone was the only non-scientist). He remembers the panel meetings as fraught, each side convinced that the other was responsible for the deaths of hundreds of thousands of people. He listened to microbiologist Peter Duesberg, a respected researcher from the University of California at Berkeley, who argued that HIV was simply a harmless “passenger virus.” AIDS in the developed world was an illness brought on by long-term recreational drug use, Duesberg said,

while the African pandemic was simply old diseases lumped under a new name. There were doctors from Australia who argued persuasively that HIV had never been isolated, and Mullis, who said he had yet to see proof that HIV caused AIDS. Could they all just be crackpots?

“For ten years I’ve lived with HIV,” Winstone told reporters after the first meeting of the panel, “and for ten years I’ve preached the main line. To hear that I could be wrong is good news. If you were in my shoes, you could understand. . . . These ideas from the other side will find fertile ground in Africa because the conventional thinking hasn’t been much use.”

By March 2001, Winstone was sick again. He was covered in fungal infections and lesions that would not heal. His toenails dropped off. Soon he had to use a wheelchair. He heard the news that one of the dissidents he had met on the panel had died of AIDS. Mbeki, meanwhile, was saying AIDS was a disease of poverty, yet Winstone could see that all around him in Zambia, well-educated and comparatively well-off people were hardest hit by the disease. So he began to reconsider. “What saved me was that I didn’t feel too ashamed to go back and ask for real advice.”

By then, he could no more deny his own illness than he could what was happening around him: all but one of his five brothers had died. His sister Rebecca died. Her husband died. His cousins, nephews, nieces died. All his friends from the early years at Kara were gone. This wasn’t an old disease under a new name: something extraordinary and terrible was happening in Zambia. “I went back on my medicines.” When Winstone had stopped taking the ARVs, his CD4 count was 536. When he went back on the same combination two years later, the count was 34. But once again, the drugs worked: within a month, he was out of the wheelchair. And back to activism.

One issue, in particular, now obsessed him: the “twin epidemics” of tuberculosis and HIV. TB had taken the lives of his HIV-positive brothers, sister and three sisters-in-law, and the vicious impact on his family wasn’t particularly unusual—more people with HIV die of TB than any other infection. Nearly two billion people around the world carry the TB bacillus; it lies harmless and dormant in most of them, but having HIV

more than doubles the likelihood that a person will develop the disease. Two-thirds of people with TB in sub-Saharan Africa are HIV-positive, and in Zambia, three-quarters of new tuberculosis cases are in people with HIV.

When Winstone himself had begun to show signs of tuberculosis four years earlier—chest pains, night sweats and weight loss—he recognized them from his brothers' experience. He went to the hospital for an X-ray and a sputum test, but a week later, staff told him he didn't have TB. Winstone was unconvinced. He started to share the drugs of his last surviving brother, Danny, who was then on TB treatment, and in just three days he was feeling better. He went back to the hospital, telling staff he was sure he had TB. They tested him again. This time, they took four months to deliver the results—and in fact, he did have TB. "I could be dead now if I'd waited for them to diagnose it." It may have been incompetence, he said, but it is equally possible that well-intentioned staff were simply misled by the notoriously inaccurate diagnostic tests, which were invented more than seventy years ago. The sputum test he had catches, at best, half the cases of active TB, a fact Winstone finds outrageous. "We need new diagnostics—you can't defeat TB without detecting it," he said. "It's the most infectious of the opportunistic infections. If you have TB, chances are you'll infect fifteen or twenty people before it's detected." Yet there is little investment in TB treatment because it is viewed in the rich world as an old-fashioned, fading disease. In fact TB incidence is exploding, but since, as with HIV, 95 per cent of people with tuberculosis live in developing countries, it's not nearly as sexy a subject for researchers as, say, bird flu.

His brother Danny died of a second bout of TB in 2003, because the antibiotics were out of stock in Zambia's clinics. "He was twenty-nine—I was nine years older," Winstone said. "Danny should really have lived and I should have died." By the time Danny died, Winstone was speaking about HIV and TB around the world; more driven than ever, he lobbied senators in Washington and members of parliament in London and lent his chiselled features to billboard campaigns and educational

videos under the slogan “Winstone Zulu Is Alive.” Alive, of course, because he got the drugs. “If my brothers had survived TB, they might have lived long enough to access HIV drugs like me.”

Effective treatment for TB could change the way people think about HIV/AIDS, Winstone said. The response to AIDS is undermined by the abstract nature of the syndrome—the idea that something is slowly and invisibly weakening the body’s ability to fight off infection. When he speaks to audiences in Europe or North America, people talk about feeling paralysis in the face of the statistics—the twenty-eight million people in Africa with an incurable illness. “Many people just want to look away because the problem looks so insurmountable. They think, how can we deal with this? But if you say, ‘Hey, wait: the biggest killer of people living with HIV in Africa and many other developing regions is tuberculosis—and if you give them drugs that cost \$10, you can save someone’s life, and you can avoid having more orphans’—then people see it differently.”

In 2003 Winstone and Vivian moved to Kabwe in the Copperbelt in the north, to open a Kara counselling centre, AIDS hospice and program for orphaned street kids. Kabwe is a mining town, but its once-vibrant economy had been choked by a World Bank–engineered privatization of the mines and railways that caused thousands of people to lose their jobs. Now young women stood on the trucking route in and out of town, selling sex for as little as \$1 per encounter.

At the new Kara centre, Winstone organized a support group: it grew from ten members the first week to eighty-three the third. He was delighted to see people coming forward, but also amazed at the pace of growth. A staff member suggested they ask the group to test for HIV. Only twenty-three of the group members were in fact infected. The rest were coming to the centre so they could collect the 80-cent transport allowance for the meetings. Told the news that they were HIV-negative and could not stay in the group, many were distraught. They were walking great distances to attend because the allowance was the only thing feeding their families. One day when Winstone gave a young woman named

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Jennifer the happy news that her TB had been successfully treated, she responded by bursting into tears: without TB, she would no longer qualify for a weekly parcel of soya powder and beans, the only source of food for her three children.

“When I went home I couldn’t sleep,” Winstone wrote about those days. “I felt terrible. What was the use of setting up Kara Counselling in Kabwe if the people wished they had AIDS so they could get a few cents? How could we fight TB if patients felt happy to be sick so they could get a few pounds of soya powder? What the fucking hell was I doing here?” He thought about his most recent speaking tour in the United States, where he was told about a cat with kidney problems on dialysis, saw massive sport utility vehicles with built-in DVD players, heard that the leading epidemic in the country was obesity. “And here I am stuck with Jennifer and Joyce in my little office as they wish they had the most serious and fatal disease to have hit the world so they can get 80 cents every week.” Some days, it was hard just to go into work, knowing what waited there for him.

While Winstone knows his decision to go public had a huge impact on people, he sometimes regrets it—he still gets hassled nearly every time he orders a beer. And while he’s had far more than the six years he originally hoped for, HIV still colours his life. The poems he wrote the day he learned he had HIV were never published, but he has since had his writing both printed and posted on AIDS sites on the internet. In 2004, he wrote of life with HIV

Yes, I have lived positively with HIV for a dozen years.

Yes, I have given hope, I hope, to some people.

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about this epidemic is its sacredness and its meaning.”

Yes, I try not to be weepy most of the time.

And yes, I am glad to be here.

But the fact remains that I will have a far shorter life than if I had stayed away from HIV. Morbidity and mortality are a permanent feature on my daily agenda.

I know what fear is. Fear of losing weight until you have no more lips to cover your teeth. Fear of being rejected by those who are closest to you. Fear of being cold and dead.

Alone in that coffin. Fear of leaving your children, your wife, your parents, friends—Lusaka. Oh yes, I love this city and I will surely miss it.

I know what anxiety is. The uncertainty of what will befall me tomorrow. Tuberculosis, herpes zoster, pneumonia, Kaposi's sarcoma, oral thrush, fungal rash, viral rash, bacterial rash, diarrhea, meningitis, cytomegalovirus, loss of weight until everyone can tell.

I know what anger is. Anger at myself for getting myself into this mess. Anger at God for not protecting me from this pestilence. Anger at the scientific world for not discovering a cure within my lifetime. Anger for still being alive.

I know what discrimination is. Being pushed off a bus by ignorant people who thought I was infectious by merely touching them. Being denied a chance to study in Russia, the USA, Canada or Australia. No red meat, alcohol, sugar, Coca-Cola, sex. Having special laws made for me. Being denied employment, promotion, insurance, God's blessing when marrying. Written off.

Beyond the personal cost, he mourns what the disease has cost Zambia as a nation. No one thinks it shocking that he lost five siblings, that his elderly parents have eighteen orphaned grandchildren. “One of the horrible things about this epidemic is that death has totally lost its sacredness and its meaning,” he said. “I go to Mandla Hill”—Lusaka’s posh shopping area—“and all these people are out shopping and it looks so normal. Walk five streets from there to the graveyard and all these people are being buried. How are we still functioning? When this whole thing is over, everyone will stop and cry. But at this point we are numb.”

Winstone and Vivian have made their stand in the face of numbness by building a family. By 2000, it was clear that the interventions for pregnant women with HIV could effectively prevent them from passing on the virus, and they could get nevirapine and Caesarean delivery in Lusaka. They had a son, Mtunduwazanso, whose name means “the clan has come back again,” in honour of Winstone’s lost brothers, and a daughter, Mwenda; both were successfully delivered HIV-negative. Michael, their adopted son, was not so fortunate. He has twice had tuberculosis and is on ARVs.

In 2004, Winstone made another public appearance to advocate for better treatment of TB, at the International AIDS Conference in Bangkok. This time he shared a stage with the one TB survivor better known than he: Nelson Mandela, who had the disease while in an apartheid prison. Mandela pleaded for more attention to the disease, more resources for treatment and faster diagnoses. And he singled out the young man on the stage next to him: “I want to acknowledge and thank Winstone Zulu, who will share his experience fighting HIV and TB with you,” Mandela said. “We need more advocates like Winstone to tell the world about TB and the effect it has on so many millions of people.”

A few minutes later Mandela stood to make his way out of the room, surrounded by bodyguards and photographers and breathless admirers. Winstone leaned on his crutches and watched them go. I nudged him with an elbow. “Not every day Nelson Mandela talks you up,” I said.

Winstone laughed and shook his head. "I can't believe that," he said.

And then he turned so that he could just see Mandela's retreating back, and spoke again.

"I want to live that long," he said. "Long enough to have so many lines on my face."