

‘I was told not to plan for old age’: The long-term survivors who beat the HIV odds.

They were expected to die, yet 40 years after HIV/AIDS rocked the world, many are holding strong – baffling medics in the process.

By Greg Callaghan

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In 1984, David Menadue was one of the first people in Australia to be diagnosed HIV-positive. “I was told not to plan for old age,” he says. *PETER TARASIUK*

Why aren't I dead? Why aren't I sick? Why am I still here when so many of my friends have died? These are the questions David Menadue, one of the oldest survivors of HIV in Australia and among the first to be diagnosed here, has asked himself since that life-changing spring afternoon in 1984 when he was told he was carrying the virus that causes AIDS. Returning to his job with the Victorian education department that day, the 30-year-old was reeling from shock. Back then, fear and isolation were constants: Acquired Immune Deficiency Syndrome (AIDS), so named only two years prior, was considered an automatic death sentence. There were no approved drug treatments and the social stigma was so corrosive that HIV carriers were warned not to share their status beyond a few trusted friends.

"I was told not to plan for old age," says Menadue, recalling a time when every lingering cough or skin outbreak would usher in a fit of high anxiety. What fortified him was Melbourne Positive Friends, a support group he helped set up that met weekly in each other's homes. "On Thursday nights at least, we could all unload our stresses," he remembers. "We'd go away for weekends and if anyone fell sick, we'd support them." Soberingly, of the group's 33 original members, only four, including Menadue, are still alive.

The first medication to treat AIDS, a re-purposed cancer drug known as zidovudine or AZT, probably saved Menadue's life in 1989, when he developed the first of many serious AIDS-related illnesses, but one of its major side effects was muscle atrophy and weakness, known as AZT myopathy. On top of that was a host of symptoms peculiar to HIV immune deficiency. "I'd get these creepy things happening to me like oesophageal candidiasis, which meant I had trouble eating, or these atrocious skin complaints."

Menadue "limped along" until the arrival of potent new antiretrovirals (ARVs) in 1996, a game-changing combination of drugs that turned a killer disease into a chronic, manageable illness by halting the replication of the virus in the body, thus reducing damage to the immune system. "Suddenly, we had a future," he recalls. "Like so many others, I'd blown most of my money on a big overseas trip, thinking I was going to die. So I had to start my life again."

By this time, the AZT and first-generation ARVs had left him with permanent side effects, including sunken cheeks, spindly arms and legs and a protuberant belly. "I used to have these big, beefy legs," he says ruefully. By his early 40s, Menadue also had a barrage of symptoms associated with accelerated ageing – arthritis, bone loss, type 2 diabetes and rheumatological disorders. "The physical changes were hard to deal with, but my priority was survival."

A warm and engaging man, Menadue threw a large birthday party for more than 180 people last year to celebrate turning 70. “I was surrounded by close friends and family. Above all, love has kept me going all these years.”

This year marks 40 years since the first Australian died from AIDS. That was in Melbourne in July 1983, two years after scientists in the US announced the first cases of a rare pneumonia, now called pneumocystis jirovecii, and a rarely seen cancer, Kaposi sarcoma, appearing among gay men in Los Angeles, New York and San Francisco. It’s 40 years, too, since two AIDS sufferers in New York, Richard Berkowitz and Michael Callen, published a booklet on “safer sex”, which recommended the use of condoms to prevent the spread of STDs, a guideline that would save countless lives.

The human immunodeficiency virus (HIV), the retrovirus that causes AIDS, was so named in 1986, replacing its former name, HTLV-111. Doctors found the first sign of HIV was usually a fever, swollen glands and a sore throat – the telltale symptoms of a seroconversion illness, which usually occurs within a month of infection, a result of the body reacting to the viral intruder by producing antibodies.

Since then, the acronyms HIV and AIDS have become so well-known that they no longer require spelling out. AIDS has killed more than 40 million people worldwide and 85 million have been infected, making it one of the deadliest epidemics in post-World War II history. By comparison, the far more easily transmitted COVID-19 has resulted in nearly 7 million deaths globally and 770 million confirmed infections.

At first, it was assumed that everyone infected with HIV was doomed to develop full-blown AIDS and die. One of the surprising discoveries in those fearful early years, though, was that a small group of people – estimates varied, but some put it as low as 0.5 to one per cent – would remain healthy for five years or more. This bunch of outliers came to be known as long-term non-progressors. Not surprisingly, they were the subject of intense scrutiny by AIDS researchers scrambling to understand the virus.

Attention focused on white blood cells called CD4 lymphocytes, the frontline defenders of the immune system and the main target of HIV destruction. In the vast majority of cases, people who became infected with HIV suffered a cataclysmic drop in their CD4 count, from a normal level of about 500-1500 cells per millilitre of blood to 200 cells or less. Once the CD4 cell count drops below 200, the risk of developing an AIDS-related illness rises dramatically.

Were these long-term non-progressors blessed with superhero CD4 cells expert at annihilating the viral invaders? Or were they infected with a weaker strain of the virus? It soon became apparent there was no simple answer: some long-term survivors, for example, lived for years with CD4 counts of less than 200. Was this because their immune systems enlisted other white blood cells to make up for the CD4 downfall? Even today, researchers don't fully understand how the immune systems of some long-term survivors have given them more robust resistance to the virus.

Jennifer Hoy, director of HIV Medicine in the Department of Infectious Diseases at Melbourne's The Alfred Hospital, has witnessed the full trajectory of the epidemic in Australia. What began as a trickle of HIV cases in the early 1980s became a tidal wave as the decade wore on. "When I returned to Australia in 1989 after a four-year stint in Texas, ward four at Fairfield Hospital in Melbourne was full of people dying in the most distressing circumstances," recalls the 69-year-old. "Fifty per cent of patients died within a year of diagnosis. Those days were tough, not only for the patients but also for the staff. We tried to keep people alive and comfortable, but the sense of loss when we had no drug treatments took its toll; there were lots of funerals to attend. I saw my patients more often than I saw my friends. My patients often became my friends."



Jennifer Hoy, now the director of HIV Medicine at Melbourne's The Alfred Hospital, says there were "lots of funerals" before drug treatments became available. *PETER TARASIUK*

David Menadue, who was awarded a Medal of the Order of Australia in 1995 for his service to community health, particularly helping those with HIV/AIDS, became one of those friends. He says advances in HIV medication have been dramatic over the past decade, enabling him to cut back on the small arsenal of tablets he once took daily – which he nicknamed his “nuclear bombs” – to just one tablet every 24 hours. (Unfortunately, he has to take a host of other pills for the multiple conditions – high blood pressure, diabetes, high cholesterol – suffered by long-term survivors.)

Australia has lost about 8000 people to AIDS, but that figure would have been far higher had our health response been slower. The speed was driven in large part by LGBTIQ grassroots communities, which rapidly set up state and territory AIDS councils and helped educate the broader public about the dangers. “Australia became a world leader in our HIV/AIDS response, and I would argue we still are today,” says Nicolas Parkhill, CEO of LGBTIQ health organisation ACON, who was inspired to become involved when his brother was diagnosed HIV-positive in the mid-1990s. “We were one of the first countries to screen all blood donors for HIV antibodies.”

There are an estimated 30,000 Australians living with HIV. If someone is newly diagnosed, antiretroviral therapy can keep their HIV levels so low they never get sick and cannot transmit the virus to others. “We should celebrate that ARV treatment is now associated with near-normal life expectancy,” says Jennifer Hoy.

While it’s early days, promising new research by the Walter and Eliza Hall Institute of Medical Research and The Peter Doherty Institute for Infection and Immunity suggests an existing blood cancer drug, venetoclax, may be able to kill off the remaining, hibernating HIV-infected cells, delaying a resurgence of the virus even if ARVs are stopped. For those at high risk of contracting the virus, there is PrEP (pre-exposure prophylaxis), a daily tablet that is 99 per cent effective at stopping infection during sex.

The inner-city areas of Sydney, the epicentre of the AIDS epidemic in Australia for more than 30 years, now look likely to become the first in the world to - extinguish new HIV infections – a once unthinkable milestone many expect to be reached this decade. “Gay men, listening to and acting on the health - messages, were excellent early adopters,” says Parkhill.

But there are blemishes on this rosy picture. Outer suburban and regional areas in NSW, especially those with higher percentages of multicultural

groups in which being gay can still be heavily stigmatised, have seen a slower decline in transmission. “The challenge now is, how we get to these more vulnerable populations?” asks Parkhill. “It’s not over yet.” AIDS continues to cast a long shadow over the developing world, too, such that there were an estimated 1.3 million new infections worldwide last year.

The ageing of Australia’s HIV population means that about half of those living with HIV today are over 50. “There are now two types of people living with HIV,” explains Jennifer Hoy. “Recently diagnosed young people on a single pill visiting the clinic twice a year, living life to the fullest, and the warriors who’ve been fighting HIV for the past 30 years or more, battle-scarred from the lasting effects of medication that, on the one hand, kept them alive but, on the other, meant they have multiple other problems.”

Some of these long-term “warrior” survivors share their remarkable stories here.

Heather Ellis, 59



In 1995, Heather Ellis was told she had five years to live. *PETER TARASIUK*

It was the end of a long, glorious summer. I'd just spent 15 months riding an off-road bike – my trusty Yamaha TT600 – from South to North Africa before winding up in London, where I landed a job as a motorcycle courier. I felt like a road warrior: in a motorcycle accessories shop, the sales assistant took one look at me and joked, “Who the f--- are you? Mad Max’s f---ing sister?” I was living on a houseboat docked on a canal, had a new boyfriend and, at 30, was planning my next big trip. What I didn’t know was that my world was about to come crashing down.

The thing that’s always stood me in good stead was my upbringing as a bush kid. My parents moved around a variety of rural locations – I went to eight different schools from years 1 to 12 – but the best years were spent at my aunt and uncle’s sheep station in South Australia while my parents went opal mining in Coober Pedy. We’d muster sheep on our motorcycles and, on weekends, my brother and I would head to Coober Pedy to explore the old opal diggings. At 20, I set off backpacking, seeing the UK, Israel, Egypt and Europe, which gave me a thirst for more travel.

In London, after my ride across Africa, I was planning the next big phase of my motorcycle adventure, to ride along the Silk Road through Central Asia beginning with a journey to Moscow, where I’d booked to study Russian for three months. I didn’t think twice about getting a blood test; it was 1995 and a three-month Russian visa required an HIV test. But when I returned for the results two weeks later, I knew something was wrong the second I was ushered into the doctor’s room ahead of others in the waiting room.

“You have HIV,” the GP said gently, placing a box of tissues beside me. The rest of his words seemed garbled, as if I was listening to him underwater. All I could hear was “you’ve got five years”, which became a loop in my head: five years, five years. I thought my life was over: I would never be a wife, a mother. I sobbed and sobbed until there were no more tears. A few weeks later, we received some good news when my boyfriend tested negative: we’d always used condoms as I wasn’t on the pill. He could have left me at this point but stayed around to support me. We’re still friends today.

People always ask, “How did you get it?” It’s a rude question because it usually comes from a position of moral judgment. For the record: a year before diagnosis, I’d had a single, unguarded encounter in Bamako, Mali, where I’d met an English teacher who saved me from an impending violent attack. I had no intention of having sex in Africa – it was a continent gripped by HIV/AIDS – so, in my naivety, I hadn’t taken condoms. This is a

familiar story for young people the world over: they go to a party, have a few drinks and don't have condoms to hand when one thing leads to another.

A visit to an HIV women's support group in London gave me hope. "Not everyone becomes sick," a young woman reassured me. So I made a plan: I'd continue my journey and write a book as a legacy. [Ellis went on to publish *Ubuntu: One Woman's Motorcycle Odyssey Across Africa* and *Timeless On The Silk Road*.] First, I returned to Australia and lived with my parents, who by then ran a banana plantation in Far North Queensland. After six months, I'd written the first draft of *Ubuntu* so went back to London, preparing for what I thought would be my last motorcycle adventure, across Central Asia and back to Australia.

"People always ask, 'How did you get it?' It's a rude question."

My doctor gave me a prescription for an antibiotic, Bactrim, in case I developed an AIDS-related pneumonia along the way, so when I became breathless and fatigued in the Austrian ski resort town of St Johann, where I had a short-term job as a waitress, I took it. By the time I reached Hanoi, I was skin and bones, and had a Kaposi sarcoma lesion on my left shoulder and a red face from the Bactrim.

When I got back to Australia in 1997, my CD4 count was down to 40; I was near death. In Cairns Base Hospital, I was put on the new life-saving antiretrovirals, but doctors held little hope. I was asked if I would like to see a chaplain. The ARVs saved my life, and my health slowly recovered.

For some years, I never thought anyone would be interested in having a relationship with me. Then, when I was in Cairns one uni break, I met the man I'd marry a year later. By this time, the virus was undetectable in my system because of the ARV treatment, which renders the virus non transmissible. Since the late 1990s, no baby has been born HIV-positive in Australia to a positive mother on ARV treatment. All my three boys were born by Caesarean, but I couldn't breastfeed. Today, mothers with HIV who are on treatment with an undetectable viral load can have a natural birth and breastfeed.

My biggest adventure is yet to come. This will be in 2027, when I dust off my beloved Yamaha TT600 and ride from South to North America and beyond. My boys will all be well over 18, and chapter three of my life will begin.

Michelle Tobin, 54



Michelle Tobin has lived with the disease since 1990. *JOSHUA MORRIS*

I knew the day would come. I'd recently moved back to Melbourne from my home town of Bendigo with my two daughters. After a few tumultuous years, things were at last stable, with the kids in a new school they liked. It was June 1997, I was 28 years old, and some persistent flu symptoms, which my GP didn't think warranted an X-ray, quickly turned into pneumonia and a rush to hospital. Not just any pneumonia, but pneumocystis pneumonia or PCP, now called PJP [pneumocystis jirovecii], which carries a high mortality rate. All I could think of, hooked up to oxygen and an arsenal of IV antibiotics, was my two girls, both under 10: how I needed to be there for them. I was no longer just living with HIV: I had AIDS.

I'd been HIV-positive since 1990, but this was my first life-threatening illness, only months after the first antiretroviral drugs became available. I was given a few drug combinations to determine which one worked best for me; because there was so little research into the effects of the drugs on women, we were given the same dosages as men. I was taking up to 30 tablets a day (including a big horse tablet I couldn't swallow) and, because of all the vomiting and diarrhoea, my weight never got above 52 kilograms (I'm 153 centimetres tall). Once I got the regimen right, though, my health started to improve.

It was a scary time because I had no support – my family walked away from me after I told them of my diagnosis – and my priority was to stay alive and as healthy as possible to look after my kids. I received help from the Aboriginal Health Service; at that point, our mob was being affected by the spread of HIV, but we'd been left out of conversations on the subject. As a descendant of the stolen generations, I was painfully aware of providing stability for my daughters, something I didn't have myself growing up.

“My greatest satisfaction is having lived long enough to see my daughters grow up.”

I'd left school at 15 to work as a machinist in Bendigo, making men's suits. My parents had split up when I was two, and my sister and I were raised by Dad's mum. We were treated differently to our younger siblings, and we learnt from Nan that our mum was, in fact, my step-mother. It was a very confusing time. I couldn't wait to get out of home and when I met Kevin, a 20-year-old unemployed refrigeration mechanic, I felt valued and loved.

When we first got together, he was already in and out of hospital with HIV-related illnesses, which he'd contracted from his IV drug use. His mother sat me down and tried to warn me about what I was getting myself into. But I was blinded because he showed me love and respect for the first time and we got

married. We always used condoms for sex and were pretty careful: all I can think was that because Kevin often had psoriasis and open cold sores, the virus was transferred.

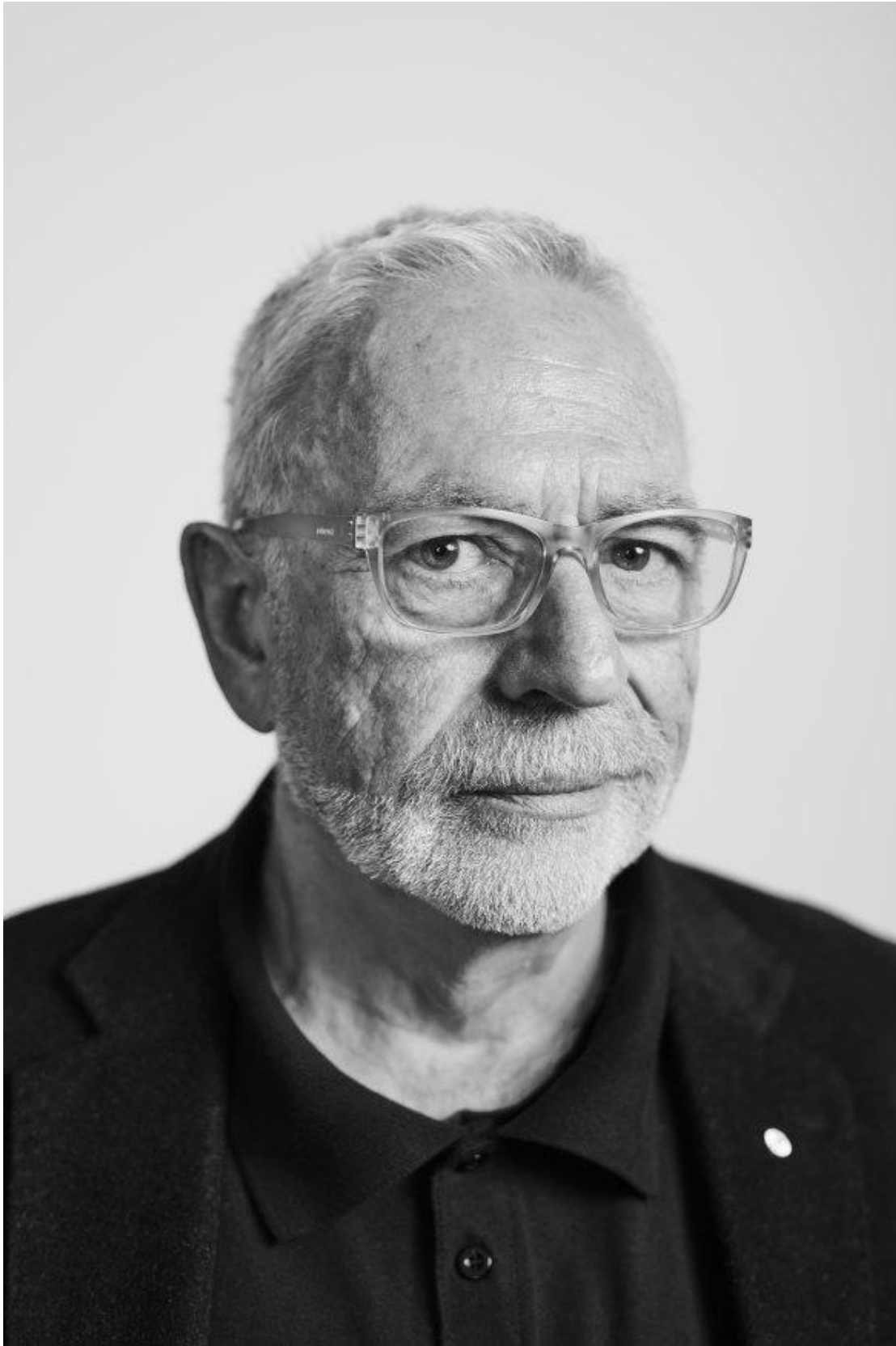
I remember having a strange, flu-like illness in April 1990 and was diagnosed HIV-positive a few months later. When Kevin passed away in 1992, I asked myself: how can you leave me with this virus?

In 1997, after my first serious illness, I became involved with services for HIV people, including Positive Women. I also attended my first international AIDS conference, in Chiang Mai, where I met another Aboriginal person living with HIV. We remained close friends until his passing in 2020.

As I aged, I knew there would be more health issues to come, such as type 2 diabetes and early-onset menopause. In 2009, while at an HIV Alliance meeting in Prahran, I happened to mention to someone the persistent ache in my right arm and tightness in my chest. She jumped up from her seat and yelled out, "Call an ambulance: she's having a heart attack!" Thankfully, I was a block away from The Alfred Hospital and made a good recovery.

My greatest satisfaction is having lived long enough to see my daughters grow up. They don't live far from me – we're on the NSW Central Coast now – and seeing them and my six grandchildren, along with my loving partner, fills me with joy.

David Polson, 68



David Polson was diagnosed HIV-positive in 1984. *JOSHUA MORRIS*

I slammed my fist down on my GP's desk. "No! I'm not going to die. AIDS will not kill me." These were brave and foolhardy words: it was 1984, when HIV/AIDS was an almost certain death sentence. But I was not yet 29 and my outburst reflected my iron will to survive. I was among the first group of Australians to be tested for HIV antibodies, and my kind, attentive doctor spent two hours talking to me, during which he advised me to tell only two or three highly trusted friends. Even though science had established the virus wasn't easily transmitted, ignorance and shunning were rampant. Some people believed it could be caught by sharing a glass or a peck on the cheek.

I'll never forget my feeling of absolute elation nearly 10 years earlier when the plane took off from Christchurch, where I'd grown up. I'd been tormented by the other boys in boarding school – "poofter Polson" was my nickname – and I'd scored a scholarship at Sydney's Ensemble Theatre. By my early 20s, I'd abandoned my dream of becoming an actor but loved living in Sydney, where I didn't feel any pressure to conceal my gayness. Homosexuality was still illegal then, but Oxford Street was emerging as a gay hub, with lots of underground bars. Life was joyous – full of movies, bars, parties, going to the beach. When I heard the first whispers about a strange illness striking gay men in New York, sometimes with purple lesions on the skin – Kaposi sarcoma – I convinced myself it wouldn't reach Sydney.

For more than two years I didn't know I'd contracted the virus, even after waking up one Saturday morning in late 1983 in screaming agony, which I later worked out was my seroconversion illness. Every muscle and joint in my body burned; I could barely move. This was before an HIV test was available and, since a recent blood test had shown my T4 cell count was a robust 1200, my doctor assured me it wasn't AIDS. Happy it wasn't serious, I dragged myself off to work – I'd just been given a promotion at the Regent Hotel. I only lasted a couple of hours before going home in a taxi.

The banner AIDS activists carried in the 1980s – "SILENCE = DEATH" – summed up the key dilemma for so many. By keeping silent you gave a free pass to those who wanted to discriminate, who blindly dismissed this as "just" a disease of gay men whose lives were considered of less value. But speaking up could come at a terrible cost. Gay men were losing their jobs, their families, their homes. The prejudice often turned violent: gangs of youths roamed the inner city bashing gay men, and murders were being reported in the gay press seemingly weekly, with little action taken by police. One night, coming home from the Regent, I was threatened by a group of thugs; fortunately, I was able to break free and run away.

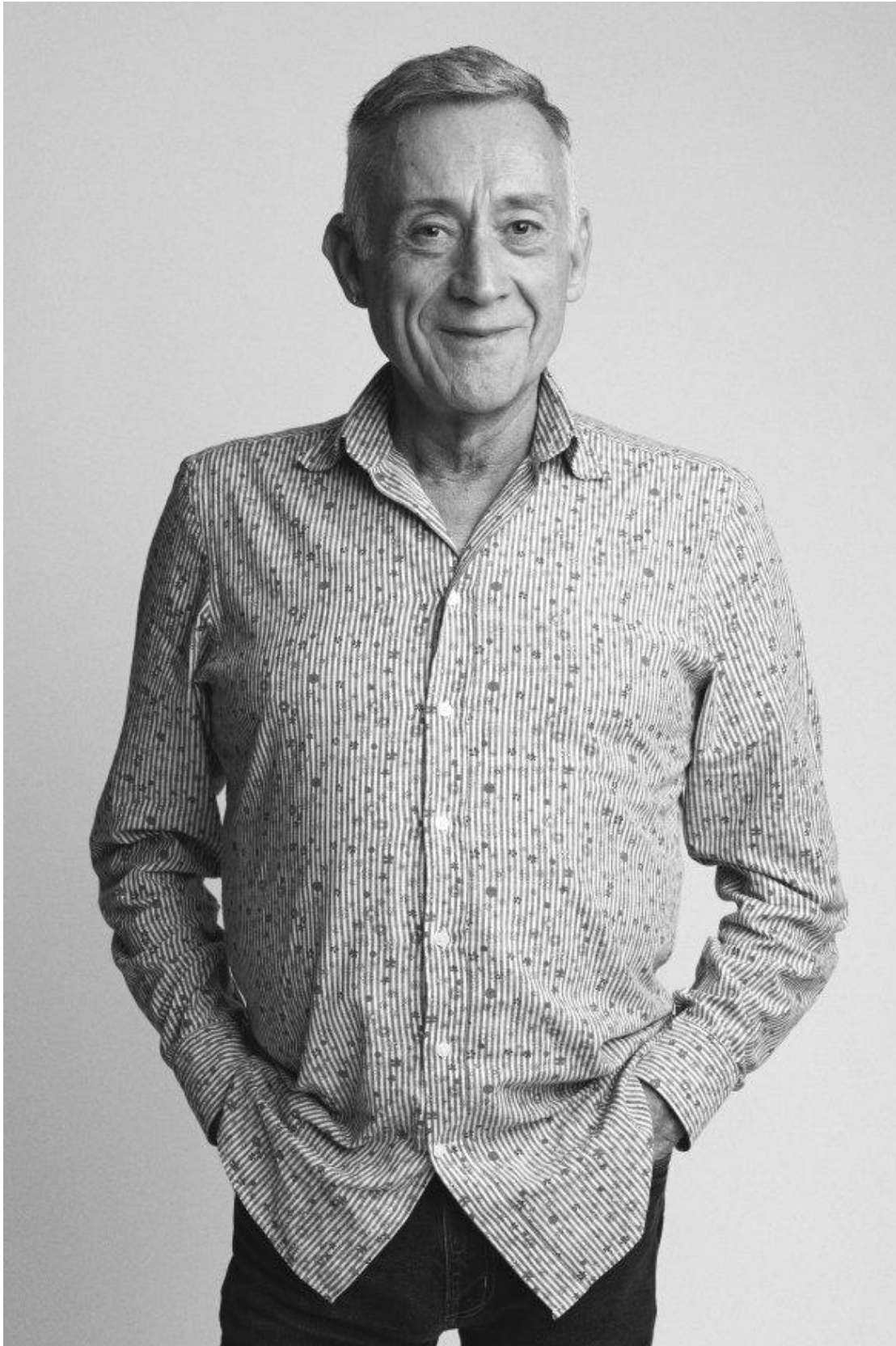
There were so many heartbreaking moments. I once visited a dying friend in Ward 17 South – the AIDS ward – at St Vincent’s Hospital in Darlinghurst. Passing all these beds, four to a room, I recognised a few familiar faces – now gaunt and haunted-looking – I hadn’t seen for a while; I didn’t even know they were sick. I seemed to be going to a funeral every month. Once, after becoming skeletal from illness myself, I went to a cafe in Bondi Junction with a couple of friends who looked like me. People just stopped and stared; it was a horrible experience. I consoled myself with the knowledge that the LGBTIQ community had come together as one, forming myriad support and lobby groups and pressuring governments to focus on education around safe sex, which helped prevent the disease from making big inroads into the general population.

“The trials had hideous side effects, but I felt it was my duty to help researchers.”

When I learnt I was HIV-positive, I made a vow to help medical science find out more about this awful disease. So when I saw a sign in my GP’s office asking gay men to become part of a study, I signed up. The study was led by David Cooper, then based at St Vincent’s Hospital, and, for the next 25 years, I did 28 HIV trials under David’s care. The trials had hideous side effects, but I felt it was my duty to help researchers find what did and didn’t work. One of the trial drugs left me with superficial siderosis, a very rare brain disorder that’s affected my legs. I now have severe balance problems.

Still, I consider myself one of the very lucky ones. Not only did I survive, but I’ve managed to found Sydney’s first queer museum, Qtopia, featuring an AIDS memorial and a tribute to David Cooper, who died in 2018. He did so much for HIV research in Australia.

Max Niggl, 69



Max Niggl says, "I hadn't even told my mum I was gay." *PETER TARASIUK*

One of my earliest memories of HIV was when I was in my early 30s and at a gay bar in Melbourne called Pokeys. It was the mid-1980s and a couple of my friends pointed to a gaunt, sickly-looking man: "Don't go near him, he's got AIDS." It sounded so discriminatory, so scary to my ears, but this was a time when someone would suddenly disappear – a barman, your hairdresser, an acquaintance – and you'd later hear they'd died.

I'd grown up in country Victoria and escaped to Melbourne in 1971 after finishing my HSC, having been bullied and bashed at school for being "different". I got a trainee management job in a department store in the city, and enjoyed a feeling of liberation I'd never thought possible – going to parties, meeting new people, having a relationship with a woman before finally accepting I was gay.

Homosexuality had been decriminalised in Victoria (1980) and NSW (1984), so it seemed especially cruel that this deadly disease came along at the very moment gay men were no longer criminals. I told myself, "This disease is not going to get me." I wasn't promiscuous and was in a long-term relationship with a man called Keith, which would last 10 years. But in 1987, I developed a nasty rash on my back and was diagnosed with shingles. My GP told me this was very unusual for someone my age and wanted to test me for HIV. I said, "What's the point? There's no treatment anyway. You can do the test, but I don't want to know the result."

Fear fed into denial: I didn't even know I could pass the virus on. A year later, I developed a severe respiratory infection and was dispatched to hospital by my GP, who suspected I had a form of pneumonia typical of HIV. I was 33 and it really hit me: "I'm HIV-positive. I have pneumonia, an AIDS-defining illness. I'm probably going to die." I worked out I probably seroconverted back in 1984 from a casual sexual encounter followed by a flu-like illness. The hospital ward was full of very sick and dying young men and I found it very confronting. After several days, still very unwell, I discharged myself: I needed to be away from there, to recover and go back to work.

My mum, formerly a nurse, came down to Melbourne to look after me; Keith, in denial, was disappointingly non-supportive. I hadn't even told my mum I was gay, let alone that I had an AIDS-defining illness, but she got straight to the point, so I told her the truth. "Why have you never told us?" she asked. "I've always been worried about Dad rejecting me," I replied. Later my dad called to say, "I wanted to say I love you and that if I could take this virus away and give you a normal life, I would." The moment I got off the phone, I bawled my eyes out.

“I was 33 and it really hit me ... I’m probably going to die.”

I was put on AZT, the first drug that promised to slow the virus, but it took a terrible toll on my body, not just with off-the-scale nausea but muscle-wasting to limbs and loss of volume in the face.

A couple of years before the arrival of the first antiretroviral that would save so many, Keith developed his first AIDS-defining illness followed by a run of opportunistic infections, including cytomegalovirus retinitis, which sent him blind within three months. Around this time I lost my job as a finance officer after my boss told the staff about my HIV status without my permission. The last 12 months with Keith, with multiple hospital admissions and his fits of grief, anger and drug-induced confusion, were pretty confronting. But I was able to grant him his final wish: to die peacefully at home. He was just 40.

The arrival of new HIV drugs in 1996 saved me – I was down to five or fewer CD4 T-cells. With this ray of sunshine came some bad news, however: I was diagnosed with anal skin cancer. After radiation it went into remission, but it came back again in 2004 requiring surgery. Afterwards, I sank into depression: I’d never processed everything, from being ostracised at school to Keith’s death to the discrimination I’d suffered as an HIV-positive man and losing my job and my relationships. Seeing a psychiatrist over three and a half years helped me unpack everything and become a better person.

I’m in a good place now. I’ve been in a relationship for nearly 10 years and have retired. I’ve had ups and downs due to my health but have good genes – Mum is now 92 and Dad was 90 when he died. HIV is only a part of me; it’s not all of me and never will be.