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Amy K. Mackinnon

Cuny Graduate School of Journalism

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Surviving a Death Sentence

Diagnosed with HIV at the peak of the AIDS epidemic, Sean McKenna had planned to die. Now, decades after life-saving drugs were first released, he and other long-term survivors are still figuring out how to live.

By Amy Mackinnon

Sean McKenna opened his eyes and was surprised to find himself alive.

He reached out to touch things around him, confirming their physical existence and, by extension, his own. He turned on the small television next to his hospital bed just as Bette Midler was singing a song from her new album, "Bette of Roses," on the Today Show.

That threw him for a moment. If there was a heaven, Bette Midler would surely be in it.

The previous night, when McKenna closed his eyes to go to sleep, he had made his peace with the idea that he might not wake up. It was 1995 and by the end of that year the 14-year-old HIV epidemic would claim its 62,682nd victim in New York City alone. For young gay men like McKenna, who was 33, the prospect of premature death had become a fact of life.

McKenna, a former model, was first admitted to St. Vincent's Hospital in Greenwich Village on Halloween. Rasping with bacterial pneumonia, he had leaned heavily on his younger sister Megan's tiny frame as they wove their way through demons, divas and drag queens, revelers in the annual Village Halloween Parade. Megan was a nervous wreck, but did her best to hide it from her brother.

The nurse who greeted them fast-tracked McKenna to a gurney in the emergency room. Another stopped by to make sure he got a piece of Halloween candy. After seeing so many plucked from life prematurely, it was as if there were an unspoken covenant among the hospital's caregivers to be extra kind to those with HIV.

As McKenna awaited admission to the hospital, people rushed by his gurney every so often to admire one of the more fantastical Halloween costumes outside. Oblivious to it all, the young couple on the gurney next to him were making out furiously. Was he really going to die next to that?

McKenna couldn't help but notice one thing when a doctor finally tended to him: the man was cute, like a human Ken doll. He was big and muscular, in stark contrast to his patients, who were wasting away in their prime.

After McKenna was admitted to a room on the seventh floor AIDS ward, his parents drove up from Virginia. His mother was her ebullient self, insisting that he have his photo taken with each vase of get-well flowers so that he could send thank you cards. His father wept. Outside his room, it was near silent on the ward. Young men shuffled up and down the corridors, dragging IV drips.

Two weeks later, McKenna was released from the hospital, his immune system so fragile that he couldn't drink tap water. The drugs used to treat his pneumonia had left him with a metallic

taste in his mouth and the only thing that he liked was a strawberry milkshake. Every day he slowly made his way down the puzzle of stairs from his fourth-floor apartment on the Upper West Side over to the Burger King on Broadway. This is what it must feel like to be old, he thought, as he sat and sipped his milkshake, watching the bustle on the street outside.

Then, after he survived another bout of pneumonia and hospitalization, something unexpected happened. The first protease inhibitors for the management of HIV were approved by the FDA in December 1995. Combined with other drugs to create a foul-tasting liquid “cocktail,” it reduced an HIV diagnosis from a death sentence to a manageable, if complicated, lifelong condition. It was the beginning of a new era for McKenna and everybody else with HIV.

Survival was now possible, but it wouldn’t be simple.

Lazarus

It came to be known as the Lazarus effect as AIDS patients rose from what they had expected to be their death beds. Having increased steadily since 1981, the number of AIDS-related deaths almost halved between 1996 and 1997. AIDS wards slowly began to empty and in 1996 a New York Times Magazine cover story heralded the end of the epidemic.

For many who were HIV-positive, there wasn’t a singular moment when it became clear that they would live. Even after the release of the new drugs, McKenna planned his funeral and picked out the music, which included plenty of Bette Midler. But over the years as the prospect of death began to retreat to a distant horizon, McKenna had to figure out how to live.

A quarter of a century after the cocktail was introduced, HIV is no longer thought of as an affliction of the young. By 2020, it is estimated, some 70% of those living with the virus in the United States will be older than 50. Although there is still no cure for HIV, daily antiretroviral therapy can suppress the virus to undetectable levels, halting its effects and drastically reducing the risk of transmission to a partner.

Of the 1.3 million people currently living with HIV in the United States, just over a quarter were diagnosed before antiretroviral drugs became available. They have come to be known as long-term survivors. Some use the term to describe those who have lived with the virus for 10 or more years, but McKenna does not. In his view, only those diagnosed before 1996 thought they were getting a death sentence. As a result, many didn’t finish school, build careers or save for retirement.

“I don’t think any gay men who were thoughtful and honest with themselves thought they were going to survive,” said Walt Odets, a clinical psychologist based in Berkeley who has worked extensively with gay men.

A recent study of HIV-positive adults over 50 in San Francisco found that for the vast majority their HIV was well managed, but they contended with extremely high levels of poverty. Long-term survivors were not the focus of the study, but it does shed light on the effects of aging with HIV. Fifty-seven percent receive disability payments, their incomes and healthcare bound up in a complicated web of government bureaucracy.

Even with modern medications, HIV takes a [toll](#) on the body and speeds the aging process. Long-term survivors often experience heart disease, osteoporosis, memory problems, cancer

and kidney failure years earlier than would be expected. People with HIV who didn't think they would live to see old age are now experiencing its effects sooner.

Beyond merely surviving, many who lived through the AIDS crisis compare the psychological toll to that experienced by combat veterans.

"The closest analogy I can think of was that it was like being dropped into a war zone," said Tez Anderson, who lived in The Castro in San Francisco, a gay neighborhood synonymous with the gay community.

"There were no bombs or burnt out buildings," Anderson said. "But there were young men that walked around the neighborhood and you'd see and them looking healthy and then they'd get sicker and then they'd have walkers, an oxygen tank and then you'd read their obituary in the paper."

At some point, Anderson stopped counting the deaths, but estimates that he lost hundreds of friends and acquaintances to AIDS.

Anderson, who tested positive for HIV in 1983 at the age of 26, coined the term "AIDS Survivor Syndrome" to describe the spectrum of trauma, which he felt came not only from watching so many friends die, but from preparing to die himself. Its manifestations include depression, isolation and feelings of despair about the future.

Anderson's definition was tested by Ron Stall, director of the Center for LGBT Health Research at the University of Pittsburgh. Stall surveyed participants in the Multicenter AIDS Cohort Study, a group of 7,000 men who have sex with men whom researchers have been tracking for three decades. Half are living with HIV, half are not.

Almost a quarter, 22%, reported experiencing three or more symptoms regularly. In a reflection of the devastating effect of the AIDS epidemic, HIV-negative men in the study were as likely to experience psychological strife as those with HIV.

Stall declined to be interviewed for this story. But he told the author of a [blog post](#) by the San Francisco AIDS Foundation that the study suggested that while many who lived through the AIDS epidemic were doing well, there was a small group in real need of help in dealing with its aftermath.

"There's a meme that we lost an entire generation to AIDS" said Anderson "But there are a lot of us still here."

Surviving

Standing recently in a small triangular park at the corner of Seventh and Greenwich avenues, McKenna, who is now 56, looked up at a luxury apartment complex called The Greenwich Lane. The street lamps illuminated the delicate bone structure of his face, and shadows sat in the gentle hollows beneath his cheeks.

"I call this the poltergeist," he said.

Pricey condos and townhouses have supplanted the hulking hospital that long ago saved his life.

A neighborhood institution known as Saint Vinny's, St. Vincent's was founded in the mid-nineteenth century to provide medical care to the overlooked and disadvantaged. Victims of New York's 1849 cholera epidemic, of the Titanic, of the AIDS epidemic and finally of the 9/11 terror attacks came [through](#) its doors before it closed in 2010 after years of financial struggle.

Now there are "residences" surrounding a formal private garden with a reflecting pool and a birch "allée" in its place. Last year, the building's penthouse apartment was sold to an anonymous buyer for \$40 million.

On an autumn evening just after dark, the blinds in almost all the apartments were still raised, exposing sleek interiors illuminated like giant display cabinets.

"If I hadn't been positive, I might have been able to live there," said McKenna.

Until 1996, McKenna worked as a casting agent at a modelling agency. Sitting at a large round table with his colleagues, McKenna took calls from casting directors, noted down the type of model they were looking for and picked out candidates from the agency's catalogue. When McKenna first revealed he was HIV positive, his boss sent him to work in a separate room. He was fired after being hospitalized with pneumonia for a second time. "I was definitely fired because of my status," McKenna said. It wasn't yet illegal for employers to do so.

When McKenna first signed up for disability payments in 1996, he received \$1,200 a month, which was just enough to get by on. It has since risen to \$1,600 but has been far outpaced by the increasing cost of living in New York City. Every six months his disability support payments are subject to review and the older he gets, the more he fears he may make a mistake on the forms that could cost him his income.

"I know I couldn't handle a 40-hour week," he said. McKenna has had arthritis since his early 40s, which he attributes to the accelerated aging that can accompany HIV. Soon he is going to explore the option of having his hip replaced. "I just feel like I'm a 70-something-year-old in a 50-something-year-old body," he said.

He has lived in the same one-bedroom apartment on the Upper West Side since the mid-1980s, long enough to watch the honey locust tree in front of his building grow up past his windows, filling them with green every spring. The room itself is a burst of color. There isn't a section of wall without a picture hung on it while every available surface is adorned with candles, ornaments or plants. In the kitchen, a tea-towel and an oven glove printed with silhouettes of dachshunds hang neatly on the oven door handle. McKenna's dog Poppet, a Dachshund-Yorkie mix, sleeps buried in a bed full of plush toys that are almost as big as her.

McKenna's rent is stabilized at \$1,100 per month and, by splitting the bills with his partner, Michael, he is just able to survive on his disability payments. His sister Megan helps with the upkeep of Poppet. He is acutely aware of how vulnerable he could be if he ever had to move. "My biggest fear is homelessness," he said. "What's worse than being a person with AIDS? Being a person with AIDS who is homeless."

From Long Island to The Village

McKenna's childhood was so perfect that he sometimes wonders if everything went so right in order to prepare him for when something went wrong. Megan says that while McKenna has had periods of depression over the years, she hasn't doubted his strength. "That's probably our family more than anything. We were just never really like poor me or anything," she said.

Born in 1962, McKenna grew up in Hauppauge, Long Island, the eldest of three platinum-blond children. With just thirteen months between them, McKenna and Megan have been extremely close their entire lives. When McKenna went to kindergarten, their mother bought Megan a kitten so she wouldn't feel alone.

Their parents, John and Rebecca, grew up next door to each other. In the summer when they went to visit their grandparents in Mount Pleasant, Pa., McKenna and his siblings would run back and forth between their two houses, which were joined by an alleyway. One set of grandparents ate dinner an hour before the other, and McKenna would often join them both. "If I only had one complaint about my childhood, it's that I was slightly chubby," he said.

When the time came for college, McKenna received scholarship offers from Boston University, American and New York University. Even though the scholarship was less generous, he decided on NYU because it was in the Village, which was then the epicenter of gay life in New York City. Arriving at the end of the summer in 1980, he had one year of carefree sexual expression before the fear of death set in.

Swept up in the party scene, and modelling, he dropped out of NYU after two years. He worked as a waiter at La Grande Corniche in the River Hotel on Christopher Street, which had white table clothes, purple carpeting, and walls of [windows](#) overlooking the Hudson River.

It was there that McKenna met Nancy Carpenter-Olson, a fellow server. She remembers the way the light caught McKenna's blue eyes. "He was the most exquisite human I'd ever laid eyes on," she said. She assumed he was the arm candy of a wealthy patron. McKenna told her he had grown tired of modelling, and wanted to be able to eat and do what he wanted.

After their first shift together, they went dancing at the gay club downstairs, Uncle Charlie's Village. Carpenter-Olson, now 56, felt like she had just met her best friend and she now describes McKenna as her soul-mate. McKenna was Maid of Honor at Carpenter-Olson's wedding and danced her mother down the aisle to Bette Midler's "We're Going to the Chapel."

The pair would walk arm-in-arm around the city and play "street games," pondering the sexuality of men that passed and spotting celebrities and their lookalikes. They'd go late-night shopping and sing the theme song of the store. "We'd just have more fun than is humanly possible," she said.

A man they worked with at La Grande Corniche became the first person Carpenter-Olson knew to die from AIDS. He was sweet and funny and would make earrings out of the garnishes at the bar. "He got sick and was gone so fast that it was head spinning," she said. But McKenna perhaps would be spared, she thought. "Sean was always so strong and young and healthy, it really did seem that he could be that lucky."

A sign of the times, the River Hotel -- once a premier gay leisure spot -- became the Bailey-Holt House in 1986, the first congregate residence in the country for people living with HIV. In those

days, it was effectively a hospice. The window-lined restaurant where Carpenter-Olson first met McKenna became the dining room.

On a chilly night in late October, McKenna and I walked through Greenwich Village looking for somewhere to go for a drink. We ended up at the Stonewall Inn, a bar famous for the 1969 riots that launched the gay rights movement and a decade of milestones. The American Psychiatric Association [removed](#) homosexuality from its list of mental disorders, the first openly-gay political candidates were elected to office, and in 1979 the first National March on Washington for Lesbian and Gay Rights took place.

In 1981, when “we had just gotten our sex lives back,” McKenna read a New York Times [article](#) about a “rare and often rapidly fatal” cancer affecting gay men in New York City and San Francisco. McKenna believes that it was around that time that he contracted HIV, although he didn’t discover it until over a decade later.

At Stonewall, McKenna bought a round of beers and shots of Jägermeister with a \$50 voucher his sister had won at an HIV fundraiser on Long Island. The tiles on the low ceiling have been painted over so many times their baroque imprints have become blurred. Towards the back of the bar there is a pool table topped with faded red felt. Neat signs that read “no drinks on the pool table” have been sellotaped twelve times around the edge.

Two young women walked over to the pool table. One placed her elbows on the edge, cradled her face in her hands, while the other took pictures. “Tourists?” I asked McKenna. He said it’s one of the reasons he doesn’t come to Stonewall that often. He asked the women if they’d like him to take the photo. It wasn’t clear whether she misunderstood or couldn’t hear him. “Sorry, we’re not from here,” the woman said.

Surviving, but not all are thriving

After the first drugs for the management of HIV were released in 1996, the sense of urgency among AIDS activists in the United States began to fade. “I think it was for reasons that we were so exhausted after 20 years of burying people, caretaking, the apathy of the public,” said Anderson. Other battles – the long fight to legalize gay marriage, for instance – loomed large, and attention was diverted.

While new medications enabled those with HIV to imagine a longer future, there were far fewer resources for dealing with the profound collective and individual trauma of having survived the AIDS crisis.

Some long-term survivors now feel that they have been forgotten.

For many in the community, the 2012 death of Spencer Cox, a veteran AIDS activist, was a moment of realization that while the epidemic might be over, the crisis was not. Cox had been instrumental in designing the clinical trials for the development of the first antiretroviral drugs. In 2006, he turned his attention to the aftermath, founding the Medius Institute for Gay Men’s Health to research the mental and physical health of gay men as they aged and the legacy of the AIDS crisis. “We have this enormous, terrible thing that happened to us that we have not confronted at all,” Cox said at the time in an interview in [Gay City News](#).

But Cox struggled to find funding for the center. "Medius was his plea for help," said Odets, the Bay Area psychologist. "But people didn't want to pay any attention."

It took a toll. Cox became addicted to methamphetamines and later stopped taking the very anti-retroviral drugs he helped bring to market. His death sparked just the kind of discussion he had tried and failed to ignite with his center.

"For many activists, there was an existential crisis of where do I put my energy?" said Olmedo, the New York psychologist. After contending with the rejection and identity struggles well before the AIDS era, many gay men threw themselves into AIDS activism and gained a sense of purpose as a result. Once that activism fell by the wayside, some felt despondent and depressed, and turned to drugs, and lost their lives to addiction, Olmedo said.

McKenna's own realization that long-term survivors needed help came the year after Cox's death at a panel discussion at his alma mater, NYU.

He had been interviewed along with a dozen other long-term survivors for Perry Halkitis' book, "AIDS Generation," and was invited to talk about it. As he entered the event space, he recognized some of the participants, having seen them around town over the years. Others were identifiable as survivors by their sunken cheeks and the hollows under their cheek bones, a side effect of both HIV and the early drugs used to treat it.

One by one, they went around the table and shared their stories. Each time, at least one person would cry in recognition. "It was a special moment," said McKenna. "It was a dozen people realizing that there were other people like us."

After the book was launched, the group decided to get together again for a potluck dinner. One participant came in with a cane. "You could tell that he'd tried to look good, but that he didn't have the energy for it," said McKenna. The man began to shove food in his pockets without even wrapping it first. "Look what this disease did to this person," thought McKenna.

Facebook has become the bedrock of McKenna's activism. "I used to just post pictures of a good-looking guy, then I'd hit them with an HIV fact," he said. Once he realized that fellow long-term survivors were struggling, he began to "constantly bitch" on Facebook about the lack of support services, often tagging AIDS services organizations themselves. Someone at the Gay Men's Health Crisis in Manhattan took notice, and Kelsey Louie, the chief executive, invited McKenna for a meeting.

McKenna suggested that GMHC reinstate the buddy program. Launched in the early 1980's, the program ran throughout the epidemic, pairing people with HIV with buddies who provided practical and emotional support. The program ended in 2005 due to a federal funding cut and lack of demand. Having been told that it would cost tens of thousands of dollars to restart the program, McKenna held a silent auction on Fire Island to raise funds. This was then supplemented by donations. The buddy program was restarted in 2015, and it is not limited to long-term survivors. Buddies are trained in active listening and meet once a week with their client. "Our goal primarily is to get them out, to have them breathe fresh air" said Susan Rowley, the program director. The man whom McKenna saw stuffing food into his pockets was first on the list to receive a buddy but had died by the time the program started.

McKenna said that in the early days of the AIDS crisis, the gay community had to do things for themselves: care for those who were sick while lobbying for government funds and research. Now he said, long-term survivors are once again leading the way. After the buddy program was relaunched, McKenna said he crashed as he was once again faced with the question of what to do next.

About a year and a half ago, McKenna noticed a patch of purplish skin on his shoulder. He has since named it Violet. After some cajoling from his partner Michael and sister Megan, McKenna went to the dermatologist. After it was removed, a biopsy showed that McKenna has a very rare form of skin cancer, called dermatofibrosarcoma protuberans. It appears in one in a million people each year.

“For some reason I’m not freaking out about it,” McKenna said, as it does not metastasize quickly. It’s hard to know whether there is any connection between the cancer and McKenna’s HIV status, but he suspects that there is.

Years ago, when he first learned that he was HIV positive, he came to a realization: “The virus isn’t out to kill me. The virus wants to live like I want to live.” So he made a pact with his HIV -- “You can live with me, if you don’t kill me.”

Doctors removed the affected skin on McKenna’s back, an area so large that it requires a graft using skin from his thigh. Biopsy results showed they were able to remove all of the cancer.

While he was recovering from the procedure in the hospital he turned on the Today Show first thing. This time, there was no Bette Midler.