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# A Reason to Live: HIV and Animal Companions

Vicki Hutton

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A REASON  
TO LIVE

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A REASON  
TO LIVE

*HIV AND ANIMAL COMPANIONS*

*VICKI HUTTON*

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## Abbreviations

ACT UP	AIDS Coalition to Unleash Power
AIDS	acquired immune deficiency syndrome
AZT	zidovudine
CDC	Centers for Disease Control and Prevention
fMRI	functional magnetic resonance imaging
HCAB	human/companion animal bond
HIV	human immunodeficiency virus
KS	Kaposi sarcoma
<i>MMWR</i>	<i>Morbidity and Mortality Weekly Review</i>
PAWS	Pets Are Wonderful Support
PCP	<i>Pneumocystis</i> pneumonia

# Introduction

In 2000, a young man in rural New South Wales (NSW), Australia, contemplated the pros and cons of killing himself. Diagnosed with HIV in 1990, Ben had been healthy and symptom-free when he met his partner, Joel, in 1995. Five years later he was bedridden, incontinent, and facing death within six months. The relentless illness had taken its toll physically and emotionally on both Ben and his relationship with Joel, and an overdose of the strong medications he required daily had become increasingly attractive. Confident his partner would survive—perhaps even feel a guilty relief—if he chose to kill himself, Ben realized it was the animals that made him hesitate. They would not understand, and they had tried so hard to get him through this.

The first time we met, Ben explained the intuitive and unconditional support that he had felt from Tiger, the scruffy rescue dog, and his horses, Ember and Flash, as his body and mind fell to pieces: “While I was still mobile, I’d go outside to the horses and give them full body hugs. I could bury my face in Ember’s mane and really let myself go. It would release so much tension and I’d just feel so much better after that. The horses knew and they’d come up to me, especially Ember. He always knew when I was at my worst.”

As Ben’s health deteriorated further and he became increasingly bedridden, Tiger took over. “He’d sit on my bed and slept with me the whole time, even when I was a scrawny little old skeleton who would wet the bed. He always knew when I was extra unwell because he’d just be glued to me. He was a lifesaver, and I knew he’d grieve if I died. I couldn’t deliberately leave him.”

Ben chose to continue fighting and, thanks to increasingly effective antiretroviral medications and the support of his animals, he survived. However, in 2010, after fifteen years together, Joel had had enough. He could no longer cope with someone who was constantly ill, and possibly going to be very ill again in the future, and so they parted ways. Tiger remained with Ben as he struggled with two losses: the end of his human relationship, and the subsequent devastating separation from Ember and Flash when he and Tiger were forced to relocate closer to the urban medical facilities that were now a constant part of Ben's life.



*Tiger*

Around the same time that Ben was discovering the difficulties of finding inner-city rental accommodation with limited income, no job, HIV, and a dog, five hundred miles away another man was considering the possible benefits of killing himself. Diagnosed with HIV in 1985, Dylan was tired of living with the legacy of this diagnosis: kidney and liver problems from early HIV medications such as zidovudine (AZT), weight loss and rapidly thinning bones, and lately, an overwhelming and exhausting depression. He was sick of waiting for the next sign that his body was giving up and had become increasingly reclusive as his gaunt frame and protruding cheekbones screamed “I have AIDS” to the world. Increasingly, he was just sick of living.

As Ben had a decade earlier, Dylan weighed up his options. His partner, Pete, would survive, and he believed Pete would eventually understand

and maybe even come to respect his decision. Dylan and Pete had been together for twenty years and their relationship was solid, but much of their lives revolved around Dylan's health. It was the animals who would struggle to comprehend his choice to leave them. Gus and Sunny, the dogs, and Celia, the cat, had never known Dylan without HIV. Gus in particular had invested so much in keeping Dylan alive. According to Dylan,



*Gus*

Gus was uncompromising about his HIV medication regimen: "There'll be days when I've had things going on in the old brain and I've forgotten to take the morning pills. I start to get things ready to take Gus and Sunny out for the morning walk and Sunny's there, bouncing around, but Gus isn't. He'll be sitting there, by the fridge in the kitchen, with his head cocked to one side, waiting. And then I realize I've forgotten to take my pills. Once he sees me swallow the pills and put the water back in the

fridge, he's bouncing all over the place and ready for his walk. I feel that he's watching to make sure I'm doing the right thing."

Dylan chose to continue living for the animals, just as Ben had years before. Dylan and Ben are both part of the HIV epidemic that, within a few years, had returned despair, blame, and stigma to a medical condition.

During 2011 and 2012 I conducted a study among people living with HIV in the United States and Australia about their health, their experiences of stigma, and their past and present animal companions. Some of the Australian participants, including Ben and Dylan, also agreed to talk to me at length about the experience of living with HIV with a companion

animal. Over the course of a year I traveled around Australia to meet with eleven men and, wherever possible, their animal companions. All were eager to communicate their individual stories of survival and their gratitude to the animals who had shared, or continued to share, their life experiences. Each story can stand alone, bringing a uniquely personal perspective to more than three decades of the public and multifaceted HIV epidemic. However, when pieced together, this collection of narratives becomes far greater than its parts, creating a dynamic and integrated picture of the bond between human and animal, and an epidemic that seemed to catch the world by surprise.

In the narratives to come, the fearful, fatal years of the 1980s are captured in the stories of Drew, who survived his partner's death, his own diagnosis, and feelings of stigma and isolation with help from a socially inept bull mastiff dog named Caesar; and Charlie, whose strong attachment to a dog named Wolf, and subsequent love affair with a stray cat named Brandy, spanned almost three decades of the epidemic. Permeating Charlie's narrative is the disenfranchised grief he experienced when Wolf's death was deemed inconsequential amid the human carnage of the epidemic, and the relief he felt at admitting to me the relentless pain that followed the loss of his dog.

HIV medications improved in the 1990s, allowing a cautious optimism to creep into the narratives of Vince, living his dream on fifty acres of bushland surrounded by the healing power of nature; Carl, unexpectedly alive and now content to live and age with HIV with Rosa, the pudgy pug cross bulldog by his side; and Robbie, with Bellamy, the kelpie-cross Australian cattle dog, who dragged him out of the hopelessness and despair of his 1997 diagnosis. Their individual stories of personal hope, and love for the animals who supported them during this decade, are contextualized within the growing body of theoretical material trying to make sense of the sometimes inexplicable human/companion animal bond (HCAB). Vince's experiences embody the concept of biophilia—humanity's evolutionarily acquired affinity with the natural world, and the powerful need in the human psyche to maintain, or reestablish, a connection with nature. Carl's and Robbie's narratives validate theories of attachment, loneliness, and

empathy within the human–animal relationship, set against the backdrop of a world still struggling to come to grips with the physical, emotional, and social complexity of living with this incurable virus.

By the start of the twenty-first century, increasingly sophisticated HIV medications had transformed the lived experience of HIV for those who had access to them. Narratives from this century build on the cautious optimism of the 1990s, but also reflect the unspoken difficulties of moving on with life once HIV, from a medical perspective at least, became just another manageable, chronic illness. There is Ben, whose horses and scruffy rescue dog, Tiger, stepped in when Ben's partner could no longer bear living with a dying invalid. Tiger's role as social support and social catalyst conveys the effortless capacity of companion animals to provide both a twenty-four-hour support system and a social conduit to other humans. Dylan's story of the ever-vigilant Gus, who refuses to set off for their much-loved walks until the medication regimen is complete, portrays gratitude that his personal death anxiety can be allayed through a strong determination to remain alive in the twenty-first century for the sake of his animals. And Brenton's reliance on his unlikely confidante, a feisty young ginger, white, and gray cat named Tom, demonstrates the therapeutic power of laughter as Tom's irresistible antics elevate Brenton's mood and boost his physical well-being on a daily basis.

Smaller animal companions with huge stories include Joe and Feathers, the intuitive African grey parrot who is "priest in confessional" to the largely housebound Joe. The pleasure in nurturing another living being, and simply feeling needed, underpins the strength of their attachment relationship, as their joint lives grow increasingly enmeshed. Mick's narrative of Axl Rose, the neotenuous axolotl, and the five fish who can always calm his strongest emotions, confirms the power of animals and the natural world to ground a person in the present, preventing ruminations on the past and worry about the future, by prompting the practice of mindfulness. And Simon, who could not face the world without Sheila the ferret tucked in his shirt for security, describes the normality he felt when rescuing and caring for wildlife in an environment where nobody knew or cared about his HIV status.

Some of these men are no longer alive, confirming the importance of piecing together their personal narratives. Photos of some animal friends have been included to honor these relationships, but this was not always possible. There have been some changes in the stories to maintain the privacy of those who shared their experiences with me. Names have been altered and backgrounds modified, but the theme remains the same time and again. For many, the enduring love between human and animal was an integral part of their life's journey.

# Part 1

The 1980s

# 1

## An epidemic of stigma

### A brief history of HIV/AIDS and companion animals

In the early 1980s, AIDS awareness drifted across the globe amid whispered rumors of a medical disaster that threatened the very existence of gay communities in New York, San Francisco, and beyond. It would be months and even years before all the elusive parts could be connected, but for some people that was too late as they succumbed to the “gay plague” that had neither name nor treatment.

Thousands of lives were touched by an epidemic that reintroduced blame and stigma into health care. Some of those affected by HIV and AIDS chose to share their lives with an animal companion who was silent witness to their struggles with an incurable disease that followed no rules. If those animals could write, they would most likely describe love and affection against a backdrop of suffering, discrimination, and death. But they would also tell tales of courage and survival, and of the cautious optimism that emerged as the tenacious virus was contained, but not destroyed, by the turn of the century. As the world struggled to come to terms with this new condition, those living with HIV sought to survive as best they could. For many, their animal companions were crucial in this story of survival.

Globally, the first official mention of the impending epidemic occurred on June 5, 1981, when the US Centers for Disease Control and Prevention's (CDC's) *Morbidity and Mortality Weekly Review* (*MMWR*; CDC 1981b) described five young men, all active homosexuals, presenting with a rare and deadly form of pneumonia traditionally limited to severely immunosuppressed patients. Two of the patients were already dead.

Despite the rapid death of two previously healthy young men, there was no hint of the scope and impact of the global epidemic to follow. Instead, risks to population groups outside the gay community were downplayed by the article's accompanying editorial note that inferred causality of this illness to the "homosexual lifestyle." The *MMWR* is considered a primary means for the publication of authoritative, timely, accurate, and objective public health information to those working in the medical and public health areas, as well as epidemiologists, researchers, and other scientists. Because it is so respected, reports in the *MMWR* can be influential in defining a new disease. In the days and weeks following the announcement, reports of gay men with frightening and inexplicable illnesses flooded into the CDC, resulting in speculative comments in the US gay press and a few mainstream newspapers in New York and San Francisco about a "gay cancer," "gay pneumonia," or "gay plague" spreading through the gay communities.

On July 3, 1981, a second article appeared in the *MMWR* describing another ten gay men with the deadly pneumonia, together with twenty-six cases of an equally rare malignancy, Kaposi sarcoma (KS; CDC 1981a). However, contrary to the normal illness trajectory of this slow-moving and largely nonfatal cancer, eight of the twenty-six gay men were dead within two years of diagnosis. Again, an accompanying editorial linked the constellation of atypical illnesses to gay men and the "homosexual lifestyle," thus validating the birth of an epidemic of stigma. In 1981, the first official attempt at naming the epidemic as gay-related immune deficiency (GRID) further positioned it as a gay issue associated with nonheterosexual and therefore what was widely considered deviant sexual desires, a flawed perception that would have long-term implications for anyone who contracted the virus (Shilts 1987).

July 1981 also saw the first Australian news article on the puzzling new disease appear in the Sydney gay newspaper, *Star Observer*, under

the header “New Pneumonia Linked to Gay Lifestyle” (Robinson 2011). Other Australian gay publications picked up the story, including the *Gay Community News*, which in February 1982 devoted significant space on page 5 to the poignant question “Will We All Die of ‘Gay Cancer?’” (Robinson 2011).

The epidemic finally received the nongay-specific name of acquired immune deficiency syndrome (AIDS) in 1982 (Shilts 1987), coinciding with the growing awareness that AIDS and the fatal wasting condition called “slim disease,” widespread among men and women in Africa, were the same (Serwadda et al. 1985). Fears that the disease could make its way into the general population through heterosexual sex and even casual contact further escalated as scientific and media reports of AIDS among injecting drug users, sex workers, heterosexual women and their children, and regular recipients of blood transfusions, especially those living with hemophilia, emerged (Sendziuk 2003).

In July 1982, eleven months after the first reports of the puzzling new disease appeared in the *MMWR*, the CDC officially declared AIDS an epidemic (Wolf 2002). Nevertheless, there were some suggestions, especially in the US gay press, that insufficient attention was being paid to a disease perceived as primarily confined to vulnerable minority groups (Shilts 1987). These claims of neglect were based on the alleged initial reluctance of the US scientific community to investigate the disease, compounded by little or no support in the areas of HIV and AIDS research, education, and services from the US federal government, most states, and most municipalities. Instead, it was left to the gay and lesbian communities, who first recognized the seriousness of the AIDS epidemic, to rally socially and politically. A sense of camaraderie amid disaster arose among these communities, a sentiment reflected by writer and human rights activist Susan Sontag in her classic monograph, *AIDS and Its Metaphors* (1989). She depicted AIDS as both a pointer to “deviant” sex and a creator of community among gay men who were no longer able to maintain an identity hidden from family, friends, and work colleagues (Sontag 1989).

By 1984, the retrovirus human immunodeficiency virus (HIV) was identified as the causal agent of AIDS, raising hopes that modern medicine would soon bring an end to the carnage (Wolf 2002). These hopes were

short-lived as the tenacious virus proved to be indestructible and confounded attempts to develop effective treatments for many years. As part of the retrovirus family, HIV has the power to integrate itself into the deoxyribonucleic acid (DNA) of a host's CD4 cells and command those cells to construct more copies of HIV rather than the host's own cells (King, Mulligan, and Stansfield 2014). CD4 cells (also called T cells and T helper cells) are a type of white blood cell that fights infection and therefore are crucial to the human body's immune system. An adversary that could slowly disable this first line of defense was a force to be reckoned with. HIV infection turns to AIDS when a person's immune system becomes so compromised that it can no longer hold off the global onslaught of certain rare and life-threatening opportunistic infections, ranging from thrush and herpes simplex to *Pneumocystis* pneumonia and Kaposi sarcoma, and more (CDC 2017c). During the early years when there was no effective means to halt the relentless HIV replication, a person would eventually succumb to the sheer volume and persistence of these opportunistic infections.

In September 1985, just over four years since AIDS was officially reported in the United States, the incumbent administration, headed by President Ronald Reagan, formally addressed what they termed “an epidemic of fear” (Krieger and Appleman 1994, 25). The resulting reassurance to the US people that there was no need to panic because HIV and AIDS remained largely confined to the gay and injecting drug user populations legitimized and exacerbated the AIDS-related hysteria and hostility sweeping some parts of the nation. The military services began testing for HIV among their personnel, and the following year the Justice Department ruled that people with, or suspected of having, HIV or AIDS could be legally fired (ACON 2012, 16). On state and local levels there were persistent attempts to make it a crime for an HIV-positive person to infect anyone else, and suggestions that all persons with HIV be confined in quarantine camps (Krieger and Appleman 1994).

Increasingly the cost of the AIDS epidemic in the United States was being borne by unpaid labor from community organizations founded by gay activists, private charities, and a few local governments—not by federal

agencies (Krieger and Appleman 1994). Within twelve months of the first *MMWR* report, nongovernment organizations such as the Gay Men's Health Crisis, San Francisco AIDS Foundation, and the Shanti Project volunteer program were mobilized to assist terminally ill people with AIDS, many of whom lacked family and social support following their double disclosure of homosexuality and HIV diagnosis (Wolf 2002).

This supportive culture even extended to companion animals, when volunteers at the San Francisco AIDS Foundation Food Bank noticed that some clients were choosing to feed their animal companions over themselves (Shanti Project 2018). In 1986, based on the belief that nobody should have to choose between caring for themselves or their animal, the volunteers created a special food bank for companion animal food and supplies. By 1987, Pets Are Wonderful Support (PAWS) was incorporated as an independent, nonprofit, volunteer-operated social service organization to help sustain the bond between people with AIDS and the animals deemed crucial to their well-being. Services included food supplies, veterinary care, in-home support (for example, dog walking), foster care during periods of hospitalization, and adoption if the person should die (Gorczyca and Fine 2015). When some clinicians in the 1980s started recommending that people with AIDS minimize contact with companion animals, in particular cats, to reduce the risk of zoonotic opportunistic infections such as toxoplasmosis (a parasitic infection associated with cat feces), PAWS was instrumental in writing and publishing the first guidelines on safe companion animal care for individuals with suppressed immune systems.

AIDS officially arrived in Australia in 1983 with the Department of Health's announcement of the first case in Sydney, quickly followed by the first death at Prince Henry's Hospital in Melbourne (Sendziuk 2003). Learning from the US epidemic of disease and stigma, Australian gay and lesbian communities rallied to defend against the social and medical threats to their existence. They used communication networks, such as the gay press and gay political and social organizations, to circulate accurate information about the epidemic and, importantly, preventative strategies well in advance of more formal government initiatives.

Homophobia in Australia escalated following the 1984 AIDS deaths of four babies in Queensland (Sendziuk 2003). Confirmation that these babies had received blood transfusions from an HIV-positive, asymptomatic gay blood donor prompted two Brisbane newspapers to print an open letter from one of the distraught fathers, in which he called on the “murderer” of his son to do the honorable thing and commit suicide (Robinson 2011, 188). Shortly after, the Queensland government passed punitive laws prohibiting any member of a “high-risk” group from donating blood, a move which publicly positioned gay males as a threat to the general population. Gay rights groups throughout Australia reported an increased incidence of gang attacks on gay men, and some politicians talked of quarantining people with AIDS (Sendziuk 2003, 91).

Early in the epidemic an implicit demarcation arose between the “innocent victims” and the “blameworthy scapegoats” (Weeks 1988). Those perceived as victims included anyone who unwittingly contracted the virus through blood transfusion, such as the Queensland babies and the increasing numbers of people with hemophilia whose lives depended on factor VIII transfusions; women whose sexual partners belonged to the largely invisible category of men who have sex with men; and babies inadvertently infected by their mothers during, or shortly after, birth. Firmly located on the blameworthy side included those whose perceived deviant lifestyle choices had put them in this predicament; that is, gay men, identifiable men who have sex with men, intravenous drug users, and men who visit sex workers. However, irrespective of whether a person was perceived as innocent or guilty, diagnosis with HIV in the early years of the deadly epidemic was associated with uncertainty, fear, and rejection.

Inevitably, many people went out of their way to avoid being labeled with AIDS right up to or, in some cases, after their death. In 1993, the *New York Times* obituary for dancer Rudolf Nureyev cited “a cardiac complication, following a grievous illness” (J. Anderson 1993); while Robert Reed, the quintessential American father in the original *Brady Bunch* sitcom, reportedly died from bowel cancer in 1992, only later revealed in the *New York Times* to have been hastened by HIV infection (Steinberg 1992). Even the first *New York Times* obituary for French philosopher Michel Foucault,

who in life had been so candid about sexuality, linked his death in 1984 to a neurological disorder rather than AIDS (P. Kerr 1984). As the epidemic progressed, even the most obliquely worded death notices could no longer protect young, unmarried males from speculation surrounding their untimely death, and some celebrities opted for a more controlled public disclosure in the latter stages of their illness. For example, in 1991 Freddie Mercury, lead singer of the British rock band Queen, died twenty-four hours after official confirmation that he was suffering from AIDS (*The Guardian* 1991).

Mercury, recognized for his musical brilliance and extravagant lifestyle, also publicly adored his cats: Tom, Jerry, Oscar, Tiffany, Delilah, Goliath, Miko, Romeo, and Lily (Hutton 1994). Between them, these cats supported Mercury throughout his life, and he would regularly phone home to talk to them while on tour. In 1985, Mercury dedicated his first solo album, *Mr Bad Guy*, to the cats with the memorable and infamous caption: “This album is dedicated to my cat Jerry—also Tom, Oscar and Tiffany, and all the cat lovers across the universe—screw everybody else” (Mercury Songs Limited 2017).

Although Mercury was increasingly reclusive from humans as his health deteriorated, the cats’ unconditional love reportedly gave him great comfort in his final days, with Delilah lying on his bed as he passed away (Hutton 1994). Mercury experienced the twenty-four-hour unconditional support system that repeatedly draws humans to share their lives with animals. An animal’s affection is predictable, not subject to human fluctuations, and unaffected by a person’s health status or appearance. Animals do not recognize stigma, thus alleviating fundamental human fears of loss, abandonment, and loneliness. While Delilah and Mercury’s other cats achieved international fame through their steadfast support of the dying musician, many other animal companions have been instrumental in quietly sustaining their humans throughout the deadly epidemic.

In 1991, Betty Carmack, an associate professor in the School of Nursing at the University of San Francisco, commented in *Holistic Nursing Practice* that the role of companion animals for persons with HIV and AIDS had received little, if any, attention. Based on discussions with eleven gay HIV-positive men over an eighteen-month period, she described several

persistent themes. The animals appeared to provide their ailing humans with affection and companionship; reduce stress and promote relaxation; enhance communication with other humans; enable the individual to feel valued and needed; ensure the person remained focused on the present; provide a sense of consistency and constancy in their presence, both physically and emotionally; and provide a major source of support (Carmack 1991). In the first methodologically rigorous and large-scale investigation, Judith Siegel and colleagues (1999) explored the psychological benefits of animal companions among 1,872 gay and bisexual participants of the 1991 Multicenter AIDS Cohort Study (MACS). Results suggested that for HIV-positive persons, the onset of AIDS was more likely to be associated with depression among those who did not live with (or did not have an attachment to) an animal. The animals' supportive presence appeared to buffer, or moderate, the relationship between symptoms of AIDS and psychological distress. A Canadian study of seven men with HIV or AIDS also described the buffering effect of the emotional bond between animal and human, especially when grieving over AIDS losses, and suggested that human-animal relationships may provide a coping mechanism to combat depression, social isolation, and stigma (Allen, Kellegrew, and Jaffe 2000). Of equal importance, caring for the animal served as a meaningful occupation by maintaining the structures of daily routines and responsibilities. Over a decade later, an analogous theme emerged among forty-eight HIV-positive women participating in focus groups to examine the social roles and self-management behaviors of women with HIV (Webel and Higgins 2012). Analysis of data revealed six social roles, including "companion animal carer," as having a potential impact on the self-management of their condition. Five women described the importance of fulfilling the animal carer social role: caring for the daily needs of the animal, providing love and support, and the perceived reciprocation by their animal companion.

Over the decades, HIV and AIDS developed a multiplicity of meanings beyond the virus and the disease. Their history became a mix of facts, myth, and lived experience, all portraying unique perspectives of a moment in time and an epidemic that defied modern medicine. Statistics and timelines for the epidemic are public knowledge, but it is the individual stories

such as the following human–animal narratives that provide a voice and perspective no medical or historical tome could ever capture.

Humans live with animals for many reasons. Some choose an animal for practical reasons, while others want to love and be loved irrespective of their life circumstances. In the 1980s, HIV changed the life trajectory of thousands of people in a way that could never have been predicted. For many HIV-positive people, their animals followed them on that trajectory and by doing so, provided some semblance of normality in a world turned upside down. For others with HIV, their animal companions joined the shifting trajectory further down the track, and provided something that medicine—and other humans—could not offer consistently and unconditionally. For this reason, animal companions are part of the narrative history of HIV, and part of the meaning-making around an epidemic that changed the world.

## About the Author

Vicki Hutton is an Australia-based writer and academic, specializing in the areas of the human–animal relationship, health psychology, and HIV. Animals have always been an important part of her life and remain a key focus in her work and family activities. Hutton’s recent research project allowed her to combine all areas of interest and create a unique narrative history of the human–animal relationship during the HIV/AIDS epidemic in Australia and the United States. She currently is a lecturer at an Australian university, and she spends as much time as possible with her many animal companions.