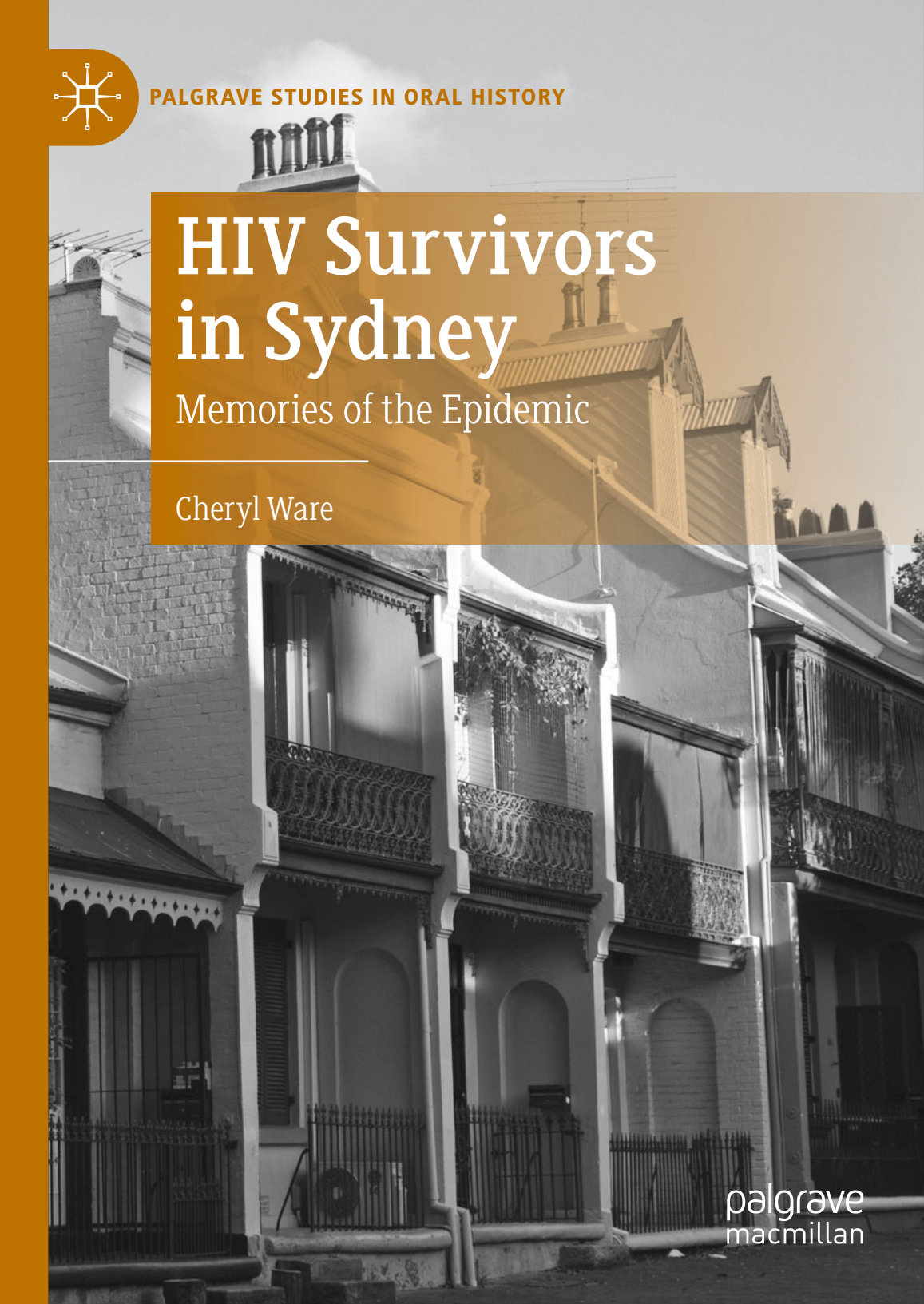
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Cheryl Ware

# HIV Survivors in Sydney

## Memories of the Epidemic

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*To the twenty-five men who participated in interviews for this project. You invited me into your homes and through your testimonies, into your lives. This book is dedicated to you.*

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# Contents

# Abbreviations

| | |
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| ACON | AIDS Council of New South Wales |
| ACT UP | AIDS Coalition to Unleash Power |
| AIDS | Acquired Immune Deficiency Syndrome |
| AZT | Azidothymidine or Zidovidine |
| BGF | Bobby Goldsmith Foundation |
| CAMP Inc. | Campaign Against Moral Persecution Incorporated |
| CSN | Community Support Network |
| d4T | Stavudine |
| ddC | Zalcitabine or dideoxycytidine |
| ddI | Didanosine or dideoxyinosine |
| GCS | Gays Counselling Service |
| GMHC | Gay Men's Health Crisis (New York) |
| HAART | Highly Active Antiretroviral Therapy |
| HIV | Human Immunodeficiency Virus |
| KS | Kaposi's sarcoma |
| NACAIDS | National Advisory Committee on AIDS |
| NAPWHA | National Association of People with HIV or AIDS |
| NSW | New South Wales (Australia) |
| PCP | Pneumocystis Carinii Pneumonia |
| PLWHA | People Living with HIV/AIDS |
| PWA | People with AIDS |
| TGA | Therapeutic Goods Administration |

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CHAPTER 1

# Our Lives Are Going to Change

On the afternoon of 27 June 1982, Ross Duffin waited on the steps of San Francisco City Hall to conduct the interview that would change his life. The twenty-six-year-old Australian had just submitted his doctoral thesis in statistics at the Australian National University in Canberra and was on an overseas trip across North America. The San Francisco Pride Parade, held earlier that day, was one of his final stops. While he was there, however, he became acutely aware of the impact the "mysterious gay cancer" was having on gay male populations. Store windows on Castro Street displayed posters warning passers-by about Kaposi's sarcoma. The ominous purple blotches on an individual's skin were some of the first identifiable signs of the otherwise "silent disease" that was sweeping through the community. Determined to learn more, Ross scheduled an interview with one of the doctors from the Bay Area Physicians for Human Rights, an organisation comprised of gay and lesbian doctors. At that point, the term AIDS was yet to be used. The virus now known as HIV was yet to be identified. One thing was certain: "what they were putting together was a picture of an infectious disease that was deadly." Ross realised, "our lives are going to change, completely and utterly change. And I have some skills in relation to some of this stuff, and I want to be involved. So, I'm going to move to Sydney!"[1] Five months later, Professor Ronald Penny diagnosed Australia's first case of AIDS at St. Vincent's Hospital in Darlinghurst, Sydney. Australia's HIV and AIDS epidemic had begun.



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Ross' decision to move to Sydney highlights important parallels between San Francisco and Sydney. Both cities had thriving gay communities by the early-1980s and initially became two of the main epicentres of the global epidemic. To date, no other city across Australasia has reported as many HIV or AIDS diagnoses or related deaths as Sydney. This was particularly devastating as the gay liberation movements of the 1970s and early-1980s solidified Sydney's international reputation as a place where gay men could live, love, and socialise openly. Many gay men had moved to inner city Sydney across the previous two decades in pursuit of the social freedom and access to a vibrant gay community that the city offered. Yet without warning, they found themselves under attack by the deadly virus that annihilated gay male populations around the world. This virus destroyed relationships, tested friendships, and left many fighting for their lives.

This book explores how HIV and AIDS impacted gay men's intimate lives across the 1980s and 1990s. It features oral history interviews conducted with twenty-five gay men who were diagnosed with HIV before the introduction of highly active antiretroviral therapy, or HAART, in 1996. This medication limited the replication of the virus in one's body. It transformed HIV from a terminal illness to a chronic condition that could be managed by taking antiretroviral medication. All the men who participated in this study were diagnosed with HIV when it was considered a death sentence. They had all witnessed others' health deteriorate and many had internalised ideas that they would succumb to the same severe physical effects of HIV and AIDS-related conditions that they had seen countless others endure. Several of the issues they described, especially regarding participating in trials for various antiretroviral medications and planning their funerals, were strongly influenced by what many perceived as the reality that they would die untimely and protracted deaths.

The actions of people like Ross who moved to Sydney to become involved in the national response to HIV and AIDS remains one of the legacies of the epidemic. The ways in which the threat of the virus galvanised gay activists have been memorialised in numerous international and Australian theatre productions, films, documentaries, and public exhibitions. Historians place similar emphasis on those who drew on the political and social networks established during the gay liberation movements of the previous decade and mobilised to provide emotional, practical, and economic support for others afflicted by the virus.[2]

This included the establishment of AIDS Action Committees in 1983, later named AIDS Councils, in each Australian state and territory.[3] Australian activists primarily collaborated with government officials, namely Health Minister Neal Blewett and his advisor Bill Bowtell or, through vocal groups such as the AIDS Coalition to Unleash Power (ACT UP), lobbied against the government. They established a proactive and effective system of peer-based preventative education that some historians have labelled as one of the best in the world.[4] Such histories are incredibly valuable. They pay due respect to the scores of activists who dedicated themselves to establishing an exceptional response to a devastating situation. These histories also occupied a prominent place in some narrators' memories of the epidemic. Several of the men in this study drew on such depictions to convey how they challenged stigma by appearing in the media as the "face of HIV," lobbied doctors to collaborate with patients under a "consult, don't prescribe" policy, and transformed Australia's drug approval process to improve access to potentially lifesaving medication. The scale and influence of existing histories that trace activists' public achievements appear to have helped some narrators to make sense of events that were, and that continue to be, emotionally devastating. They recalled mobilising and persevering in the face of a virus that threatened their lives.

Such histories, however, predominantly focus on a select group of activists' public responses to HIV and AIDS. They do not always account for the impact the virus had on gay men's intimate lives. The lives and memories of HIV-positive men who were not involved in activism and those who felt disconnected from Sydney's gay community are particularly underrepresented in such discussions. These men did not always have access to support networks. Yet many struggled to articulate their memories of isolation and exclusion amidst existing understandings that Sydney's gay community mobilised across this period. They expressed particular difficulty talking about times when highly publicised HIV-related discrimination and vilification, coupled with a lack of support, meant they felt compelled to conceal their positive status. Narrators' struggles to have sex after they were diagnosed with HIV, and instances when their health had depleted and they were not able to achieve an active role in their healthcare also emerged as the interviews delved further into their private memories to uncover important, yet perhaps previously unspoken, aspects of their pasts.

The interviews that feature in this book explicitly aimed to uncover narrators' personal memories. By emphasising the value of their individual accounts, they offered these men a unique forum to narrate their life stories in ways that both aligned with and departed from existing understandings of how HIV and AIDS impacted Sydney's gay community. The oral testimonies reveal, for the first time, how HIV-positive gay men dealt with the virus both within and outside of existing support networks and organisations. They add further depth to understandings of how these men's private lives were affected by the epidemic and how they remember and reflect on this period nearly three decades later. Narrators' personal memories and private reflections reveal how their lives were forever changed by a virus that threatened their survival, damaged their bodies, and decimated their peer groups.

## Oral History as a Source

Since oral history emerged as a professional discipline in the 1960s, it has proven to be instrumental for researchers interested in the intimate lives of individuals and groups whose perspectives were omitted from the written historical record.[5] Yet the value of oral history extends beyond its ability to retrieve previously undocumented memories of the past through the narrators' voices. Rather, oral historians analyse interviews to uncover the hidden messages that are inherent in oral testimony.[6] To borrow from Lynn Abrams, the main questions that informed my analysis of the interviews centred on "not just *what* is said, but also *how* it is said, *why* it is said and *what* it means."[7]

The use of oral history has also garnered significant criticism.[8] Critics claimed that oral history exposes the inaccuracies and inconsistencies in individuals' memories over time. They therefore deemed oral testimony to be an unreliable historical source. Yet it is the individual subjectivity inherent in oral testimony that often interests oral historians, and that is the focus of this book. In response to scepticism about the reliability of oral history, Alessandro Portelli notably argued that oral history has "a *different* credibility" to that of written sources. He explained that the value of oral testimony "may lie not in its adherence to fact, but rather in its departure from it, as imagination, symbolism, and desire emerge."[9] While individuals' recollections may depart from and at times contradict existing evidence, this does not render the use of oral history as unreliable. Rather, narrators' memories and personal accounts reveal

what specific events meant to those involved, why people acted a certain way, and how they reflect on their pasts.[10] Oral historians therefore urge researchers to treat all autobiography as true and to "discover in which sense, where, for which purpose."[11]

Theoretical discussions about composure informed my analysis of the interviews. Emphasising the significance of composure enables this book to explore beyond the content of the interviews. It places particular value on considering how interviewees both remember past events and why they choose to relate specific stories in certain ways. There are two distinct elements to composure. Firstly, researchers who were involved with Britain's Popular Memory Group at the Centre for Contemporary Cultural Studies, University of Birmingham, argue that individuals' memories of the past are a product of both public representations and private influences.[12] Public representations include the mass media and commemorations. Alternatively, private or particular publics refer to the more intimate groups with whom narrators identify. Within these cohorts, "Certain representations achieve centrality and luxuriate grandly; others are marginalized or excluded or reworked."[13]

Individuals' desires for recognition is a major factor to consider when exploring how narrators compose memories and stories about their pasts. Oral historians including Alistair Thomson and Graham Dawson place recognition at the centre of composure, whereby individuals seek affirmation that their version of the past resonates with the experiences of others.[14] Narrators therefore often compose stories in ways that their given audience will recognise and affirm. Considering the significance of recognition, narrators sometimes struggle to not only remember but also to articulate personal memories that depart from and at times challenge dominant understandings about their experiences.[15] Such memories only emerged as the interviews progressed, or upon gentle probing. It is these memories with which this book is primarily concerned.

The second central element of composure involves interviewees narrating stories that help them to make sense of their pasts and to feel more comfortable with their memories and identities.[16] Dawson identifies this process as subjective composure. He argues that the "story that is actually told is always the one preferred amongst other possible versions."[17] Narrators, often subconsciously, reconstruct their memories and stories to make them more emotionally manageable. In this regard, narrators compose what Thomson terms "a past we can live with."[18]

The interviews covered intimate, sensitive, and potentially traumatic topics.[19] These included being diagnosed with a terminal illness and losing lovers, partners, and close friends. Trauma is particularly relevant to this study considering the impact it has on how individuals compose stories about their pasts. Dawson's definition of trauma, as outlined in his investigation into conflict in Northern Ireland from 1969, encapsulates the emotional devastation that individuals encounter and their struggles to reconcile and to articulate their experiences. He argues that trauma "refers to the psychological impact of some violent or otherwise shocking event, producing deep-rooted effects which are difficult for those individuals affected to come to terms with."[20] In this regard, considerations of trauma and composure in oral history interviews provide an entry point to investigate how HIV-positive gay men both remembered and understood their experiences during the HIV and AIDS epidemic. The processes of remembering and forgetting are even more complex when trauma is involved, and survivors of trauma are particularly likely to tell stories that are—at least in part—"imaginary, fragmented or disjointed, and loaded with symbolism."[21] The impact of trauma was most apparent when narrators discussed the implications of participating in trials for antiretroviral medication and losing countless friends to HIV and AIDS-related conditions. These topics involved more misremembering, more pauses, and more explicit reflecting than that which emerged during any other part of the interviews.

The psychological impact of trauma renders it even more essential to carefully analyse oral history interviews to uncover what the narrators are really saying. This involved listening to themes, repetitions, and making note of silences, all of which are emphasised across the following chapters. Narrators' pauses, fragmented sentences, false starts and dependence on crutch words are particularly indicative of their discomfort and struggle to articulate raw and potentially painful memories and reflections. Other "trauma signals," as outlined in Gadi BenEzer's influential study into detecting trauma in interviews with Ethiopian Jewish immigrants in Israel, also emerged across the oral history interviews conducted for this project. These included "self-reporting" by explaining how the event was traumatic, long silences, and narrators detaching themselves from difficult memories by recounting traumatic events with little emotional expression. Omissions were another clear "trauma signal" which became apparent as the interviews progressed.[22]

Existing scholarship also highlights a tension between narrators repressing unhappy memories and expressing a desire to share their stories. Verbalising traumatic experiences can sometimes help individuals to process traumatic memories and potentially lead to closure.[23] Psychiatrist Dori Laub identifies this as a process of re-externalisation.[24] Re-externalisation occurs "when one can articulate and *transmit* the story, literally transfer it to another outside oneself and then take it back again, inside."[25] Laub's assessment suggests that talking about painful experiences can help interviewees to revise these traumatic memories into more emotionally manageable accounts. In this vein, interviews can help people to place their experiences into "coherent frameworks" by encouraging interviewees to revisit and recount their pasts in ways that help them to make sense of these difficult experiences.[26] Most of the men I interviewed appeared to have a repertoire of safe stories that they were accustomed to telling. This was especially the case for men who were involved in HIV and AIDS activism and who have participated in several interviews about their public political actions during the epidemic. Considering the relative safety of retelling composed accounts of the past, we must also explore the emotional impact of narrating stories that individuals have not yet processed and retold.

While oral history interviews can offer narrators a platform to talk about difficult memories, I was conscious that interviewing people about traumatic events can be emotionally taxing for interviewees and interviewers alike.[27] The interviews focused on individuals' intimate lives and had the potential to arouse difficult memories. Such interviews can be emotionally challenging for the narrator, especially considering oral historians are neither purposefully trained to identify the more subtle signs of distress nor do we provide the ongoing emotional support that therapists offer.[28] The lasting psychological impact of trauma renders oral history interviews as particularly sensitive. Indeed, Penny Summerfield argues that a certain memory or an unsympathetic response from the interviewer may result in "discomposure" or "disequilibrium." Discomposure may manifest in an interviewee's confusion, anger, discomfort, and their difficulty to sustain a narrative.[29]

When conducting the interviews, I aimed to avoid pressing narrators to discuss events that they might not have been ready to revisit. Many of the men who participated in this study had previously told versions of their life stories to family members, friends, and counsellors.

Some had been employed as public speakers with the Positive Speakers' Bureau and had delivered guest speeches to schools, businesses, and hospitals, among other audiences. One of the men in this study described giving such talks as "kind of good in terms of being valued, and having a story validated, and having a role in the community."[30] Such statements speak to the value of having a public forum to retell a particular version of the past. The oral history interviews, however, generated a different type of remembering. They specifically focused on narrators' intimate personal experiences and provided an extended and more concentrated setting than that which many had previously encountered. Thomson argues that the best interviews involve a "dynamic, dialogic relationship that encourages active remembering and meaning-making." The interviewee may start by sharing their familiar accounts of the past. In the process of remembering and with encouragement from the interviewer, however, "more complex and unexpected memories may emerge."[31] I therefore followed Dori Laub's recommendation to be "*unobtrusively present*, throughout the testimony."[32]

Intersubjectivity was another important factor to consider when I conducted and analysed the oral history interviews, especially considering my position as a heterosexual HIV-negative woman in my late-twenties interviewing HIV-positive gay men in their forties, fifties, and sixties. Summerfield argues that intersubjectivity is a "necessary and inescapable" part of the way memory is produced. She asserts that the audience, and the type of social recognition they offer, influences the narrative that is delivered.[33] Certainly, my HIV-negative status, gender, sexuality, and age meant that I had no first-hand experience with the events that featured most prominently across the interviews. I could not offer the recognition that someone who had such experiences might have been able to provide. For the most part, narrators seemed less concerned with my background than they were with having an opportunity to share their stories. Thomas Parker made this clear in our initial email correspondence. He anticipated the interview would raise "emotional stuff but glad someone is doing some research."[34] Thomas' comment that "someone" is conducting "some" research is suggestive. In this context, a shared identity was less important than a shared understanding that his experience had yet to feature in the historical record. My explicit focus on narrators' personal experiences thus appears to have been a primary factor in establishing common ground. It underscores

a point Portelli has raised when speaking of "a shared will to listen and accept each other critically" being instrumental in establishing trust between an interviewer and a narrator: some of the most important things he has had to offer narrators were "ignorance and a desire to learn."[35]

## The Interviews

The conclusions drawn in this book are primarily based on twenty-five original oral history interviews conducted between May and November 2014.[36] I aimed to interview a diverse cohort and placed few restrictions on the participant criteria. I simply limited participation to self-identifying gay men who were diagnosed with HIV between 1982 and 1996, and who lived in Sydney between these dates. Restricting the interviews to those who were diagnosed with HIV before the introduction of HAART enables this book to examine the shift from living with HIV as a terminal illness to a chronic condition in 1996. This shift is the focus of Chapter 9.

I recruited participants by circulating an advertisement on several online forums. These included a paid space on the online national gay newspaper, the *Star Observer*. The AIDS Council of New South Wales (ACON) also distributed the advertisement to those on their mailing list with approval from ACON's Research Ethics Review Committee.[37] The most effective strategy, however, was circulating the advertisement on Facebook pages hosted by the Australian Lesbian and Gay Archives and Lost Gay Sydney. These pages provide important forums for members of the LGBTIQ community to share photographs and anecdotes. A further five men made contact after they had learned of this study through other respondents or through healthcare workers who had verbally promoted the study within their networks.

The interviewees were self-selected, and I accepted all the men who offered to participate in this study and met the research criteria. There are two main points to make regarding the group of interviewees. Firstly, this was a group of willing narrators who survived long enough to see the introduction of effective treatment. One of the narrators spoke about feelings of frustration among those who did not make rapid recoveries with antiretroviral medication. They felt confusion and a sense of failure when they watched others make seemingly instant improvements while taking the same treatment that seemed to have no positive effect on their

own bodies. Such topics might have featured even more prominently among those who did not survive until 2014. Secondly, and perhaps even more significant to discussions about composure, is that those who were concerned with the history of HIV and AIDS in Sydney, and who paid attention to archival social media forums, appeared to be particularly interested in this study. Many of these men had specific stories they were willing to share in the interviews.

Considering the longevity of the illness, I selected the life story interview style as the most suitable format for this study. Robert Atkinson, a psychologist who specialises in life story interviewing, argues that this approach is "built on a respect for individual storytellers and a regard for the subjective meaning carried within their stories."[38] Life story interviews allow for a high level of flexibility that is crucial to uncovering how narrators both remember and reflect on the significance of past events. They not only trace the key events that have occurred in an individual's lifetime but also aim to uncover narrators' personal interpretations of the key influences in their lives, the obstacles they faced, and the contexts in which their testimonies are set.[39] The interviews were also loosely guided by a set of open-ended questions that explored narrators' memories of growing up and coming out as gay, learning about HIV and AIDS, receiving an HIV-positive diagnosis, experiences with trial medication, and the introduction of HAART. I rarely had to refer to the questions, however, as narrators spoke at length about each issue without being prompted. Most of the interviews lasted around three hours, well over the anticipated ninety minutes that was set out in the information sheet I sent to participants prior to the interview.

Interviewees were also asked to indicate whether they wanted anonymity. While ten of the twenty-five narrators selected anonymity, one of these men advised me to use his real name once he had reviewed parts of the final manuscript. The other nine participants are referred to throughout this book by pseudonyms, as indicated in the endnotes. Narrators were not required to provide a reason for selecting anonymity, although some cited their concerns about future employment prospects and prior issues with discrimination as primary factors. The Oral History Association recommends that oral historians always identify interviewees by their real names unless in "exceptional circumstances."[40] Alternatively, Summerfield advocates for the importance of anonymity to protect interviewees from the historians' interpretations.[41] Acknowledging the value of anonymity, I left this decision to the interviewees. Doing so was

especially important considering the political debates about coming out as gay in the 1970s and discussions about the importance of disclosing one's HIV-positive status the following decade.

## The Book Ahead

The nine analytical chapters that follow centre on the main themes that emerged from the interviews. Each chapter also focuses on a specific aspect of Australia's histories of HIV and AIDS. In doing so, the chapters reveal the extent to which parts of these histories meld with, and which parts perhaps omit and even marginalise the voices of individual HIV-positive gay men who lived through this period. Each chapter features a selection of oral history interviews. This selection was based on which narrators placed particular emphasis on each theme, although several interviewees appear more than once throughout this book. Together, these chapters trace the impact the HIV and AIDS epidemic had on these men's intimate lives across the 1980s and 1990s.

Chapter 2 explores gay life in Sydney prior to the onset of HIV and AIDS. In doing so, it sets out the social and political context in which the narrators' life stories are set. The significance of Sydney not only rests on its proactive community-based response to the epidemic, nor entirely on its position as the Australasian city most severely affected by the virus, although these factors certainly render the city an important focus of historical inquiry. For many HIV-positive gay men, the trauma of the epidemic was amplified by the value they placed on living in inner city Sydney prior to this time.

Chapter 3 moves on to trace narrators' changing attitudes towards disclosure. The immense fear attached to HIV and AIDS, coupled with compulsory notification legislation, meant that doctors, the gay press, and members of the ACON cautioned gay men about the potential social and legal ramifications of disclosure across the 1980s. The chapter considers the isolation narrators experienced during this critical period and some men's present disappointment that they did not "come out" as HIV-positive earlier. It explores their motivations to publicly identify as HIV-positive from the late-1980s and early-1990s and the consequences of these decisions.

Chapter 4 considers narrators' concerns about developing painful and highly visible physical symptoms of HIV or AIDS-related conditions. Visible symptoms were particularly alarming because, for many,

they signalled that one had entered the final stage before death. It reveals the ostracism that some people encountered, sometimes from other gay men, when they started to exhibit what some described as the tell-tale signs of AIDS. It also examines narrators' efforts to prolong their lives or to euthanise to avoid having to endure the same painful and protracted deaths that they had seen countless others endure. Narrators' prevailing trauma, coupled with dominant public representations of HIV survivors, meant that many men struggled to talk about a period when they believed they would die.

Chapter 5 investigates how HIV and AIDS impacted gay men's sex lives across the 1980s and 1990s. It reveals the rejection some HIV-positive gay men endured amidst concerns about an impending "antibody apartheid" and considers how some narrators abstained from sex as they internalised ideas that they posed a threat to others' health. It also considers how dominant discussions about the effectiveness of safe sex meant that some interviewees were reluctant to discuss times when they did not adhere to these guidelines. By using oral history to engage with individuals remembering and reflecting on their sexual behaviour during this period, Chapter 5 teases out the contours of this neglected critical history.

Chapter 6 explores how HIV-positive gay men navigated their relationships with doctors across the 1980s and 1990s. Activists challenged existing medical hierarchies that placed doctors in authoritative positions. They urged doctors to collaborate with patients under a "consult, don't prescribe" policy. Yet depictions of gay men with HIV as active and assertive patients do not always account for the challenges these individuals faced when their health declined and they were relegated to the role of the "patient." Most interviewees struggled to talk about times when they were forced to relinquish control over their health to medical professionals. The interviews became sites for them to portray themselves achieving the agency that may have been unattainable in the late-1980s and 1990s.

Chapter 7 explores narrators' memories of sacrificing their physical and emotional health to support others living with HIV. It demonstrates how the public emphasis on HIV and AIDS activism helped some activists to achieve composure in how they collectively and publicly lobbied governments to provide further funding for potentially lifesaving medication. Yet, these histories can also overshadow both the emotional strain of being involved in activist endeavours and the significant—but perhaps

more private—contributions that others made to the HIV and AIDS cause.

Chapter 8 moves on to consider how narrators dealt with others' deaths both within, and outside of the support networks and annual public commemorations that activists had established. Most of the men who participated in this study composed their narratives to uphold public representations of community solidarity. They depicted themselves as part of a gay community that persevered despite the insurmountable losses they collectively faced. Narrators recalled attending Candlelight Memorials, the use of humour and nightclubs as outlets to cope with their prevailing grief, and the trauma of attending—or avoiding—countless funerals.

Chapter 9 utilises oral history to disturb dominant narratives that predominantly focus on the triumph of medical developments. Antiretroviral medication has undoubtedly saved numerous lives and entirely transformed the experience of living with HIV. At the same time, however, people who were diagnosed with HIV or AIDS in the 1980s and early-1990s—many of whom expected to die—had to deal with the significant emotional and physical challenges that living with HIV as a chronic condition entailed. Chapter 9 explores the debilitating and irreversible physical side effects interviewees endured from taking antiretroviral medication in 1996, and the challenges these men faced to rebuild their lives. Their personal memories of struggling to take antiretroviral medication are often silenced by their perceptions that unlike many people who were also diagnosed with HIV as a terminal condition, they are fortunate to be alive.

Chapter 10 is the final analytical chapter and explores narrators' motivations for participating in this study. I have placed this chapter at the end of the book to allow space to consider how narrators' present personas shaped their memories and the stories they told in the interviews. Narrators were enthusiastic about participating in this study. They aimed to both challenge and extend existing understandings of their collective experiences as gay men with HIV across this period. They appeared to be frustrated that the struggles they continue to endure appear to have been forgotten in a society that has essentially moved on from the epidemic. For some of the men in this study, the interviews offered a space to affirm that their experiences were significant, meaningful and, above all, worth remembering.

Ross' prediction that "our lives are going to change" materialised over the next two decades as HIV and AIDS devastated Sydney's gay community. Narrators in this study told stories of hope, endurance, loss, and resilience. Their personal memories and private reflections guide us towards a deeper understanding of the epidemic that is only accessible through the voices of those who lived through this period. Importantly, they disturb dominant historical narratives that almost exclusively focus on the public achievements of a select group of activists who mobilised to establish a leading response to the threat of HIV and AIDS. The oral testimonies reveal the distinct and diverse ways these men navigated living with a terminal and highly stigmatised illness. They provide original insight into how the virus permeated these men's intimate lives, and how they cope with these experiences over thirty years later.

## Notes

1. Ross Duffin, interview with the author, 16 July 2014, Sydney.
2. Dennis Altman, "The Emergence of a Non-government Response to AIDS," in *Social Perspectives in Lesbian and Gay Studies: A Reader*, eds. Peter M. Nardi and Beth E. Schneider (New York: Routledge, 1998), 510; Dennis Altman, "Legitimation Through Disaster: AIDS and the Gay Movement," in *AIDS, The Burdens of History*, eds. Elizabeth Fee and Daniel M. Fox (California: University of California Press, 1988), 313; Jennifer Power, *Movement, Knowledge, Emotion: Gay Activism and HIV/AIDS in Australia* (Canberra: ANU E Press, 2011), 3; Peter Robinson, *The Changing World of Gay Men* (New York: Palgrave Macmillan, 2008), 97; Graham Willett, *Living Out Loud: A History of Gay and Lesbian Activism in Australia* (St Leonards, NSW: Allen & Unwin, 2000), 169.
3. Garry Wotherspoon, *Gay Sydney: A History* (Sydney, NSW: NewSouth Publishing, 2016), 225. The Northern Territory AIDS Community Advisory Group was established two years later in 1985.
4. Paul Sendziuk, *Learning to Trust: Australian Responses to AIDS* (Sydney: University of New South Wales Press, 2003), 9; Graham Willett, "How We Saved Our Lives: The Gay Community and the Australian Response to AIDS," *HIV Australia* 12, no. 3 (2014): 4.
5. Caroline Hoefferle, *The Essential Historiography Reader* (New Jersey: Pearson Education, 2011), 183; Paul Thompson, "The Voice of the Past: Oral History," in *The Oral History Reader*, eds. Robert Perks and Alistair Thomson, Second (Oxon: Routledge, 1998), 28; Alistair Thomson, "Oral History," in *Australian History Now*, eds. Anna Clark and Paul Ashton (Sydney: NewSouth Publishing, 2013), 75.