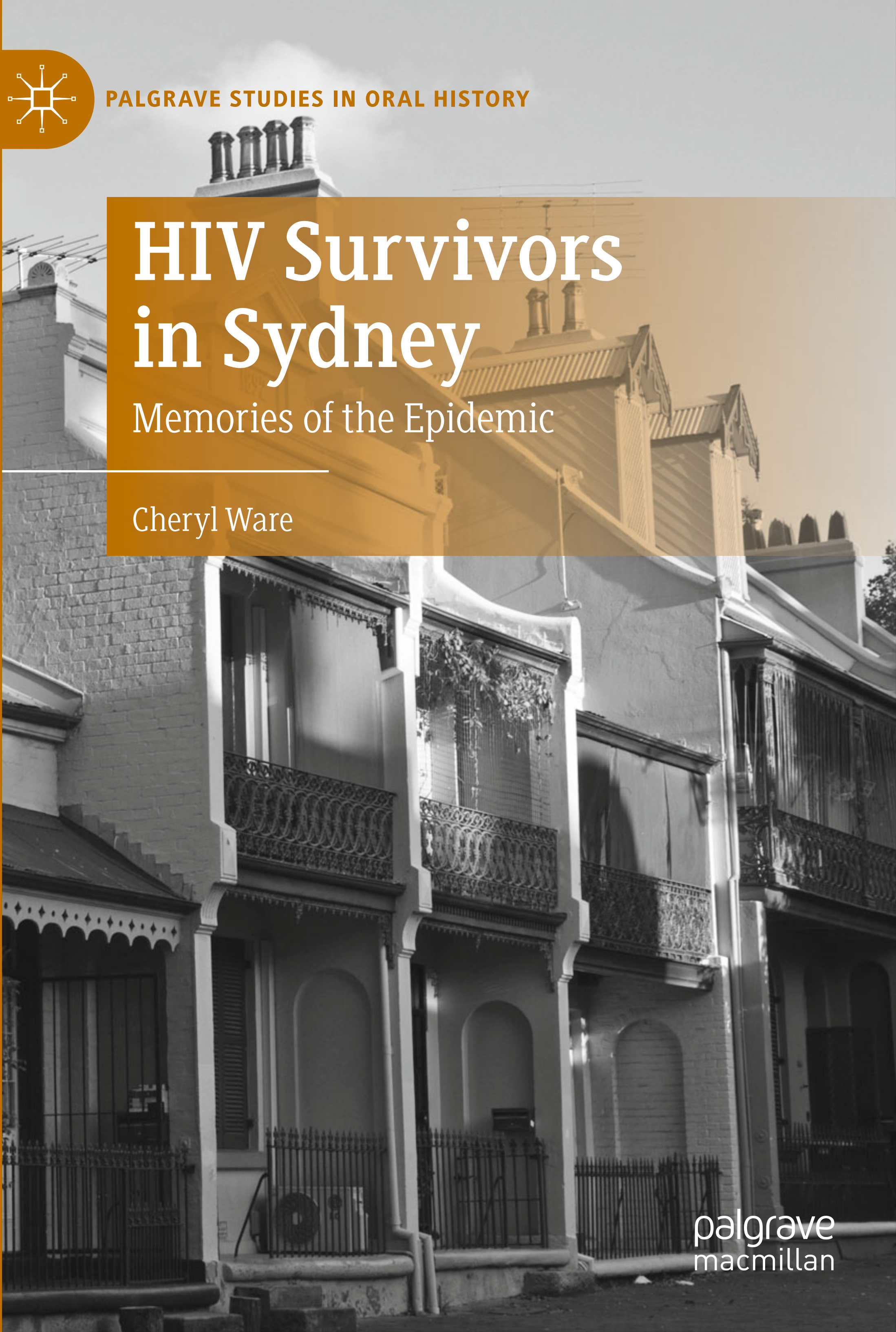
PALGRAVE STUDIES IN ORAL HISTORY

HIV Survivors in Sydney

Memories of the Epidemic

Cheryl Ware



palgrave
macmillan

Palgrave Studies in Oral History

Series Editors
David P. Cline
Virginia Tech
Blacksburg, USA

Natalie Fousekis
California State University
Fullerton, USA

‘A premier publisher of oral history.’ - CHOICE The world’s leading English-language oral history book series, *Palgrave Studies in Oral History* brings together engaging work from scholars, activists, and other practitioners. Books in the series are aimed at a broad community of readers; they employ edited oral history interviews to explore a wide variety of topics and themes in all areas of history, placing first-person accounts in broad historical context and engaging issues of historical memory and narrative construction. Fresh approaches to the use and analysis of oral history, as well as to the organization of text, are a particular strength of the series, as are projects that use oral accounts to illuminate human rights issues. Submissions are welcomed for projects from any geographical region, as well as cross-cultural and comparative work.

More information about this series at
http://www.palgrave.com/gp/series/14606

Cheryl Ware

HIV Survivors in Sydney

Memories of the Epidemic

palgrave
macmillan

Cheryl Ware
University of Auckland
Auckland, New Zealand

Palgrave Studies in Oral History
ISBN 978-3-030-05101-3 ISBN 978-3-030-05102-0 (eBook)
https://doi.org/10.1007/978-3-030-05102-0

Library of Congress Control Number: 2018963733

© The Editor(s) (if applicable) and The Author(s), under exclusive license to Springer Nature Switzerland AG 2019
This work is subject to copyright. All rights are solely and exclusively licensed by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.
The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.
The publisher, the authors and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, express or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Cover illustration: Bosiljka Zutich/Alamy Stock Photo

This Palgrave Macmillan imprint is published by the registered company Springer Nature Switzerland AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

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.

ACKNOWLEDGEMENTS

I am deeply grateful for the support and guidance I received from so many wonderful people I have had the pleasure of working with throughout this project. To the twenty-five men who participated in interviews, thank you for engaging with me so openly. Thank you for sharing your memories with me and for your valuable feedback on various parts of this book. It has been an honour to work with you.

This project started as a PhD, and my supervisors, Shirleene Robinson and Robert Reynolds, generously shared their time and knowledge. Shirleene Robinson's expertise and critical engagement with this project ensured it was an enriching, enjoyable, and incredibly rewarding experience. Robert Reynolds' valuable guidance and thoughtful feedback has been central to my growth as a historian. My sincere thanks also go to the broader research community at Macquarie University. I thoroughly enjoyed the encouraging discussions, writing retreats, and writing "boot camps." My particular thanks to Chelsea Barnett, who was a great writing companion and made Australia feel like a second home, Julia Miller, Leigh Boucher, and Tanya Muscat, each of whom read chapters at various stages of this project and offered valuable and insightful comments. I am thankful for the feedback I received from Frank Bongiorno, Alistair Thomson, Chris Brickell, and for the close engagement from the two anonymous reviewers with Palgrave Macmillan. I also benefitted immensely from the encouragement and advice I received from Catharine Coleborne, Nēpia Mahuika, and colleagues at Macquarie University, the Australian National University, and at the University of

Auckland, especially Linda Bryder and Barry Reay. Thank you also to the team at Palgrave Macmillan, especially the commissioning editor Megan Laddusaw and the editorial assistant Christine Pardue.

The recruitment phase of this research was completed with the generosity of several individuals and organisations that helped to promote my study within their networks. Thank you to Mike Smith for your engagement with this project, Nick Henderson at the Australian Lesbian and Gay Archives, and Alan Brotherton, Johann Kolstee, and Luka Upcroft at the AIDS Council of New South Wales. Many librarians and archivists helped me to access sources for this book. Staff at the National Library of Australia, the State Library of NSW, the Australian Lesbian and Gay Archives in Melbourne, Sydney's Pride History Group, and the Noel Butlin Archives Centre at the Australian National University were especially helpful.

The research for this project was made possible by an Australian Postgraduate Award. I was also fortunate to receive funding from the Department of Modern History, Politics and International Relations at Macquarie University, the Macquarie University Post Graduate Research Fund, and the Oral History NSW Grant. I am grateful for the opportunities to share many parts of this book at conferences hosted by TEDx Macquarie, the Oral History Association of Australia, the Australian Historical Association, the Oral History Society, the Australian and New Zealand Society for the History of Medicine, and the National Oral History Association of New Zealand. Seminars hosted by the University of Newcastle, Australian National University, the University of Auckland, and the Sydney Feminist History Group also offered great opportunities to discuss this work. Thank you to those who organised and attended these events.

My family and friends have been a vital source of support throughout this book. In addition to those I have already mentioned, my particular thanks to Basil Nicoll, Cassie Snow, Melissa Hempstead, Parva Zareie, Halie Edmonds, and Emma Gleadhill, and to my in-laws Michele, Ian, and David Rowe, June and Ginna Day, and Margaret and Kevin Gorman. My siblings, Maria and Michael Ware, have been an endless source of support, laughter, and love. My parents Mina and Cyril Ware (who proof read the entire monograph twice) have always shown confidence in me and taken a keen interest in my research. Thank you for everything. I would like to especially thank my husband Philip Rowe whose unwavering love and support was a source of strength throughout this process. Thank you all for engaging with this project, and for encouraging me every step of the way.

CONTENTS

ABBREVIATIONS

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

LIST OF FIGURES

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.

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0_1

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.

6. Lynn Abrams, *Oral History Theory*, Second (Oxon: Routledge, 2016), 106–15; Anna Green, "'Unpacking' the Stories," in *Remembering Writing Oral History*, eds. Anna Green and Megan Hutching (Auckland: Auckland University Press, 2004), 11; Passerini, "Introduction," 18; Alistair Thomson, *Anzac Memories: Living with the Legend*, Second (Melbourne: Monash University Publishing, 2013), 11.
7. Abrams, *Oral History Theory*, 1.
8. For a selection of scholarship that outlines the criticisms that oral history has garnered, see Alistair Thomson, "Four Paradigm Transformations in Oral History," *Oral History Review* 34, no. 1 (2007): 51, 63; Alistair Thomson, Michael Frisch, and Paula Hamilton, "The Memory and History Debates: Some International Perspectives," *Oral History* 22, no. 2 (1994): 33–43.
9. Alessandro Portelli, "What Makes Oral History Different," in *The Oral History Reader*, eds. Robert Perks and Alistair Thomson, Second (Oxon: Routledge, 1998), 37.
10. Ibid., 6. See also Anna Green, "Oral History and History," in *Remembering: Writing Oral History*, eds. Anna Green and Megan Hutching (Auckland: Auckland University Press, 2004), 2–3.
11. Luisa Passerini, "Women's Personal Narratives: Myths, Experiences and Emotions," in *Interpreting Women's Lives: Feminist Theory and Personal Narratives*, ed. Personal Narratives Group (Bloomington: Indiana University Press, 1989), 197.
12. Popular Memory Group, "Popular Memory: Theory, Politics, Method," in *Making Histories: Studies in History-Writing and Politics*, eds. Richard Johnson, Gregor McLennan, Bill Schwarz, and David Sutton (Minneapolis: University of Minnesota Press, 1982), 211.
13. Popular Memory Group, "Popular Memory: Theory, Politics, Method," 207.
14. Graham Dawson, *Soldier Heroes: British Adventure, Empire and the Imagining of Masculinities* (Oxon: Routledge, 1994), 23; Alistair Thomson, *Anzac Memories: Living with the Legend*, Second (Melbourne: Monash University Publishing, 2013), 11.
15. Abrams, *Oral History Theory*, 97; Anna Green, "Individual Remembering and 'Collective Memory': Theoretical Presuppositions and Contemporary Debates," *Oral History Society* 32, no. 2 (2004): 40; Alistair Thomson, "Anzac Memories: Putting Popular Memory Theory into Practice in Australia," *Oral History* 18, no. 1 (1990): 25.
16. Thomson, *Anzac Memories*, 8.
17. Dawson, *Soldier Heroes*, 23.
18. Thomson, *Anzac Memories*, 214; Alistair Thomson, "A Past You Can Live With: Digger Memories and the Anzac Legend," *Oral History Association of Australia Journal* 13 (1991): 12–8.

19. For a selection of discussions about identifying "trauma", see Gadi BenEzer, "Trauma Signals in Life Stories," in *Trauma and Life Stories: International Perspectives*, eds. Kim Lacy Rogers, Selma Leydesdorff, and Graham Dawson (London: Routledge, 1999), 29; Selma Leydesdorff et al., "Introduction," in *Trauma: Life Stories of Survivors*, eds. Kim Lacy Rogers, Selma Leydesdorff, and Graham Dawson (New Jersey: Transaction Publishers, 2004), 1.
20. Graham Dawson, *Making Peace with the Past? Memory, Trauma and the Irish Troubles* (Manchester: Manchester University Press, 2007), 61.
21. Katharine Hodgkin and Susannah Radstone, "Introduction: Contested Pasts," in *Memory, History, Nation: Contested Pasts*, eds. Katharine Hodgkin and Susannah Radstone (New Jersey: Transaction Publishers, 2006), 6; Leydesdorff et al., "Introduction," 1.
22. BenEzer, "Trauma Signals in Life Stories," 30–5.
23. Abrams, *Oral History Theory*, 121; Sean Field, "Beyond 'Healing': Trauma, Oral History and Regeneration," *Oral History* 34, no. 1 (2006): 31; Alison Parr, "Breaking the Silence: Traumatised War Veterans and Oral History," *Oral History* 35, no. 1 (2007): 62; Alison Parr, *Silent Casualties: New Zealand's Unspoken Legacy of the Second World War* (Auckland: Random House New Zealand, 1995); Paul Thompson, *The Voice of the Past*, Third (Oxford: Oxford University Press, 2000), 183.
24. Dori Laub, "Bearing Witness, or the Vicissitudes of Listening," in *Testimony: Crises of Witnessing in Literature, Psychoanalysis and History*, eds. Shoshana Felman and Dori Laub (New York: Routledge, 1992), 69.
25. Ibid.
26. David W. Jones, "Distressing Histories and Unhappy Interviewing," *Oral History* 26, no. 2 (1998): 51–2.
27. Ibid., 54–6; Mark Klempner, "Navigating Life Review Interviews with Survivors of Trauma," *Oral History Review* 27, no. 2 (2000): 72.
28. Thomson, "Anzac Memories: Putting Popular Theory into Practice in Australia," 243. Wendy Rickard, "Oral History—'More Dangerous than Therapy'? Interviewees' Reflections on Recording Traumatic or Taboo Issues," *Oral History* 26, no. 2 (1998): 42.
29. Penny Summerfield, "Culture and Composure: Creating Narratives of the Gendered Self in Oral History Interviews," *Cultural and Social History* 1, no. 1 (2004): 69–70; Penny Summerfield, "Dis/composing the Subject: Intersubjectivities in Oral History," in *Feminism & Autobiography: Texts, Theories, Methods*, eds. Tess Coslett, Celia Lury, and Penny Summerfield (London: Routledge, 2000), 93.
30. Victor Day (pseudonym), interview with the author, 28 August 2014, Sydney.

31. Alistair Thomson, "Memory and Remembering in Oral History," in *The Oxford Handbook of Oral History*, ed. Donald A. Ritchie (New York: Oxford University Press, 2011), 88.
32. Laub, "Bearing Witness, or the Vicissitudes of Listening," 71.
33. Ibid. See also Abrams, *Oral History Theory*, 54.
34. Thomas Parker, email message to the author, 30 June 2014.
35. Alessandro Portelli, *They Say in Harlan County: An Oral History* (New York: Oxford University Press, 2011), 7.
36. The interviews for this study were conducted with approval from Macquarie University's Human Research Ethics Committee. Reference: 5201000093.
37. ACON ethics reference: 2013/24.
38. Robert Atkinson, "The Life Story Interview as a Bridge in Narrative Inquiry," in *Handbook of Narrative Inquiry: Mapping a Methodology*, ed. D. Jean Clandinin (California: Sage, 2007), 224.
39. Robert Atkinson, "The Life Story Interview as a Bridge in Narrative Inquiry," in *Handbook of Narrative Inquiry: Mapping a Methodology*, ed. D. Jean Clandinin (California: Sage, 2007), 224; Paul Thompson, "Introduction," in *Oral History, Health and Welfare*, eds. Joanna Bornat, Robert Perks, Paul Thompson, and Jan Walmsley (London: Routledge, 2000), 7.
40. Donald A. Ritchie, *Doing Oral History*, Third (Oxford: Oxford University Press, 2015), 120–1.
41. Penny Summerfield, *Reconstructing Women's Wartime Lives* (Manchester: Manchester University Press, 1998), 26.

CHAPTER 2

The Gay Capital of the Southern Hemisphere

The global HIV and AIDS epidemic began in the wake of the gay liberation movement. Gay men and lesbians publicly and collectively protested against political and social oppression. They agitated for an end to discrimination and declared pride in their sexualities. In the Australian context, Sydney's gay community was more visible and united than it had been at any time in history. Scholars maintain that these networks formed the foundation on which HIV and AIDS activism and community support developed over the following decades.[1] As historian and activist Graham Willett argues, "If AIDS *had* to reach Australia – and it is impossible to imagine how it could have been avoided – it came at the best possible time."[2] In other ways, for many of the men who participated in this study, the timing of the epidemic was particularly devastating. Most of these men had relocated from Melbourne, Brisbane, New Zealand, the United Kingdom, and from Sydney's outer suburbs in pursuit of a gay community with whom they could explore and celebrate their sexualities. Just as they managed to establish themselves as part of a community, this community started to deteriorate in what sociologist Peter Robinson describes as a "cruel irony."[3] The significance of metropolitan Sydney in histories of HIV and AIDS therefore not only rests on its proactive community-based response to the epidemic, nor entirely on its position as the Australian city most severely affected by the virus.[4] 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.

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0_2

HIV and AIDS deprived them of the hope and possibility that living in Sydney, the “gay capital of the southern hemisphere,” entailed.[5]

This chapter explores narrators’ memories of living in inner city Sydney across the late-1970s and early-1980s. These men converged in inner city Sydney in pursuit of a place where they felt they no longer had to conceal their sexualities. They were enticed by the nightlife and access to the community that the city had to offer. For most of the men in this study, the emotional liberation and social acceptance that they achieved when they arrived in Sydney exceeded their expectations. They emphasised outrageous parties and unforgettable friendships. Yet such positive memories can also overshadow the tensions and prejudices that existed within Sydney’s gay community. Some narrators’ experiences with social exclusion meant they were denied the support and acceptance that proved to be so important to others. The final part of this chapter moves into the 1990s and early-2000s. Several participants left Sydney during this period as the city served as a constant reminder of the friends they had lost. Together, their life stories reveal their emotional attachment to the Sydney that preceded the epidemic.

The concept of place attachment provides a useful framework to consider the significance that interviewees placed on living in inner city Sydney across the late-1970s and early-1980s.[6] Individuals’ emotional connections to an area often reflect positive experiences of security, a sense of belonging, and an affirming self-identity.[7] Robert L. Rubinstein’s and Patricia A. Parmelee’s investigation into place attachment among older generations demonstrates how an individual’s attachment to a place in their past is one way of “keeping the past alive.”[8] It not only protects them against “deleterious change” but also reflects the individual’s affection for a critical period in their lives. Narrators’ fond memories of living in Sydney not only reflected their attachment to the city itself but also their nostalgia for the “golden era” that preceded the epidemic.[9]

Coming Out in the City

Inner city Sydney has a long-standing reputation as a gay space. It surpasses that of other Australian metropolitan areas including Melbourne and Brisbane. Historian Robert Aldrich argues that the prevalence of same-sex activity between male Europeans meant colonial Sydney became known as “the ‘Sodom’ of the South Seas.”[10] Over the following decades, public perceptions of Sydney as a city of possibility, coupled with its affordability, especially in comparison to Melbourne, attracted many gay men.[11] Further, Sydney's flat building boom of the 1930s provided young single men with an alternative form of accommodation from the family home or boarding houses. It helped them to achieve a level of independence that was not attainable elsewhere.[12] Inner city Sydney was already gaining credibility as a gay-friendly precinct by the late-twentieth century. The gay liberation movements of the 1970s and early-1980s solidified this image. It increased the public profile of gay men and lesbians and fuelled representations of Sydney as a place where individuals could embrace their sexualities and "come out."

Australian activists took the lead from their British and American counterparts and urged gay men and lesbians to challenge oppression by "coming out." In 1970, Sydney activists John Ware and Christobell Poll established Australia's first openly gay organisation, Campaign Against Moral Persecution (CAMP Inc).[13] A Homosexual Law Reform Society and an Australian chapter of the San Francisco lesbian rights organisation Daughters of Bilitis had already been established in Canberra and Melbourne, respectively by that time. Yet it is the shift towards publicly coming out that CAMP Inc. pursued which distinguished Sydney from other Australian cities. Across the 1970s, CAMP Inc. and Sydney Gay Liberation published a number of articles that encouraged their gay male and lesbian readers to come out.[14] As Sue Wills, co-president of CAMP Inc from 1972 to 1974 argues, coming out helped other gay men and lesbians to develop a positive self-image.[15] They confronted the community with individuals who did not subscribe to "stereotypes," and who were willing to fight for their rights.[16]

Such depictions of gay activists who challenged oppression and achieved emotional liberation by coming out resonated with several of the men who participated in this study. Greg Iverson was particularly adamant that living in Sydney afforded him a level of freedom that was not accessible elsewhere. As I will discuss, Greg left Sydney in 2002 after his last friend from the 1980s and 1990s died from an AIDS-related illness. His nostalgic memories of the preceding years reflect his trauma at witnessing his entire peer group deteriorate. Greg described an idyllic middle-class upbringing in Sydney and shared fond memories of living with his parents and four sisters. On numerous occasions, he asserted that he felt fortunate in comparison to other gay men. He attributed his fortune to living in Sydney in the late-1970s:

> Again, [sighs] again I was so fortunate that when I was eighteen – that was 1978 ’cause I was born in 1960 –I distinctly remember at that time it was almost *cool* to be gay because there was a lot of coming out in society itself. […] And of course, that period from like the mid-to-late ’70s right through to say 1990, Oxford Street was heaven! It was just pumping! You know, I used to go home with someone different every night. It was a wonderful existence, it was so idyllic and so self-affirming to just know you’re not the only one and to have them all there partying with you! And of course, the Mardi Gras and Sleaze Balls, I mean Oh My God I was so disgustingly filthy but having a great time! [Laughs] And again, that’s another aspect of my life that I find was very fortunate that I wasn’t living in Melbourne at the time I was in Sydney! And it was the time to be in Sydney![17]

Greg’s memories of this period as one when it was “almost *cool* to be gay” reflects the emerging visibility of gay men and lesbians in inner city Sydney. The growth of Sydney’s gay commercial scene was an important part of this development. The 1970s witnessed a proliferation of bars, nightclubs, bookshops, and sex-on-site premises that catered to a gay male clientele. These venues were primarily located within Sydney’s “gay triangle.” This comprised Oxford Street and surrounding suburbs including Darlinghurst, Paddington, and Surry Hills.[18]

Greg’s emphasis on the year 1978 is particularly significant as it marks the demonstration that became known as Sydney’s first Gay and Lesbian Mardi Gras. The demonstration was a collective effort by gay men and lesbians to commemorate the ninth anniversary of the Stonewall Riots in Greenwich Village, New York. The Stonewall Riots are widely regarded as the birth of the international gay liberation movement.[19] In Sydney, activists marched against discrimination, police harassment, and campaigned for law reform. Greg’s sentimentality reflects how the anniversary of the event became an annual celebration of gay and lesbian rights. By the mid-1990s, Sydney’s Mardi Gras had transformed into what Graham Carbery, an activist, author, and founding president of the Australian and Lesbian Gay Archives in Melbourne, described as “a cultural extravaganza of national importance with an international reputation. There is nothing else like it in Australia.”[20] In 1978, however, the demonstration had serious ramifications for those involved. These included reports of police brutality and the arrest of fifty-three people, whose names and addresses were subsequently published in the *Sydney Morning Herald*.

Greg's recall of frequenting gay bars and nightclubs on Oxford Street—Sydney's "golden mile"—overshadowed his memories of a time when he struggled to accept his sexuality. At the very beginning of the interview, Greg declared, "I've always been quite militant, and quite frankly proud of my sexuality because of what we fought for."[21] As the interview progressed, however, he conceded that this was a considerably more gradual process than he initially described:

> Even though I [came out] at the age of seventeen I never really accepted my gayness inside here [points to his chest] fully until I was twenty-two. I "fought" I 'spose is the right word. Knew it was there, knew it was me, but because of my Catholic upbringing – and that's totally what it was from – I struggled with that guilt for many, many years until the age of twenty-two when I finally said to myself "oh for mm sakes, stop worrying about it, it's who you are!" And that, even though I was going out to gay bars prior to that, and [laughs] going to bed with lots of men, I wasn't happy or settled about it until I think that point.[22]

As a self-identified "political animal," Greg perhaps struggled to reconcile his difficulty accepting his sexuality with his identity as an activist. This was evident as he could not identify a particular moment or a reason why his attitude changed at the age of twenty-two, four years after he had come out. These memories disturbed the narrative that Greg had composed about enjoying an "idyllic" life in Sydney in the late-1970s. In this regard, the Catholic Church's well-documented prejudice against gay men and lesbians provided him with the vocabulary to articulate why he struggled to come to terms with his sexuality.

Several of the other men in this study attested to the significance of Sydney as a place where they felt they no longer had to conceal their sexualities. David Polson was particularly adamant that Sydney provided gay men with a distinct level of social freedom that was not attainable elsewhere. David moved to Sydney in 1972. After eighteen years of growing up in a "gay intolerant" city, he was ready to leave. David attended his local public high school in Christchurch, New Zealand where, "if you weren't a sportsman you were nothing, and I wasn't a sportsman, so I was [laughs] nothing. So all in all, it was a horrible – it was a horrible time, and I couldn't wait to get out so that as soon as I left school I left the country." With the exception of public toilets and other areas where men met other men for sex, David was not aware of any other gay people throughout his youth. Yet he has since learned that several other boys at his school were also gay and “obviously going through the same torment I was because you couldn’t tell anyone.” These fears were justified. David recalled one particular occasion when the headmaster at his high school “issued this edict that homosexuals were sick and if anyone knew any they had to report them to him. That’s the sort of school I went to it was horrible, I hated it.” When I asked how other students responded to this announcement, he simply replied: “well they started beating me up even more.”[23]

In the 1960s and early-1970s, sex between men was outlawed in New Zealand and across all Australian states and territories. Homosexuality was also categorised as a medical condition in both countries until 1973.[24] Nevertheless, David interpreted such explicit homophobia as characteristic of 1960s’ New Zealand. Leaving the country enabled him to escape from the social constraints that he felt New Zealand culture imposed on him at a time when “it was all so closeted.”[25] David stated that he never explicitly came out as gay in Sydney. This rather occurred organically when he left New Zealand immediately after he finished high school:

> As the plane took off I had this huge burden lift off my shoulders, and I came here and, oh just straight away. Everyone knew I was gay so they all accepted it, and I didn’t even have to say anything. I didn’t have to say, “I’m gay,” “I’m gay,” “I’m gay.” I just – they knew … It all happened on the plane; I shed my closet on the front of the plane coming over.[26]

David’s assertion that “I shed my closet” encapsulates the emotional liberation that leaving New Zealand and feeling as though he no longer had to conceal his sexuality entailed. David recounted these feelings forty-two years after he left Christchurch. He had been awarded a scholarship to attend Ensemble Studios, an acting school on Sydney’s North Shore, and left the school six months later when he secured a position as an actor at The Music Hall. He moved into a flat in Elizabeth Bay with four other actors and started to meet other gay men. His fond memories of leaving New Zealand were partly influenced by the strong friendships he established once he arrived in Sydney.

Moving to Sydney provided several other interviewees with an escape from environments where they were actively persecuted for being gay. John Whyte and Victor Day also grew up in New Zealand and cited similar reasons for moving to Sydney.[27] Shortly after I arrived at his home, John recognised my New Zealand accent and informed me that he had fled persecution and discrimination in Wellington, the capital city of New Zealand. He returned to this point during the interview. John trained as a police officer after high school, but he was pressured to leave the force after he was caught in a compromising position with a fellow officer. He also explained that he was denied job opportunities and promotions despite working tirelessly for two other companies, "and it was about homophobia as I said, persecution and discrimination screaming me in the face."[28] Such explicit distinctions between Sydney and the narrators' hometowns were not limited to those who grew up in New Zealand. Participants who grew up across Australia and even suburban Sydney made similar comparisons when they moved to inner city Sydney across the late-1970s and 1980s. These men described a distinct attachment to inner city Sydney, which provided them with the freedom to explore and embrace their sexualities in ways they did not know were possible.

All the men who participated in this study moved to inner city Sydney either during or shortly after the gay liberation movement. They had access to a thriving commercial nightlife filled with parties, parades, nightclubs, sex venues, and scores of other young gay men. Yet, not all men who ventured to inner city Sydney in pursuit of a gay community achieved the same level of acceptance and liberation that characterised gay Sydney during this period. Some narrators attested that racial and social distinctions meant they often felt uncomfortable and, at times, unwelcome in the gay scene. Their memories of such fractures and divisions are often overshadowed by others' recollections of a level of community solidarity that they felt they lost in the aftermath of HIV and AIDS.

On the Margins

Most of the men in this study depicted inner city Sydney as a distinct enclave created by and for members of the LGBTIQ community.[29] Such memories of community solidarity, however, only represent a selection of gay men's experiences during this period. Historians and public health researchers have found that many men in suburban and rural areas felt isolated from Sydney's gay community and travelled to the cities to meet other men for sex.[30] This isolation extended to some of those who relocated to the city in pursuit of a gay community. These men, however, sometimes struggled to articulate experiences that departed from understandings of Sydney as a “strong and diverse gay community.”[31]

Tony Creighton was the first of two Aboriginal men I interviewed. Tony was born in Sydney in 1963 and moved to Wagga Wagga, a small town in regional NSW, with his family six years later. After his parents separated in 1970, Tony moved into public housing with his mother and his two younger siblings. He explains that while there was likely a strong Aboriginal community in Wagga Wagga, he was surrounded by white families and they “never talked about dad being Aboriginal.” Tony resented his hometown. He endured racism and homophobia from other students who “made my life hell” during high school and concluded: “outside of Sydney, it’s just a nightmare if you’re gay. […] There are people out there that hate you with a vengeance. You know, just because you’re gay. And I get the double whammy because I’m Aboriginal and I’m gay.”[32] Tony started to visit Sydney on weekends from the mid-1970s. He stayed in the inner west with his father, with whom he had reconnected in 1975 or 1976 and, too young to gain entry into the bars and nightclubs, wandered Oxford Street and browsed record stores. He moved to the city in September 1980 and shared a flat with university students in Newtown. Tony felt inner city Sydney was the only place where he could live openly as a gay man. He reflected, “I think I came here at a perfect time, you know, Mardi Gras was only two years old. Everyone was happy about being gay. The venues, you know, there were a lot of them.”[33]

Tony’s assessment of gay life in Sydney took a sharp turn when he discussed racial discrimination within the gay community. He had signalled this discussion as soon as I arrived at his home, and he expressed his frustration at the limited representation of Aboriginal actors on Australian commercial television. He returned to this point two hours into the interview and explained that he did not see any Aboriginal figures on television when he was growing up, and he therefore did not have any Aboriginal role models. When I questioned Tony about whether he had experienced racial discrimination from other gay men, he promptly replied:

> Oh Christ, yes! Oh please! If you’re black, you’re fucked. Unless, unless the men like – there’s a nickname for them, “gin jockeys” we call them. You know, we get men that like Asians: “rice queens.” We get Asians that

> like white men: "potato queens." "Leather queens," "muscle queens," "sauna queens," "beat queens." You know, "suck my toe queens" and all that sort of stuff. Yeah, "gin jockeys."[34]

There is a clear discrepancy between Tony's memories of a burgeoning gay community and the racism he and others encountered. As Tony's testimony reveals, such nicknames were common among gay men. They were not only designated according to race but also on gay men's sexual preferences more broadly.[35] Nevertheless, Tony's decision to recite such nicknames suggests that the use of the pejorative term "gin jockey" meant he felt marginalised by the predominantly white gay male community.

Tony's description of racial discrimination within Sydney's gay community highlights the nuances in dominant historical narratives that depict a unified community in the wake of the gay liberation movement. It suggests that this community was perhaps more disjointed than some of the other narrators remembered. By returning to his earlier discussion about the absence of Aboriginal representation on commercial television, Tony perhaps intended to prompt a discussion about racism. His immediate and emphatic response—"Oh Christ, yes!"—suggests this was a question he had anticipated. Yet while Tony willingly condemned racism from wider society, he only discussed such distinctions within the gay community in response to my direct question. He might have felt he could only address racial discrimination within Sydney's gay community when he was explicitly asked. The initial omission in the interview reveals his struggle to articulate experiences that do not align with his affirmed narrative about engaging with a supportive and unified gay community.

Contrary to Tony's account, Evan Richardson asserted that he has never experienced racism or homophobia. Evan moved to Sydney from Western Australia in 1991 at the age of twenty-one. He shared fond memories of living in inner city Sydney in the early-1990s at a time when "I felt everyone enjoyed everybody's company. No conflict, no tension."[36] Evan's recall of living in Sydney melds with the broader life story he had composed. He reinforced that he felt "fortunate" on several occasions throughout the interview. This appears to be a reflection of his upbringing. Evan was born in a small town in Western Australia, nearly one thousand kilometers north of the state capital, Perth. He was fostered to a white Christian family at the age of six months. It was not entirely clear whether he was forcibly removed under the Aborigines

Protection Act. Indeed, while most removals ceased in 1969 with the abolition of the Aborigines Welfare Board, child removals continued into the early-1970s.[37] Unlike many other Aboriginal children removed from their parents during this period, Evan had—albeit limited—contact with his biological mother and father, although they died in 1996 and 2003, respectively. He remained close with his elder sister who was also adopted by a white family. Evan spent most of his childhood in Perth as his foster parents pursued better employment prospects in a larger city. Although he briefly stated that his Christian parents "shunned" homosexuality, he recalled sharing positive relationships with his adopted and biological family, peers, and medical professionals.

Evan perhaps emphasised his fond memories of growing up in Western Australia, attending a school where he was good at sport and "quite popular," and moving to Sydney in 1991 to deal with the trauma of being removed from his parents. When questioned about his relationship with his foster parents, Evan promptly responded that they were "very good to me. Fed me, clothed me, and educated me. All those sorts of things. Really good. Very loving family."[38] Upon further discussion, however, he noted his prevailing anger:

> I still get angry. I still get angry about it. Don't know why. Just occasionally sometimes I get irritated. Pissed off that I was taken away … but at the same time, you know, I wouldn't have had the … I wouldn't have had the kind of things that I had with my white family here.[39]

The first part of Evan's testimony reflects his anger that he was removed from his biological parents. This appears to be a particularly difficult topic to discuss. It was not only a traumatic experience but it also disturbed the life story that he had composed which centred on the positive aspects of his life. After a particularly lengthy pause, Evan reverted to his usual and perhaps safer account that highlighted the parts of his upbringing for which he was grateful. Evan's extended pauses, as signalled in the above extract, might therefore reflect his struggle to articulate his anger that he was removed while simultaneously acknowledging the close relationships he shares with his foster parents.

Evan's emphasis on feeling fortunate also likely reflected his concerns about his mortality. Before starting the interview, I mentioned that I would make contact at the end of the following year regarding the progress of this study to which he responded, "hopefully I'm still alive."

Further, when questioned about whether he had experienced any physical symptoms of HIV or AIDS-related conditions, he promptly replied: "not yet." On another instance, he stated that he was fortunate that he has not been "sick yet." At the very end of the interview, Evan explained that he believes he will die as a result of the virus and estimated that he has five years left. Such concerns can be attributed to his low T cell count. He stated that he has a T cell count of 165 which classifies him as someone whose illness has progressed from HIV to AIDS. The version he told in the interview reflected both the past he wanted to remember and one that aligned with how he wanted to be remembered.

Narrators' struggles to feel accepted within the gay community were not solely based on race. Steven Jottileb is an Anglo-Australian man born in 1956. He grew up in a small town in the Tamworth region of New South Wales, four hundred kilometers North-West of Sydney. Steven described a "very tough" upbringing after his father was killed in a sawmill accident in 1965. His grief at losing his father—which "was very horrible, it was hard to take when he died"—was exacerbated by conflict with his extended family. They had no contact from 1969 to 1972 when his mother died of cancer. Although Steven moved to Paddington in 1974 "'cause that's where the gay people live," he did not become part of the gay community that he pursued. When questioned about whether he frequented gay nightclubs and bars in Sydney in the 1970s, he explained:

> I didn't do that, really. I went a couple of times. I thought they were too … I don't know … I was a bit scared to "come out" I think. They're a pretty tough place, the gay bars. You know, pretty tough. I went to the gay centre once or twice and picked up a couple of guys there just to see what it was like and everything. But I was in the mental health system for about ten years. I had to make sure I was well enough to go out somewhere 'cause I didn't wanna say the wrong thing in a gay bar and get beaten up or something.[40]

Steven's fear of saying "the wrong thing" emerged at several other points in the interview. He felt he had previously said "the wrong thing" and caused conflict with other gay men, doctors, family members, and neighbours whom he suspected wrote the threatening notes he found in his letterbox. His testimony appears to be closely shaped by his experiences in the public health system. In 1977, Steven was placed in a psychiatric unit as he had become depressed and suicidal. He experienced his first major breakdown the following year and was diagnosed with schizophrenia at the age of twenty-two. Steven struggled to reconcile his personal experiences with dominant depictions of a supportive and thriving gay community, and he reverted to this other narrative with which he was familiar and comfortable telling. He blamed himself and felt that he did not fit the standard.

I returned to Steven's fear of being "beaten up" at the end of the interview and asked him to elaborate. He explained:

> I used to see it on the news, like, guys being bashed. And you know, I saw in a paper – the *Sydney Star Observer* – a gay guy was bashed in the flats down there. He took somebody home and the person may have bashed him to death. But I'm not familiar with the gay scene. You know, I'm afraid. You could meet people and you might say the wrong thing to them when you're home and they could turn against you. But I usually wait for them to crack onto me [laughs]. So, I don't, I nearly got put into jail in the early '80s 'cause I tried to crack onto someone, to a guy. […] I was in a boarding house and he told his friends what had happened and they called the police straight away and I got taken away. And they turned against me. I felt really bad after that.[41]

Brutal attacks against gay men across the 1980s and 1990s are well documented.[42] In December 1983, *Campaign* raised concerns about "the new defence" which had been applied in murder cases across California.[43] The "homosexual panic defence," which suggested the victim was killed in "self-defence" after initiating sexual contact with the defendant, also reportedly saw several murders of gay men in Australia remain unpunished.[44] Such violent crimes against gay men in Sydney have also garnered recent attention. In 2018, the NSW Police Force released their final report on the suspected murders of over eighty men from 1976 to 2000.[45]

Steven, however, appeared to be particularly concerned about other gay men, rather than violence from the general public. He traced such concerns to an incident in 1980 when he tried to seduce a man he met in a boarding house and was subsequently charged with indecent male assault. The experience "scared the shit out of me, I decided I'd better be careful."[46] Steven managed to avoid jail by paying a fine of two hundred dollars. Nevertheless, this encounter had a lasting impact on Steven's confidence and his ability to interact with other gay men. He conceded, "it happened about thirty, twenty years ago but it still scares me today. I mean, he was gay himself, and he still didn't like me so, you know, I don't know. I don't know what to do."[47] Consequently, Steven remained on the margins of the gay community.

Social and racial divisions impeded some men from feeling welcome and accepted within the community they had eagerly pursued. Nevertheless, they appeared to be reluctant to explicitly challenge depictions of Sydney's gay community as one that mobilised and thrived across this period. Indeed, Tony only discussed racial discrimination from other gay men after he was prompted by my question, while Steven attributed his feelings of exclusion to his subjectivity as someone who has knowingly been living with schizophrenia since 1978. The arrival of HIV and AIDS exacerbated these men's perceptions that they were on the fringes of this community. As Chapter Six outlines, they did not always have access to the level of support that was vital to others.

Last Man Standing

Across the 1980s and early-1990s, inner city Sydney transformed into a site of devastation as numerous young gay men succumbed to the virus. Many of the men who participated in this study witnessed their entire peer groups deteriorate within a few years. The sheer amount of death that these men endured across this period meant that many felt remaining in Sydney was not a viable option. From the early-1990s, fourteen of these men relocated to Melbourne, Brisbane, Tasmania, and the Northern Rivers region of New South Wales in order to rebuild their lives. They hoped to geographically and emotionally distance themselves from the traumatic memories of living through an epidemic that decimated their community. Nearly all of those who left the city stayed away. Howard Clarke and Scott Martin, however, felt compelled to return to Sydney when their health declined in 1996 and 2013, respectively. They found that medical services for people with HIV or AIDS were much more accessible in Sydney than they were in other parts of Australia. Access to medical expertise and support services were perhaps two of the reasons why none of the eleven interviewees who remained in Sydney mentioned any desire to leave the area. Further, eight of these eleven men received subsidised housing. They had considerably less flexibility to relocate than those in more stable economic positions.

Reports about a "parasitic pneumonia" or "rare viral cancer" first emerged in the Australian gay press in 1981.[48] Yet most men became aware of the severity of the virus when it started to affect their immediate social groups. One narrator recalled "there was this disease that was coming from America that was killing gay men and they didn't know what it was," while another noted "it took a while for the information to kind of filter to Australia and Sydney, and so probably '84 was the first time I heard about HIV."[49] Despite the slow beginning, they were soon confronted with the devastation that HIV and AIDS would cause. Adrian Eisler explained, "it's like on a lovely summer's day you start to see a few clouds developing over the horizon. As the day goes by the clouds get bigger and bigger and blacker and blacker and blacker, and therefore you think 'oh God, it's gonna rain soon.' And then it's a thunderstorm."[50] Over the following years, HIV and AIDS decimated Sydney's gay community. Gay newspapers were filled with "pages upon pages upon pages of obituaries" and death notices of men "at such terribly young ages."[51] Many men removed themselves from bars, nightclubs, and their intimate social groups as concerns about the virus infiltrated Sydney's gay community.[52] Historian Robert Reynolds traces this decline to as early as 1984, by which time "the 'good old days' were over."[53]

Geoff Anderson became intimately involved in the response to HIV and AIDS through his work as a volunteer for the Gays Counselling Service (GCS) from 1983 until he was diagnosed with HIV three years later at the age of twenty-seven. Activists established the GCS, formerly Phone – A – Friend in 1973 to provide emotional support for gay men and lesbians. Although it was not an HIV and AIDS organisation, it was one of the first groups to respond to the threat of the virus. In July 1983, the GCS liaised with the Metropolitan Community Church, the Gay Disabled Club, and Acceptance, the latter a Catholic organisation, to form the AIDS Support Group in Surry Hills.[54] The following year, three counsellors from the AIDS Support Group joined the Immunology Clinic at St Vincent's Hospital in Darlinghurst to help people to cope with diagnoses of impaired immunity.[55] In May 1984, the *Sydney Star Observer* reported that the director of the GCS, activist Terry Goulden planned to attend the First International Lesbian/Gay Health Conference in New York.[56] He also reportedly aimed to liaise with international gay community centres. These included the Gay Men's Health Crisis in New York, which provided an exceptionally proactive and effective response to HIV and AIDS in America.[57] In doing so, Goulden aimed to gain further insight into how other community organisations supported people with HIV and AIDS.[58] Considering the intense fear and uncertainty that prevailed, the GCS was also one of the few avenues through which gay men could access information and seek guidance about the virus in the early-1980s. Indeed, Geoff recalled that his role as a counsellor primarily involved communicating updates on HIV and AIDS to concerned callers and recommending suitable doctors. Phone services that specifically focused on providing information about the virus to the public followed shortly afterwards. On 20 December 1984, the New South Wales Department of Health launched an “AIDS Hotline.” The Albion Street Hotline was established the following September and reportedly received eight thousand calls in the first eight weeks.[59]

Geoff was the first interviewee to leave Sydney. He relocated to regional New South Wales with his partner in 1992. Geoff initially stated that they decided to move in order to care for his partner’s mother who had been diagnosed with breast cancer. Upon further discussion, however, he revealed that their decision to leave inner city Sydney was more closely based on the devastation caused by HIV and AIDS. Geoff conceded that:

> One of the reasons for leaving Sydney – which was in the early-’90s – apart from my partner’s mother getting breast cancer, was that Mark worked at the Albion Street AIDS Clinic, he was a nurse there. And sometimes he would – he would come home and he’d be in tears and he’d go “how many more of us need to die?” You know, so many good people dying, and I just don’t think he could deal with it anymore. So it was time to move.[60]

Geoff and Mark could only distance themselves from the emotional devastation that HIV and AIDS caused in their personal lives by physically removing themselves from the city. The Albion Street Clinic was established in 1985 and was one of the main medical centres in Sydney that provided testing and counselling for people concerned about the virus.[61] Both men were therefore closely involved in the response to HIV and AIDS from the outset. They were acutely aware of the extent to which the virus decimated Sydney’s gay male population. Geoff’s testimony also reveals his effort to emotionally distance himself from the difficult memories of losing numerous people to the virus. He placed particular emphasis on the impact the epidemic had on his partner, whom he felt could not "deal with it anymore."[62] The grief that the epidemic caused Geoff only became apparent at the very end of the interview.

Geoff returned to his decision to leave Sydney during the final five minutes of the two-hour interview. When I asked Geoff to comment on how he felt about narrating his life story, he reflected:

> I do miss some of those people so much. Just seeing their smiles you know, you knew what could make them laugh, or you knew what they were like. And I think another reason of – as I said earlier on to leave Sydney was to escape the fact of not seeing their face anymore.[63]

Geoff estimates that he lost forty to fifty members of his social network. Leaving Sydney was therefore an attempt to avoid having to regularly confront the trauma of losing numerous friends and acquaintances to HIV and AIDS-related causes. Inner city Sydney had initially provided many of the interviewees, including Geoff, with a place where they could both explore their sexualities and establish strong social networks. Yet the ongoing deaths these men endured in a concentrated period meant the city served as a constant reminder of the lives that had been lost.

Greg Iverson cited similar motivations for leaving Sydney. I interviewed Greg in Melbourne, where he had relocated in 2002 after Phillip, his last friend from the 1980s and 1990s died. As I have discussed, Greg shared particularly fond memories of living in Sydney across the late-1970s and early-1980s. He described hosting "the most outrageous parties" with other gay men who occupied the entire floor of the tallest apartment block in Waverley, a suburb in Eastern Sydney. They decorated their balconies with bucket loads of sand from Tamarama Beach during summer and filled the hallways with polystyrene balls for their snow parties during the winter months. Yet he conceded that,

> All of those people from those days are dead. Every single one. Except me. And that was what Phillip said to me about six months before he went, he said: "do you realise we're the last two from those days?" And I just didn't really think much of it at the time. But then when he went it made me realise "I'm the last one. I'm the last one standing. I've gotta get out of here."[64]

Greg's assessment that he was the "last one" reinforces his sense of isolation once all of his close friends had died. Phillip's death severed the last connection he had to this past. Yet Greg's decision to relocate to Melbourne also reflects his declining interest in Sydney's gay commercial scene. Greg left Sydney in 2002, twenty-four years after he "came out" as gay. By that time, "it wasn't worth going out. And I was forty-two, and you felt isolated from Oxford Street in those days because the bars were all catering to that 'young twenty-year-old.'"[65]

Many of the men in this study placed immense value on living in Sydney's "gay triangle" at a distinct historical moment. By this time, activists had formed a number of support networks and political organisations, a gay press had been established, and a commercial scene was thriving. At the same time, however, their memories of this period are also influenced by nostalgia for a community that the epidemic decimated over the following years. Most narrators' memories of living in the inner city reflect not only their attachment to the city but also to a period when their lives were uninhibited by the virus. This was a time before they witnessed friends die, before they had any idea of the damage that the virus would cause, and before anyone had heard of AIDS. These men appear to have composed memories that depict the gay community as particularly united, which inadvertently overshadowed any social and racial tensions that prevented others from gaining access to these same support networks. Having set out the historical context in which the men's narratives are located, the following chapters investigate the impact HIV and AIDS had on HIV-positive gay men's intimate lives.

Notes

1. 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; Graham Willett, *Living Out Loud: A History of Gay and Lesbian Activism in Australia* (St. Leonards, NSW: Allen & Unwin, 2000), 169; Graham Willett, "How We Saved Our Lives: The Gay Community and the Australian Response to AIDS," *HIV Australia* 12, no. 3 (2014): 4–7.
2. Willett, *Living Out Loud*, 169.
3. Peter Robinson, *Gay Men's Relationships Across the Life Course* (Hampshire: Palgrave Macmillan, 2013), 33.
4. James Jansson, David Wilson, and Jo Watson, *Mapping HIV Outcomes: Geographical and Clinical Forecasts of Numbers of People Living with HIV in Australia* (Sydney: National Centre in HIV Epidemiology and Clinical Research, 2010), 32.

5. Larry Galbraith et al., *Sydney & Beyond '89*, Second (Sydney: Southpaw Press, 1989), 25.
6. Barbara B. Brown and Douglas D. Perkins, "Disruptions in Place Attachment," in *Place Attachment*, eds. Irwin Altman and Setha M. Low (New York: Plenum Press, 1992), 283; Claire Cooper Marcus, "Environmental Memories," in *Place Attachment*, eds. Irwin Altman and Setha M. Low (New York: Plenum Press, 1992), 109; Setha M. Low, "Symbolic Ties That Bind: Place Attachment in the Plaza," in *Place Attachment*, eds. Irwin Altman and Setha M. Low (New York: Plenum Press, 1992), 165; Setha M. Low and Irwin Altman, "Place Attachment: A Conceptual Inquiry," in *Place Attachment*, eds. Irwin Altman and Setha M. Low (New York: Plenum Press, 1992), 2.
7. Barbara B. Brown and Douglas D. Perkins, "Disruptions in Place Attachment," in *Place Attachment*, eds. Irwin Altman and Setha M. Low (New York: Plenum Press, 1992), 283; Claire Cooper Marcus, "Environmental Memories," in *Place Attachment*, eds. Irwin Altman and Setha M. Low (New York: Plenum Press, 1992), 109.
8. Robert L. Rubinstein and Patricia A. Parmelee, "Attachment to Place and the Representation of the Life Course by the Elderly," in *Place Attachment*, eds. Irwin Altman and Setha M. Low (New York: Plenum Press, 1992), 140.
9. Scholars argue that nostalgia reflects the loss that individuals feel in their present lives. Sean Field, "Imagining Communities: Memory, Loss, and Resilience in Post-Apartheid Cape Town," in *Oral History and Public Memories*, eds. Paula Hamilton and Linda Shopes (Philadelphia: Temple University Press, 2008), 115; Christina Goulding, "Corsets, Silk Stockings, and Evening Suits: Retro Shops and Retro Junkies," in *Time, Space, and the Market: Retroscapes Rising*, eds. Stephen Brown and John F. Sherry Jr. (New York: M. E. Sharpe, 2003), 65.
10. Robert Aldrich, *Colonialism and Homosexuality* (London: Routledge, 2003), 218.
11. Garry Wotherspoon, *City of the Plain: History of a Gay Sub-culture* (Sydney: Hale and Iremonger, 1991), 21.
12. Ibid., 54–7.
13. Robert Reynolds, "CAMP Inc. and the Creation of the 'Open' Homosexual," in *Australia's Homosexual Histories*, eds. David L. Phillips and Gary Willett (New South Wales: Centatime (NSW), 2000), 134.
14. Dennis Altman, Gillian Leahy, and Germaine Greer, "Sydney Scene," *CAMP INK*, February 1972, 9–10; Mike Clohesy and Peter De Waal, *Oppression Upon Reflection* (Sydney: CAMP NSW, 1975), 8; Sydney Gay Liberation, *A Gay Liberation Manifesto* (Sydney: Sydney Gay Liberation

Publications Group, 1972). See also Dennis Altman, *Coming Out in the Seventies* (Sydney: Wile & Woolley, 1979).

15. Sue Wills, *The Politics of Sexual Liberation* (Ph.D. Thesis, The University of Sydney, 1981), 64.
16. Ibid.
17. Greg Iverson, interview with the author, 31 August 2014, Melbourne.
18. Galbraith et al., *Sydney & Beyond '89*, 27; Catherine J. Nash and Andrew Gorman-Murray, "Lesbian Spaces in Transition: Insights from Toronto and Sydney," in *Planning and LGBTQ Communities: The Need for Inclusive Queer Spaces*, ed. Petra L. Doan (New York: Routledge, 2015), 191.
19. David Carter, *Stonewall: The Riots That Sparked the Gay Revolution* (New York: St. Martin's Press, 2004).
20. Graham Carbery, *A History of the Sydney Gay and Lesbian Mardi Gras* (Melbourne: Australian Lesbian and Gay Archives, 1995), 5.
21. Greg Iverson, interview with the author.
22. Ibid.
23. David Polson, interview with the author, 18 June 2014, Sydney.
24. In 1973, the American Psychiatric Association removed homosexuality from their Diagnostic and Statistical Manual of Mental Disorders. That same year, the Royal Australian and New Zealand College of Psychiatrists released a memorandum that supported ideas that homosexuality was not associated with "neurotic symptoms." Nevertheless, Australian historian Emily Wilson argues that physicians continued to "treat" gay men in an attempt to "cure" homosexuality for several years. See Emily Wilson, "'Someone Who is Sick and in Need of Help': Medical Attitudes to Homosexuality in Australia, 1960–1979," in *Homophobia: An Australian History*, ed. Shirleene Robinson (Sydney: The Federation Press, 2008), 148–71.
25. David Polson, interview with the author.
26. Ibid.
27. Gay communities were also developing in New Zealand at that time. For a selection of studies into New Zealand's homosexual histories, see Chris Brickell, *Mates and Lovers: A History of Gay New Zealand* (Auckland: Random House/Godwit, 2008); Nigel Gearing, *Emerging Tribe: Gay Culture in New Zealand in the 1990s* (Auckland: Penguin Books (NZ), 1997); Laurie Guy, *Worlds in Collision: The Gay Debate in New Zealand, 1960–1986* (Wellington: Victoria University Press, 2002).
28. John Whyte, interview with the author, 17 June 2014, Sydney.
29. Rebecca Jennings has highlighted how some women felt marginalised within the gay community, especially within political organisations including CAMP Inc. See Rebecca Jennings, "Lesbians in Sydney," *Sydney Journal* 2, no. 1 (2009): p. 30.

30. Robert Aldrich, “Gay and Lesbian History,” in *Gay Life and Culture: A World History*, ed. Robert Aldrich (London: Thames and Hudson, 2006), 24; John Ballard, “Sexuality and the State in Time of Epidemic,” in *Rethinking Sex: Social Theory and Sexuality Research*, eds. R.W. Connell and Gary W. Dowsett (Melbourne: Melbourne University Press, 1992), 114; Garrett Bennett, Simon Chapman, and Fiona Bray, “Sexual Practices and ‘Beats’: AIDS-Related Sexual Practices in a Sample of Homosexual and Bisexual Men in the Western Area of Sydney,” *Medical Journal of Australia* 151, no. 6 (1989): 309–14; Wotherspoon, *City of the Plain*, 204.
31. Galbraith et al., *Sydney & Beyond ’89*, 25.
32. Tony Creighton, interview with the author, 30 July 2014, Sydney.
33. Ibid.
34. Ibid.
35. Such racial-based nicknames are well acknowledged: Frank Bongiorno, *The Sex Lives of Australians: A History* (Collingwood, Australia: Black Inc., 2012), 274.
36. Evan Richardson (pseudonym), interview with the author, 10 November 2014, Sydney.
37. Human Rights and Equal Opportunity Commission, *Bringing Them Home: Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families* (Sydney: HREOC, 1997).
38. Evan Richardson, interview with the author.
39. Ibid.
40. Steven Jottileb, interview with the author, 29 August 2014, Sydney.
41. Ibid.
42. Rick Sarre and Stephen Tomsen, “Violence and HIV/AIDS: Exploring the Link Between Homophobic Violence and HIV/AIDS as a ‘Gay Disease,’” in *Homophobic Violence*, eds. G. Mason and S. Tomsen (Sydney: The Hawkins Press, 1997), 80; Sue Thompson, “Hate Crimes Against Gays and Lesbians: The New South Wales Police Response,” in *Homophobic Violence*, eds. G. Mason and S. Tomsen (Sydney: The Hawkins Press, 1997), 133.
43. Barry Lowe, “Panic Murders, The New Defence,” *Campaign*, December 1983, 14.
44. Tony Magnusson, “Homophobic Panic Defence: Where to Now?” *Campaign*, June 1994, 6; Carp Ruthchild, “Don’t Frighten the Horses! A Systemic Perspective on Violence Against Lesbians and Gay Men,” in *Homophobic Violence*, eds. Gail Mason and Stephen Tomsen (Sydney: The Hawkins Press, 1997), 5.

45. The findings of this case were detailed in: NSW Police Force, *Strike Force Parrabell: Final Report* (Sydney: Allbook Bindery, 2018).
46. Steven Jottileb, interview with the author.
47. Ibid.
48. The *Star* (later the *Sydney Star Observer*) was the first Australian newspaper to mention the "mysterious new condition." Shirleene Robinson, "HIV/AIDS and Gay Community Print News Media in 1980s Australia," in *Out Here: Gay and Lesbian Perspectives VI*, eds. Yorick Smaal and Graham Willett (Melbourne: Monash University Publishing, 2011), 91.
49. David Polson, interview. Thomas Parker, interview with the author, 13 July 2014, Brisbane.
50. Adrian Eisler, interview with the author, 23 May 2014, Macquarie Park, Sydney.
51. Ibid.
52. Shirleene Robinson, "Responding to Homophobia: HIV/AIDS, Homosexual Community Formation and Identity in Queensland, 1983–1990," *Australian Historical Studies* 41, no. 2 (2010): 186.
53. Robert Reynolds, *What Happened to Gay Life?* (Sydney: University of New South Wales Press, 2007), 60, 80.
54. Gays Counselling Service of NSW, *Sydney Gay Guide* (Sydney: Gays Counselling Service of NSW, 1984), 12. The AIDS Support Group became known as Ankali in May 1985: Norman Booker, *Strengthening the Community, ACON & the HIV Epidemic in NSW* (Sydney: ACON, 1995), 13.
55. Terry Goulden et al., "AIDS and Community Support Services: Understanding and Management of Psychological Needs," *Medical Journal of Australia* 141, no. 9 (1984): 583.
56. "GCS Director to Attend International Gay Health Conference," *Sydney Star Observer*, May 31, 1984.
57. 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), 512; Jonathan Engel, *The Epidemic: A Global History of AIDS* (New York: HarperCollins, 2006), 103.
58. "GCS Director to Attend International Gay Health Conference," *Sydney Star Observer.*
59. "US Anti-Flu Drug Latest Hope for AIDS Sufferers," *Sydney Morning Herald*, December 22, 1984, 1; "Life and Death in the AIDS Age," *Sydney Morning Herald*, October 19, 1985, 9.

60. Geoff Anderson (pseudonym), interview with the author, 9 August 2014, Brisbane. Mark is also a pseudonym.
61. Larry Galbraith, “Gold on Albion Street Clinic,” *Sydney Star Observer*, March 7, 1985, 4.
62. Geoff Anderson, interview with the author.
63. Ibid.
64. Greg Iverson, interview with the author.
65. Ibid.

CHAPTER 3

The Face of HIV

When Ross Duffin entered the great hall to listen to the final plenary speech at Australia's Third National AIDS Conference in Hobart, he did not realise he would become part of a movement that would permanently shift the visibility of HIV and AIDS in Australia. For the first time, Ross and several other conference delegates publicly identified as HIV-positive. These individuals were conscious of the threat that HIV posed to their health and increasingly frustrated that their medical needs were not being met. They tore down the silence that suppressed discussions about living with the virus and asserted themselves as active agents in the national response to HIV and AIDS. The power of those who were willing to identify as HIV-positive has remained one of the legacies of the epidemic. Ross recalled the events that unfolded on the afternoon of Saturday 6 August 1988: "while Terry Giblett was doing his presentation, he asked all the people who had tested HIV-positive to get up on the stage [laughs]."[1] The audience was stunned. "And everyone starts looking at each other: 'ooh.' Then about ten staff of ACON, including me, walked up on stage and everyone's jaws dropped 'cause suddenly HIV went from this thing that someone else had to being in the room!" The significance of this moment cannot be overstated. The "silence was just palpable, and suddenly people had this notion of what they're actually dealing with."

The Third National AIDS Conference in 1988 is a significant milestone in Australia's histories of HIV and AIDS. It instigated a key shift whereby HIV-positive gay men continued to share their personal

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0_3

stories through the printed press, televised documentaries, and as public speakers over the following years. Existing historical representations of gay men with HIV or AIDS in Australia predominantly focus on those who publicly identified as HIV-positive across the late-1980s and 1990s. Such histories highlight the significance of community action that characterised Australia's political response to the epidemic. Yet the movement towards public disclosure among HIV-positive gay men was a considerably more complex and gradual process than existing historiography suggests. Such histories tend to omit the voices of those who struggled to disclose their HIV-positive status. In doing so, they overshadow individuals' memories of the silence that shrouded discussions about living with the virus across the mid-1980s, their personal motivations to conceal or disclose their HIV-positive status, and the ramifications of being identified as a gay man with a stigmatised virus.

This chapter traces HIV-positive gay men's changing attitudes towards disclosure. This evolved from concealing their positive status in the mid-1980s to appearing in the media as the "face of HIV" the following decade. It primarily focuses on interviews with Ross Duffin, Scott Martin, David Polson, Lloyd Grosse, and Jamie Richards. Most of these men were involved in HIV and AIDS activism at some point. They initially depicted their decisions to disclose—often referred to as a second "coming out"—as simply a continuation of this activism. Further discussion revealed that they were also motivated by a combination of camaraderie, guilt, and their determination to present themselves living with, rather than dying from HIV. Although some men faced severe backlash after they disclosed their positive status, they shared fond memories of disclosure. Their accounts reflect nostalgia for a level of activism and community solidarity that some feel is missing in their present lives.

Don't Ask, Don't Tell

The emphasis on HIV and AIDS activists who publicly disclosed their positive status tend to overshadow individuals' memories of the silence and fear that suppressed discussions about living with the virus across the mid-1980s. Some narrators appeared to feel guilty for not "coming out" as HIV-positive earlier. For these men, the prejudice that gay men with HIV or AIDS endured from the wider public, and at times from within the gay community, meant they felt compelled to conceal their HIV diagnoses. Yet these decisions were not solely based on their personal concerns. Several narrators explained that doctors and members of ACON cautioned them about the potential social and legal ramifications of disclosure. Concealing their positive status was not only emotionally taxing, but it also prevented them from being able to establish or engage with the support networks that have been a major part of the community response to HIV and AIDS.

The intense fear that HIV and AIDS generated meant that most of the men in this study did not personally know anyone else who was HIV-positive until several years into the epidemic. Scott Martin is one of the few exceptions. Scott maintained that he had immediate access to support after he was diagnosed with HIV in 1984 at the age of twenty-seven. Scott's introduction to a left-wing political group through the Gays Counselling Service in 1982 meant that he had established a strong network in Sydney by the time he received his HIV-positive diagnosis. He displayed photos of these friends marching at Sydney's first AIDS Candlelight Memorial and at a Hiroshima Day rally and fondly remarked, "we were such activists!"[2] They held political meetings, attended marches, and organised rosters to care for mutual friends who had succumbed to the virus. These individuals formed the basis of Scott's support network in the 1980s, and he recalled:

> [I was] amongst the first people to know in Sydney that he was positive. So, I thought, well I did have a lot of … we should talk about the support I guess. Over half the people I knew were positive by that time. There was a group that I'd call my family, gay family. And then there's socially the next group out from that, like maybe brother – cousins, you know [laughs]. If you think of an extended family of mainly gay men, sometimes there's straight people in it too, and lesbians, a group of people that you'd call your gay family, and extended family. And we'd just say "yeah, the test came in positive" and tell each other at that time. And I never knew discrimination on it, in regard to it. But over half the people that I knew were positive in my particular group.[3]

Scott's familiarity with disclosure meant that he perhaps did not face the same dilemmas about whether to reveal his HIV-positive status that the other men in this study described. He was in a rare position whereby he could observe how his friends had responded to others' diagnoses and gauge the response he might receive. His emphasis on receiving immediate support might also signal his effort to establish positive memories from a traumatic event. In 1984, a positive diagnosis , was essentially a death sentence. People were encouraged to leave work, take a final trip overseas, and enjoy what many believed to be the final moments of their lives. Scott maintained that he did not expect to die. He recalled telling his doctor, "I don't know if there any illness in the world that all people die from. You know, there's always some that don't and I'd give myself a pretty good chance." Nevertheless, Scott's awareness that many of his friends were also HIV-positive meant they were forced to confront their mortalities decades before any of them should have expected.

Scott's testimony also reflects his pride in being part of a distinct group of friends who offered one another vital support during this critical period. His description of his gay family contrasted with his recollections of growing up in suburban Sydney in the 1960s and 1970s. While Scott had sex with other boys during high school and discovered the "beat culture" that existed in the suburbs, he was "an angry young man" who was "horrified by the idea of being gay." He attributes these feelings to his religious upbringing and homophobia from the general public. As a young adult, he had his employment terminated after his co-workers harassed him about his sexuality and he attempted suicide twice in two years. Scott had an almost parallel experience with ostracism in the mid-2000s when he lived in a small town in regional New South Wales. On this occasion, the perpetrators were other gay men who outed him for being HIV-positive. These experiences left a lasting impression. Scott was concerned about anonymity and was careful to avoid including any specific details in this study that might reveal his identity. The 1980s were therefore a select period in his life when he felt he was able to be open about his HIV-positive status without fear of such repercussions.

Scott's assertion that he received immediate support might not be surprising considering several community-led support groups and organisations were established in Sydney by that time. These included the AIDS Action Committee, later known as ACON, and the Bobby Goldsmith Foundation, the charity named after one of the first Australians to die from an AIDS-related condition in 1984.[4] He and his friends identified Sydney as "one of the better places to be" as an HIV-positive person at that time. Nevertheless, Scott was one of the few men I interviewed who recalled having access to a support network in the early-1980s. On the contrary, David Polson maintained that his concerns about prejudice and ostracism meant he heeded his doctor's advice to only tell his closest friends that he was HIV-positive. In 1984, David became one of the first five hundred men to enrol in the Sydney AIDS Project, also known as the Sydney AIDS Prospective Study.[5] This long-term project aimed to determine the spread of the virus within Sydney's gay community.[6] Participants completed a questionnaire about their sexual behaviour and undertook a blood test for HIV antibodies. They were required to return to the clinic for repeat tests at six-month intervals for over two years. David was therefore one of the first gay men in Sydney to be tested and diagnosed with HIV.

David's present role as a motivational speaker appears to have fuelled his disappointment that he did not publicly disclose his HIV-positive status in the 1980s. He attested to the importance of public disclosure and asserted that unless people openly identify as HIV-positive, "we're always going to be stigmatised and always going to be discriminated against."[7] David interpreted public disclosure as a marker of solidarity with other HIV-positive gay men. In 1990, he started to appear on public campaigns for the Bobby Goldsmith Foundation after a close friend died from cancer, and he felt it was time to "step forward." Despite such close involvement in the HIV and AIDS cause, David appears to continue to feel guilty that he did not "come out" as HIV-positive sooner. Earlier in the interview, I questioned David about whether he was involved in HIV and AIDS activism. He promptly responded that he wasn't, "to my dying shame." This assessment is perhaps based on both his present stance on the value of disclosure and, as Chapter 7 outlines, an acknowledgment of dominant histories that position activists as the heroes of the epidemic. Featuring on public campaigns was itself an important form of activism. David's sense of shame, however, suggests that he continues to feel as though his contribution to the HIV and AIDS cause was inadequate.

David emphasised the prevalence of HIV and AIDS-related discrimination to explain that disclosing his HIV-positive status in the 1980s was not a viable option. He recalled one particularly severe incident:

> [A friend] worked in this building and a certain sector of the staff were going'round – were very anti-gay, very horrible about AIDS. They insisted on having their own toilet, they didn't want to share a toilet with gay men. So to their lasting shame, this corporation gave the gay men a toilet down the end of the corridor, a dirty old toilet that hadn't been used or cleaned for years, and the people had sprayed on it "AIDS Toilet." And then they would come – and this part is truly disgusting, and nothing was ever

> done about it – they would come and spray the people with Glen 20, and their desks, and their workstations with Glen 20, and they'd say, "there you go, you're free of AIDS now, you're clean from AIDS!" [...] That's just the way they were treating all gays at that stage, which made anyone with HIV even more tremulous, and scared, and unwilling to come out, because if that's what they're willing to do on a blanket campaign, what would they do to someone they knew was positive?[8]

David heard about this incident several years after he started to feature on public HIV and AIDS campaigns. While other publicised cases of discrimination may have influenced his decision to conceal his HIV-positive status in the 1980s, this particular case served an important purpose in David's narrative. Recounting such an explicit and horrific example of ostracism in the oral history interview suggests that David perhaps felt he needed to justify his decision to conceal his HIV-positive status. He therefore recounted what he described as the most extreme example of discrimination that he had heard.

David's concerns about discrimination were compounded by what he described as a broader lack of support for people with HIV or AIDS. When I questioned David about whether he joined support groups in the 1980s, he promptly replied:

> There was nothing. There was nothing. None of those support groups existed when I was diagnosed. You got diagnosed, and you're on your own. You went back to the doctor every six weeks to have your CD4 count taken. That was it.[9]

As was the case with Scott, David had established a close group of gay male friends shortly after he arrived in Sydney. Yet he did not have access to the support that Scott described. David understood such isolation—at a time when "there was nothing"—as a shared feeling among gay men who were diagnosed with HIV in the early-1980s. He explained that "because everyone was closeted no one was going to come out and say, 'I need help.'" While ACON and the Bobby Goldsmith Foundation were established in 1984, it is important to acknowledge that not all men were aware of these groups or had access to these networks during these critical years.

David's justification for concealing his HIV-positive status across the 1980s reflects the broader social and political climate that rendered disclosure as potentially dangerous. He asserted that "because of the hatred and uh, distrust and loathing in the general community about anyone who was HIV or *had AIDS* as they said in those days, the doctors told me to tell only a couple of people."[10] Doctors' concerns for the safety of gay men with HIV or AIDS were understandable. Public anxieties about the spread of the virus meant that some people with HIV or AIDS were alienated and vilified. The mid-1980s also saw proposals—often led by the controversial Reverend Fred Nile—to enforce mandatory testing and quarantine measures in Australia.[11] Such backlash was particularly dangerous for men like David who were involved in the Sydney AIDS Prospective Study. In 1985, the year after David was diagnosed with HIV, the *Sydney Star Observer* urged participants in the Study to insist that doctors only refer to them by an identification number or a false name and to demand staff return any records that might expose their identities. They advised readers that despite the Study being ethically sound, they were living in "exceptional circumstances" whereby "the law can force doctors to break faith with you."[12] Later that year, the same newspaper published advice from the Anti-Discrimination Board that warned readers against disclosing their HIV-positive status.[13] The article cited complaints from people with or suspected of having HIV. They reported being subjected to harassment, graffiti, having their employment terminated, and asked not to use toilets.[14] Advice against disclosure was evidently an attempt to protect people from discrimination. Yet it had severe ramifications for people living with HIV or AIDS.

Organisations that were specifically established to deal with the epidemic adopted a similar stance against disclosure. As a member of ACON's first elected committee, Ross Duffin was heavily involved in developing strategies to prevent the further spread of HIV and to support people with the virus. Nevertheless, even he did not have access to the level of support that Scott described. Ross attributed the silence around HIV and AIDS to compulsory notification legislation. In 1985, under the leadership of Premier Neville Wran, the NSW government passed the Public Health (Proclaimed Diseases) Amendment Bill. This law made HIV and AIDS notifiable diseases in NSW and required clinicians to notify health authorities of any diagnoses.[15] Wran had garnered favour from the gay community the previous year when he introduced a Private Member's Bill which led to the decriminalisation of sex between men in NSW.[16] Compulsory notification legislation, however, outraged some members of Sydney's gay community who retaliated by taking an HIV test under the pseudonym "Neville Wran."[17] Activists were particularly concerned that any breach of confidentiality could result in a person being labelled as an "AIDS carrier" and potentially face having their employment terminated, eviction, and losing their superannuation.[18] Medical professionals adopted a similarly critical stance. The NSW Chair of the Australian Association of Surgeons reportedly accused Wran of treating people with HIV and AIDS like lepers.[19] Furthermore, doctors at the Albion Street Clinic maintained that they would not release records without the patient's permission, while staff at the Taylor Square Clinic vowed to burn files rather than pass them to the government.[20]

The gravity of such legislation cannot be overstated. The law passed the day after Ross undertook a test for HIV and he subsequently decided to refrain from learning the results. This decision was taken away from him eighteen months later when his doctor, whom he was visiting about an unrelated health issue, unexpectedly informed him that the test was positive. Ross felt that other members of HIV and AIDS organisations echoed this silence:

> The rule that ACON had in relation to testing was "don't get tested," in relation to HIV was "don't ask, don't tell." You know, don't – so don't ask anyone's HIV status and don't tell your HIV status 'cause ACON was run by lawyers and you'd get in trouble. So of course I told someone that I was HIV-positive who was on the committee, and he said: "oh you're not meant to tell me that!" I thought, "gee, this is just – this is just completely balked! Here it is, there are thousands of gay men getting tested […] and all ACON was saying was don't ask and don't tell, don't talk about it!" [Laughs] Yeah that really worked well! [Laughs][21]

ACON evidently attempted to protect people from prejudice and the legal ramifications of having HIV by both discouraging testing and by implementing the mantra: "don't ask, don't tell." For Ross, however, this stance further marginalised those living with the virus as it rendered HIV as something they were prohibited from discussing. Another interviewee, Mark Tietjen, described receiving a similar response when he disclosed his HIV-positive status to a close friend who was a lawyer: "he said 'oh, don't tell anyone! Don't tell anyone!' And I'm sort of like 'why?' You know, 'you're my friends, I'm trying to tell you.'"[22] The responses these men received when they attempted to confide in their friends reveal how the tense social climate silenced any discussions about living with HIV or AIDS, even within their intimate circles.

Compulsory notification legislation had an undeniable impact on HIV-positive individuals' attempts to establish support networks. Yet emphasising this law change also enabled Ross to deflect any suggestion that other members of ACON might have been reluctant to talk about HIV. He elaborated: "some of the early New South Wales government stuff was shocking! And some of the people that worked for the New South Wales government – gosh they were awful."[23] It was not only Wran's role in introducing compulsory notification legislation that outraged activists, but he had also made controversial comments about people with HIV or AIDS. In 1985, he reportedly stated that doctors who treated patients with HIV suffered from Stockholm Syndrome, a condition where hostages sympathise with their captors.[24] In this regard, the "government as villain" narrative that permeated international histories of HIV and AIDS helped Ross to recount his feelings of isolation without disturbing his shared memory that the gay community mobilised and solidified with the onset of the epidemic.[25]

Together, narrators' personal testimonies complicate histories that predominantly centre on those who resisted stigma by publicly identifying as people with HIV or AIDS. They revealed that some men were forced to conceal their HIV-positive status from their friends, the same people who would be expected to form the support networks on which they could rely. They were not only silenced by fear of backlash, but also by policies that aimed to protect them from the social and legal ramifications of being identified as someone living with the stigmatised virus. Such attempts to shelter these individuals from discrimination instead further ingrained their isolation and marginalisation. Considering these circumstances, activists' distinct efforts to alleviate the silence that suppressed discussions about HIV and AIDS are even more significant.

Australia's Third National AIDS Conference, August 1988

Australia's Third National AIDS Conference marks a distinct turning point in the emerging visibility of gay men with HIV and AIDS. As I have mentioned, conference delegates challenged oppression by publicly disclosing their positive status. Their actions led to the establishment of the National People Living With AIDS Coalition, and the periodical *Talkabout: Newsletter of People Living with AIDS (N.S.W.)* in 1989.[26]

It also inspired the establishment of the first Living Well conference organised solely by and for people with the virus and their supporters, which reportedly attracted over two hundred delegates.[27] The conference theme, "Listen to Us, Not Talk About Us" encapsulated activists' collective efforts to shift the focus back to the voices of people living with HIV or AIDS and to ensure policymakers were attuned to the medical urgency that the epidemic generated. Indeed, the *Sydney Star Observer* reported that public disclosure at the National AIDS Conference reflected individuals' frustrations with the public health system and their dissatisfaction with the limited representation of antibody positive people on AIDS Councils.[28] Some also felt the decision to host the conference in Hobart reflected the organisers' attempts to exclude people with HIV and AIDS who might not be well enough to endure a bitter Tasmanian winter.[29]

Individuals' decisions to publicly disclose their positive status are located in broader international shifts towards the increasing visibility of people with HIV and AIDS that had been underway in America since the early-1980s. Scholars trace the official beginning of the People with HIV/AIDS (PWA) movement in America to the Second National AIDS Forum in Denver in 1983.[30] The Denver Principles, established at this forum, focused on increasing the visibility of people living with the virus.[31] They condemned the use of the passive term "victim" and urged people to become actively involved in HIV and AIDS forums and organisations. The American PWA movement gained momentum across the 1980s. Activists formed a National Association of People with AIDS and marched with the familiar "Fighting for our Lives" banner at several public parades. These included the first National AIDS Vigil in 1983 and the 1984 Gay Freedom Day Parade, both held in San Francisco. Further, since its inception in 1987, the various international chapters of the vocal activist group AIDS Coalition To Unleash Power (ACT UP), some of whom were living with HIV or AIDS, aroused considerable publicity by staging controversial demonstrations. The PWA movement in America provided a model for Australia's PWA movement that developed at the end of the decade.[32]

The events that unfolded at Australia's Third National AIDS Conference were also influenced by the International AIDS Conference in Stockholm held two months prior. This was the first conference to include a forum that specifically catered to people with the virus. This forum, titled the "Face of AIDS" was renowned as a "revolutionary change."[33] Yet delegates also voiced criticisms about the lack of plenary speakers who publicly identified as antibody positive.[34] On the contrary, Australia's Steering Committee adopted a concessions policy that enabled a considerable contingent of people with HIV and AIDS to attend the Australian conference.[35] It also included plenary sessions and special interest workshops that specifically catered to these attendees. The increasing international visibility of people with HIV and AIDS evidently led to an acknowledgement, and an appreciation of their perspectives.

The public presence of people with HIV or AIDS was apparent from the beginning of Australia's Third National AIDS Conference. An increasing number of delegates reportedly wore badges that read "alive and visible."[36] During the session "Living with AIDS," Michael Callen, co-founder of the PWA movement in America, delivered his seminal "Surviving and Thriving with AIDS" speech.[37] Discussing what he felt was "the best kept secret of the AIDS epidemic," Callen aimed to dismantle the "myth" that everyone with HIV or AIDS dies.[38] Callen openly identified as a person with AIDS, and some attendees suggested that it was his presence and charisma that made others feel confident to "come out" as antibody positive.[39] As I have discussed, during the final plenary session, Professor Peter Karmel invited people living with HIV or AIDS and their families to approach the stage. In doing so, he urged delegates to "show that we are all ordinary people, that you can't distinguish us by our colour, by the way we wear our hair or the cut of our clothes."[40]

The act of inviting individuals onto the stage also reflects broader public developments that helped to create an audience willing to engage with people's personal experiences of living with the virus. From the mid-1980s, the Australian gay press published several HIV-positive individuals' anonymous personal accounts.[41] These accounts provided rare insight into the perspectives of those living with HIV or AIDS and offered advice for others concerned about the virus. Moreover, from January 1988, the *National AIDS Bulletin* started to appeal for contributions for a special edition about "People Living with HIV and AIDS" scheduled for release that December.[42] Sociologist Ken Plummer argues that "Stories come into their time when a community has been fattened up, rendered ripe and willing to hear such stories."[43] While they exist in the private sphere, they lay "dormant" until an audience has been established.[44] The emphasis on publishing individuals' personal stories suggests that such an audience had indeed been established in Australia by the time the Third National AIDS Conference took place.

Ross was one of the people who accepted the invitation to step onto the stage. Ross was a key figure in HIV and AIDS activism across the 1980s and early-1990s. He served on ACON's first elected committee in 1985 and co-organised one of the first public demonstrations to lobby for faster access to antiretroviral medication two years later.[45] As outlined in the opening of this chapter, Ross initially depicted public disclosure as simply a continuation of his activism. This was especially apparent in his assertion that Terry Giblett delivered the final speech and invited people onto the stage. Others have identified either Giblett or Chris Carter as the instigator.[46] Both men were instrumental to the HIV and AIDS movement in Australia. They also featured in the gay press in the months following the conference and openly discussed living with HIV.[47] Yet it was neither of these men, but Professor Peter Karmel, Chair of the Australian National Council on AIDS and the Australian Institute of Health who delivered the final speech. Unlike Giblett and Carter, Professor Karmel was not an activist, nor did he identify as someone living with the virus. The identification of Carter or Giblett as the leader reflects the extent to which this event has been interpreted as an important demonstration of political activism.

Ross' role as an activist also shaped his initial rendition of this event as one where members of ACON promptly walked onto the stage without hesitation. Ross' memories of his involvement in activism occupied the first forty minutes of the ninety-minute interview. He shared fond memories of growing up in Melbourne, attending a high school that was colloquially known as "poofter's paradise," and working as ACON's Education Officer. Ross' recall of publicly disclosing his HIV-positive status at the Third National AIDS Conference in 1988 was part of this broader narrative. Further discussion, however, revealed the gravity of his decision to openly identify as someone with the virus, especially considering many of his friends were in the audience and did not yet know he was HIV-positive. After the first forty minutes of the interview, he concluded:

> So that's a brief sum of my story. Which bits would you like to talk about? [Laughs]
>
> *Interviewer: All of them! [Laughs] So what did you think when he said, 'come onto the stage'?*
>
> [Laughs] What did I think? I was crawling under the seat! [Laughs] Like, "ooh this is" – my first thought was "this is gonna be good"

> [laughs]. I thought no one would go, and it started as two or three, and then two or three more, and then whoosh! And then all of a sudden there's like hundreds on the stage, and it's like "oh my goodness."[48]

This encounter reveals how interviews that explicitly focus on individuals' intimate lives create platforms to tell stories that depart from, and at times challenge dominant historical narratives. This was especially clear when Ross shifted to focus more explicitly on his personal reaction: "What did *I* think?"[49] The disparity between the above discussion and Ross' initial assertion that he and other members of ACON immediately walked onto the stage reveals that this event was significantly more confronting than he initially described. It illustrates the value of oral history to uncover "more complex and unexpected memories."[50] While others have placed the number of activists on the stage as between twenty and sixty, Ross' reflection that hundreds of people stormed the stage emphasises his surprise at witnessing an entire collection of people disclosing their positive status, many for the first time.[51]

Ross' recall of this event also suggests that had his boss not approached the stage, he may have refrained from doing so. This can be surmised from his earlier reflection that he was "crawling under my seat" and assumed no one else would disclose. He continued:

> There were thirty staff at ACON and twelve I think ended up on stage. And none of us knew about each other, we suspected but before then you just didn't talk about having HIV, it was this closely guarded secret. And people from other states that we knew really well as well, and doctors … woah. And we're all looking at each other: "ooh what have we done?" [Laughs] Yeah, it was extraordinary. But, you know that moment when someone gets up and walks. And the boss – the executive director of ACON got up, and I thought "well if he's going, I've gotta go up as well 'cause he's a friend of mine."[52]

In this regard, Ross' decision to publicly disclose his HIV-positive status also reflects a sense of camaraderie. His identification of the moment the first person accepted the invitation to approach the stage signals how the event marked an important turning point in the evolving visibility of people with HIV and AIDS in Australia. Although the conference was a concentrated forum with other people who were or were expected to be compassionate towards people with HIV and AIDS, the gravity of disclosing one's HIV-positive status should not be underestimated. It was this same conference where Liberal MP Wilson Tuckey, member of the Federal Parliamentary Liaison Group on AIDS, outraged his audience by declaring, "AIDS is very much a disease that results from deliberate and possibly unnatural activity. You don't catch AIDS; you let someone give it to you."[53] Outside of the conference, the ramifications of identifying as antibody positive were particularly severe. Historian Paul Sendziuk argues that in 1988, "disclosure entailed the possibility of abandonment by one's lover, friends or family and, in the longer term, discrimination and ostracisation by workmates and employers, co-tenants and landlords."[54]

Revisiting Australia's Third National AIDS Conference through the voice of one man who accepted the invitation to publicly identify as HIV-positive provides rare and valuable insight into individuals' complex and highly personal motivations for public disclosure. Ross drew on dominant histories that depict this event as a particularly explicit illustration of HIV and AIDS activism to articulate his memories of what was a difficult yet spontaneous decision. By coming out as HIV-positive, Ross and others appear to have fulfilled Karmel's aim to reduce stigma by demonstrating that they were "ordinary people." Their willingness to come out facilitated more open discussions about living with HIV or AIDS. It created a model for other HIV-positive gay men to discuss living with the virus in various public forums in subsequent years.

Public Disclosure in the 1990s

The 1990s witnessed a proliferation of avenues through which gay men with HIV or AIDS continued to share their distinct personal experiences of living with the virus. Televised current affairs programmes and the gay and mainstream printed press provided particular insight into the perspectives of those who had been diagnosed with HIV or AIDS. HIV-positive gay men's memoirs also started to emerge in the 1990s. These included Eric Michaels' *Unbecoming: An AIDS Diary* (1990) that was published two years after his death, John Foster's memoir *Take Me to Paris, Johnny* (1993), and *Holding the Man* (1995) written by Australian playwright Timothy Conigrave. In 1994, the National Association of People with HIV Australia launched the Positive Speakers' Bureau.[55] This organisation provided a platform for people to share their stories, "putting a human face onto a condition that most people understood only through media stereotypes, and hopefully helping reduce prejudice against people with HIV."[56]

Lloyd Grosse was particularly ready to appear in the media as the "face of HIV." Lloyd is one of the few men I interviewed who grew up in Sydney. He attended a school in southern Sydney that was "a harbour for gay and lesbian teachers" and received a lot of support from his family, peers, and teachers when he came out as gay at the age of sixteen. He describes his school years as "diametrically opposed to a lot of my friends who had tough, tough times." Lloyd was heavily involved in HIV and AIDS activism from the early-1980s. In addition to his work with the Albion Street Hotline, the Bobby Goldsmith Foundation, and ACON, he explained that he was the first person to publicly identify as HIV-positive when he featured on an anti-discrimination poster.[57] Lloyd cited altruistic motivations, and recalled "my attitude to HIV was, you know, 'who knew when we were all gonna die?' And so my attitude was 'do the absolute best we could.'"[58] He also reflected on his distinct role in ensuring policymakers were attuned to the urgency of the epidemic:

> Not only did I have to know what hat I was wearing, but I sometimes had to change spots, I had to … If I'm sitting in the Ministerial Advisory Committee on AIDS Strategy and people started talking about *them*: "*they* had to do – *they'll* have to this," and then I'd have to say, "hang on, a person with AIDS here!" [Laughs] Or you'd get to the [Therapeutic Goods Administration] discussions with Peter Bowman and they'd all be talking about you know, "oh well, a couple of weeks' delay in getting approval for a drug isn't gonna be that bad because it's only a couple of weeks." And I'd have to say, "in that week I could die." […] You'd go, "hang on! You're talking about my life here." And so it was that moment where you'd have to change spots and bring reality into the consciousness of people who were making these decisions. And that was why we were so powerful at doing what we did because we weren't ashamed or afraid of going "hang on people! You're talking about me here, [laughs] and you can't talk to me about me in that way! You can't just write that off. A week is important; a week could save a life."[59]

Lloyd's memories of being a member of a group that established an uninhibited response to the epidemic highlight a distinction between the fearless radical activism in which he was involved, and members of what he termed the AIDSocracy. The AIDSocracy comprised activists whom he felt were primarily concerned with furthering their political positions within HIV and AIDS organisations and "washed everything with beige" to avoid losing government funding.

Jamie Richards was also among those who publicly identified as HIV-positive during this period. Jamie shared fond memories of being embraced by other members of Sydney's gay community across the late-1980s and 1990s. He recalled sharing a close friendship with the well-known Australian playwright Timothy Conigrave and his partner John Caleo, and proudly informed me that he was famous for getting arrested at public protests against Reverend Fred Nile, the NSW politician and church minister who led several public demonstrations against the Sydney Gay and Lesbian Mardi Gras. Jamie's emphasis on being embraced by the gay community and being involved in political demonstrations may have helped him to deal with his present frustration at feeling excluded from HIV and AIDS organisations at his new home in Tasmania. He explained that despite his efforts to make contact, he does not receive any support from these organisations who "don't want to talk to me." He perhaps sought comfort in the knowledge that he had previously been of value to others affected by the virus. Jamie's memories of being part of Sydney's gay community also posed a direct contrast to his memories of growing up in a violent household. At the time of the interview, he had not been in touch with either of his parents since they discovered he was gay in 1989. That year, he left home and stayed in Twenty-Ten, a refuge for young gay men and lesbians.[60]

Jamie featured in two current affairs programmes after he was diagnosed with HIV in Sydney in 1989 at the age of 18. These included a special edition of the ABC documentary *Guess Who's Coming to Dinner*, which was televised on World AIDS Day in 1993. He also appeared on the *Today Show* after he received what he described as a lifesaving bone marrow transplant. In response to my question about his motivation to identify as an HIV-positive person, Jamie indicated that his decision to participate in these episodes was simply a continuation of his activism:

> I don't know I just did it, just did it. Because I was already public, like I was already a nuisance at demonstrations and rallies and things. It was: "oh, here comes Jamie, [laughs] he's gonna get arrested!" And I was quite famous for that, "uh oh! [Laughs] Here comes Jamie!"[61]

Jamie's repetition that he "just did it" suggests that he was nonchalant about appearing in the media. Further discussion, however, revealed that his decision to make his HIV-positive status public was closely based on his determination to defy his parents. Jamie was hospitalised in the early-1990s, at which point his health had deteriorated considerably:

> [The doctor] actually got to that point when he rang my parents and said that I wasn't gonna pull through. And my dad turned around and said, "I don't give a fucking shit, throw him in a bag and throw him in the river for all we care" and hung up on him. And [the doctor] came back and – he was in tears – he said: "I have never, ever, ever, ever heard that!" He said, "the way your parents went on." And I – and I just said: "you know, that gives me the strength just to pull through just to piss them off." So I often have a saying: "I'm not surviving; I'm just hanging around just to piss you off."[62]

Jamie's determination to retaliate against his parents was particularly pronounced when he recounted his decision to appear on the *Today Show*. He explained: "all my relatives [laughs] and everybody saw it! See, they didn't know, that like, they just didn't know that I was positive […] I just knew that my parents weren't happy about it at all." Jamie's delight that his relatives saw the documentary demonstrates how appearing publicly as someone with HIV enabled him to defy his parents. He was conscious of the stigma attached to the virus and the way his parents would be implicated by his decision to come out as HIV-positive. Moreover, while his parents expected him to die, featuring in the documentary provided him with the avenue through which he could challenge their image of him as sick and dying. Appearing in the media also had severe personal ramifications. Jamie explained that he was forced to leave his home in Bondi Junction shortly after the documentary aired as he received anonymous threats and had a Molotov cocktail thrown through his window. Nevertheless, his light-hearted laughter suggests that he felt his sacrifice was worthwhile.

By appearing on such public forums, men like Lloyd and Jamie challenged the stigma attached to HIV and AIDS and presented a personal side to the epidemic. It is also important to consider that their appearances in the media were part of a broader shift towards focusing on HIV survivors that had been underway since the late-1980s. Neither of these men displayed any visible physical symptoms of HIV or AIDS-related conditions. They presented a face of HIV that appeared to be unaffected by the virus. In doing so, they resisted the perceived trajectory from diagnosis to an inevitable and painful death and rather asserted that they were *living* with HIV. Public representations of "HIV survivors" contested depictions of "guilty victims" or dying patients that prevailed in the international and Australian mainstream press in the early-to-mid 1980s.[63] They presented the message that it was possible to live, and to live well after receiving a positive diagnosis. In doing so, the stories of survivors served as "proof that it is possible to live a long time with HIV."[64] As the following chapter outlines, however, such public representations do not account for the voices of those whose health had declined and who internalised ideas that they would die as a result of HIV or AIDS.

Narrators' memories of public disclosure complicate histories of HIV and AIDS. They reveal that the movement towards individuals being able to publicly disclose their positive status was considerably more gradual and complex than existing discussions suggest. Indeed, publicised cases of HIV-related backlash, combined with compulsory notification legislation meant that many of the men in this study felt compelled to conceal their HIV-positive status throughout most of the 1980s. This silence even extended to some of those who were involved in HIV and AIDS organisations. Yet, the willingness of members of ACON to disclose their positive status in 1988 when they were explicitly asked suggests it was a conversation they wanted to have. While most narrators initially described their decisions to disclose as a continuation of their activism, their distinct personal motivations emerged as the interviews progressed. These ranged from a sense of community solidarity with other HIV-positive gay men to a determination to seek revenge against abusive family members. For some, the ramifications of publicly identifying as a gay man with a highly stigmatised illness were severe. It led to alienation and public abuse. Nevertheless, the majority of interviewees reflected on this period with nostalgia. The epidemic decimated their support networks, and some men feel excluded from current HIV and AIDS organisations. They appeared to have composed memories of this period which help them achieve pride in the knowledge that they were members of a distinct group that provided a proactive and uninhibited response to the epidemic.

NOTES

1. Ross Duffin, interview with the author, 16 July 2014, Sydney.
2. Scott Martin (pseudonym), interview with the author, 17 July 2014, Sydney.

3. Ibid.
4. Garry Wotherspoon, *Gay Sydney: A History* (Sydney, NSW: NewSouth Publishing, 2016), 225; Peter McCarthy, “The Community Support Network,” *Sydney Star Observer*, June 14, 1985, 14.
5. Sydney AIDS Study Group, “The Sydney AIDS Project,” *Medical Journal of Australia* 141, no. 7 (1984): 571.
6. Brett Tindall, David Cooper, and Julian Gold, “The Saint Vincent’s Study by the Organisers,” *Sydney Star Observer*, March 20, 1985.
7. David Polson, interview with the author, 18 June 2014, Sydney.
8. Ibid.
9. Ibid.
10. Ibid. Italics indicate emphasis in David’s voice.
11. “Australian Diary,” Australian, August 29, 1983, 7; Lex Watson, “Quarantine Possible Under NSW AIDS Laws,” *Sydney Star Observer*, December 1985, 17. In the late-1980s and 1990s surveys found that some members of the Australian public continued to support quarantine measures: Justice Michael Kirby, “AIDS—The Quarantine Option—Occam’s Razor.” Australian Broadcasting Commission. 1991. Speech.
12. Bob Hay, “The Research Project,” *Sydney Star Observer*, February 7, 1985, 2.
13. “Don’t Tell, Says ADB,” *Sydney Star Observer*, August 9, 1985, 7.
14. Ibid.
15. HIV and AIDS were already notifiable diseases in South Australia, Tasmania, Queensland and Victoria.
16. Crimes (Amendment) Act, no. 7, New South Wales (1984): 2–8.
17. “A HIV/AIDS Timeline Emphasising the Australian/New South Wales Perspective,” The Albion Centre, available from http://www.acon.org.au/wp-content/uploads/2015/04/History_of_HIV_5th-Edition.pdf.
18. Adam Carr, “What Now for the Antibody Test?” *Sydney Star Observer*, September 6, 1985, 20.
19. John Wishart, “Wran Faces Dilemma as Opposition to AIDS Law Grows,” *Sydney Star Observer*, September 6, 1985, 1.
20. Ibid.
21. Ross Duffin, interview with the author, 16 July 2014, Sydney.
22. Mark Tietjen, interview with the author, 27 August 2014, Sydney.
23. Ibid.
24. Larry Galbraith, “Wran’s Jackboot Legislation,” *Campaign*, November 1985, 8–9.
25. Virginia Berridge traces the “government as villain” narrative: Virginia Berridge, “AIDS and Patient-Support Groups,” in *Medicine in the Twentieth Century*, eds. Roger Cooter and John Pickstone (Amsterdam: Overseas Publishers Association, 2000), 687.

26. This later became the National Association of People Living with HIV and AIDS.
27. The first Living Well conference was held in Melbourne three weeks later. Paul Young, "200 Attend PWA Conference," *Sydney Star Observer*, September 2, 1988, 3; "'Living Well': A Conference for People with AIDS," *AFAO National AIDS Bulletin*, September 1988, 53.
28. Terrence Anderson, "The Hobart Conference," *Sydney Star Observer*, August 19, 1988, 6.
29. Ibid.
30. For a history of the PWA movement in America, see Michael Callen and Dan Turner, "A History of the PWA Self-Empowerment Movement," in *Surviving and Thriving with AIDS: Collected Wisdom*, ed. Michael Callen, Second (New York: PWA Coalition, 1987), 288–95; James Gillett, *A Grassroots History of the HIV/AIDS Epidemic in North America* (Washington: Marquette Books LLC, 2011), 27.
31. Callen and Turner, "A History of the PWA Self-Empowerment Movement," 288–95; Gillett, *A Grassroots History of the HIV/AIDS Epidemic in North America*, 27.
32. For a history of Australia's PWA movement, later known as the People Living with HIV/AIDS (PLWHA) movement, see Ariss, *Against Death: The Practice of Living with AIDS*, 135–52; Mark Counter, "A History of the People Living with HIV/AIDS (PLWHA) Movement in Australia," *Social Alternatives* 15, no. 4 (1996): 25–7; Jennifer Power, *Movement, Knowledge, Emotion: Gay Activism and HIV/AIDS in Australia* (Canberra: ANU E Press, 2011), 131–5; Paul Sendziuk, *Learning to Trust: Australian Responses to AIDS* (Sydney: University of New South Wales Press Ltd., 2003), 198–202.
33. "A History of the International AIDS Conferences," International AIDS Society, available from https://www.iasociety.org/Web/WebContent/File/WAD2011/History%20of%20the%20IAC_final.pdf.
34. Justice Michael Kirby, "Aids—Insights from the Stockholm Conference." Third Australian National Conference on Aids Hobart, Tasmania. August 6, 1988. Speech.
35. "Special Highlights of the Third National Conference," *AFAO National AIDS Bulletin*, September 1988, 42.
36. Sendziuk, *Learning to Trust*, 199.
37. Michael Callen, "Surviving and Thriving with AIDS," in *Report of the Third National Conference on AIDS* (Canberra: Australian Government Publishing Service, 1988), 662–70; "Special Highlights of the Third National Conference," *AFAO National AIDS Bulletin*.
38. Callen, "Surviving and Thriving with AIDS," 662.

39. Stephen Edwards, "Michael Callen: Lessons in Hope," *Sydney Star Observer*, August 19, 1988, 7.
40. Peter Karmel, "Concluding Remarks," in *Report of the Third National Conference on AIDS* (Canberra: Australian Government Publishing Service, 1988), 785.
41. Cheryl Ware, "'Time to Speak Out': The 1980s Australian Gay Press and Personal Accounts of Living with HIV," *Journal of Australian Studies* 41, no. 4 (2017): 472–86.
42. The *National AIDS Bulletin* was a monthly magazine established by the Australian Federation of AIDS Organisations Inc. in September 1987.
43. Ken Plummer, *Telling Sexual Stories: Power, Change and Social Worlds* (London: Routledge, 1995), 121.
44. Ibid., 120–1.
45. Ross' involvement in public demonstrations to gain further access to AZT is further explored in Chapter 6.
46. Sendziuk, *Learning to Trust*, 200.
47. Chris Carter, "Living with AIDS: A Personal Account," *Campaign*, December 1988, 80–1; Terry Giblett, "Antibody Positive? Build a Bridge!" *Sydney Star Observer*, April 21, 1989, 20.
48. Ross Duffin, interview with the author.
49. Ibid. My italics.
50. Alistair Thomson, "Memory and Remembering in Oral History," in *The Oxford Handbook of Oral History*, ed. Donald A. Ritchie (New York: Oxford University Press, 2011), 88.
51. Shirleene Robinson, "Activism Revisited," National Association of People with HIV Australia, available from http://napwha.org.au/about-us/poz-action/activism-revisited.
52. Ross Duffin, interview with the author.
53. "The Politics of AIDS: Wilson Tuckey's Address," *AFAO National AIDS Bulletin*, September 1988, 45–6.
54. Sendziuk, *Learning to Trust*, 200.
55. This was formerly the National People Living with AIDS Coalition.
56. Garry Wotherspoon, *Making a Difference: A History of Positive Life NSW* (Sydney: Positive Life NSW, 2009), 18.
57. Lloyd Grosse, interview with the author, 27 August 2014, Sydney; Abigail Groves, "A Time to Be Loud and Furious: AIDS Activism in Australia," *HIV Australia* 12, no. 2 (2014): 17–18. Lloyd also featured in a televised episode of *Couchman Over Australia:* "Living with AIDS." *Couchman Over Australia*. ABC, 1991. Television.
58. Lloyd Grosse, interview with the author.
59. Ibid. Italics indicate emphasis in Lloyd's voice.

60. Twenty-Ten was established in late 1981. For a history of Twenty-Ten, see Garry Bennett, *Young & Gay: A Study of Gay Youth in Sydney* (Sydney: Twenty-Ten, 1983); Gemma Edgar, *What Does It Mean to Engage with the State? A Comparative Case Study of Two Non-government Organisations Working with Marginalised Young People* (Ph.D. Thesis, University of New South Wales, 2009), 151.
61. Jamie Richards, interview with the author, 2 September 2014, Tasmania.
62. Ibid.
63. Deborah Lupton, "Archetypes of Infection: People with HIV/AIDS in the Australian Press in the Mid-1990s," *Sociology of Health and Illness* 21, no. 1 (1999): 37–53.
64. Ibid., 44.

CHAPTER 4

“The Disease of a Thousand Rehearsals”

In 1984, Franc Hancock became one of the first people to be diagnosed, with HIV in Australia. His housemate Eddy was diagnosed with HIV three days later. While Franc survived his illness and became one of the twenty-five people I interviewed for this study, Eddy’s health rapidly declined. He developed Kaposi’s sarcoma and was dead within nine months. Franc shared vivid memories of witnessing Eddy succumb to his illness: “Eddy looked like a leopard [laughs]. I bought him a pair of leopard skin speedos [laughs].” Both men shared “a very twisted sense of humour,” and Eddy “used to parade them around the flat, [laughs] often when I had guests! [Laughs] He said, ‘Franc bought these for me, what do you think?’ People would be horrified! [Laughs] They wouldn’t know what to say!” The humour of the leopard print speedos not only helped these men to cope with the pain of witnessing Eddy’s health deteriorate but also to deflect the fear of the virus that was ravaging their community. Eddy’s death in 1985, however, “brought it a lot closer to home for me, even though friends were dying everywhere.” Franc’s concerns about succumbing to the virus surfaced. He explained, “I don’t know if I felt frightened, I sort of had the feeling that sooner or later I was going to start showing the symptoms of whatever was going to kill me.”[1]

Franc’s concerns about “showing the symptoms” resonated with several of the other men in this study. Narrators also endured a combination of fatigue, severe night sweats, nausea, diarrhoea, and peripheral neuropathy, or nerve damage. Yet it was the visible symptoms, namely

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0_4

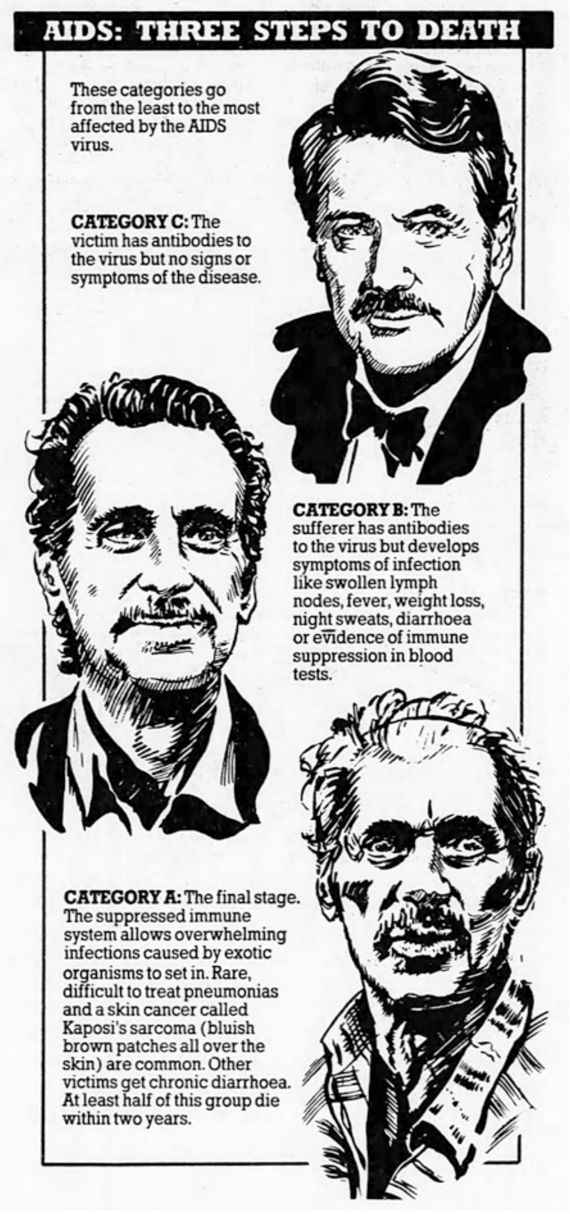
Wasting Syndrome and Kaposi's sarcoma, which caused the most alarm. Exhibiting visible symptoms not only exposed one to the ostracism that surrounded HIV and AIDS but for many, they signalled that one had entered the "final stage" before death. This chapter explores such concerns by drawing on interviews with Stephen Allkins, Wayne Oldrey, Brian Mitchell, Victor Day, Jamie Richards, and Mark Tietjen. It considers the strategies narrators employed to prolong their lives and some men's decisions to euthanise to avoid having to endure the final stage of AIDS. At times, narrators struggled to both remember and articulate their standpoints at a time when they believed they would die. The interviews created an important yet somewhat rare forum to consider and convey the emotional trauma they faced at a time when HIV was deemed a terminal condition. Such discussions about illness and death perhaps aroused memories that remain emotionally challenging. This discomfort can also, at least in part, be attributed to public representations of HIV survivors that prevailed from the late-1980s. Narrators portrayed themselves persevering in the face of a virus that threatened their lives.

The Tell-Tale Signs of AIDS

Before the introduction of antiretroviral medications in the late-1980s and early-1990s, Wasting Syndrome and Kaposi's sarcoma were two of the most common and identifiable HIV and AIDS-related conditions.[2] Wasting Syndrome was characterised by rapid and severe weight loss, while Kaposi's sarcoma manifested in elevated purple patches on an individual's skin. It is these illnesses that interviewees recalled comprised "the look." Many of those who lived through the epidemic have vivid memories of seeing countless young men succumb to such afflictions. They attested that those they termed the "cadavers in the street" or "the walking dead" served as constant reminders of the severity of the virus. Deaths from HIV and AIDS-related conditions were not only highly visible but also drawn out. Many people were in and out of hospital as their health depleted, improved, and declined again. This process led Australian-based academic Eric Michaels, who died from AIDS-related conditions in 1988, to conclude: "you don't die, at least right away. This is AIDS, the disease of a thousand rehearsals."[3]

Some of the men in this study described feeling optimistic about their prospects of survival from the outset. For many others, the uncertainty and unpredictability of the virus meant that an HIV-positive diagnosis triggered an immediate change in how they perceived their bodies. They became conscious that their health might rapidly and irreversibly deteriorate without warning. Victor Day attested to a persistent fear that he would develop pneumocystis carinii pneumonia (PCP), one of the leading causes of death among people with HIV in the 1980s.[4] He explained: “back in the old days, if I’d get like a cough there’d be this concern, ‘ooh I wonder if this’ll turn into PCP or pneumonia.’ You know, ‘will I ever get out of bed again?’”[5] Such concerns are understandable. Across the mid-1980s, the Australian mainstream press almost exclusively focused on men whose bodies had already succumbed to a host of illnesses and opportunistic infections. These reports, like many other public portrayals of people with HIV or AIDS in the 1980s, depicted death as an inevitability for people with the virus. One of the most controversial reports appeared in the *Sydney Morning Herald* in October 1985. The accompanying illustration, which traced “Three Steps To Death,” (Fig. 4.1) appears to be of the American film star Rock Hudson who had died from AIDS-related complications earlier that month at the age of fifty-nine. Hudson’s physical decline and subsequent death aroused heavy media coverage around the world. The third step of the illustration was particularly confronting. It warned readers that individuals whose health had declined to that point would succumb to “overwhelming infections” and prophesied that at least half of those who progressed to the third stage would die within two years. While it was common to identify illnesses in terms of stages, the apparent inevitability of death as presented in the article understandably outraged members of Sydney’s gay community. The editors of *Campaign*, the Sydney-based national magazine, reprinted the image the following month. It condemned such illustrations as “indicative of the kind of drawings in 1940s medical books purporting to show the ill effects of masturbation.”[6]

Although *Campaign* firmly denounced the article, many doctors, gay community leaders, and others living with the virus believed that an HIV-positive diagnosis was essentially a death sentence. In 1985, Reverend Jim Dykes, the pastor at Sydney’s inclusive Metropolitan Community Church reportedly proposed establishing a counselling service in Sydney to help people come to terms with their impending deaths.[7] Death was a particular concern once someone exhibited physical symptoms. Wayne Oldrey attested that “once you saw someone with [Kaposi’s sarcoma], and they were horrible looking lesions, you know. You’d see someone with them and you’d go ‘oh he hasn’t got long.’”[8]



AIDS: THREE STEPS TO DEATH

These categories go from the least to the most affected by the AIDS virus.

CATEGORY C: The victim has antibodies to the virus but no signs or symptoms of the disease.

CATEGORY B: The sufferer has antibodies to the virus but develops symptoms of infection like swollen lymph nodes, fever, weight loss, night sweats, diarrhoea or evidence of immune suppression in blood tests.

CATEGORY A: The final stage. The suppressed immune system allows overwhelming infections caused by exotic organisms to set in. Rare, difficult to treat pneumonias and a skin cancer called Kaposi's sarcoma (bluish brown patches all over the skin) are common. Other victims get chronic diarrhoea. At least half of this group die within two years.

Fig. 4.1 "Life and Death in the AIDS Age," *Sydney Morning Herald*, October 19, 1985, 9

Stephen Allkins concurred, "in those days if you got sick you died. There was no way back."[9]

Disclose or Disappear

As we saw in the previous chapter, the stigma attached to the virus meant many narrators felt compelled to conceal their positive status from family members, friends, employers, and the wider public. At times, this silence extended to other gay men. Yet the visibility of HIV and AIDS-related conditions meant that discretion was not always possible. This was especially the case in inner city Sydney, where many gay men were attuned to what the physical symptoms of HIV or AIDS-related conditions entailed. Visible symptoms threatened the unity of the gay community. Many men isolated themselves once they began to exhibit the "tell-tale" signs of AIDS, while others faced ostracism and alienation.

The ways in which anxieties about displaying visible symptoms threatened some men's social networks was most apparent in Stephen Allkins' account. Stephen grew up in the outer-western suburbs of Sydney. He visited his first gay nightclub in 1976 at the age of fifteen and likened the experience to "coming home." He moved into a terrace house with two other gay men in Darlinghurst two years later and worked as a DJ at various gay nightclubs across the following four decades. He attested that the "power of music" which has been "a nurturing, uplifting, positive force in my daily life since I was born" saved him from thinking that he would die after he was diagnosed with HIV in 1988. For the first twenty minutes of the two and a half hour interview, Stephen shared particularly fond memories of Sydney's gay community across the late-1970s and early-1980s. He described this as a "perfect" time in Sydney, and "for these five or six years everybody loved us! And then AIDS hit."[10] Stephen's final assessment "and then AIDS hit" indicates how the epidemic marked a devastating shift in the vibrant gay community in which he was intimately involved.

Witnessing friends physically deteriorate was a key motif in Stephen's life story. After a short break, he immediately stated: "so I'll tell you about the first person I ever saw with AIDS." He then recounted a time he visited a friend who was staying in a hospice in Homebush, a suburb fifteen kilometres west of Darlinghurst. Stephen expressed his shock at seeing his friend, a twenty-five-year-old fellow DJ who "looked eighty […] I didn't know it was him for a second." He continued,

> And it was so early that they didn't have anywhere for people to go. And a hospice in Homebush was so not us! People were going home to families who didn't understand or want to take care of them. It was really full on.[11]

The lack of adequate services to provide the necessary full-time care for people afflicted by the virus meant that retreating to a hospice in "the middle of straight suburbia" was a final resort in a desperate situation. From the early-1980s, Sydney started to host a range of medical services that specialised in HIV and AIDS-related care. One of the most significant developments was the establishment of Ward Seventeen at St Vincent's Hospital in Darlinghurst in 1984. This became Australia's first hospital ward dedicated to HIV and AIDS. Activists established community-based organisations including the Bobby Goldsmith Foundation and the Community Support Network that same year. These groups offered essential financial and emotional support for people with HIV and AIDS.

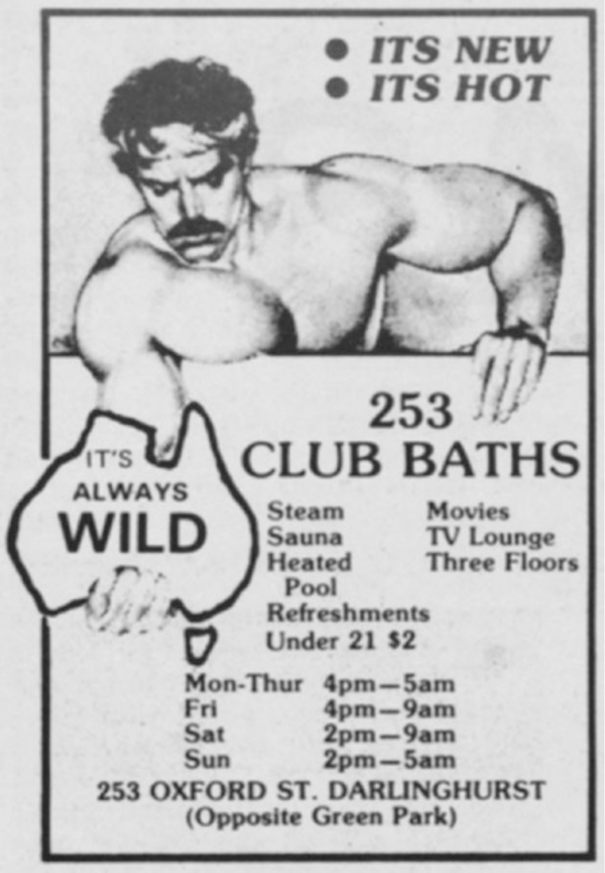
Stephen lost his entire peer group between 1984 and 1989. His grief was compounded when he felt some of his friendships dissolve once friends' health had severely declined, they displayed visible symptoms, and they lost control over their bodies in a matter of weeks. These were all "strong and successful men" in their twenties, thirties, and forties who were "too full of life to die." Stephen recalled one particular instance when he tried to visit a friend whom he had heard was unwell:

> I kept being fobbed off and I kept thinking, "that's funny." Because people were disconnecting with each other just through their own grief and fear. There was a lot of joining together, but I think once people got sick they just didn't want anybody to see them 'cause we're all so – and I don't mean this in a bad way – but vain. You're sick, and when you get sick, that's it. You're not getting better, and so you shut down, and you know, you get taken care of.[12]

Stephen's recall of being "fobbed off" was a recurring theme throughout the interview. He offered detailed accounts of six close friends, all of whom he had witnessed rapidly deteriorate in the 1980s, before they succumbed to their illnesses. In addition to friends feeling ashamed about displaying visible symptoms and not wanting to be seen, he also cited AIDS-related dementia, one of the many neurological conditions associated with HIV and AIDS as a reason for drastic behaviour changes. Nevertheless, these memories continued to be painful three decades later as "I never got to say goodbye."

Steven Berveling also observed that some gay men appeared to be ashamed of displaying visible symptoms. He noted, "obviously, friends of mine were finding out they had HIV. But in those days, they wouldn't say until it became *blindingly obvious*."[13] The physical effects of HIV marked a clear departure from constructions of gay male masculinity that developed the previous decade. This was embodied by the emergence of "clonism" across international and Australian gay male communities. Physical characteristics of the clone included facial hair, tight-fitting clothing, and—most importantly—a muscular physique.[14] The emphasis on the clone's muscular body challenged existing public representations of gay men as effeminate. Clonism emerged during what Australian sociologist Peter Robinson identifies as the "gay period" from the early-1970s to the mid-1980s. During this time, gay men "rejected prevailing public narratives of the homosexual as effeminate and weak and instead developed their own image of the gay man as masculine in manner and appearance."[15] While clonism marginalised gay men who did not, or could not fit this stereotype, many gay men perceived clonism as an ideal.[16] Michael Glynn, the founder of the *Sydney Star Observer*, justified the gay press' emphasis on clonism by stating that it reflected Sydney's gay male market at that time.[17] Advertisements for saunas, many of which featured illustrations of men with bulging biceps, featured in the gay press across the 1980s and 1990s (Figs. 4.2 and 4.3). They are a testament to the gay male community's widespread adoption of clonism.

Not all men, however, felt that concealing their visible symptoms was an appropriate strategy. On September 6, 1988, activist Paul Young, a leader in the people with AIDS (PWA) self-empowerment movement, urged attendees at ACON's annual general meeting to create new approaches to education that featured "realistic images of people with AIDS."[18] He contested existing public health campaigns that featured images of "beautiful-young-men."[19] Such campaigns emerged across the late-1980s and 1990s and recast public representations of HIV and AIDS to emphasise health rather than sickness.[20] Nevertheless, Young proposed "what about a poster with the message KS is beautiful?"[21] Activist and anthropologist Robert Ariss argues that the audience at ACON expressed their agreement with a short applause.[22] Yet such a campaign does not appear to have eventuated. The underlying message that centred on combatting discrimination resonated with others' decisions to publicly disclose their HIV-positive status. Changing public attitudes to perceive KS as beautiful was another matter.



253
CLUB BATHS

Steam
Sauna
Heated
Pool
Refreshments
Under 21 $2

Movies
TV Lounge
Three Floors

Mon-Thur	4pm—5am
Fri	4pm—9am
Sat	2pm—9am
Sun	2pm—5am

253 OXFORD ST. DARLINGHURST
(Opposite Green Park)

Fig. 4.2 Advertisement for a sauna on Oxford Street, Darlinghurst

Individuals' concerns about displaying visible symptoms were amplified by the way people with visible symptoms were treated by others. Wayne Oldrey was especially critical of how HIV-positive gay men who exhibited physical symptoms were subjected to discrimination and social alienation. Wayne explained that he rarely socialised with large crowds and preferred to stay with a select group of close friends. He was therefore perhaps in a better position to critique other gay men than those

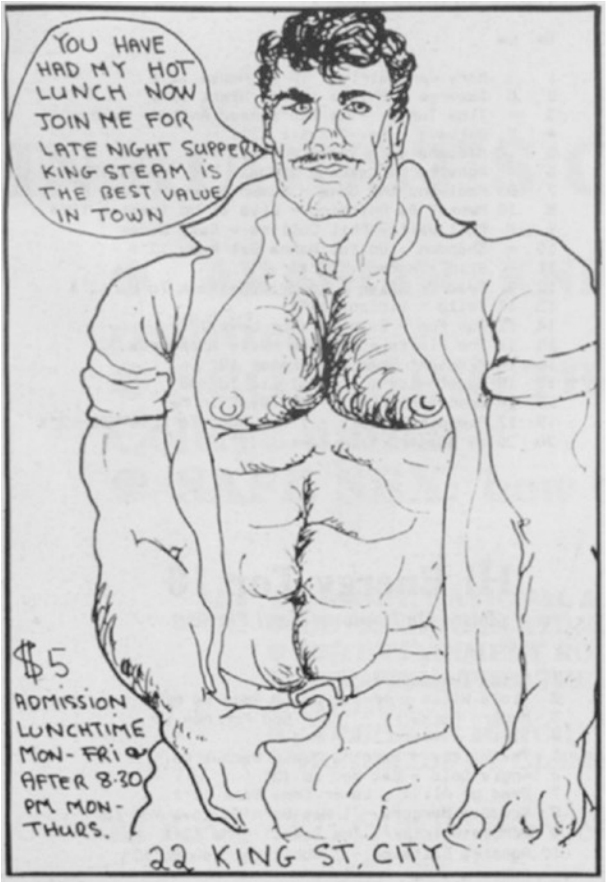


Fig. 4.3 Advertisement for a sauna in inner city Sydney. Advertisements such as this regularly featured in the *Sydney Star Observer*

who took pride in being part of a community that mobilised in the face of the deadly virus. Some have argued that prejudice within the gay community came from a place of fear as people who displayed visible symptoms served as constant reminders of the severity of the epidemic.[23] They also confronted people with their behaviour that may be considered "at risk."[24] Yet such reactions had severe implications for gay men with HIV or AIDS. Wayne asserted that:

> And the sad, the horrible thing is the community – you've just got those few bitchy, nasty individuals and they'd go "ooh, look at him he's got 'the look.'" You go "define what 'the look' is?" "Oh, he's got 'the look' that he's got AIDS," and "don't go near him." And that was one of my fears I guess. I thought "I'm gonna have to live like a hermit then because I don't want anyone to know."[25]

Contrary to Stephen's account, Wayne asserted that the social ramifications of displaying visible physical symptoms meant these men were forced to withdraw from the broader gay community. Such discrimination was not exclusive to gay men. The valuable emotional and practical support that the gay community provided those afflicted by the virus is well acknowledged. Wayne's reasons for citing discrimination within the gay community may have been partly based on his expectation that other gay men would be more empathetic. This was apparent as he consciously shifted from saying "sad" to "horrible." For Wayne, simply stating that it was "sad" did not adequately convey the trauma of witnessing gay men being ostracised by their community. In this regard, visible symptoms of HIV and AIDS-related conditions threatened the unity of Sydney's gay community. Visible symptoms were particularly damaging as they projected HIV-positive gay men's private medical information onto the public arena. At times, they accentuated existing tensions based on physical attractiveness, whereby those who could not adhere to such ideals were sometimes excluded.

Resisting Death

Many of the men who participated in this study internalised ideas that they would die untimely and painful deaths as a result of the virus. Several interviewees, however, recalled that they attempted to delay entering the final stage of the illness by establishing milestones to stay alive to reach. These included Sydney's annual Mardi Gras parade, Christmas Day, or reaching a particular birthday. Although this practice is well acknowledged, few scholars consider why these men established such goals.[26] The interviews revealed that some men set certain targets as part of a broader effort to survive until effective medication became available. This motivation was especially apparent considering many narrators modified each target as they achieved them. It is also important to note that several interviewees appeared to have particular difficulty recalling the extent to which they anticipated death. Their narratives reflect a distinct level of strength and resilience that is perhaps hard to articulate at a time when HIV is no longer considered a terminal condition.

Around the same time that the diagram depicting "Three Steps to Death" appeared in the *Sydney Morning Herald*, the *Sydney Star Observer* started to publish advice for HIV-positive readers to minimise stress in order to potentially reduce the impact the virus had on their bodies. Such discussions were instigated by the return of Peter Todd, a psychologist who had spent eighteen months investigating the psychological aspects of HIV and AIDS at the University of California. Todd was well known in the gay community. He was a regular contributor to the gay press and served as captain of the Australian team at the 1982 Gay Games in San Francisco, where he won a gold medal in men's physique. In July 1984, *Sydney Star Observer* reported, "According to Peter, there is reason to believe that psychological factors may play a role in susceptibility to the disease as well as being important in determining a patient's survival time."[27] Discussions about how one's psychological wellbeing impacted on their ability to survive longer with HIV gained momentum over the following years. In 1987, researchers at California's School of Medicine outlined distinctions between long-term survivors living beyond the average life expectancy of eighteen months and those who succumbed to HIV and AIDS-related conditions sooner.[28] They characterised long-term survivors as assertive individuals who refused to accept their HIV or AIDS diagnosis as a "death sentence."[29] Further, as mentioned in the previous chapter, American activist Michael Callen discussed the possibilities of living with HIV in his seminal "Surviving and Thriving" speech that he delivered at Australia's Third National AIDS Conference in 1988. He questioned, "[h]ow many PWAs obediently fulfilled the gloom and doom prophecy because they weren't lucky enough to know long-term survivors?"[30] Guidebooks and documentaries that encouraged people to feel optimistic about the possibility of surviving with HIV also emerged across the late-1980s and early-1990s. These include Callen's edited collections *Surviving and Thriving with AIDS: Hints for the Newly Diagnosed* (1987) and *Surviving and Thriving with AIDS: Collected Wisdom* (1988), and his renowned monograph *Surviving AIDS* (1990). These publications are a testament to the increasing emphasis on adopting the mindset of a survivor.

Discussions about adopting a positive mindset in an effort to survive continued into the following decade. In 1992, Michael Glynn, founder of the *Sydney Star Observer* published an article simply but aptly titled "Survive!" He proclaimed, "the first step [to surviving] is believing that you can be among those who are beating the odds."[31] He urged readers to "believe that you can be healthy, active, and living a full quality life."[32] Long-term survival was considerably more complex than adopting a positive mindset. Clinical researchers have investigated a number of factors including one's age, mode of transmission, and genetic factors that may impact an individual's survival time.[33] Nevertheless, at a time when effective antiretroviral medication was not yet widely available, a positive outlook was understood as being pivotal to prolonging one's life.

Brian Mitchell was particularly explicit regarding his determination to adopt a positive mindset to extend his chances of survival. Brian was born in Southern Ireland. After living in London and then in New York for several years, he moved to Australia at the age of thirty-five. He was diagnosed with HIV five years later in 1991. Brian maintained that he was optimistic about his prospects of survival from the point of diagnosis. He attributed his optimism to his ability to prevail through an especially traumatic experience in the late-1960s. Brian began a relationship with another young man during his final year of high school. Yet they were forced to end their relationship when their local Catholic priest intervened. Brian subsequently endured severe depression, which he attributed to a combination of guilt and the breakdown of the relationship. Brian's depression developed to the point that he was coerced into visiting a psychiatrist. He was placed in a psychiatric ward and underwent Electroconvulsive therapy. Although this treatment was to cure his depression, some psychiatrists also used Electroconvulsive therapy to "treat" patients for homosexuality in Ireland at that time.[34] Brian asserted that his resilience during this period translated to his response to HIV over two decades later. He maintained that no experience could be as hard as the time he underwent Electroconvulsive therapy, the emotional trauma of which was compounded by the pressure of studying for his final high school examinations:

> I always felt that whatever challenge came up in life I could always meet it because nothing could be quite as bad as those years. And it's more or less turned out that way. And I feel that way of thinking really helped me with

> the whole HIV/AIDS thing when that came along. You know, because way back when I was seventeen or eighteen or whatever it was, having been through all that stuff, whenever I thought about it as I grew older I always thought "well nothing could be as bad as that."[35]

Brian cited this experience as the moment that helped him to maintain a positive mindset after he was diagnosed with HIV over two decades later. For Brian, the onset of HIV and AIDS "was so dire, people were just dropping." He explained "if you were a gay male you didn't live a normal life because you were constantly aware of this dreadful disease that was probably going to affect you or kill you." While Brian believed he seroconverted in the mid-1980s, he refrained from undertaking a test for HIV for several years. He was conscious of the discrimination that people with HIV or AIDS endured and "there was a faction at that stage that said, 'if you're not sick, don't get tested' so you can truthfully say, 'I don't know whether I'm positive or not'." Yet he started to develop skin conditions and, with encouragement from his doctor, undertook a test for HIV in 1991. Although Brian asserted that he did not believe he would die after he received a positive diagnosis, he also set specific targets in an effort to stay alive until treatment became available. He explained:

> People were always talking about … in fact I specifically remember one guy that I knew here in Sydney who was always saying, "just try and hang in there. They're gonna come up with a cure eventually." I mean, I don't know if it's ever been or going to be as simple as that and unfortunately he passed away, but he used to always say that. But I guess in the big scheme of things I've always been a bit of an optimist. I guess I'm a believer in "just try and get through today or this week. And don't try and project out to next year or whatever, you just try and do one day or one week at a time." So, I guess in that sense I've always been a bit of an optimist.[36]

Brian started AZT almost immediately and supplemented the treatment with various alternative therapies his friends had recommended, namely Chinese medicines, bitter melon therapy, and the herbal treatment St. John's-wort. His account reflects a tension between his previous determination to stay alive in the hope for a cure in the 1990s, and his present acknowledgement that a cure for HIV is yet to be developed. He perhaps maintains this stance in his hope that a cure will be developed in his lifetime.

Considering the interviews took place at a time when HIV is considered a chronic manageable condition, several interviewees struggled to both remember, and articulate the concern and uncertainty they felt when they believed their deaths were imminent. This was most apparent in Victor Day's life story. Victor moved to inner city Sydney in the mid-1970s, a period he described as the "heyday of sex and gay." He was diagnosed with HIV ten years later in 1986 at the age of thirty-one. He described watching the annual Sydney Gay and Lesbian Mardi Gras from the roof of the PLWHA building in Oxford Street and stated:

> There was always a thing about "will I be here next year?" And that was always Mardi Gras […] I remember how often I would look and just think "I wonder if I'll be here next year" as a real thing. And of course, that has helped me around appreciating life more. But like you said, remembering this narrative is … heart full. It's very good to remember. I think what's interesting is to tell you that it's a very – I feel emotional – and at the time you can't afford to feel that emotional. You can be thinking it, but you don't go … but now I find myself going like "oh, I remember when I was, when I …" You know, I can remember looking down and wondering, and when I remember that I find a little bit of emotion for whoever I was then that I couldn't have experienced back then because there's too much going on.[37]

Victor's pauses and fragmented sentences reflect the raw emotions that emerged during the interview. While he had previously suppressed his concerns about dying, it was perhaps safer for him to reflect on this event over two decades later at a time when HIV is no longer considered a terminal condition. He was also prompted by the research objectives of this study. This was evident when he directly addressed me: "like you said […] it's very good to remember." This comment was in reference to a conversation that Victor and I had shortly after I arrived at his home, whereby we discussed the importance of engaging with individuals' personal memories. As I will discuss, Victor often suppresses discussions about the impact HIV and AIDS has had on his intimate life in order to uphold the image of the survivor. He perhaps felt he needed encouragement to discuss such intimate memories, and justified his emphasis on his emotions directly citing my research goals. In doing so, Victor not only revealed his acute concerns about dying but also narrated his story to cater to me as his audience.

An oral history interview that explicitly focused on HIV-positive gay men's intimate lives also offered Victor the encouragement to consider the persona of a survivor that he projected in his daily life. The extent to which Victor portrayed himself as a survivor was apparent from the first email he sent me in response to my advertisement. It simply stated that he was "[d]iagnosed in 1986—doing well. Open to participating. Let's talk."[38] From the outset, he portrayed himself not as someone who has been affected by illness for thirty years, but rather as someone who continues to persevere. During the interview, he spoke openly about his relationships with his family, his painful sexual experiences during his adolescence and into early adulthood, and his sense of isolation from the broader gay community. It was therefore not immediately apparent that he was holding back. At the very end of the interview, however, Victor disclosed that his emphasis on "doing well" was a position he felt compelled to project. He explained:

> You allow me to be HIV-positive. And that brings up a whole emotional thing about … I mainly have to be doing so well. I mainly have to be doing so well. I mean you have to be more than HIV-positive. You know? It's like, knowing that there's this strong feeling that I have to keep pursuing good health, knowing that my gut's not good, and my bowels and all that is a bit messy, and that's particularly messy for someone who has anal sex. And these are all just things you can't talk about, you can't share. And it's only when someone sits with me and says, "I'm interested in the fact that you are HIV" that I realise I spend most of my time being better than HIV, fighting. You know, HIV's the thing that wants to kill me. I'm always fighting that and presenting a … I remember the story of *The Little Train That Could*, that sort of "I think I can" type sense of being more than it. And so the talk reminds me to give myself a bit of slack, and even just to touch on those emotional places that are … But push comes to shove I have to say I'm quite alone with that 'cause as soon as you tell someone they wanna go, "oh! But it's not true!" or "oh, but you're all – oh! Come to me!" Like, whatever it is I don't have a place that feels right.[39]

Victor's account reveals how his narrative is not only marginalised by his own inhibitions but also in a society that he feels is reluctant to talk about HIV, especially among those who have been living with the virus for some time! He was especially conscious that talking about his "messy" bowels would be considered distasteful in most social contexts. To continue to project this public image of a survivor, Victor often moderates his behaviour and topics of discussion. Although Victor acknowledged the severe impact HIV has had on his life, he was not willing to relinquish his position as a survivor outside of the interview. Victor was particularly careful to maintain anonymity and reminded me not to mention identifying details. This was also because he was aware that his previous willingness to identify as someone with HIV had led to unwanted sympathy. He was particularly frustrated by others who treated him as someone who was unwell and opened doors for him when "I was fine."

As the oral histories reveal, a positive mindset was one of the few strategies these men could employ in the hope of increasing their chances of surviving until effective medication or a cure became available. Several narrators appeared to struggle to talk about a period when they internalised ideas that they would die from their illnesses. The interviews created a distinct forum for narrators to consider and articulate the extent to which they were and continue to be affected by HIV. These men were not only trying to avoid death but more specifically, the final stage of AIDS. Other interviewees considered euthanasia to avoid having to endure the protracted and agonising deaths that they witnessed countless other gay men experience. In this regard, euthanasia offered a final resort in a desperate situation.

It's My Party and I'll Die if I *Have* to

From the late-1980s, several Australian activists and others working in the HIV and AIDS cause voiced their support for voluntary euthanasia.[40] This was a direct response to the painful and lengthy deaths that people whose bodies had succumbed to AIDS-related conditions often endured. Activists in favour of euthanasia drew on the "dignity in dying" concept that arose during the international euthanasia movement of the 1930s. Specifically, a 1989 edition of *Talkabout: Newsletter of People Living with AIDS* referred readers to the Voluntary Euthanasia Society of New South Wales.[41] The authors asserted that "It is natural to hope that when the time comes we shall die peacefully, with dignity, and without prolonged suffering. However, many people now endure a long drawn-out and deeply distressing process of degeneration, pain, and dependence on others."[42] Support for voluntary euthanasia continued into the following decade. Members of ACON were particularly vocal. In the early-1990s, the organisation agitated for the decriminalisation of euthanasia in Australia and published a guidebook for "people thinking about euthanasia and for those asked to assist" written by activist Paul Van Reyk.[43] ACON also drafted legislation to be introduced to parliament by Labour MP Paul O'Grady, the first openly gay member of the NSW parliament, as a Private Member’s Bill in 1996.[44] Yet the Bill did not eventuate after O’Grady became unwell with AIDS-related conditions and resigned from his position.

Jamie Richards was especially forthcoming regarding the prospects of euthanasia. As a trained caregiver and a volunteer for the BGF and The Ankali Project in the early-1990s, he had close contact with people who had succumbed to the physical effects of the virus. One of his neighbours had developed Kaposi’s sarcoma and was mostly housebound with very few visitors, so “I think as soon as the sun rose he thought it was okay to visit.” The visibility of the virus was particularly confronting for Jamie’s partner Joe, whom he would “often catch crying sometimes ’cause he’d never met these people. He knew I was positive. He had that thing in his head that that’s what’s gonna happen, that’s what happens.”[45] Jamie’s close contact with people who had succumbed to the physical effects of the virus also shaped his sense of mortality. He explained: “I mean I was always under the impression that I was gonna be a corpse within five years. That’s just how my brain worked.”[46]

Jamie was convinced that he would die and planned to euthanise if his health deteriorated to the extent that he had seen other young gay men endure. Indeed, he confided that he had previously stopped taking medication as he feared developing physical side effects and would “rather die looking beautiful.” While he viewed euthanasia as a preferable way to die, it was not a solo endeavour. Rather, he recalled being part of a close community of friends who farewelled one another by hosting dinner parties:

> We had, “the dinner party’s being held tonight.” So you’d go to a certain person’s place, and there’d be ten or twelve closest people there, and you’d all be having dinner, and talking and stuff. And then the person would – and most of the people that did this had boyfriends or husbands or whatever you’d wanna call them back then – “okay everybody, I’m off now, going upstairs and I will see you all later.” And everybody knew what was gonna happen. No tears, no crying, it was all “okay darl see you soon!” ’Cause that’s how it’s gotta work. Everybody would get a kiss and a cuddle and stuff, and they’d go upstairs, and then half an hour later the boyfriend would come down and say “he’s – he’s gone.” So we’d go upstairs and, you know, they did what they did. And you’d go there and they’d be lying there … dead. So, that’s what you did. And everybody always had the family doctor or a friend doctor. A gay doctor living with HIV was usually the best one! And we had a couple of those. And he’d always be the one going upstairs too.[47]

Recounting such a regimented process appears to have offered Jamie the emotional distance from the difficult memories of witnessing friends' euthanise at a time when they felt they had no other option. He attested that this structure also protected attendees from any potential legal implications. Some doctors' involvement in euthanasia reveals the extent to which they were engaged in their patients' health care. In lieu of effective medication, doctors in these situations felt there were few viable alternatives once their patients had developed AIDS and succumbed to opportunistic infections. This appears to have been a reasonably widespread practice. In November 1995, the *Australian* reported that as many as one-fifth of doctors who were members of the Australasian Society for HIV Medicine had helped patients to die by suicide.[48] That same month, some Australian HIV and AIDS doctors urged for legislative changes that would enable them to assist patients with suicide without the fear of being imprisoned.[49] Researchers involved in Australia's HIV General Practice Workforce Project from 2009 to 2012 have also alluded to doctors' participation in euthanasia. One doctor who participated in the study noted, "there were all these euphemisms for 'killed themselves' … There were quite a few last suppers … where they'd invite all their friends around and their doctor."[50] While these doctors did not implicate themselves in such accounts, their memories of attending "last suppers" accords with Jamie's testimony.

Although Jamie suggested that many gay men supported others' decisions to euthanise, they considered euthanasia to be a final resort in dire circumstances. He contended that if they thought it was possible, they would attempt to stop others from euthanising. In doing so, he emphasised his role as part of a community that continued to fight for their survival. He explained, "there were people that said that they were gonna have a dinner party that we would dob in, have committed whatever, 'cause everybody stood up for one another. 'Nah this is going a bit too far there, mate.'"[51] Jamie's testimony hints at the circumstances under which some men would accept others' decisions to euthanise. Mark Tietjen also noted, "there was quite a bit of [euthanasia] happening because they didn't want to go through the final stages of AIDS, you know, that really hideous illness."[52] While the men they described euthanised after their health had declined and they began to exhibit physical symptoms, others ended their lives well before they had reached that point. One of Steven Berveling's friends was "diagnosed with HIV and shot himself the following day. And I don't believe he was the only one.

But this gives you an indication of the strength of the issue, the emotion that's attached to an HIV diagnosis, the stigma that was a consequence of that and the horrible deaths that just happened."[53]

The extent to which Jamie had essentially prepared himself for death became clear when I asked if he had ever considered the possibility of hosting his own dinner party. He promptly responded: "yeah, yeah, I designed it down to a T. I was with Joe at that point and that was something we had planned. That's just how your brain worked."[54] Jamie's assertion that "that's just how your brain worked" is a repetition of an earlier part of the interview when he stated that he expected to be a "corpse" within five years. The phrase not only indicates the extent to which he internalised ideas that death was inevitable, but it also reflects his decision to avoid engaging with his concerns about death over two decades prior. He simply attributed such thoughts to how his "brain worked" at that time.

Narrators' struggles to articulate their acute concerns about death were particularly pronounced in the discrepancies in Mark's narrative. After being diagnosed with HIV in 1986, Mark consciously planned his funeral. He recalled that attending friends' funerals made him consider the farewell he would want to receive. Yet, he recanted this later in the interview and asserted that: "my approach has always been—and I say to all my friends "when I die, I'm dead. Toss me out with the garbage." [Laughs] I'm not really fussed."[55] As Chapter 8 demonstrates, planning funerals were an important coping strategy at a time when HIV and AIDS-related deaths were seemingly ongoing. Death is no longer such a central part of life for people with HIV who have access to effective medication. As was the case with Jamie, he appears to have distanced himself from the emotions that anticipating what many perceived as their inevitably early deaths likely generated. Such emotional distance not only acts as a distinct "trauma signal," but also suggests that narrator's acute concerns about dying are difficult to remember and convey nearly two decades after HIV became a chronic condition.[56]

In spite of activists' efforts to recast representations of people with HIV or AIDS away from that of dying patients to those living with the virus, many interviewees had internalised ideas that they would endure untimely and prolonged deaths as they had seen countless others face. This chapter revealed that the debilitating physical effects of HIV and AIDS-related conditions were an undeniable and unavoidable concern for the many gay men who were diagnosed with HIV as a terminal illness across the 1980s and the first part of the 1990s. These men were particularly concerned about displaying “the look,” which many understandably perceived as an indication that one’s health had started to deteriorate irreversibly. The oral history interviews aimed to uncover narrators’ personal and intimate accounts, and offered a forum for them to revisit the period when they believed their deaths were imminent. Their testimonies nuance dominant and public representations of HIV survivors that prevailed from the late-1980s and give a much-needed voice to topics about death and mortality that are usually silenced.

Notes

1. Franc Hancock, interview with the author, 4 August 2014, New South Wales.
2. Kaposi’s sarcoma often subsided with the introduction of antiretroviral medication. Asha Persson, “Incorporating Pharmakon: HIV, Medicine, and Body Shape Change,” *Body and Society* 10 (2004): 47.
3. Eric Michaels, *Unbecoming: An AIDS Diary* (Durham: Duke University Press, 1990), 139.
4. Alison Morris et al., “Current Epidemiology of Pneumocystis Pneumonia,” *Emerging Infectious Diseases* 10, no. 10 (2004): 1713.
5. Victor Day (pseudonym), interview with the author, 28 August 2014, Sydney.
6. “AIDS: Three Steps to Death,” *Campaign*, November 1985, 4.
7. “Need for Shanti-Type Project in Sydney,” *Sydney Star Observer*, April 4, 1985, 2.
8. Wayne Oldrey, interview with the author, 8 August 2014, Gold Coast.
9. Stephen Allkins, interview with the author, 6 August 2014, Northern Rivers.
10. Ibid.
11. Ibid.
12. Ibid.
13. Steven Berveling, interview with the author, 17 July 2014, Sydney. My italics.
14. Martin P. Levine, *Gay Macho: The Life and Death of the Homosexual Clone* (New York: New York University Press, 1998).
15. Peter Robinson, *The Changing World of Gay Men* (New York: Palgrave Macmillan, 2008), 37.
16. Robert Reynolds, *What Happened to Gay Life?* (Sydney: University of New South Wales Press, 2007), 58–9.

17. Michael Glynn, interview with Larry Galbraith, 3 December 1995, Pride History Group.
18. Robert Ariss, *Against Death: The Practice of Living with AIDS* (Amsterdam: Gordon and Breach, 1997), 141.
19. Ibid.
20. Douglas Crimp, "Portraits of People with AIDS," in *Cultural Studies*, eds. Lawrence Grossberg, Gary Nelson, and Paula Treichler (New York: Routledge, 1992), 117–33; Persson, "Incorporating Pharmakon," 61.
21. Terrence Bell, "ACON Elects New Committee," *Sydney Star Observer*, September 16, 1988, 3.
22. Ariss, *Against Death*, 141.
23. *Living with AIDS*. SBS and Current Affairs. 1989. Retrieved from Australian Lesbian and Gay Archives #108.
24. Ibid.
25. Wayne Oldrey, interview with the author.
26. Ariss, *Against Death*, 125; Richard Wherrett, "Introduction," in *Mardi Gras! True Stories*, ed. Richard Wherrett (Victoria: Penguin Books Australia, 1999), 1.
27. "AIDS—The Psychological Aspects," *Sydney Star Observer*, July 12, 1984, 3, 5.
28. George F. Solomon et al., "An Intensive Psychoimmunologic Study of Long-Surviving Persons with AIDS: Pilot Work, Background Studies, Hypotheses, and Methods," *Annals of the New York Academy of Sciences* 496 (1987): 647–55.
29. Ibid., 651.
30. Solomon et al., "An Intensive Psychoimmunologic Study of Long-Surviving Persons with AIDS," 665.
31. Michael Glynn, "Survive!" *Sydney Star Observer*, October 2, 1992, 15.
32. Ibid.
33. Susan Buchbinder and Eric Vittinghoff, "Long-Term Non-Progressive HIV Infection," in *AIDS Pathogenesis*, eds. Hanneke Schuitemaker and Frank Miedema (Dordrecht, The Netherlands: Kluwer Academic Publishers, 2000), 65–76; J. Kaldor et al., "The Acquired Immunodeficiency Syndrome in Australia: Incidence 1982–1991," *Medical Journal of Australia* 158, no. 1 (1993): 10–17; Chatterjee Koushik, "Host Genetic Factors in Susceptibility to HIV-1 Infection and Progression to AIDS," *Journal of Genetics* 89, no. 1 (2010): 109–16; K. Luo et al., "The Role of Initial AIDS-Defining Illness in Survival Following AIDS," *AIDS* 9, no. 1 (1995): 57–63.
34. Marian Duggan, *Queering Conflict: Examining Lesbian and Gay Experiences of Homophobia in Northern Ireland* (Surrey: Ashgate Publishing, 2012), 124–6; B.D. Kelly, "Homosexuality and Irish

Psychiatry: Medicine, Law and the Changing Face of Ireland," *Irish Journal of Psychological Medicine* (2016): 4.

35. Brian Mitchell, interview with the author, 10 June 2014, Sydney.
36. Ibid.
37. Victor Day, interview with the author.
38. Victor Day, email message to the author, 21 August 2014.
39. Victor Day, interview with the author.
40. In 1995 the Northern Territory legalised euthanasia by passing the *Rights of the Terminally Ill Act*. The law change aroused considerable debate in New South Wales and other parts of Australia about legalising euthanasia. Margaret Otlowshi, "Active Voluntary Euthanasia: A Legal Perspective," in *The Quality of Death: Euthanasia in Australia*, eds. Ian Hunt and Lynda Burns (Adelaide: Centre for Applied Psychology, Flinders University, 1996), 20–59.
41. The Voluntary Euthanasia Society of New South Wales was founded in 1974. Milton James Lewis, *Medicine and Care of the Dying: A Modern History* (Oxford: Oxford University Press, 2007), 211.
42. "Dying with Dignity," Talkabout: Newsletter of People Living with AIDS (NSW), June 1989, 17.
43. Barbara Farrelly, "Euthanasia Law Reform Urgent for PLWHAs," *Sydney Star Observer*, May 14, 1993, 4; Paul Van Reyk, *Choosing to Die: A Booklet for People Thinking About Euthanasia and for Those Asked to Assist* (Sydney: AIDS Council of New South Wales, 1994).
44. Ian H. Kerridge and Kenneth R. Mitchell, "The Legislation of Active Voluntary Euthanasia in Australia: Will the Slippery Slope Prove Fatal?" *Journal of Medical Ethics* 22 (1996): 273; Geoffrey Walker, "Australia's Response to AIDS: The Law and the Policy Issues," in *Legal Responses to AIDS in Comparative Perspective*, ed. Stanislaw Frankowski (The Hague: Kluwer Law International, 1998), 186.
45. Jamie Richards, interview with the author, 2 September 2014, Tasmania.
46. Ibid.
47. Ibid.
48. Justine Ferrari, "Doctors Help in HIV Patients' Suicides," *Australian*, November 17, 1995, 3.
49. Melissa Sweet, "18% of Doctors Admit Helping AIDS Suicides," *Sydney Morning Herald*, November 30, 1995, 5.
50. Christy Newman et al., "Surviving an Epidemic: Australian GPs on Caring for People with HIV and AIDS in the Early Years," *Australian Family Physician* 42, no. 10 (2013): 735.
51. Jamie Richards, interview with the author.
52. Mark Tietjen, interview with the author, 27 August 2014, Sydney.
53. Steven Berveling, interview with the author, 12 July 2014, Sydney.

54. Jamie Richards, interview with the author. Although Jamie did not select anonymity, I have used the pseudonym "Joe" to protect the identity of his former partner who did not participate in this study.
55. Mark Tietjen, interview with the author.
56. Gadi BenEzer, "Trauma Signals in Life Stories," *Trauma and Life Stories: International Perspectives*, eds. Kim Lacy Rogers, Selma Leydesdorff, and Graham Dawson (London: Routledge, 1999), 34–5.

CHAPTER 5

Living by the Code of the Condom

In late-1989, twenty-two-year-old Damien Roberts and his partner Benjamin received the news they had been dreading. Benjamin's HIV test had come back as positive. The two men met three weeks earlier while sunbathing on a rock at Lady Jane Beach, a nudist beach popular among gay men in Sydney's eastern suburbs. From that evening, "it was all on." The positive diagnosis, was a crushing blow to both men. Benjamin, terrified that he would transmit the virus to his partner, promptly tried to end the relationship. Damien refused. Like many other young gay men, Damien had relocated to inner city Sydney several months earlier. He was enticed by the educational opportunities that the city offered and promptly enrolled in a vocational evening course at the Sydney Institute of Technical and Further Education. Yet Sydney offered more than education. It provided him with an escape from the struggles of growing up gay in country New South Wales, where his sexuality made him a target of schoolyard bullying. He also faced continual public reprisal from teachers for having the incorrect uniform and stationary—neither of which were affordable in his family of five children. Home life offered little reprieve. Although Damien shared close relationships with his sisters, mother, and grandparents, witnessing the physical and emotional abuse his mother endured at the hands of various partners was a constant struggle. Moving to Sydney and meeting Benjamin was a welcome change. Everything was finally coming together.

On that day in 1989, Damien faced a life-changing decision: leave the relationship or stay with the man he loved. He chose the latter.

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0_5

> I said, "well there's safe sex so, you know, use condoms. That's what the message is isn't it? So let's just have a little time to think about it. I'm okay with it, we just practice safe sex and I'm okay with it." It was love at first sight almost, we just fell in love – "and I'm okay with it so we just have to find out what we can and can't do and practice safe sex."[1]

Damien's initial response is a testament to the influence of safe sex education in Australia. From the late-1980s, international and Australian HIV and AIDS organisations adopted the Code of the Condom, which advocated the use of condoms to prevent the spread of HIV. The Code of the Condom held all sexual partners accountable for preventing HIV transmission. It was not one's HIV status, but their use of condoms that mattered. In this regard, information about the use of condoms enabled these men to continue to have sex while minimising the risk that Damien would contract the virus. Yet, Damien's digression, whereby he stated that they immediately fell in love, suggests that he may have felt he needed to explain or even justify his decision to stay in a relationship with someone who was HIV-positive. This can be explained by considering the events that unfolded three months later when Benjamin's acute concern that he would transmit HIV to his partner materialised. It was the third Saturday in February 1990. The two men "were fucking like rabbits and we ran out of lube and decided to use spit instead and the condom broke and yeah … fill in the blanks."[2]

Damien recounted this story to me in an oral history interview in 2014, twenty-four years after he contracted HIV, and eighteen years after Benjamin died in his arms. His testimony offers a glimpse into some of the issues gay men faced to continue to have sex during the epidemic. Benjamin's fear of transmitting the virus to his HIV-negative partner was all too real at a time when a positive diagnosis was essentially a death sentence. We will return to Damien's story at the end of this chapter.

This chapter explores how HIV-positive gay men negotiated sex as an act that was affirming and pleasurable, yet also potentially dangerous. Narrators' personal accounts, especially their struggles to implement safe sex measures, are often marginalised amidst existing discussions that predominantly focus on the success of preventative education. Such histories portray a gay community that willingly adopted the use of condoms and continued to have active sex lives while minimising the risk of contracting HIV or transmitting the virus to others. Indeed, the threat of the virus created divisions among some gay men and led to concerns about an impending “antibody apartheid.” Others subsequently internalised ideas that they were “infectious.” Yet they struggled to articulate such tensions amidst existing understandings that the majority of gay men embraced safe sex. The influence of public discussions about safe sex and community responsibility perhaps also made it difficult for other narrators to talk about instances when they did not adhere to these guidelines. The oral histories illuminate the tensions between gay community pressures to adopt safe sex and HIV-positive gay men’s lived experiences of having sex in the time of an epidemic.

A New Era of Safe Sex

The arrival and spread of the virus posed a serious threat to a culture popular among gay men who had experienced the liberation movements of the 1970s. Gay activists not only asserted a powerful political voice and agitated for the rights of gay men and lesbians, but also succeeded in their aim to move sex “out of the beats and onto the streets.” Sex with different partners was celebrated as a reaction against the years of oppression that gay men had collectively endured. All the narrators moved to inner city Sydney in pursuit of the social freedom and access to a vibrant gay community that the city offered. They reveled in the thriving commercial nightlife filled with parties, parades, nightclubs, sex venues, and scores of other young gay men who were relishing their newfound sexual freedom. The outbreak of HIV and AIDS not only threatened to deprive these men of the physical pleasure of sex but also of an important means by which they expressed their sexualities and resisted oppression.

Government officials and health workers in Britain and America responded to the crisis by urging members of the public to practise celibacy or monogamy. They reasoned that limiting sexual partners was the only way to stop the spread of the virus. Posters published by the Dallas County Health Department across the early-1980s were particularly declarative. One exceptionally grim poster featured a tombstone and cautioned, “A bad reputation isn’t all you can get from sleeping around.” Another warned, “every time you sleep with someone, you’re risking your life.” Such ideas appeared to have similar credence in Australia. Writing in their 1985 guidebook *AIDS in Australia: What Everyone Should Know*, Australian physicians Alister Brass and Julian Gold proclaimed abstinence as the only effective strategy to stop the spread of the virus. They asserted that “[t]he argument for using condoms to prevent transmission of the AIDS virus is based on the ‘better than nothing’ theory.”[3]

The terror caused by HIV and AIDS also generated heated discussions within international and Australian gay male communities over whether a sex-positive culture should continue in the face of the epidemic. Some gay American activists, namely writers Randy Shilts and Larry Kramer—the latter an avid critic of gay men’s post-liberation sex culture—publicly denounced sexual promiscuity among gay men.[4] Others went even further. In 1984, deputy sheriff Larry Littlejohn, a gay activist and co-founder of the Pride Foundation in San Francisco, organised a petition in favour of banning sex at bathhouses in his city. Perhaps unsurprisingly, the petition reportedly caused “some fairly serious divisions within the gay community” in San Francisco.[5] Most activists, however, took the opposite stance and proposed strategies that encouraged both HIV-positive and HIV-negative gay men to sustain active sex lives while preventing the further spread of HIV. In 1982, the Sisters of Perpetual Indulgence, an activist organisation based in San Francisco, pioneered the concept of safe sex in their pamphlet, *Play Fair* The following year, gay activists Richard Berkowitz and Michael Callen produced their seminal text *How to Have Sex in an Epidemic: One Approach*. The same authors had caused considerable outrage among gay male communities six months prior when they controversially “declare[d] war on promiscuity.”[6] On the contrary, their new booklet advised gay men to have safe (mostly non-penetrative) sex by preventing the exchange of blood or semen. They also provided detailed information about how gay men could continue to enjoy “fucking,” “sucking,” and “rimming” while minimising their risks of contracting HIV or transmitting the virus to their sexual partners. In contrast to their earlier article, which warned gay men to abandon promiscuous lifestyles, the authors encouraged readers to sustain positive attitudes towards sex. They urged gay men to modify how they had sex, “not how often you do it nor with how many different partners.”[7] Such sex-positive messages resonated with Australian audiences. That same year, contributors who wrote for the fortnightly gay newspaper, the *Sydney Star Observer*, adopted a similar stance and urged readers: “do have sex, do get close to others.”[8]

Australian activists took the lead from their American counterparts and developed a system of peer-based preventative education that some historians have labelled as one of the best in the world.[9] Gay activists, often with financial assistance from the Australian government, were primarily in charge of devising and delivering preventative education directed at gay or bisexual men. These peer-delivered education campaigns marked a clear departure from offical national HIV and AIDS material, especially the infamous Grim Reaper Campaign of 1987 that featured the cloaked figure knocking down Australian men, women, and children in a bowling alley. Australian public health responses to HIV and AIDS, however, differed considerably from that which existed in America. Australian health ministers rejected proposals by the Commonwealth AIDS Task Force to close gay bars, bathhouses, and discos in 1984, and to cancel the 1985 Sydney Gay Mardi Gras to prevent further spread of the virus.[10] On the contrary, such venues and the annual Mardi Gras quickly became important platforms for HIV and AIDS educators and volunteers to communicate information about safe sex to the wider gay community in the form of posters, pamphlets, and video clips.[11] The Safe Sex Sluts—a volunteer group that distributed condoms and information about preventative education in Sydney—were especially visible at public events.

Australian safe sex campaigns were creative, sexually explicit, and promoted safe sex as intimate, erotic, and pleasurable. Yet these campaigns primarily targeted white middle-class Australian men who identified with a gay community. Such campaigns, which often featured evocative images or illustrations of Caucasian men, may not have been suitable for Indigenous audiences, especially considering the "taboo of discussing sex and Aboriginal men having more than one partner."[12] In 1989, the Department of Community Services and Health established the Working Panel on Aboriginal and Torres Strait Islanders, and HIV/AIDS. Members were reportedly notified of the need for further preventative education, especially among Indigenous youth. Indigenous communities had also raised concerns that they would be coerced into testing for HIV, have their confidentiality breached, and encounter discrimination from medical staff.[13] Nevertheless, Indigenous gay men remained a particularly noticeable absence in the national and gay community-based responses to HIV and AIDS throughout the first decade of the epidemic.

This silence remained the case until 1993, the International Year of the World's Indigenous Peoples, when Australian policymakers reportedly first consulted with Aboriginal people living with HIV and AIDS.[14] By that time, Indigenous medical professionals had taken the lead in communicating information about safe sex within their communities.

Specifically, in May 1987, Indigenous health workers in Townsville, Queensland, conceived the idea of a superhero—later known as Condoman—which bore the colours of the Aboriginal flag and promoted safe sex (Fig. 5.1).[15] Further, in December 1991, the Aboriginal Medical Service established an information stall in Sydney as part of World AIDS Day. Health workers and volunteers distributed pamphlets and videos about HIV and AIDS, some of which were specifically designed for Aboriginal audiences.[16]

The delayed national response to the threat HIV and AIDS posed to Indigenous populations was not forgotten. In 1993, Dr Michael Wooldridge, spokesperson for the Liberal Party on HIV and AIDS-related matters, condemned Australia's failure to prevent what he deemed "an HIV/AIDS holocaust in Aboriginal Communities."[17] He insisted on an increase in Aboriginal health workers, educational material in Aboriginal languages, and improved clinical services and research into Aboriginal health. As previously mentioned, such concerns had arisen four years earlier with the Working Panel on Aboriginal and Torres Strait Islanders, and HIV/AIDS. Nevertheless, Woolridge urged for an advisory committee to be established independently from the Department of Community Services and Health due to their "abysmal record in addressing HIV among Aboriginals."[18] Woolridge addressed this issue once again during parliamentary debates for the Human Rights (Sexual Conduct) Bill the following year in 1994. He proclaimed that Australia's response to the threat HIV and AIDS posed to Aboriginal people "has been pathetic, and we will be condemned by future generations for it."[19] The anticipated threat that the virus posed to Indigenous communities materialised over the following two years. Researchers involved with the Commonwealth Department of Human Services and Health and the National Centre in HIV Social Research expressed concerns about rising rates of HIV among Indigenous populations despite an overall national decline.[20]

Another limitation with Australian safe sex campaigns was that despite their efforts to eroticise safe sex, many gay men struggled to adopt sexual behaviour that they felt was neither exciting nor appealing. Writing in a 1984 edition of *Campaign*, social worker Garry Bennett highlighted the resistance that some Australian gay men felt towards using condoms, arguing that "[t]he very mention of 'safe sex' would provoke chuckles and sarcastic comments. No-one seems to want to take it seriously."[21] Bennett outlined safe sex strategies that gay men in America

Fig. 5.1 Condoman poster produced by the Commonwealth Department of Community Services and Health, Aboriginal Health Workers of Australia (Queensland)

had developed, including phone sex and "jack off" (masturbation) parties. These tactics, however, did not achieve the same momentum among Australian men. Not everyone was surprised. Two months later, Bob Hay, an Australian psychologist and counsellor, publicly condemned the emphasis that Australian safe sex campaigns placed on America. He asserted that: "Aussie men regard masturbation and oral sex as 'good for starters but not the real thing.' The 'real thing' is being screwed."[22] Activists' concerns about Australian gay men's resistance to safe sex measures continued into the decade. Adam Carr, co-founder of the Victorian AIDS Council, was particularly vocal. Writing in an August 1985 edition of the national gay magazine, *OutRage*, Carr contested what he termed the "official position" on safe sex, being that "gay men have taken to safe sex like ducks to water."[23] He reported that many gay men preferred sexual practices that they deemed "unsafe," and proclaimed that education campaigns did not inform their audiences about how to make the transition to having safe sex. Even worse, he found that "they don't tell you how to cope with the rejection that you get from guys who think that safe sex is boring, wimpy, and unmasculine."[24]

In response to many gay men's struggles to sustain safe sexual behaviour, Phil Carswell, founding president of the Victorian AIDS Council, voiced the need for more workshops that eroticised safe sex during his keynote presentation at the National AIDS Seminar in Sydney in April 1986. The seminar took place as an adjunct to the National Homosexual Conference and covered topics including the work of community AIDS organisations, education and prevention campaigns, and legal and political issues. Carswell urged attendees that "we need to physically show people how to use condoms. One of the problems we face is that people will try condoms once or twice, and because something goes wrong, they give up using them."[25] He was particularly inspired by a Fuckerama—a workshop that aimed to resolve misconceptions about safe sex—he had recently attended in San Francisco. The Fuckeramas, some of which were so popular with people "hungry for news" that "you couldn't get into them," involved attendees comparing lists of sexual activities that were no longer considered safe with lists of safe sexual behaviour they could still enjoy. Upon comparing the two lists, members "found there wasn't a great deal of difference."[26]

Activists also responded to gay men's struggles to negotiate safe sex by devising creative and non-verbal strategies to help individuals to propose the use of condoms. One such strategy included the use of a white handkerchief. This was based on the hanky code first used by gay men in San Francisco in the 1970s, whereby men placed a coloured bandana in their rear trouser pocket to indicate their sexual preferences. Further, in 1987, ACON recommended individuals wear a safety pin as a "non-threatening way to communicate that an individual is into safe sex and sexual responsibility in the era of AIDS."[27] While the use of a safety pin as a symbol of safe sex reportedly gained traction in America and Britain, the proposal garnered severe criticism from some Australian gay men who feared they would be ostracised if they refrained from wearing the safety pin. Such concerns were understandable considering, as I will discuss, safe sex messages that urged gay men to take responsibility for the health of others.

Considering many men found condoms to be awkward and uncomfortable, it may not be surprising that community educators not only struggled to encourage Australian gay men to adopt, but also to sustain safe sex. As early as 1993, *OutRage* raised the alarm that gay men were "relapsing" by abandoning the use of condoms.[28] Others were practising "negotiated safety."[29] This involved couples in seroconcordant relationships, where both partners were of the same HIV status, having unprotected sex with one another. Consequently, in May 1996 ACON launched the "Talk, Test, Test, Trust … Together" campaign. Acknowledging that the face of safe sex in Australia was changing, ACON urged men practising "negotiated safety" to communicate openly with one another regarding their HIV status and their sexual behaviour outside of the relationship. Concerns about encouraging gay men to sustain safe sex continued into the decade. In 1998, the NSW Department of Health reported that increasing numbers of gay men were reverting to having unprotected sex. Health researchers attributed this behaviour shift to individuals' complacency about transmission as antiretroviral medication was becoming available.[30] Negotiating and sustaining safe sex may have been difficult regardless of one's HIV status. Yet, it was especially problematic for those with HIV or AIDS. Many of these men faced rejection when they disclosed their HIV-positive status to potential sexual partners.

ANTIBODY APARTHEID

Despite the Code of the Condom—which maintained that all gay men should continue to have (safe) sex regardless of their HIV status—intense fears about contracting the virus created clear divisions between some HIV-positive and HIV-negative gay men. Many men faced rejection from potential sexual partners when they disclosed their positive status. One man remembered that simply taking out a condom at a sex venue was enough to make his potential sexual partner walk away. Such divisions among gay men were likely influenced, or at least validated, by publications that explicitly encouraged people to avoid having sex with others they believed to be HIV-positive. One of the earliest examples featured in a March 1983 edition of the *Morbidity and Mortality Weekly Report (MMWR)*, the official publication of the Centres for Disease Control and Prevention in Atlanta. The article included advice from the United States Public Health Service, which advised readers to avoid having sex with people they knew or even suspected of having AIDS.[31] Six months later, some gay men in the San Francisco and Bay areas confirmed that they consciously avoided "people who look less healthy."[32] Australian men received similar advice to refrain from having sex with those they believed to be HIV-positive. This was particularly pronounced in the controversial Sydney publication: *Living and Loving in the AIDS Free Zone* (1987). The authors, Yvonne Allen, a relationship consultant and Dr. Harry Michelmore, then-Vice-President of the Venereologists Society of NSW, and part-time employee at the Albion Street Clinic in Sydney, urged gay men who had tested negative for HIV to exclusively have sex with other HIV-negative men. They proclaimed "AIDS is now a voluntary disease. You can choose whether or not you want to catch it."[33]

Proposals to establish an AIDS Free Zone undermined safe sex campaigns that encouraged people to adopt standard universal precautions. The publication understandably received severe criticism in the gay press. Critics not only condemned the discriminatory messages inherent in the concept of an AIDS Free Zone, but also cautioned that such advice did not account for the twelve-week "window period."[34] This meant that one could still test negative for HIV, even if they had contracted the virus in the last three months. Distinctions based on one's HIV status continued throughout the 1980s and into the following decade. In 1993, a commentator in the *Sydney Star Observer* reported that "antibody apartheid" was imminent between HIV-positive and-negative gay men. He questioned, "What is this community bullshit?" and asserted that these distinctions threatened the strength and unity that characterised Sydney's gay community.[35]

Prejudice was often primarily based on some gay men's attempts to protect themselves from contracting the virus. It was therefore mostly driven by fear, rather than animosity towards people with HIV. Yet this observation provided little comfort for the men who felt ostracised by their own community. In October 1992, *OutRage* raised concerns that some HIV-positive gay men had internalised fears that they would transmit the virus to their sexual partners, and subsequently ended relationships. The article quoted Ross Duffin—one of the men who participated in this study—and attributed this guilt to the scale of rejection these men had endured. Ross reported that rejection on the basis of one's HIV-positive status "is entirely different from being rejected for any other reason. People can accept that they're not attractive to someone. If you're being rejected because you're HIV-positive, the message is that you can't have sex, basically."[36] Prejudice within the gay community remained a painful memory for Ross when we met for an interview twenty-two years later in 2014. He remembered:

> Stories we heard – which were dreadfully painful – was the absolutely dreadful way gay men with HIV were treated by other gay men. It was shocking. That was the worst. That was the thing that people had the most trouble with. That really used to wipe them out. And so we're caught in this double bind: the expectation was that if you were HIV-positive, you would disclose and tell a potential sex partner, but if you did you got heaps of crap put on you. [Laughs] So, of course, your response was "well, if that's what you're gonna do I'm not going to tell!" Which was completely unsurprising. It was just bizarre, it was horrible.[37]

Ross' assertion that HIV-positive gay men found rejection to be one of the hardest parts of dealing with HIV indicates both the emotional impact of rejection and the value they placed on being part of a gay community. These men grew up at a time when homosexuality was classified as a psychological medical condition and sex between consulting adult men was outlawed throughout most Australian states and territories. As young men, they had gravitated towards inner city Sydney in pursuit of a place where they could explore and embrace their sexualities. Sydney's gay community had initially provided many of these men with a sanctuary of hope, friendship, and love. It posed a stark contrast to many men's memories of group up around family and peers who neither understood nor accepted their sexualities. Yet for some, having HIV meant they were once again rendered as outsiders.

Ross' observation that HIV-positive gay men stopped disclosing did not come across during any of the other interviews. On the contrary, the men in this study affirmed that despite such rejection, they continued to disclose across the 1980s and 1990s. In doing so, they complied with the NSW Public Health Act of 1991 which mandated that people disclose their HIV-positive status to potential sexual partners before having sex.[38] Yet, it is important to acknowledge that the combined impact of legal requirements and social pressure to disclose perhaps made it difficult for some men to talk about times when they did not adhere to these demands.

Some HIV-positive gay men also refrained from having sex with men they believed to be HIV-negative. Ross explained, "one of the big things for people with HIV was that they often wanted relationships with other people with HIV. And negative men hated that idea that we would discriminate on the basis of serostatus."[39] "Serosorting" not only relieved HIV-positive gay men of the risk that they would transmit the virus to their sexual partners, but also of the pressure to use condoms. Medical concerns about the transmission of various viruses including Herpes, Hepatitis, Cytomegalovirus and Epstein-Barr Virus meant that all people were encouraged to adopt the use of condoms, regardless of their HIV status.[40] Such messages faced particular resistance from couples where both partners were HIV-positive. Ross recalled, "what ACON tried to impose was a 'condoms every time' culture. What positive men said was 'if I'm with another positive man, I'm not using condoms.'"[41] Such resistance among HIV-positive men was not only based on their preferences, but the physical act of wearing a condom was particularly difficult for men who were unwell.

Sex was a particular concern for Geoff and he guided the interview towards a discussion about the rejection he faced from a former partner in the late-1980s. He explained: "this is going to be a long story, but …" Although Geoff warned that it would be a "long story," the conjunction followed by a lengthy pause indicated that it was a story worth telling, and one that was significant in his overall experience with HIV. Geoff met his former partner at a mutual friend's party in 1986, two months after he was diagnosed with HIV. He explained:

> I was upfront that I was positive. But whenever we started to get intimate I was not allowed to take my underwear off. I was not allowed to reveal any of my genitals or anything for fear that he would get HIV. And this went on for a couple of weeks, a couple of months I think. And I was telling [another friend] about this and saying "this is my life! This is what I'm gonna be like for the rest of it! I'll never be able to have sex again! I'll never be able to do anything! I won't be able to undress in front of anybody or anything like that!" And he looked at me and he said, "this is stupid" and he went away and came back and [laughs] we had sex. He got a condom and afterwards he said "see, it's simple. This is what you do."[42]

These experiences were not uncommon. The stigma attached to having HIV or AIDS meant some people living with the virus were denounced as "unclean."[43] Such explicit rejection meant that Geoff felt he was denied the intimacy that people without HIV or AIDS were able—or *allowed*—to experience. Nevertheless, he seemed to recall this difficult memory with relative ease. Geoff's description of having sex with his friend suggests that this single encounter as provided him with the validation that he did not pose a threat to his sexual partners. It meant he could continue to enjoy sex and intimacy with other men. In this regard, he described having sex as an act that was both affirming and empowering. Further discussion, however, suggested that overcoming such blatant rejection was a more recent development.

Geoff's ability to distance himself from the emotional pain of being prohibited from removing his underwear was likely influenced by his recent contact with his ex-partner. Eight months before I met Geoff, he received a message from his ex-partner via Facebook. They exchanged several emails and then shared a two-hour phone call when his ex-partner apologised. His ex-partner apologised once again when they met for lunch, and Geoff explained:

> I said, "look, I don't think you need to apologise." I said "it was devastating for both of us, we were both scared, we were both fearful. Look at the times that we were in and the information we had compared to the information we have now. It's completely different […] We were two scared young men."[44]

Receiving an apology twenty-eight years later helped Geoff to compartmentalise this event into one that was located solely in the 1980s when they were in their mid-twenties and had little information about HIV.

Although Geoff valued the apology, his ex-partner's reaction impacted how he interacted with others. He braced himself for receiving negative responses when he disclosed his HIV-positive status.

Narrators' accounts of facing rejection from other gay men offer insight into the complexities in histories that emphasise the success of safe sex education in Australia. The intense fear the epidemic aroused led to clear divisions between some HIV-negative and HIV-positive gay men, the latter of whom often faced rejection and sometimes abuse upon disclosing their positive status to potential sexual partners. As the oral histories reveal, such responses were emotionally painful for HIV-positive gay men and caused lasting damage to their self-esteem. Although Geoff attested to the importance of having sex, which provided him with the validation that his life could continue—to an extent—as it did before the epidemic, others were unable to continue to have sex after they were diagnosed with HIV.

Abstinent and "Untouchable"

Across the mid-1980s, HIV and AIDS activists encouraged HIV-positive gay men to adopt safe sex strategies in order to protect others from contracting the virus. In January 1985, the *Sydney Star Observer* urged readers to undertake an antibody test and argued that "To refuse to know your antibody status and still have sex […] is irresponsible to others individually and the community collectively."[45] Other gay periodicals also maintained that HIV-positive gay men were responsible for protecting their sexual partners. Adam Carr was particularly firm. Writing in *OutRage* four months later, he declared, "while each individual has a right to run risks with his own health and his own life if he chooses, he has no right, in my opinion, to run risks with other peoples."[46] Such discussions about peer-responsibility provided some narrators with the vocabulary to articulate their decisions to abstain from sex after they received a positive diagnosis. These men explained that they practised abstinence out of fear that they would transmit the virus to others. Yet they not only stopped having sex with those they believed to be HIV-negative but rather withdrew from intimacy with other gay men entirely.

Ross' role as ACON's Education Officer from 1985 to 1996 meant that histories that convey a community transforming their sexual behaviour to protect themselves and others from the virus are a testament to his professional success in these endeavours. Anecdotes about gay men who willingly adopted safe sex practices were therefore ones with which he was both familiar and comfortable telling. He affirmed that "the adoption of condoms by gay men is one of the great health success stories of the last hundred years."[47] Ross' account highlights a tension between existing histories that emphasise the success of safe sex education during this period and his own concerns about transmitting the virus to his partner.

As previously outlined, Ross openly discussed the rejection that some HIV-positive gay men endured from the wider community. Yet he did not mention how HIV affected his own sex life until the final five minutes of the ninety-minute interview. The significance of this silence became apparent when Ross indicated that his acute fear of transmitting HIV to his former partner contributed to the demise of their relationship. Ross had met his former partner in 1975 at the age of nineteen. His partner was a political activist and "I quite liked that." Together, they were involved in the gay radio programme that featured on 2XX FM, a community radio station in Canberra, and organised the Eighth National Homosexual Conference in 1982 with the theme "Building the Gay Movement." Ross had previously stated that their twenty-year relationship ended in the late-1990s as it had simply "run its course." At the end of the interview, however, he conceded that "I found having sex with a negative person when you're HIV-positive really impossible. Just the thought of infecting him. And he was like 'don't worry about it.' It just didn't work [Laughs]."[48] Ross' concerns were not uncommon. In 1992, *OutRage* reported that HIV-positive gay men were experiencing a "new age of guilt," whereby several men internalised ideas that their semen was "venom" and that they were "poisonous" and "infected."[49] Despite Ross being especially well informed about the effectiveness of condoms, preventative education was not enough to allay his fears about transmitting HIV to his partner.

Other interviewees appeared to be much more at ease when they told similar accounts about abstaining from sex to protect others from contracting the virus. Wayne Oldrey was particularly forthcoming regarding his concerns about risking others' health. Such concerns can be partly explained by considering the context in which he received his positive diagnosis. Wayne underwent a routine mandatory blood test after he joined the Australian Defence Force in 1995. This policy aimed to detect, prevent, and manage HIV. It was established in consultation with the Surgeon General of the Australian Defence Force, the Department of Community Services and Health, and advisory bodies including the AIDS Task Force and the National Advisory Committee on AIDS.[50] Wayne recalled, "they called me back two weeks after they had taken blood. And this time they were in space suits, I kid you not. They were in the full biohazard suits."[51] By 1995, medical researchers were well aware that HIV was nor airborne but rather transmitted through the exchange of body fluids. Wayne's memory of this event as one where the medical staff protected themselves—from him—by wearing biohazard suits left a lasting impression.

While his medical officer explained that the army was the best place for him "because you're fed well, you're exercised," others were not as supportive. Wayne was released from the army on medical discharge. He subsequently abstained from sex for several years and spent this time focusing on work, the gym, and his nutrition:

> A lot of people probably thought "oh look at him, little gym princess; he probably thinks he's too good for everyone." It wasn't that, it was that I didn't want someone to have to go through what I was going through, so I didn't wanna do the sex thing. Because even with condoms I was paranoid that if I passed on HIV to someone I'd never forgive myself […] And I think back now, and I think "ah I wasted probably the best years of my life being untouchable."[52]

Wayne's emphasis on abstaining from sex to protect others was certainly easier than talking about the circumstances by which he contracted HIV. Wayne traced his seroconversion to a time he was hospitalised with suspected Hepatitis in 1987 at the age of seventeen. This occurred shortly after he was sexually assaulted. The trauma of being sexually assaulted was compounded by his earlier memory of being abused by a relative at the age of thirteen. He described himself as "damaged goods"—a term that is familiar among survivors of sexual violence—and confessed that although he would go to beats and watch other people have sex, he refused to let anyone touch him.

There are two important points to make regarding how Wayne's conclusion that he "wasted" the best part of his life is shaped by his present stance on sex. Firstly, Wayne's assertion that he wasted his youth reflects his trust in condoms at a time when antiretroviral medication can reduce one's level of HIV to the point that their viral load is undetectable. Such medication drastically reduces or eliminates an HIV-positive person's chances of transmitting the virus to their sexual partners. The significance of an undetectable viral load has gained even more traction since the Prevention Access Campaign in the United States launched the Undetectable = Untransmittable (U = U) slogan in 2016. The slogan, which conveys that HIV-positive people with an undetectable viral load will not transmit the virus to their partners, has been endorsed by international and Australian HIV and AIDS groups. Twenty-seven years passed between Wayne contracting HIV and participating in the oral history interview. During this period, he not only resumed having sex, but also educated other gay men about the effectiveness of condoms and the importance of taking universal precautions. Wayne's perception that he "wasted" part of his life therefore reflects his understanding that he should have been able to continue to have sex in the late-1980s and 1990s. Secondly, Wayne's testimony was shaped by his recent experiences with discrimination in online dating. He condemned "elitist negative" gay men who exclusively have sex with other men they believe to be HIV-negative. He expressed remorse for the period when he denied the sex that was readily offered.

Revisiting Responsibility

The increasing awareness of the effectiveness of condoms from the late-1980s heightened discussions about HIV-negative gay men's responsibilities to protect themselves from contracting the virus. In 1988, the National Association of People with HIV Australia (NAPWHA) adopted the mantra "you don't catch AIDS, you let someone give it to you."[53] As outlined in the previous chapter, Liberal politician Wilson Tuckey outraged his audience when he made this declaration at Australia's Third National AIDS Conference that same year. While Tuckey condemned gay men and people with HIV or AIDS, NAPWHA intended to remind people that there were preventative measures they could take to protect themselves from contracting HIV. Shifting ideas about responsibility were reinforced in *The New Joy of Gay Sex* (1993), the sequel to the best-selling 1977 sex manual, *The Joy of Gay Sex*. The authors argued that gay men had three responsibilities regarding safe sex: to ensure they did not place their lives in danger, to influence friends' sexual behaviours, and to become involved in activism.[54] The order in which these were listed marked a clear departure from 1980s gay press reports that urged HIV-positive gay men to adopt the use of condoms to protect others. This shift in discussions about personal responsibility gained momentum in the years preceding the interviews. Several narrators drew on such discussions when they explained instances when they did not use condoms, or when they felt condoms had failed to protect them from contracting the virus. I did not ask interviewees when or how they contracted HIV. I was interested in their experiences as gay men who lived with HIV across the 1980s and 1990s and their transmission was not the main focus of this study. Further, as HIV can lay dormant for several years, some men would not be able to trace the virus. Many, however, volunteered this information.

In 1984, David Polson became one of the first people to be diagnosed with HIV in Australia. At that time, "there was no information, so we couldn't do anything. We didn't know what to do. Wish we had."[55] David's lack of access to preventative education in the early-1980s continued to be a cause of remorse. Although he was "among the first batch of people" to adopt the use of condoms, he conceded that "unfortunately by then it was too late." Alternatively, Victor's understanding that information about safe sex was not widely available when he was diagnosed with HIV in 1986 enabled him to relieve himself of any possible guilt for contracting the virus. He found solace in the knowledge that "I have the benefit that I didn't do anything wrong."[56] He continued, "we didn't know about contagion in my day and so I just happened to get HIV. But, nowadays of course there is a critique, "how could you be so stupid to get HIV?"[57] Victor was diagnosed with HIV at a time when the Australian mainstream press condemned HIV-positive gay men as "guilty victims."[58] He may have been determined to distance himself from these images by reinforcing his position as someone who was not aware of preventative information.

Discussions about the lack of access to information raise important questions about the memories of men who were aware of preventative strategies. It is here that we return to Damien's testimony. Of the twenty-five interviewees, Damien dedicated the most time to discussing the events that led to him contracting the virus. During a short phone call to confirm the date and time of the interview, Damien disclosed that he had contracted HIV from his late-partner, Benjamin. This discussion, so early in our correspondence, reveals the significance he placed on this moment. He returned to this discussion during the interview and recounted the moment the condom broke on that fateful day in late-February 1990:

> Nothing was said about it, my partner didn't say a damn thing, he did not say one thing to me. He didn't say, "hey the condom broke we need to you know …" There was nothing we could have done then anyway. Now it would be, "oh shit! The condom broke, we need to get PEP or PrEP or whatever. We need to go and get PEP now!" Seventy-two hours and you'd be fine in most cases, but back then, no. So there was almost this underlying knowledge that I was positive. He knew that. He knew that he'd infected me. Didn't know quite – it was never discussed. I never blamed him, ever. It wasn't his fault. It wasn't my fault. I chose to stay with him, not the other way around. He gave me ample opportunity to leave the relationship, I could have left there and then but I chose to stay. And so we just stopped using condoms, and we had a great sex life and did other things together.[59]

Damien's account also reveals how adopting and sustaining safe sex practices raised particular challenges for those in relationships. Although Damien explicitly stated that it was neither his nor his partner's fault that he contracted HIV, his repetition that he chose to stay in the relationship suggests he felt that contracting HIV was inevitable in a relationship with an HIV-positive person. He also appeared to be frustrated that "my partner didn't say a damn thing." Damien conceded that after they briefly separated in late-1990, he used HIV as a "weapon" for them to stay together. His admissions suggest that he might have indeed blamed Benjamin at that time, but he has since composed a narrative that absolves Benjamin of any fault. The availability of present-day medication helped him to assert that there was little he could have done at that time to prevent infection. Specifically, Post-exposure prophylaxis (PEP), an antiretroviral medication used by HIV-negative people within seventy-two hours of being exposed to the virus, has been available in Australia since 1998. Further, Pre-exposure prophylaxis (PrEP), a daily dose of treatment used by people to prevent contracting HIV, was introduced in Australia in 2012.

Considering the emphasis on the effectiveness of safe sex strategies, some interviewees struggled to talk about times when condoms did not protect them from contracting the virus. Howard Clarke was particularly careful when he discussed his issues with using condoms. Howard was born in rural New South Wales in 1952. He spent four years in Sydney after he finished high school. He then moved overseas and returned to the city in 1985. As an avid reader of *Time Magazine*, Howard was conscious of how HIV and AIDS decimated gay male populations across

America. Despite always using condoms, he was diagnosed with HIV in 1993, eight years after he returned to Sydney. He explained:

> I've never told this to anybody actually, but I've always had safe sex … So I don't know how I got it. But the IMC, Immune Monitory Clinic, the professor at RPA [Royal Prince Albert Hospital] where I go every sixteen weeks for monitoring said, "you can get HIV either from blood or sperm. Contaminated blood or contaminated sperm." So, he said, "you must have somehow or another touched." "Well", I said, "I did take the condom off him." He said, "that's where, you've just had a tiny bit of sperm even on [points to the tip of his finger] there on your skin, is enough to be infected." So, you see what I mean? But I've never told, never say anything about it to anybody because people say, "no you've…" Safe sex doesn't always work. So, it's a catch twenty-two.[60]

Howard's account reveals his struggle to articulate experiences which disturb histories that promote the effectiveness of safe sex strategies. The limitations of condoms have been noted. From the late-1980s, the term "safer sex" started to be used to acknowledge that most preventative strategies reduced, rather than eliminated the possibility of contracting or transmitting HIV. Nevertheless, Howard's experience with the use of condoms failing to protect him from contracting the virus was something he felt he was unable to express outside of the context of the one-off interview. Howard's silence is reinforced by his perception that he would be met with disbelief if he confided in others.

On one level, the interview—which provided Howard with anonymity—created a platform for him to convey his distinct experiences of having sex during the epidemic, and to voice his conclusion that "safe sex doesn't always work." Yet even within the relative safety of an interview, Howard remained reluctant to contest the effectiveness of condoms in preventing the transmission of HIV. This was apparent as he cited an instance when his sexual partner's semen may have touched the tip of his finger and he believes he came into direct contact with the virus. It is not possible to contract HIV the way that Howard described. This memory, however, enabled him to affirm that condoms were not always effective without explicitly challenging existing depictions of the value of safe sex strategies.

Histories that promote the effectiveness of safe sex strategies do not always account for the voices of those who struggled to continue to have sex after they were diagnosed with HIV. HIV and AIDS created clear distinctions between some HIV-positive and negative gay men, the former of whom were sometimes positioned as infectious. These men often faced rejection from potential sexual partners on the basis of their HIV-positive status. Others not only struggled to adopt the use of condoms but also refrained from having sex entirely for several years after they received HIV-positive diagnoses. Discussions about gay men's responsibilities to adopt safe sex strategies to protect their sexual partners provided them with the vocabulary to depict themselves abstaining from sex to avoid transmitting the virus to others. As the oral histories revealed, however, some men's decisions to do so were more closely based on their unease around other men. Finally, this chapter traced the impact that contemporary discussions that promote individuals' personal responsibilities had on gay men's recall of this period. The increasing public emphasis on HIV-negative gay men's responsibilities to prevent themselves from contracting HIV meant some interviewees struggled to talk about times when they did not use condoms, or when condoms were not effective. Together, their narratives reveal that having sex was complicated by a number of social and emotional factors that carried more weight than the sex-positive messages that safe sex campaigns espoused.

Notes

1. Damien Roberts (pseudonym), interview with the author, 5 August 2014, Northern Rivers.
2. Ibid.
3. Alister Brass and Julian Gold, *AIDS in Australia: What Everyone Should Know* (Sydney: Bay Books, 1985), 150.
4. Larry Kramer, *The Normal Heart* (New York: New American Library, 1985), 37; Randy Shilts, *And The Band Played On* (London: St. Martin's Press, 1987), 19–24.
5. "Out of the Tubs and into the Shrubs," *Sydney Star Observer*, 20 April 1984.
6. Michael Callen and Richard Berkowitz, "We Know Who We Are: Two Gay Men Declare War on Promiscuity," *New York Native* 8, no. 21 (1982): 23–9.
7. Richard Berkowitz and Michael Callen, *How to Have Sex in an Epidemic: One Approach* (New York: News From The Front Publications, 1983), 3.
8. Tom Smith, "Joy of Gay Sex: It's Still There," *Sydney Star Observer*, June 3, 1983, 10.

9. Paul Sendziuk, *Learning to Trust: Australian Responses to AIDS* (Sydney: University of New South Wales Press, 2003), 106–35; Graham Willett, “How We Saved Our Lives: The Gay Community and the Australian Response to AIDS,” *HIV Australia* 12, no. 3 (2014): 4–7.4.
10. “Bar Closures Rejected by Health Ministers,” *Sydney Star Observer*, January 10, 1985, 1; Willett, “How We Saved Our Lives,” 4–7.
11. Susan Kippax et al., *Sustaining Safe Sex: Gay Communities Respond to AIDS*, 15. For an overview of some of the posters designed during this period, see L.K. Chan and Raymond Donovan, “Safer Sex Messages: Australian HIV/AIDS Campaigns 1985–2014,” *HIV Australia* 12, no. 3 (2014): 8–11.
12. “AIDS Awareness Campaign Targets At-Risk Aborigines,” *Koori Mail*, December 18, 1991, 9.
13. Department of Community Services and Health, *Report of the Working Panel on Aboriginals, Torres Strait Islanders and HIV/AIDS* (Canberra, 1989), 12.
14. Barbara Farrelly, “Time to Pay the Piper,” *Sydney Star Observer*, November 26, 1993, 10.
15. Ted Gott, “Where The Streets Have New Aims: The Poster in the Age of AIDS,” in *Don’t Leave Me This Way: Art in the Age of AIDS*, ed. Ted Gott (Canberra: National Gallery of Australia, 1994), 204–6.
16. “World AIDS Day–Education on a Global Scale,” *Koori Mail*, November 20, 1991, 20.
17. “Australia Fails to Act to Stop an AIDS Induced Holocaust,” *Koori Mail*, June 2, 1993, 7.
18. Ibid.
19. Commonwealth of Australia Parliamentary Debates: House of Representatives, Human Rights (Sexual Conduct) Act, No. 197, 1994, 2264.
20. Richard G.A. Feachem, *Valuing the Past … Investing in the Future Evaluation of the National HIV/AIDS Strategy 1993–94 to 1995–96* (Canberra: Australian Government Publishing Service, 1995), 5; Murray Chapple and Sue Kippax, *Gay and Homosexually Active Aboriginal Men in Sydney* (Sydney: National Centre in HIV Social Research, 1996), 3.
21. Garry Bennett, “Safe Sex: Eroticism in the Eighties,” *Campaign*, November 1984, 10.
22. “AIDS, Trying to Reduce the Risk,” *Sydney Star Observer*, January 10, 1985, 19.
23. Adam Carr, “Safe Sex: Can You Keep It Up?” *OutRage*, August 1985, 18.
24. Ibid.
25. Phillip Carswell, “We’re Doing Better than Overseas,” *Sydney Star Observer*, May 2, 1986, 6.

26. Ibid.
27. "The Safety Pin: Safe Sex Symbol," *Sydney Star Observer*, May 29, 1987, 1.
28. Adam Carr, "Are We Relapsing?" *OutRage*, October 1993, 48; Martyn Goddard, "The Politics of Relapse," *OutRage*, December 1993, 40.
29. S. Kippax et al., "Sustaining Safe Sex: A Longitudinal Study of a Sample of Homosexual Men," *AIDS* 7, no. 2 (1993): 257–63; Adam Carr, *Keeping It Up: Sustaining Safe Sex in the Second Decade of AIDS* (Sydney: National Centre for HIV Social Research (Macquarie Unit), 1992), 10.
30. Bollen et al., *Understanding the Contexts of Risk-Taking Among Sydney Gay Men: Re-analysis of Significant Others 1997 Focus Group Data.* Report to AIDS and Infectious Diseases Branch, NSW Department of Health (Sydney: Sociology Department, School of Behavioural Sciences, Macquarie University, 1998), 3; June Crawford et al., *Male Call 96, National Telephone Survey of Men Who Have Sex with Men* (Sydney: National Centre in HIV Social Research, 1998), 59.
31. Centres for Disease Control and Prevention, "Current Trends Prevention of Acquired Immune Deficiency Syndrome (AIDS): Report of Inter-Agency Recommendations," *MMWR Weekly* 32, no. 8 (1983): 101–3.
32. "Sex on Castro," *Campaign*, September 1983, 5, 18.
33. Yvonne Allen and Harry Michelmore, *Living and Loving in the AIDS Free Zone* (Sydney: Australian Consolidated Press, 1987), 39.
34. "AIDS Experts Reject 'Free Zone,'" *Sydney Star Observer*, December 25, 1987, 1, 8.
35. Campion Decent, "What is This Community Bullshit?" *Sydney Star Observer*, June 25, 1993, 26.
36. Martyn Goddard, "Guilt is Back," *OutRage*, October 1992, 18.
37. Ross Duffin, interview with the author, 16 July 2014, Sydney.
38. John Godwin et al., *Australian HIV/AIDS Legal Guide*, Second (Sydney: The Federation Press, 1993), 36.
39. Ross Duffin, interview with the author.
40. Charles Silverstein and Felice Picano, *The New Joy of Gay Sex* (London: GMP Publishers, 1993), 13.
41. Ross Duffin, interview with the author.
42. Geoff Anderson, interview with the author, 9 August 2014, Brisbane.
43. Patricia G. Devine, E. Ashby Plant, and Kristen Harrison, "The Problem of 'Us' Versus 'Them' and AIDS Stigma," *American Behavioral Scientist* 47, no. 7 (1999): 1214.
44. Geoff Anderson, interview with the author.
45. "Antibody Tests—Are They Any Use?" *Sydney Star Observer*, January 10, 1985, 5.

46. Adam Carr, "You Pays Your Money and You Takes Your Chances," *Sydney Star Observer*, May 2, 1985, 18.
47. Ross, interview with the author.
48. Ibid.
49. Goddard, "Guilt is Back," *OutRage*.
50. Lieutenant Colonel Kevin Farrell, "Human Immunodeficiency Virus (HIV) Testing in the Australian Defence Force," *Defence Forces Journal* 94 (1992): 21–3; Major General William O. Rodgers, "AIDS Policy and Mandatory Testing in the Armed Forces," paper presented at AIDS and the Health Professional Summit Conference, 28–9 April 1989. The first entrant HIV screening was introduced in April 1988.
51. Wayne Oldrey, interview with the author, 8 August 2014, Gold Coast.
52. Ibid.
53. Jennifer Power, *Movement, Knowledge, Emotion: Gay Activism and HIV/AIDS in Australia* (Canberra: ANU E Press, 2011), 59.
54. Charles Silverstein and Felice Picano, *The New Joy of Gay Sex* (London: GMP Publishers, 1993), 162.
55. David Polson, interview with the author, 18 June 2014, Sydney.
56. Victor Day, interview with the author.
57. Ibid.
58. Sendziuk, *Learning to Trust*, 65–7; Deborah Lupton, "Archetypes of Infection: People with HIV/AIDS in the Australian Press in the mid-1990s," *Sociology of Health and Illness* 21, no. 1 (1999): 38.
59. Damien Roberts (pseudonym), interview with the author.
60. Howard Clarke (pseudonym), interview with the author, 29 August 2014, Sydney.

CHAPTER 6

Patient Stories

On the morning of 6 May 1996, Steven Berveling arrived at the Emergency Department of St. Vincent's Hospital in Sydney. He could hardly walk into the building. Steven had been unwell for months, and he knew what to do: "I get tested, and I get tested, and I get tested, and it's negative, negative, negative, negative, negative."[1] That morning was different. He had received a phone call from his doctor regarding an HIV test he had taken a few days earlier "and he says, 'go straight to the hospital. Now. Do not pass Go.'" Once Steven arrived at the emergency department, the doctor on duty "looks at my fingernails—and I'm thinking, 'I hope I washed them' – looks at them and says, 'Seventeen.' I knew what Seventeen meant." Ward Seventeen was Australia's first hospital ward specifically for people with HIV or AIDS. For Steven, hearing that single word "made it all the more difficult to, you know, [laughs] get out of that and get myself up to Seventeen 'cause I just couldn't believe that this was happening." By 11 a.m., the results of his HIV test were confirmed. Steven was HIV-positive.

The worst news was yet to come. As Steven was drifting in and out of consciousness, he overheard two nurses speaking at the foot of his bed. They had booked an appointment for him at the morgue in two days' time. He described his reaction:

> I remember thinking – leaving aside the expletives – I remember thinking, "I've just been diagnosed with HIV, you get an average of ten years, they're giving me two days. This sucks!" It was extraordinary! But

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0_6

> I remember thinking that through, and I also remember thinking “they’ve made an appointment for me at the morgue,” ’cause apparently in those days you had to book space there, do I care? You know, “they’ve made an appointment at the morgue, I’m not going. There’s no way I’m going!”[2]

Steven’s testimony, recounted in little more than a whisper, reveals the dire situation individuals faced when their health deteriorated, they were hospitalised, and in this case on the brink of death. It offers a glimpse into how narrators revisit and recount these experiences decades later. Above all, the men in this study appeared to be particularly comfortable retelling accounts of challenging their doctors’ authoritative positions. They drew on the language of the patient empowerment movement and depicted themselves taking an active role in making decisions about their health care.

The emphasis on patient empowerment, however, meant most narrators struggled to talk about times when their health declined and they became reliant on doctors, especially their regular general practitioner, for medical advice and access to treatment. The oral history interviews became a site for narrators to revisit these experiences and to portray themselves achieving the agency that may have been unattainable in the late-1980s and 1990s when they were unwell. While Lloyd Grosse, Richard Mcdonell, and Steven Berveling recounted verbally protesting against doctors, demanding medication, and going “doctor shopping” to find a medical practitioner that catered to their individual needs, not all interviewees resisted their doctors’ authority. Steven Jottileb’s ongoing reliance on health care at the time of the interview meant that he was perhaps more comfortable with the role of the compliant patient than the other men in this study. Together, their testimonies offer rare insight into the challenges narrators faced when their health declined and they were relegated to the role of the patient, and how they resisted or succumbed to his position.[3]

The stories that interviewees felt comfortable telling reflect the influence of depictions of “good patients” that tend to dominate discussions about HIV-positive gay men’s experiences with physicians across the 1980s and 1990s.[4] In 1994, the authors of *Good Doctors, Good Patients: Partners in HIV Treatment* characterised a “good patient” as someone who engaged with HIV and AIDS organisations and made informed decisions about their health care.[5] Their definition of a “good patient” reflected the position that HIV and AIDS activists had pursued since the mid-1980s. Activists challenged the existing medical hierarchies that placed doctors in authoritative positions. They urged doctors to collaborate with patients under a "consult, don't prescribe" policy. The construction of a "good patient," however, also implies that there are "bad patients." If a "good patient" took charge of their treatment, perhaps "bad patients" were those who did not or could not do so. Depictions of "good patients" therefore overshadow the voices of men whose bodies had succumbed to opportunistic infections, and they were subjected to their doctors' care. Men who were not involved in HIV and AIDS activism, and others who rarely had access to support networks within the gay community have been particularly overlooked in these discussions.

A Fabulous AIDS Story

From the early-1980s, several doctors and nurses dedicated themselves to caring for patients with HIV or AIDS. They acted as impromptu counsellors, drove patients to the hospital, and visited patients in their homes after their work days ended.[6] These private actions, however, have had little impact on HIV-positive gay men's shared memories of their interactions with medical staff across the 1980s and early-1990s. For the most part, narrators' hostile encounters with unsympathetic and fearful hospital staff overshadowed the positive relationships they might have developed.[7] Some men's unfavorable experiences with individual doctors led them to distrust the medical establishment entirely. Their triumphant accounts of challenging medical staff were perhaps in part a response to the many publicised cases whereby doctors and nurses had refused to treat gay men with HIV or AIDS.

Several men in this study shared vivid memories of being subjected to prejudice by the very people who were appointed to treat them. Mid-way through the two-and-a-half-hour interview, Stephen Allkins recounted the moment his elder brother Michael received an HIV-positive diagnosis in the early-1990s. Michael had just returned to Sydney to live with his new partner. While both men were confident Michael was HIV-negative, his partner had lost his previous boyfriend to AIDS-related conditions and encouraged Michael to undertake an HIV test as a formality:

> Oh, another fabulous AIDS story: one of my brothers died from AIDS […] The way he found out that he was positive was – it was a new doctor

> because Michael had just moved back to Sydney to be with a new partner and they were madly in love. So the doctor called him into his office, intentionally left his results open on the table facing Michael and said, "I'll be back in a minute." And my brother started looking at the results and saw whatever it was, like he was "Positive for HIV." He saw it and stood up and fell to the ground in shock. And when the doctor came back in he went "just sit there don't worry." He did not even want to touch him.[8]

Stephen's sarcastic rendering of this encounter as "another fabulous AIDS story" suggests he was aware such accounts were common in men's recall of this era. He emphasised that the doctor—a heterosexual man in suburban Sydney—left the results on the table "so he wouldn't have to even say the words." Instances whereby HIV-positive gay men encountered unsympathetic medical staff across this period also resonated with Greg. Eleven minutes into the interview, Greg stated that he was accepted into the prestigious National Institute of Dramatic Art (NIDA) in 1985, the same week that he was diagnosed with HIV. He recalled:

> And another story, the first time I went back to the clinic for my very first check up after the diagnosis, after about three to four weeks, I walked in there to the little area where the doctor was. It wasn't Julian Gold it was a different doctor. And she looked at me and she said, "so, how are you coping with the diagnosis?" And I said, "oh yeah, oh all right." And I was. I was fine. I had seen a counsellor for two sessions – all of two sessions – and then after that I thought "shit, I can handle this. This is okay." 'Cause just a little imagery he mentioned that worked for me. But I said to her "nah, nah okay." She said, "well, what are you doing with your life?" I said, "well I just started NIDA." "NIDA? Isn't that a three-year full-time course?" "Yeah." "Ooh, that's very optimistic of you!" [Points to my facial expression.] Never forgot that. Some bedside manner there is all I can think of![9]

There are important parallels between Stephen's and Greg's portrayals of hostility at the hands of medical professionals. Although both men prefaced their anecdotes but stating it was "another story," neither had mentioned prejudice or medical professionals until that moment. My preceding discussion with Stephen centred on his decision to move to inner city Sydney in the late-1970s and the number of close friends he had lost to HIV or AIDS-related conditions. Greg had discussed his family, his experiences "coming out" as gay, and being diagnosed with HIV by Dr. Julian Gold. Both men therefore presented these experiences as simply "another story" in addition to the numerous other cases whereby gay men endured prejudice from medical professionals, of which we were both aware.

Greg's body language indicated that he anticipated this anecdote would generate recognition and shock his audience. This was especially clear when he pointed to my facial expression, one of horror, as signalled in the extract. As someone who had not experienced the epidemic, I was not able to offer the same level of recognition that an HIV-positive gay man might have been able to provide. My subconscious physical reaction to his anecdote however, offered him the affirmation that this was indeed an alarming experience. By pointing to my facial expression, Greg simultaneously indicated that I had delivered the response that he had hoped to achieve. He therefore provided me with the affirmation that I had reacted appropriately to his account. Such exchanges are instrumental considering the private and potentially difficult memories that can arise in oral history interviewing.

Publicised cases whereby HIV-positive gay men endured prejudice at the hands of medical professionals had an immediate impact on how Steven Berveling responded to receiving his positive diagnosis in 1996. He became aware of his potential reliance on medical staff and how he may be handled—or rather neglected—as a patient. Steven's passion for cycling was evident from the first email he sent me in response to the advertisement for this study. He had just led the first HIV-positive team in the Race Across America, a bicycle race that covers nearly five thousand kilometres. During the interview, Steven explained that he temporarily stopped cycling in the late-1990s, at which point the virus had damaged his optic nerve and he lost his eyesight for twelve months. Yet once his eyesight returned:

> I didn't resume either. I didn't start again. And I didn't start again because I was very concerned that the ambulance people wouldn't treat me if I had a crash. Now, here's a person who you might have guessed is fairly obsessive about cycling, and I stopped doing the thing that I loved more than anything else because I was frightened. I was absolutely petrified that they would just leave me dying in a gutter … Acknowledging that, I recall the hospital nurses not helping the people with HIV. You know, the food would be left outside. They just wouldn't be assisted with their sheets or their bedding. I mean, I'm talking really early days, but those things stick in your mind.[10]

Steven's account reveals the acute fear that such publicised cases of mistreatment from medical staff generated among some HIV-positive gay men. He anticipated that he would encounter the same fate that he believed befell many others. Such neglect was especially damaging for men who were hospitalised and in need of emergency medical attention. Other interviewees attested to the degradation they experienced when their bedding was not changed and they were left lying in their own waste as they did not have the physical strength to stand.

Together, the oral histories reveal that publicised cases of prejudice and mistreatment from doctors led these men to mistrust and at times resent medical staff. Some medical professionals' acute fears of contracting the virus impeded them from providing adequate health care to their gay male patients. In 1982, the Centers for Disease Control and Prevention in Atlanta advised clinical staff and laboratory technicians to apply the same precautions when tending to people with AIDS that they had practised with Hepatitis B patients.[11] Such procedures included wearing gloves and gowns to avoid contact with a patient's blood and other body fluids, and immediately cleaning any "blood spills" with a disinfectant solution.[12] Nevertheless, cases whereby hospital staff refused to treat gay men with HIV or AIDS or left food outside of hospital wards are a testament to the level of fear that prevailed within medical circles. In the late-1980s, the *Sydney Star Observer* reported that some doctors in Sydney had allegedly tested patients for HIV without their knowledge or consent.[13] Other doctors reportedly demanded that patients requiring major surgery undergo compulsory testing.[14] In addition to their concerns about contracting the virus from their patients, some medical professionals' prejudices against gay men meant they failed to provide adequate health care.[15] A number of scholars have argued that many physicians exhibited the same prejudices towards gay men with HIV or AIDS as the wider community.[16] As Shirleene Robinson and Emily Wilson assert, however, medical staff "were in a significantly more responsible role than the rest of the population, and their pronouncements on the subject had correspondingly greater weight."[17]

It is also important to acknowledge that many medical staff genuinely wanted to support their patients and provide them with high-quality medical care.[18] Yet, they were not always able to do so. The influx of patients with HIV and AIDS across the late-1980s and early-1990s exhausted hospital resources. In 1986, activist Greg Tillett agitated for urgent government intervention to deal with the expected increase of people with AIDS-related conditions in Sydney. He predicted that by the end of the year "there will be around 30 hospital beds allocated for people with AIDS. That is plainly inadequate, and results in people lying in casualty when available beds are occupied, and sometimes, dying in casualty."[19] Tillett's concerns eventuated. Over the following years, the *Sydney Star Observer* published complaints from gay men with HIV or AIDS who had been left on stretchers in the hallway of St Vincent's Hospital due to a lack of available beds.[20] Also, in 1991, the Australian chapter of the vocal activist group ACT UP protested against the Anti-Discrimination Board, citing similar grievances by people who had been left untreated in casualty wards.[21]

Instances of gay men with HIV or AIDS being neglected or mistreated by medical staff permeate international and Australian social histories of health. Such cases are infamous and unforgettable parts of the epidemic. While individuals were dependent on doctors, nurses, paramedics, and other medical staff when their health declined, a combination of existing prejudices, fear, and exhausted hospital resources meant some men were denied adequate treatment. Against this backdrop of prejudice and insufficient treatment from doctors and nurses, narrators told triumphant stories of rejecting the role of the "compliant" patient and establishing an active position in making decisions about their health care.

THE "GOOD PATIENT"

HIV-positive gay men's efforts to assert agency in their health care are located in broader transnational shifts towards patient empowerment that had been underway since the late-1950s. Sociologist James Gillett argues that many gay men living with HIV and AIDS drew on the political tenets of the Disability Rights Movement and the Women's Health Movement and asserted a role in establishing policies, services, and organisations to deal with the epidemic.[22] They "refused to adopt the conventional patient role of compliance and subservience to institutional authority."[23] Gillett's assessment is based on the North American context. A consideration of broader transnational shifts towards patient autonomy adds further insight into the complex relationship that had ensued between patients and doctors by the time the epidemic began in the early-1980s. Specifically, a patient empowerment movement had been underway in the United Kingdom since the late-1950s.[24] Charlotte

Williamson identifies this movement as an “emancipation” effort against the constraints and dominance of the health care system.[25] She argues that while doctors had risen in esteem in the late-nineteenth century, criticisms of hospitals and medical care began to be published from 1959 onwards.[26] Activists firmly resisted sociologist Talcott Parsons’ controversial 1951 concept of the passive “sick role.”[27] They asserted themselves as active and informed partners in their health care.

The international patient empowerment movement formed the foundation on which HIV-positive gay men’s active roles in their health care evolved across the following decades. Activists and community groups pioneered the empowerment of people with HIV and AIDS in Australia. From the early-1980s, the *Sydney Star Observer* and *OutRage* communicated information about ongoing medical research, drug trials, and alternative therapies to their predominantly gay male readership.[28] Activists also published reviews about antiretroviral treatments and alternative therapies in various community newsletters. These included the *AIDS Advocate* and *Talkabout*: *Newsletter of People Living with AIDS*, established in 1988 and 1989, respectively. Many gay men were therefore no longer reliant on their doctors for updates about treatment, but rather had a number of avenues through which they could access medical information. The prevalence of community-based advice reflects a broader international shift towards a “patient-centred” or an “informative model” of health care that was underway at that time.[29] In the Australian context, the return of the Labor Government in 1983 meant that “a more positive approach to consumer participation in federal health policy and planning became possible.”[30] This included the establishment of the Consumers’ Health Forum of Australia in 1986.[31] Under such models, physicians provided patients with relevant information, and patients then selected the medical intervention they felt appropriate.

Such collaborative relationships developed between gay activists and medical professionals from the early-1980s. Gay male doctors were particularly well regarded within the gay community. In 1983, the *Sydney Star Observer* encouraged concerned readers to seek out a gay doctor through the Gays Counselling Service. Gay doctors, they argued, would not only be more empathetic but also more knowledgeable about HIV and AIDS.[32] The newspaper contested other medical practitioners’ knowledge about the virus. It declared that some doctors “are unaware of the symptoms [of AIDS] or even what AIDS stands for.”[33] Such concerns were understandable. Not only was medical professionals’ prejudice against patients with HIV or AIDS well publicised, but homosexuality was categorised as a psychological medical condition in Australia until 1973, well within the authors' lifetimes.[34] Yet several doctors also played a vital role in helping their patients to make informed decisions about their health care. From the early-1980s, some Sydney-based doctors participated in public meetings and published guidebooks to provide concerned readers with medical information about HIV and AIDS.[35] These included *AIDS in Australia: What Everyone Should Know* (1985), written by Sydney doctors Alister Brass and Julian Gold.[36]

Interviewees whose health did not decline until several years after they were diagnosed with HIV were in a particularly strong position to manage their illnesses without relying on doctors than those whose health declined sooner. Although Lloyd contracted HIV in the early-1980s, he did not exhibit any physical symptoms until the end of the decade. He reflected on his distinct position as someone who campaigned for patients to have an active role in their treatment: "it was a weird time of being a well person with HIV, struggling with all these sick people."[37] By the time the epidemic began in Australia, Lloyd had been involved in the Local Community Services Association and *Gaywaves*, Sydney's first gay and lesbian radio program. He had become adept at agitating for the rights of marginalised groups. Lloyd's activism intensified after he was diagnosed with HIV in 1985. He continued:

> As part of my activism, I'd gone into doctors' surgeries and I'd gone "don't be prescriptive with people." You know, "you are just a consultant. [Laughs] You're a consultant who is being consulted about how people manage their health. Don't tell people what they should do, consult them. Involve them in the process of their care." And I'd done it with Julian Gold, you know, I'd gone in and been really heavy handed with these people.[38]

Dr. Julian Gold worked as the director of the Albion Street Clinic which specialised in HIV treatment, testing, and counseling. He established a public profile by discussing the epidemic in newspaper reports and during televised debates.[39] Lloyd's account reveals that he was equally assertive with doctors who were considered medical experts in HIV and AIDS. He inadvertently asserted his own political status as an activist and as an equal, or "good patient," rather than as a recipient of health care.

Although Lloyd recalled that he challenged doctors' authoritative roles, he was forced to re-evaluate this position when his health declined in the late-1980s and he required medical intervention:

> When I came to getting sick and I thought "I'm gonna need to go on therapy," you know, I'd go in and say "what do I do?" And they'd go "well, we can do this, or you can do that, we can do this." [Laughs] I'd be like "just tell me!" They'd be like "well …" And because I'd been so heavy handed with them everyone was really, kind of, very "well, here's all the information, you make a decision." I'd be like "no, I need you to make – help me make the decision." And so I shopped, I went doctor shopping.[40]

It was not uncommon for narrators to describe going "doctor shopping." Mark Tietjen and John Whyte also attested to changing doctors on numerous occasions to find practitioners who catered to their individual medical needs. Lloyd's decision to shop for a physician who would maintain the authoritative position that he had previously sought to dispel illuminates the challenges that some men faced to maintain an active role in their healthcare while acknowledging their doctor's medical expertise.

Revisiting the "Patient"

Those who quickly succumbed to the physical effects of HIV or AIDS-related conditions found themselves hospitalised and in the "sick role." Richard and Steven placed most emphasis on challenging their doctors' authoritative positions when they thought the medical staff had failed them. These men were not involved in HIV and AIDS activism and did not recall any strong support or friendship networks within the gay community. They depicted their efforts to challenge their doctors as solo endeavours. Their testimonies reflect both the dire situations they faced when they succumbed to life-threatening conditions, and their desires to depict themselves ultimately achieving an active role in making decisions about their health care.

Richard described his relationship with doctors as one that evolved from him being the subject of discrimination to being in a position where he was ultimately able to dismiss staff whom he felt had not completed an adequate job. Richard was born in Melbourne in 1964. He spent most of his childhood in country Victoria where his parents owned a general store and moved to the Mornington Peninsula with his family at the age of thirteen. He worked as a plasterer for a few years after high school and travelled to Sydney to explore the gay scene on weekends. Aware that his peers would not accept his sexuality and tired of having to conceal who he was, he decided to move to Sydney for one month in 1986. He stayed for fourteen years. Richard was diagnosed with HIV in Sydney in 1987 at the age of twenty-three. He described living in denial, working three jobs, and using alcohol and recreational drugs to cope with what he perceived as the reality that he would not reach his twenty-fifth birthday. Richard continued this cycle for eighteen months until he was admitted to St. Vincent's Hospital in September 1988 with severe headaches, vision loss, and partial paralysis. His health had deteriorated to the point that the hospital staff phoned his parents and advised them to immediately travel to Sydney as they did not expect him to survive the night. Yet after taking a combination of steroids and oral medication over the next two months, Richard's health improved enough for him to be discharged from hospital. He continued to have difficulty with his mobility and his speech, which he observed remained slightly slurred over twenty-five years later. Richard's health once again declined very shortly after he was discharged from St. Vincent's Hospital. He was sent to a different hospital in south-eastern Sydney, although he could not recall the name. He underwent an MRI and explained:

> They said, "you're going for a biopsy" and they hadn't told me anything, and I was worried. I thought they were going to cut my head open. And a guy came to see me, the anesthetist and he said "oh," you know "they're only gonna drill a couple of holes in, we'll dope you up with Valium or whatever and you won't know what's going on." So, the next day they come […] and then they're screwing this frame thing into my skull. I'm nearly hysterical by this stage. And they didn't give me any drugs. And then they take me into the theatre. After they've done the MRI so they know exactly where it is, this frame gets bolted to the operating table, so you can't move at all. So, I'm stuck there, and they still didn't give me any drugs. And they just give me this local in the head, then they've got this hand drill, drilling into my skull. And I'm just "that's it!" I'm just hysterical. And then this nurse comes in, she just sort of holds my hand … So anyway they finish up, and I'm still there. And the guy who went out there, who started this procedure, it was only a new procedure, he didn't even do it, he got his residents, these wom-*girls* to do it. And then he came in later and he said, "you should think yourself lucky." There was

> no one else in there. “You should think yourself lucky, your fucking type shouldn’t get this procedure.” And I’m like, and I’m stuck bolted to the … I thought, “if I could get up now I’d just fucking smack you right in the mouth.” That was oh just … terrible. But of course, there was no one else around so I couldn’t complain.[41]

Richard’s assertion that the anesthetist denied him any information about the procedure and stated he would be “dope[d] up,” and therefore “won’t know what’s going on” reinforces his vulnerability as a patient. This statement may have been the anesthetist’s attempt to reassure Richard that the procedure would be neither particularly intrusive nor painful. Yet, there are clear differences between receiving medication to relieve pain and being “doped up.” Richard’s recall indicates that he felt excluded from making any decisions about his treatment and that he was simply the subject of medical intervention. His role as a subordinate patient is reinforced by the imagery of him alone in the room after the procedure and physically fastened to the operating table.

Richard’s perception that he “couldn’t” rather than “didn’t” complain reflects his distinct powerlessness as a gay male patient with HIV in 1988. This encounter occurred six years before discrimination and vilification on the basis of one’s HIV status were outlawed under an amendment to the NSW Anti-Discrimination Act.[42] Richard did not have access to adequate legislation to protect him from discrimination or to ensure the perpetrator was held accountable. He could have pursued legal redress against the anesthetist through the Complaints Unit of the NSW Department of Health. Yet this was a lengthy process and complainants rarely received recognition.[43] Richard’s reluctance to lodge a complaint was reasonably commonplace at a time when persecution at the hands of medical professionals was severely underreported.[44] His observation that nobody else was present during this encounter posed another barrier to him being able to seek retribution. He had no witnesses and perhaps suspected that his complaint would not have been taken seriously.

The pain this memory continues to cause Richard was apparent as he needed to take a moment alone after he recounted this event. Richard mentioned this encounter within the first twenty minutes of the three-hour interview. It appeared to be a story that he wanted to tell and one which he felt was significant to the study. On one level, the oral history interview created a forum for Richard to revisit this event and to undermine the anesthetist’s authority and expertise. His assertion that the doctor did not complete the procedure, but rather assigned the residents the task appears to be his attempt to contest the doctor's claim that he should consider himself fortunate to have received such medical care. Richard consciously stopped himself from referring to the residents as "women." His emphasis that "girls" completed the procedure suggests that he was aware of belittling the residents through the use of this term. He indicated that they were inexperienced and he perhaps received inadequate treatment. Richard's vivid recall of the operation—which left him "just hysterical"—marks a clear departure from the straightforward procedure the anesthetist had promised. At the same time, however, he may not have anticipated, nor prepared himself for the raw emotions that remembering and retelling this experience generated.

As was the case with Stephen and Greg, Richard located his traumatic encounter amidst instances whereby other gay men with HIV or AIDS were mistreated in hospitals across the 1980s. He returned to this memory as one of his final reflections at the end of the interview, thus signaling the significance this event had on his overall life experience with HIV. He concluded:

> Still, [laughs] still pissed off at that doctor in Sydney. 'Spose there's been people worse off. I remember, oh I remember seeing the footage of people, the guys in the States just lined up in the hallways in hospitals on bloody trolleys and, you know, just left there.[45]

Such cases were not limited to the United States. Gay men in Sydney cited similar grievances across the late-1980s and early-1990s. Nevertheless, well-known cases whereby medical professionals mistreated patients with HIV and AIDS created a narrative with which Richard, while obviously traumatised by his own experience, was able to relate. Such cases also provided him with the vocabulary to articulate his variation of this publicly recognised story. By aligning himself with other HIV-positive gay men who were neglected in hospitals and were therefore "worse off," Richard presented his experience as less severe and one which he could possibly overcome.

Richard perhaps sought composure by recounting a time he was ultimately able to challenge his doctor and break away from the "sick role" in a way that was not possible during his first hospital visit. Richard was hospitalised once again in the early-1990s. He recalled that he dismissed a doctor after three failed attempts to conduct a lumbar puncture procedure used to extract fluid from the spinal cord. After the third unsuccessful attempt, he responded:

> And I'm just, "fuck off, get out!" She goes, "no I have to try," and I said, "fuck off, you've had three strikes, you're fucking out!" I just lost it, completely. So – I mean they're painful enough anyway, but this is just agony. And just, you know, I totally lost it.[46]

Richard's reference to giving the doctor "three strikes" is a particularly clear marker of empowerment. Rather than being under the physician's control, his narrative, recounted over two decades after the events took place, signals a shift whereby he established himself in a position to determine whether the doctor completed an adequate job.

The use of oral history as sites for individuals to revisit and to compose memories and narratives about their pasts was especially clear in Steven's testimony. As outlined in the opening of this chapter, Steven was diagnosed with HIV in 1996, the same year HAART became available in Australia. He recalled that he demanded medication and in doing so, resisted his doctor's prognosis and insisted that he was not going to die as the medical staff expected:

> So, I'm in his hospital bed, and I'm going "where's my medication?" And they said, "we thought we'd let you get used to the idea of having HIV." And I lied and said, "I'm used to it, now give me the medication." Knowing full well that whether or not I was used to it made absolutely no difference! And in time I was gonna have to get used to it, but at the moment if that's what you wanted me to say to get these meds into me [laughs] that's fine! I remember the statement, "I'm used to it, now give'em!"[47]

Steven's testimony reflects the desperate situation he faced when presented with an early death. The appointment at the morgue signalled that those treating him were certain he was not going to survive. He may have suspected that he would receive inadequate care as the doctors and nurses expected him to die. As I have mentioned, Steven's awareness of cases whereby medical staff had refused to treat patients with HIV or AIDS led him to stop cycling in the mid-1990s. He may have felt that he needed to fight his doctors for his survival in a way that patients with other illnesses did not. In 1996, Steven's health had declined to the extent that the doctors expected him to die within the next two days. He remained in the hospital for two weeks and recalled the “success at being able to get out my hospital bed and walk to the end of the corridor and back … it took me three visits later to learn that my hospital bed was at the end of the corridor [laughs] so I basically walked three steps!” As was the case with Richard, the events Steven described took place at a time when his health had declined and he was hospitalised and under the care of doctors and other medical staff. Their explicit rejection of the “sick role” indicates both their desires to assert themselves in situations of utter vulnerability and to compose memories of hospitalisation that they were comfortable remembering and retelling. While they depicted themselves as especially active in their narratives of survival, not all of the men in this study felt this was an ideal position.

Dependence on the Health System

Representations of activists’ determinations to transform usual doctor–patient relationships can potentially omit the voices of men who were not able to assert a role in making decisions about their health care. Although some of the men in this study became reliant on their doctors when they became unwell, others were subjected to their doctors’ orders even before their physical health started to decline. At the time of the interview in 2014, Steven Jottileb was living in public housing and received weekly visits from a community nurse who specialises in mental health and HIV. His ongoing engagement with health services meant that he was perhaps more comfortable acknowledging his dependence on doctors, and he depicted his doctor maintaining an authoritative role throughout their exchanges. This was most clear when he described feeling compelled to start treatment. By the time Steven was diagnosed with HIV in 1994, the antiretroviral medications Zidovudine (AZT), Didanosine (ddI), and Zalcitabine (ddC) were licensed for use in Australia.[48] His interview reveals that not all men were involved in making decisions about their health care, especially regarding whether medication was the best option for them.

The gravity of the decision to start medication cannot be overstated. Many narrators in this study endured severe physical side effects from various treatment regimens. Some suspected that their friends died because of taking certain medications rather than the virus itself. As the following chapter demonstrates, several interviewees participated in drug trials to improve their health and to assist in the development of effective treatment for HIV, yet many refrained. Ross Duffin delayed starting medication for several years after he was diagnosed with HIV as he was concerned about developing a resistance to treatment.[49] Scott Martin also refused AZT as he did not want to take "the first thing off the shelf."[50] Although Scott was diagnosed with HIV in 1984, he did not start treatment until he developed AIDS nearly three decades later in 2013. Further, Tim Alderman recalled that his relationship with his general practitioner deteriorated when he felt she tricked him into starting AZT in the late-1980s. He not only experienced severe side effects but he also felt dependent on medication and feared he would die if he stopped taking the treatment.[51]

Men who had little support outside of the public health system were significantly more dependent on their doctors than those who were involved in activism, or who had established support networks among family members or friends. Steven was raised in a small town in regional New South Wales, nearly five hundred kilometres north-west of Sydney. He had spent nearly two decades between group homes, rehabilitation centres, and psychiatric units by the time he received his HIV-positive diagnosis. As Chapter 2 outlined, Steven's experience with medical establishments began when he became suicidal and his relatives placed him in a psychiatric ward in 1977 at the age of twenty-one. He experienced his first breakdown the following year and was diagnosed with schizophrenia. From the beginning of the interview, Steven emphasised his doctor's authoritative role in his health care. He underwent an HIV test in 1994 upon his doctor's advice, even though he did not understand why he was being tested for HIV. This early encounter signals the level of trust and control that Steven placed in his doctor. He recalled that upon receiving his positive diagnosis, "I felt really bad, I thought 'oh no, my life has ended. I'm gonna die some horrible death. And people would inject me or something like that.'"[52] Steven's concern that people would "inject" him draws on medical discourses about patients in psychiatric units being sectioned. It signals how his prior experiences in the mental health system meant he had resigned himself to the "sick role." This created a barrier to him being in a position where he could make decisions about his HIV treatment.

Unlike most other interviewees who decided when they were going to start medication, Steven felt compelled to comply with his doctor's orders. He recalled that the doctors were careful to ensure that Steven was "genuine" about wanting to start treatment and would adhere to treatment regimens before they prescribed him with antiretroviral medication. This might suggest that Steven had a choice about whether taking medication was the best option for him. Yet he was conscious that refusing to take medication could result in him being evicted from the halfway house. He reflected on his stance on treatment in 1995:

> I took them religiously. I don't know. I thought I'd – I was in a halfway house for a while and they made you take, it was like "you gotta take your medication otherwise you get kicked out." So I thought I'd better take my medication. And I had to take the medication, the HIV medication every day.[53]

Steven's concerns about being "kicked out" of the halfway house were not solely based on the practicalities of needing somewhere to live. Rather, losing his position in this home would also mean losing access to his support network. Steven had lost both of his parents by the age of seventeen, and his only sibling died in 2006. With the exception of his grandmother, he was alienated from his entire extended family as a result of his schizophrenia: "it's hard to explain, it's like, with schizophrenia you're with a certain group of people, and when you've been in hospital you can't go back to your family."[54] Steven did not elaborate further on this separation. It was perhaps due to a combination of conflict with his family, the stigma attached to having been hospitalised with schizophrenia, and what he described as a lack of support for mental illness in his hometown. Indeed, historian Katie Holmes argues that despite the increasingly open discussions about mental illness in Australia, certain conditions such as schizophrenia and other forms of psychosis "remain clouded by ignorance and stigma."[55] For Steven, then, returning to his hometown was not an option.

Steven's support network was also restricted in Sydney. He affirmed that he did not have any contact with other gay men or other people with HIV. Rather, he had experienced more acceptance from people he had met in halfway houses and rehabilitation centres as "they have their own problems."[56] He recalled, "I've had more acceptance from the people with schizophrenia than HIV I think. People with HIV don't understand mental health. They never would. They've never had mental health problems."[57] Several other men in this study attested to the psychological impact of having HIV and did, in fact, endure severe depression.

Others including Stephen and Wayne identified AIDS-related dementia as one of the major medical issues they have experienced as a result of HIV. Nevertheless, being in a halfway house with other people who experienced mental health issues offered Steven access to a level of support that he felt was otherwise unattainable. Consequently, he predominantly dealt with HIV outside of the support networks and organisations that have been a major part of Australia's response to HIV and AIDS. Steven's testimony highlights the distinctions between his experience with medication and that of other interviewees who were able to resist treatment without such consequences. Although most doctors appeared to have had a genuine desire to help their patients and recommended treatment that they believed would help to improve their patients' health, the important point is that not all men involved in making decisions about their health care.

The oral histories disturb dominant historical narratives that focus on activists who achieved a place in making decisions about their health care. These histories do not account for the experiences of HIV-positive gay men whose health declined, and who were subsequently relegated to the role of the patient. These men found themselves dependent on doctors, nurses, and other medical staff. Yet these experiences were not part of the narratives they had composed about their lives. Several interviewees dedicated a significant part of the interviews to focus on how they challenged their doctors' authoritative positions, especially after they felt healthcare workers had failed them. In this vein, the oral history interviews offered narrators a forum to portray themselves achieving the agency that might not have been attainable in the late-1980s and 1990s when they became unwell. They were able to achieve closure by composing "safe" versions of what were undoubtedly traumatic events. Anecdotes about resisting medical hierarchies appeared to help these men to deal with difficult memories of being subjected to medical care and link them to a wider trend of defying authoritarian medical practices. As a counterpoint to these narratives, Steven Jottileb's life history reveals that some men remained in the "sick role" well before their physical health declined as a result of the virus. His account indicates that individuals' abilities to achieve control in their health care were largely dependent on their physical and emotional states, and their access to support. Together, the oral histories reveal that the construction of a "good patient" meant that many men struggled to talk about times when they had to relinquish control over their health to the medical profession.

Notes

1. Steven Berveling, interview with the author, 17 July 2014, Sydney.
2. Ibid.
3. Scholars attest to the value of using oral history to uncover patients' personal accounts: Kate Fisher, "Oral Testimony and the History of Medicine," in *The Oxford Handbook of the History of Medicine*, ed. Mark Jackson (Oxford: Oxford University Press, 2011), 601, 603; Paul Thompson, "Introduction," in *Oral History, Health and Welfare*, eds. Joanna Bornat, Robert Perks, Paul Thompson, and Jan Walmsley (London: Routledge, 2000), 4.
4. In the Australian context, Robert Ariss argues that patient empowerment, as American community groups promoted, "was quickly to become the standard rhetoric of AIDS activists in Australia also." Robert Ariss, *Against Death: The Practice of Living with AIDS* (Amsterdam: Gordon and Breach, 1997), 78; Andrea M. Whittaker, "Living with HIV: Resistance by Positive People," *Medical Anthropology Quarterly* 6, no. 4 (1992): 388–9.
5. Judith Rabkin, Robert Remein, and Mark Wilson, *Good Doctors, Good Patients: Partners in HIV Treatment* (New York: NMC Publishers, 1994), 13–5. Some sociologists have conceptualised the "good" person with HIV or AIDS (PHA) in similar ways. See Eric Mykhalovskiy, Liza McCoy, and Michael Bresalier, "Compliance/Adherence, HIV, and the Critique of Medical Power," *Social Theory & Health* 2, no. 4 (2004): 326.
6. Christy Newman et al., "'We're All On The Same Side': Relationships Between General Practitioners and Their Patients and Peers in HIV Medicine," *HIV Australia* 12, no. 1 (2014): 47–8; Christy Newman et al., "Surviving an Epidemic: Australian GPs on Caring for People with HIV and AIDS in the Early Years," *Australian Family Physician* 42, no. 10 (2013): 734–8.
7. For a selection of studies into discrimination by medical professionals in Australia, see Elizabeth Herdman and Susan Kippax, *Institutional Discrimination: Critical Ethnography of HIV/AIDS Related Discrimination in a Hospital Setting* (Sydney: HIV AIDS & Society Publications, 1995); School of Medical Education, The University of New South Wales, *HIV/AIDS Related Discrimination Health Care Worker Project* (Canberra: Australian Government Publishing Service, 1994).
8. Stephen Allkins, interview with the author, 6 August 2014, Northern Rivers.

9. Greg Iverson, interview with the author, 31 August 2014, New South Wales.
10. Steven Berveling, interview with the author.
11. Centres for Disease Control and Prevention, "Current Trends Acquired Immune Deficiency Syndrome (AIDS): Precautions for Clinical and Laboratory Staffs," *MMWR Weekly* 31, no. 43 (1982): 577–80.
12. Ibid.
13. "No-Consent Tests Flout AIDS Guidelines," *Sydney Star Observer*, July 10, 1987, 1, 7.
14. "Blood on Their Hands? Doctors Demand AIDS Tests," *Sydney Star Observer*, April 29, 1988, 1; "HIV in the Operating Theatre," *Australian*, April 7, 1994, 10.
15. Joel J. Wallack, "AIDS Anxiety Among Health Care Professionals," *Hospital Community Psychiatry* 40 (1989): 507–10.
16. Jeffrey A. Kelly, "Stigmatization of AIDS Patients by Physicians," *American Journal of Public Health* 77, no. 7 (1987): 789–91; Jennifer Power, *Movement, Knowledge, Emotion: Gay Activism and HIV/AIDS in Australia* (Canberra: ANU E Press, 2011), 137; Shirleene Robinson and Emily Wilson, "Working Together? Medical Professionals, Gay Community Organisations and the Response to HIV/AIDS in Australia, 1983–1985," *Social History of Medicine* 25, no. 3 (2012): 702.
17. Robinson and Wilson, "Working Together?" 702.
18. Some doctors have documented their experiences of treating patients with HIV and AIDS during this period: Ronald Bayer and Gerald M. Oppenheimer, *AIDS Doctors: Voices from the Epidemic: An Oral History* (Oxford: Oxford University Press, 2000).
19. Greg Tillett, "Perspective: Bicentennial AIDS," *Sydney Star Observer*, October 17, 1986, 4.
20. "Hospital Accused of 'Appalling' Conditions," *Sydney Star Observer*, February 10, 1989, 5; "New Beds: Too Little, Too Late, Patients' Need Patience at St Vincent's," *Sydney Star Observer*, March 10, 1989, 1.
21. Phillip Barker, "ACT UP Storms Anti-Discrimination Board," *Green Left Weekly*, February 25, 1991.
22. James Gillett, *A Grassroots History of the HIV/AIDS Epidemic in North America* (Washington: Marquette Books LLC, 2011), 9. See also Laurie Edwards, *In the Kingdom of the Sick: A Social History of Chronic Illness in America* (New York: Walker Publishing, 2013), 91–6; Sandra Morgen, *Into Our Own Hands: The Women's Health Movement in the United States, 1969–1990* (New Jersey: Rutgers University Press, 2002), 120.
23. Gillett, *A Grassroots History of the HIV/AIDS Epidemic in North America*, 9.
24. Charlotte Williamson, *Towards the Emancipation of Patients: Patients' Experiences and the Patient Movement* (Bristol: The Policy Press, 2010), 33.
25. Ibid., 40.

26. Ibid., 34.
27. Talcott Parsons, *The Social System* (London: Routledge & Kegan Paul, 1951).
28. Australian historians attest to the importance of the gay press in providing the wider community with medical information about the epidemic. See 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 (London: Routledge, 1998), 511; Shirleene Robinson, "HIV/AIDS and Gay Community Print News Media in 1980s Australia," in *Out Here: Gay and Lesbian Perspectives VI*, eds. Yorick Smaal and Graham Willett (Melbourne: Monash University Publishing, 2011), 88.
29. Alex Mold, "Making the Patient-Consumer in Margaret Thatcher's Britain," *Historical Journal* 54, no. 2 (2011): 509; Alex Mold, "Patient Groups and the Construction of the Patient-Consumer in Britain: An Historical Overview," *Journal of Social Policy* 39, no. 4 (2010): 505–21.
30. Milton J. Lewis, *The People's Health: Public Health in Australia, 1950 to the Present* (Westport, CT: Praeger Publishers, 2003), 139.
31. Ibid.
32. "Fear and Loathing in America, AIDS Inevitable Here?" *Sydney Star Observer*, May 6, 1983, 1–2.
33. Ibid.
34. Emily Wilson, "'Someone Who is Sick and in Need of Help': Medical Attitudes to Homosexuality in Australia, 1960–1979," in *Homophobia: An Australian History*, ed. Shirleene Robinson (Sydney: The Federation Press, 2008), 148–71; Robert Reynolds, *From Camp to Queer* (Melbourne: Melbourne University Press, 2001), 12–20.
35. "Stonewall Scintillations," *Campaign*, August 1983, 8.
36. Alister Brass and Julian Gold, *AIDS in Australia: What Everyone Should Know* (Sydney: Bay Books, 1985). A guidebook written by the director of the Melbourne Communicable Diseases Centre, David Bradford, was also published that year. See David Bradford, *A.I.D.S., Herpes, and Everything You Should Know About V.D. in Australia*, Second (Melbourne: Melbourne University Press, 1985).
37. Lloyd Grosse, interview with the author, 27 August 2014, Sydney.
38. Ibid.
39. Some examples include: Larry Galbraith, "Gold on Albion Street Clinic," *Sydney Star Observer*, March 7, 1985, 4; Does Dracula Have AIDS? & Other Geoffrey Robertson Hypotheticals. Documentary. North Ryde, NSW: Angus & Robertson in association with the Australian Broadcasting Corporation, c. 1987.
40. Lloyd Grosse, interview with the author.

41. Richard McDonell, interview with the author, 23 July 2014, Melbourne, Australia. Italics indicate emphasis in Richard's voice.
42. Discrimination and vilification on the basis of one's HIV status was outlawed in 1994 under the Anti-Discrimination Act, 1977—Section 49ZXB. Katharine Gelber, *Speaking Back: The Free Speech Versus Hate Speech Debate* (Amsterdam: John Benjamin's Publishing, 2002), 140.
43. Ariss, *Against Death*, 76.
44. Ibid.
45. Richard McDonell, interview with the author.
46. Ibid.
47. Steven Berveling, interview with the author.
48. Didanosine (ddI) and Zalcitabine (ddC) were licensed in September 1990, and October 1992 respectively.
49. Ross Duffin, interview with the author, 16 July 2014, Sydney.
50. Scott Martin, interview with the author, 17 July 2014, Sydney.
51. Tim Alderman, interview with the author, 29 October 2014, Brisbane.
52. Steven Jottileb, interview with the author, 29 August 2014, Sydney.
53. Ibid.
54. Ibid.
55. Katie Holmes, "Talking About Mental Illness: Life Histories and Mental Health in Modern Australia," *Australian Historical Studies* 47, no. 1 (2016): 29.
56. Steven Jottileb, interview with the author.
57. Ibid.

CHAPTER 7

The Heroes of the Epidemic

On the morning of 6 June 1991, members of the Australian chapters of ACT UP travelled to Parliament House in Canberra. D-Day had arrived.[1] ACT UP made sure the politicians knew they were coming. In the lead up to D-Day, members of the Sydney branch sent each MP an obituary of an individual who had died from AIDS-related causes that year, accompanied by a note that read: "This name is for you."[2] The message was clear. The delays in gaining access to antiretroviral medications had cost lives and ACT UP was furious. They deployed distress flares, staged their signature "die-in" whereby members lay on the ground as though dead, displayed a large quilt that featured the names of people who had died that year, and publicly declared Federal Health Minister Brian Howe a murderer.[3] Historian and activist Graham Willett explains that D-Day centred on: "Decrying *deaths* as a result of *delays*, especially of *drug* trials, it set a *deadline* of 6 June for the Health Minister to respond to its demands for easier access to lifesaving treatments."[4] D-Day was only one of the many highly public and often controversial demonstrations that the Australian chapters of ACT UP had staged since their establishment fourteen months earlier.[5] Recently released documentaries and films have highlighted activists' public responses to the threat of HIV and AIDS. Such public representations of activists' endeavors have, Abigail Groves argues, "turned HIV activists into heroes."[6]

Public representations of HIV and AIDS activism offered some men in this study with the acknowledgement and affirmation of how they

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0_7

proactively and collectively lobbied governments to provide further funding for potentially life-saving medication. Yet these public narratives can also overshadow both the emotional strain of being involved in activist endeavours and the significant—but often unseen—contributions that others made to the HIV and AIDS cause. This chapter explores narrators' memories of sacrificing their physical and emotional health to support others with HIV or AIDS. It details their involvement in facilitating faster access to antiretroviral medication, participating in drug trials, and nursing other gay men who were dying from AIDS-related conditions. These men detailed prioritising others' wellbeing above their own in an effort to contribute to the wider HIV-positive gay community. In doing so, they gave a voice to the emotional impact of engaging in HIV and AIDS activism and support work and added their contributions to the historical record.

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 role in the HIV and AIDS epidemic. The impact of trauma was most apparent with this topic. It involved more misremembering, more pauses, and more explicit reflecting than that which emerged during any other part of the interviews. Many of these men live with the visible physical side effects of various antiretroviral medications. They also continue to deal with painful memories of nursing partners and friends in the final moments of their lives. Telling their stories were perhaps efforts to achieve the closure that oral historians argue is pertinent to narrators who have endured traumatic experiences.[7] They were able to assert that they had indeed contributed to others with HIV or AIDS. As Selma Leydesdorff et al. argue, "[t]he telling itself gives meaning to the trauma: suffering may not have been in vain."[8]

The Fight for AZT

Any mention of the first approved antiretroviral medication, AZT, aroused unfavourable memories for most of the men I interviewed. While two narrators "tolerated" the medication with few side effects, others endured a combination of severe nausea, diarrhoea, headaches, insomnia, anemia, muscle discomfort, and bone marrow failure. Those who did not take AZT were equally critical of the medication. These men had witnessed friends and acquaintances rapidly deteriorate while taking the treatment. Some speculated that their friends died as a result of taking AZT, rather than the virus itself.[9] Stephen Allkins was particularly adamant that “it felt like they put twenty guinea pigs on it and let them die.”[10] The physical and neurological damage that AZT caused was partly due to the extremely high daily dosage of 1000–1500 milligrams, over double the current recommended amount.[11] Furthermore, only people whose health had already deteriorated to a T-cell count of less than 200, or “full AIDS” were initially eligible for a place on a trial.[12]

Narrators’ grim memories of AZT, however, overshadow the hope that news of the medication initially generated among clinical researchers, activists, and other people living with HIV or AIDS. Reports about the effectiveness of AZT, initially developed as an anti-cancer agent in 1964, galvanised Sydney’s gay community. They had heard promising stories about patients with HIV and AIDS in America who had regained weight and returned to work after taking the treatment.[13] The inadequate availability of the medication that appeared to have immense success overseas sparked outrage among those affected by the virus. In August 1987, the pharmaceutical director of Wellcome Australia, the company responsible for AZT, stated that limited government funding meant the first trial for AZT would only include 200 places across Australia.[14] Medical researchers’ concerns about the toxicity of AZT had already begun to surface at that point. They identified bone marrow suppression, anaemia, insomnia, and nausea as among the serious adverse reactions to the treatment, and advised it be “administered with caution.”[15] The gay press also cautioned that AZT may only be suitable for people with “certain kinds of AIDS conditions.”[16] In lieu of any other effective medication, however, AZT offered a glimmer of hope. By the end of August 1987, a total of 319 people had reportedly died from AIDS-related causes in Australia.[17] It is little wonder that many were anxious to gain access to the only medication that appeared to have had any clinically proven success. Two months later in October 1987, Health Minister Peter Anderson announced that the state government intended to fund a further 210 places on the first AZT trial.[18] At that time, an annual supply of AZT cost $10,000 per person. To the disappointment and frustration of people involved in the HIV and AIDS cause, however, Anderson announced that funding would be phased in at approximately twenty new places each month.[19] Consequently, on the afternoon of 24 November 1987, ACON staged an “emergency rally” outside of State Parliament House against what they deemed an immoral quota. The protestors placed cardboard skulls on the fence of Parliament House, and dressed as the Grim Reaper to illustrate the impact of the government’s quota for AZT (Fig. 7.1).

Fig. 7.1 Demonstration for AZT. "Quota Is Immoral," *Sydney Star Observer*, November 27, 1987, 7

As a self-identified treatments activist, Ross Duffin took an active role in accelerating Australia's drug approval process. One of his main duties involved serving on the McDonald Review, which preceded the influential and revolutionary Baume Review of 1991.[20] Ross has outlined his public achievements as an HIV and AIDS activist in oral history interviews, articles published in the gay press, and as a guest speaker for the Positive Speakers Bureau.[21] By the time I interviewed Ross in 2014, he had composed a narrative that predominantly centred on the positive aspects of HIV and AIDS activism. He affirmed that "in the face of all this death people constructed a really good time."[22]

At the time of the interview, Ross was revising a chapter he had written about the epidemic, appropriately titled "Best of Times and Worst of Times." Ross sent me a copy of his chapter immediately after the interview. A slightly revised version was published in *Through Our Eyes—Thirty Years of People Living with HIV Responding to the HIV and AIDS Epidemics in Australia* (2014) by the National Association of

People with HIV Australia.[23] There was little deviation between Ross' written account and his oral testimony. In both forums, he asserted that HIV was the "glue" that brought people together, and he proudly recounted the success of the public demonstration for further funding in 1987:

> They were only gonna give fifty places in New South Wales when there were about a thousand people who wanted on [the trial], who would qualify. We had them at ACON every day. 'Cause what they were gonna do was just do a lottery. And we decided that we somehow had to get more places. And the only way we could think of getting more places was for the government to fund it. So we organised the first "treatments demonstration" outside New South Wales' Parliament House. We got a thousand people to turn up dressed like the Grim Reaper and la la la. [Laughs] Anyway, that afternoon we had the state government – it wasn't even their job – they funded an extra 250 places for an enormous cost! But it was a real demonstration. Like at that point there was no competition. We came out of the period where the assumption was that infectious diseases were completely solved, and the idea of dying patients protesting, you know, had enormous power! It doesn't anymore, but it did then. You know, now it's competition for limited resources. But then we got an immediate, an extra 250 places. It's an extraordinary demonstration of how demonstration can work![24]

Ross' repetition that the state government immediately agreed to fund an additional 250 places on the trial reflects both the success of the demonstration in 1987 and the lasting importance of this event as an example of activists' triumph in widening access to potentially lifesaving treatment. The process to gain further access to AZT in NSW was slightly more drawn-out. Two days after the demonstration, Health Minister Peter Anderson announced that the state government would fund an extra twenty places on the trial.[25] Portelli argues that discrepancies between events and individuals' memories are valuable when considering how narrators make sense of their pasts.[26] For Ross, the importance of this event rests on the way activists successfully lobbied the state government to respond to the medical urgency that the epidemic generated. Further, by referring to himself and other protestors as "dying patients," Ross emphasised their marginalised position and highlighted the magnitude of their achievements.

Ross' assessment that the state government immediately agreed to fund extra places on the first AZT trial when "it wasn't even their job" is also suggestive. Three months before the protest, the *Sydney Star Observer* reported that Australian AIDS Councils planned to approach their respective state governments and the federal government to provide further funding for AZT.[27] Their decision to hold the protest outside of the NSW Parliament House is a particularly clear indicator that they held the state government responsible for financing the trials. Yet Ross was perhaps suggesting that it was the federal government who was responsible for allocating funding. This would be understandable considering the Pharmaceutical Benefits Scheme meant responsibility for subsidising certain treatments fell on the Australian Government.[28] Another argument in favour of government funding was based on Medicare, Australia's national public health scheme, which has provided free or subsidised access to medical services since 1984.[29] Indeed, ACON's then-president, Don Baxter, argued that the national quota for AZT was a poor economic decision considering people with HIV or AIDS who did not have access to AZT would eventually require more expensive medical care.[30] Members of ACT UP Sydney targeted the Australian Government in the 1990s. They traveled to Canberra to demonstrate against Australia's lengthy drug approval system at the Fifth National Conference on AIDS in August 1990.[31] As outlined in the opening of this chapter, they returned to Canberra for their D-Day protests at Parliament House the following June.

As mentioned, there were considerable overlaps between Ross' written account and the topics he discussed in the oral history interview. The emotional toll of being involved in gaining access to treatment, however, was notably absent from his written chapter. It was not part of the narrative that Ross had composed about his public involvement in facilitating faster access to potentially lifesaving medication. The significance of this omission became apparent when Ross discussed his involvement in ACON's Treatments Access Scheme, or Buyers Club, in the early-1990s. In February 1991, the Australian Government passed an amendment to the Therapeutic Goods Act which legalised the importation of medication for individuals' personal use.[32] ACON established the Buyers Club under this amendment.[33] By importing bulk orders of antiretroviral medication that was yet to be approved in Australia, they not only facilitated access to treatment but also reduced the exorbitant costs which, ACT UP argued, rendered the personal importation scheme otherwise inadequate.[34] Lyle Chan, an acclaimed composer and HIV and AIDS activist, was instrumental to Sydney's Buyers Club. He reportedly imported medication for over 400 clients.[35] Ross, however, was more sceptical of their achievements. He was particularly forthcoming about the ethical dilemmas this process entailed and noted, "the doctor who we'd got to do the importing for us ran off with drugs and used them himself!" He continued:

> But you know the moral dilemma was: we've got twenty doses, who are we gonna give them to? We can't make that choice. But the doctors asked us to do it. But you know, we were more able to get the pills than the doctors were. [Laughs] Pretty silly. But there are a couple of people I know would have died without getting access to those early drugs. But you know; we couldn't do it for our friends. We talked it over a lot … and the rule was if – if they requested it and they got the money for it – 'cause it's thousands, and thousands, and thousands of dollars. And we had, you know, no guarantee that we could keep it up, or da da da. So, you know, if they requested it then we'd do it. But, um, we couldn't pay for one without paying for everyone. Shocking. I hated it. [Laughs] Knowing that treatment was around, you know, around the corner and watching your best friend die. It's just like, you know … And I said to him "look, why don't you try and get these pills? We can get them for you." And he said, "no, no, it wouldn't be fair."[36]

Ross' recall of participating in the Buyers Club was considerably tenser and more fragmented than his earlier discussion of organising the public demonstration in 1987. His frequent pauses, short laughter, and dependence on "crutch words" reveal that it was an especially raw account, and not one he had composed into a safe narrative.[37] Ross' body language also reflected his struggle to articulate the ethical dilemmas that he and others faced about whether to prioritise their friends. He started to slap his legs rhythmically when he recounted the difficulty of not being able to provide his best friend with access to treatment. When I returned to the recording, I noticed the intermittent slapping was only apparent during five minutes of the ninety-minute interview. It started slightly earlier when Ross explained that the year 1995 was especially difficult as he knew treatment was becoming available but was not able to stop friends from euthanising, and it ended shortly after this anecdote. This was not only a difficult experience but it remains a particularly uncomfortable memory.

Ross' memory of "watching" his best friend die destabilises the account he had composed which centred on staging highly effective public demonstrations and attending bureaucratic meetings. Through the Buyers Club, Ross was able to help numerous people gain access to medication that improved their chances of survival. Nevertheless, he appears to continue to feel guilty about not being able to save his best friend. Ross' attempt to distance himself emotionally from this decision was apparent in his shift from the first person to second person narrative: "watching *your* best friend die."[38] His final reflection that he did indeed offer his best friend access to medication suggests that he was ultimately unable to make this decision. It also shifts the focus away from himself to his best friend, whom he recalled made the final moral decision to refrain from gaining preferential access to the treatment.

Ross' testimony reveals the value he placed on being involved in public demonstrations to gain access to potentially lifesaving medication. Yet, there are clear distinctions between Ross' recall of the public protests and the ethical dilemmas he faced when placed in a position of distributing treatment. Ross lost most of his closest friends during the epidemic. His emphasis on his public accomplishments might have helped him to temper the trauma of losing most of his closest friends, and to cope with the guilt of having outlived them. HIV-positive gay men's involvement in the process towards making effective medication available in Australia did not stop there. Several narrators recalled participating in drug trials in an effort to contribute to the development of effective treatment. They highlighted both their motivations and the emotional effects of participating in drug trials, and asserted their role in this shared history.

Becoming "Guinea Pigs"

The interviews took place twenty-eight years after the first trials for AZT began in Australia. HIV is no longer considered a terminal illness, and many are now attuned to the implications of starting medication early and developing a resistance to various treatments. Several narrators not only developed such a resistance but also continue to endure the physical side effects of various antiretroviral medications they ingested or injected across the late-1980s and early-1990s. These men recalled participating in trials as an effort to improve their chances of survival and to help researchers to develop an effective treatment for HIV and AIDS. By citing the drastic improvements in medication that have taken place over the last three decades, they were able to assert that they had indeed contributed to the development of effective treatment and that their suffering was not in vain.

The critically acclaimed and commercially successful film *Dallas Buyers Club* (2013) resonated with several of the men in this study, despite its limited representations of gay men with HIV or AIDS. The film centres on Ron Woodroof, a heterosexual American man diagnosed with AIDS in 1985. When his health continued to decline while taking AZT, Woodroof smuggled unapproved medication into America for his personal use and to sell to others able to pay the $400 membership fee for entry into his buyers club. The film captures some of the ostracism, fear, and desperation that people with HIV or AIDS faced across the 1980s and 1990s. It also illustrates the drastic measures that individuals took to gain access to potentially life-saving medication. The film offered some of the men in this study with a public reference to describe how they were part of a community that supported one another in the face of a life-threatening disease. Mark Tietjen proudly informed me that a buyers club existed in Sydney, and Tony Creighton offered to lend me his DVD to gain insight into life for people with HIV or AIDS during that period. Thomas' recollection of the film was particularly suggestive:

> I really like, there's a – *Dallas Buyers Club* is a movie that just came out. And that really captured something there about the horror of the time, but also how people … stuck together. And how people did outrageous things 'cause they really wanted to help, they really wanted to make a difference. Yeah, I love that *Dallas Buyers Club* movie. That was great.[39]

Thomas' recollection marks an important departure from the plot. On the contrary, *Dallas Buyers Club* featured an extremely homophobic and transphobic heterosexual man who smuggled medication into America for his personal use and for financial profit.[40] Yet Thomas' interpretation reveals how the film provided him with the public narrative on which he could draw to explain that he participated in drug trials as a form of altruism. Earlier in the interview, Thomas explained that he preferred natural remedies, namely drinking carrot juice and practicing yoga. He aimed to strengthen his immune system and maintain a positive mindset until treatment became available. Across the 1990s, he also followed advice on alternative medicines that featured in the periodical, *With Compliments: Official Newsletter of HIV Complementary Therapies Collective*. The negative reports he read about AZT in the gay press led him to conclude, "that's what's really killing people."

Despite his reservations, Thomas participated in a trial for AZT in 1989, and another trial for combination therapy in 1995. These trials involved taking the prescribed medication (or placebo) for a pre-determined period and returning to his clinician at regular intervals for blood tests. Thomas endured severe nausea during the first trial. He was unable to complete the full twelve months as he felt the medication made him anxious and depressed. He explained:

> Sometimes I feel like I was used a bit as a guinea pig, but I was willing to do that at the time. I really was willing to try anything I guess to see if it would work, that would hopefully benefit me or benefit the researchers, you know, in a step towards finding a cure.[41]

Thomas' willingness to participate in these trials despite his concerns that medication was killing people reflects the dire situation he faced at a time when HIV was considered a terminal condition. His decision to participate in a trial in 1995, the year after HIV and AIDS-related deaths peaked in Australia, suggests that he might have also been influenced by concerns about his mortality or a sense of survivor guilt, both of which were common feelings among the men in this study.

Thomas appears to have found comfort in the knowledge that he was a willing participant who contributed to the development of antiretroviral medication. Alternatively, David Polson expressed frustration that his involvement in these trials is ignored in histories and public memorials that prioritise more explicit forms of activism. As outlined in Chapter 3, David struggled to reconcile his decision to conceal his HIV-positive status across the 1980s with his present role as a motivational speaker. His sense of "shame" for initially concealing his HIV-positive status manifested once again when he described sacrificing his physical health to contribute to the development of effective treatment. He perhaps participated in these trials in an effort to alleviate some of this guilt. David affirmed that after he started to appear on public HIV and AIDS campaigns in 1990:

> I immediately went on trials, and [sighs] that's been my big contribution to the world because there was nothing known about these drugs.

> They had no idea what they were going to do to us and a lot of people died from being on these trials. Uh, and there are a lot of people who remember them vividly and they were all horrible. They were ghastly. The drugs were just vile. Yeah, I can't tell you how awful they were, every single one of them. I had side effects from all of them. I had to stop drug, after drug, after drug, after drug, 'cause the side effects were so awful, which has affected me now because I'm resistant to so many classes of drugs. I've only got a certain amount of drugs available to me to be used.[42]

David's recollection of the "horrible" medication was a familiar memory among those who participated in these trials. In addition to AZT, many narrators recalled struggling to take the large "horse tablet" that was didanosine and the pain at having to inject D4T.[43] David's final assessment that he has since developed a resistance to medication and has limited treatment options reinforced his initial statement that participating in trials were his big contribution.

By testifying to the ongoing physical side effects that he continues to endure, David inadvertently contested any suggestion that he may have participated in the trials to improve his chances of survival. Participating in trials was the only way that people with HIV or AIDS were able to potentially access antiretroviral medication.[44] Instances when people had their medication tested to check if they were on a placebo, found a "compliant" doctor to prescribe the active medication, and shared their pills to increase each other's chances of taking AZT, are well acknowledged.[45] Many people also participated in these trials in the hope of improving their quality of life, their chances of survival, and for the benefits of having their health closely monitored.[46] Considering such factors, David may have also felt that he needed to affirm that he was motivated by altruism.

David's emphasis on the physical side effects of antiretroviral medication can be read as a reaction against the broader silence that he felt suppressed any public acknowledgement of his and others' roles in these trials. He had recently spoken to one of the organisers of the Candlelight Memorial in Sydney to ensure their significant contributions are recognised:

> I think it's important – I don't think it's important, I know it's important to keep the history there, and make sure that people know the

> history, and know where they came from, and know where they are today. 'Cause if it wasn't for people like me – and there are quite a few of us – the drugs wouldn't have been able to have been brought forward as quickly. 'Cause there was no – if you don't have people trialing the drugs, the drugs don't get made. So people wouldn't be where they are today. So … I'm not asking for thanks, I'm just saying that there is a group of people that need to be acknowledged. And that's the sad thing when they have these functions like the Candlelight Parade – and I brought it up this year with the convenor – I said, "it's wonderful to have this remembrance of people that died, but I think next year there needs to be some mention of those that survived but were part of the drug trials that made people where they are today."[47]

For over twenty-four years, David has lived with the severe physical side effects of various treatments. He not only developed a resistance to several medications, but he also experienced peripheral neuropathy (nerve damage), severe migraines, muscle pain, fatigue, and lipodystrophy.[48] He concluded, "HIV isn't a problem anymore, but I've got this brain disease called Superficial siderosis, which is bleeding on the brain, and it was caused by [a trial drug]."[49] Superficial siderosis is a rare, yet incurable disease that may result in neurological damage. His involvement in these trials was, therefore, an important sacrifice from which others living with HIV currently benefit. Until he receives this recognition, however, David may continue to perceive his and others' contributions as less significant than the public—and publicised—cases of other forms of HIV and AIDS activism.

Leaving a Legacy

The magnitude of death that the epidemic caused across the late-1980s and early-1990s created a high demand for volunteers who were willing to provide palliative care. Many people endured lengthy illnesses and preferred to die in the comfort of their homes, rather than in public hospitals. While HIV and AIDS activists in America and Britain voiced their frustrations that volunteer work relieved governments of their responsibilities to care for their citizens, there were few alternatives.[50] Indeed, writing in a 1986 edition of the *Sydney Star Observer*, activist Greg Tillett asserted that the anticipated increase in HIV and AIDS-related deaths would exhaust hospital resources.[51] In lieu of a "desperately needed" hospice in inner city Sydney, he predicted “the stark reality will be that many people with AIDS will have nowhere to die in peace and with adequate support. The choice of dying at home is generally possible only with adequate volunteer support.”[52] The community answered Tillett’s call.

Across the interviews, narrators shared fond memories of helping others in the final moments of their lives. Jamie recalled taking men for a “final drink” at a bar on Oxford Street, the heart of gay Sydney; Elliot delivered home-cooked food to patients at St. Vincent’s Hospital; and Geoff volunteered with the Gays Counselling Service in the mid-1980s, which he recalled predominantly involved advising people about the virus over the phone. Gay men also volunteered more formally through HIV and AIDS support organisations. These included the Ankali Project, formerly the AIDS Support Group that was established by the Gay Counselling Service in July 1983.[53] The Ankali Project was particularly valuable as it assigned volunteers to provide emotional support to clients with HIV or AIDS. The demand for volunteers to provide home-based care was amplified by the prejudice from other mainstream services which were sometimes reluctant to care for people, especially gay men, with the virus.[54] Yet this work came at a significant personal cost for the volunteers. As early as 1987, psychologist Peter Todd reported that gay male carers in Australia were experiencing emotional burn out after losing so many clients to HIV or AIDS-related causes.[55]

Narrators who nursed friends and partners in the final stages of their illnesses endured the emotional trauma of helplessly watching their loved ones’ bodies deteriorate. Damien dedicated a third of the three-hour interview to focus on his relationship with his late-partner Benjamin, whom we met in Chapter 5. He recounted meeting Benjamin at Bondi Junction railway station in Sydney’s Eastern Suburbs, the development of their relationship, and Benjamin’s eventual death from AIDS-related lymphoma in 1996. Damien’s prevailing grief became clear when he mentioned Benjamin had died. He explained: “it’s a long time ago, but it’s still …” Damien’s raw emotions and his acknowledgement of the length of time that had passed since Benjamin’s death suggests these are memories he has not been able to discuss at length in other contexts.

Their relationship began in 1990, three weeks before Benjamin was diagnosed with HIV and five years before his health started to deteriorate. Yet Damien recalled that they shared a distinct closeness and intimacy during the final months of Benjamin’s life:

> In that time, we became very close, really. A lot closer than we'd ever been 'cause I was taking care of him. He had an anal fissure on his arse, which had to be operated on. In the end, I just insisted that they operate on it 'cause they wouldn't do it because his immune system wasn't strong enough. I was just: "what does it fucking matter now anyway? If it kills him, it kills him! He's gonna die from something else more than likely; he's got fucking lymphoma, he's got – and AIDS is gonna ravish his body, so it doesn't matter, just do it!" So, they did the operation and then I was packing this wound every day with fucking gauze and cleaning it out, you know. But he didn't want anyone else to do it – it was me. He could have had the community nurse do it, no.[56]

Through his testimony, Damien rejected any possible suggestion that he nursed Benjamin in lieu of adequate support systems. Rather, he portrayed himself as Benjamin's preferred primary carer. He was not only "needed," but "wanted." Despite the closeness of their relationship, Damien received little recognition from Benjamin's family whom he recalled tried to claim Benjamin's estate after his death. Benjamin's brother was the sole exception: "his brother said to me, 'I'm entitled to part of the estate apparently. So, whatever's mine is *yours.* You're having all of it. You took care of him […] You're the one he chose to be with.'"[57] Nevertheless, his exclusion from the rest of Benjamin's family indicated that they perhaps neither acknowledged nor accepted the strength of the relationship. It was not uncommon for gay men to be left with little after their partner's deaths. Michelle Grimshaw's 1992 study into gay men's mourning rituals demonstrates how gay partners grieved in a society that did not sanction their relationship, and they were often denied the status and level of support that the bereaved usually receive.[58] Further, same-sex couples were not recognised under de facto laws in New South Wales until 1999.[59]

Some HIV-positive gay men who felt isolated from the rest of the gay community placed particular value on the affirmation that they had helped others. Victor described himself as a "loner." While he has been "very good at relating" to other people, he struggles to maintain these relationships as people find him "too intense." Victor's isolation from the broader gay community intensified when he was diagnosed with HIV in 1986. He recalled that the Sydney Day Centre, a support network established to help people deal with grief and isolation, was often crowded and he did not feel comfortable with people who attended other HIV and AIDS support groups and organisations.[60] The one variation in Victor's testimony was when he recalled giving massages to patients in Ward Seventeen at St. Vincent's Hospital, the ward dedicated to people with HIV or AIDS-related conditions. Providing massages helped him to establish a sense of purpose and he found comfort in the knowledge that he had been helpful and supportive for others, while preparing himself for the possibility that his health would also soon decline. His existing sense of isolation, however, was compounded when these men died. He reflected that "a lot of those experiences were extremely rich and deep and real, and no one knows about them. No one knows I have any relationship with those people and those people are dead."[61]

Victor's emphasis on the intimate connections he managed to develop with these men helped him to deal with his disappointment in his present lack of relationships. He attested to the value his memories of providing support and comfort for others offer in his present life:

> I feel like a failure. I try and hold on to this spiritual narrative that I've certainly done a lot of very beautiful things for a lot of people and I've been very committed to my personal growth path and I certainly have a nice – I don't know how I've managed to create a nice life on the pension – but I do. But relationship-wise, people don't ring. […] A lot of disappointment. No relationship. And it's like just talking to you now, it's like well remembering these, you know. You know, there's probably fifty HIV people who I've just really touched in a big way, because of these qualities that I have and have developed through my training, and through who I am, and through my family, that if I don't achieve another thing, I should be, you know, proud of myself.[62]

Victor's conclusion that he should be proud of himself reflects his mindset at the time of the interview. He noted that he had twice-weekly sessions with a therapist via Skype and achieved a major breakthrough the day before the interview. During that session, he "shifted" to appreciate the positive things that have happened in his life. Speaking to his therapist the day before the interview gave Victor the forum to consider what kind of narrative he wanted to tell about his life. Unlike his therapist to whom he speaks every few days, he understood that the interview was a single occurrence. It offered one opportunity to construct a life story that emphasised his personal qualities, and that helped him to achieve solace in how he had helped others.

The oral history interview created a distinct platform for Victor to achieve composure and to ensure his contributions to other men would not be forgotten as they were when the men he nursed died. This was particularly apparent in his final reflection at the end of the interview. I ended all the interviews by asking narrators to comment on how they felt about speaking about their lives. I was interested in their personal reflections of the interview process and wanted to create space for interviewees to include any memories they had not yet discussed. He reflected:

> I wouldn't say I was surprised I was emotional, but becoming emotional was I think one of the great things about the fact that, you know, we have a culture that increasingly is valuing people's stories. And so I feel the privilege of being of some value to somebody so that I get to share my story; so that I get to remember things like … I don't know how to describe this 'cause when you say "these people meant something to me," it's like I can't even remember their names. No one else knows, you know, I can't even find out any of these – just nothing to speak for it except for when I remember them in my heart. There's a certain pain for that lack of completion, for that fact that other people have these stories: "oh remember when, you know, this one died or that" – and they're part of a family narrative. […] All I can do is brag and say, "oh there was a time when I was looking after people and it was really special." No, just to be able to share that in my heart, which is a place where I'm not feeling a whole lot. There is a lot of special feeling both for the ways I was able to be of value to other people and that those experiences were a value to me. Um … and yeah, just remembering.[63]

Victor's lack of connection with others who lived through the epidemic meant that his personal history, for the most part, remains unspoken. The frustration that not being able to express his memories of this period caused is apparent in his reflection that there was a "certain pain for that lack of completion."[64] Victor's comment that he felt the privilege of being of value to someone speaks to the benefits participating in such projects can have for interviewees. Although he regularly speaks to a therapist, his relationship with his therapist is based on working through some of the emotional and psychological impacts of the epidemic and other experiences. Their interaction has a distinct power imbalance as the therapist is employed to help Victor. This is not to suggest that oral history interviews are more balanced, and oral historians are attuned to the power dynamic that places interviewers in a position of authority.[65]

For Victor, however, participating in an interview and receiving the acknowledgement that someone wanted to hear his story affirmed that his past was important. It offered him a space to achieve some sense of closure, and composure by articulating how he had helped others in their final moments. While he treasures these memories, he felt they might be disregarded as “bragging” in other contexts.

Watching others die from the same illness they were living with was undoubtedly painful for the men in this study. Damien’s and Victor’s life stories reveal how they constructed memories of this period to emphasise the significant and particular ways they nursed others with HIV or AIDS. These memories appeared to serve distinct roles in each man’s life. They sustained Damien through his prevailing grief and helped Victor to deal with a lack of relationships in his present life. Their dedication meant others’ wishes to die at home, rather than in a hospital, could be fulfilled. By retelling their accounts, they were able to achieve affirmation that their contributions during this period were significant and meaningful. Neither of these men was involved in HIV and AIDS activism and therefore lack the public recognition that activists receive. They face a particular level of silence as the people they nursed died. They are therefore the only ones who witnessed the help they provided to other gay men with HIV or AIDS during this critical time.

Together, the oral history interviews reveal the significant contributions narrators in this study made to the HIV and AIDS cause, the personal toll of being involved in activism and altruism, and how narrators remember and reflect on these experiences several years later. Existing histories that predominantly focus on HIV and AIDS activism not only document an important part of the epidemic. They also helped activists to achieve composure in how they collectively and publicly lobbied governments to provide further funding for potentially life-saving medication. Yet such histories also come at the expense of those who made significant, yet perhaps more private contributions to the HIV and AIDS cause. Most of the men who participated in this study do not have access to the level of recognition that a select group of activists who were involved in such public political demonstrations receive. During the interviews, narrators emphasised sacrificing their physical health and emotional wellbeing to help to improve the lives of people with HIV or AIDS. In doing so, they wrote themselves into the history of the epidemic. Some interviewees’ memories of caring for others during the 1980s and 1990s also helped to sustain them through their ongoing grief and present sense of isolation. Their memories of nursing friends in the final stages of AIDS reveal how closely these men were involved in others' deaths. It also raises important questions about how they coped when others died. The impact of death is further explored in the following chapter.

Notes

1. The date marked the anniversary of the first reports of AIDS in America and the Normandy landings of 1944.
2. Michael McDougall, "D-Day Attack," *Sydney Star Observer*, June 14, 1991, 1.
3. Ibid.
4. Graham Willett, "How We Saved Our Lives: The Gay Community and the Australian Response to AIDS," *HIV Australia* 12, no. 3 (2014): 6.
5. For an overview of activists' collective and public efforts to make potentially lifesaving medication available for people with HIV and AIDS, see Dennis Altman, *The End of the Homosexual?* (Queensland: University of Queensland Press, 2013), 118; Dennis Altman, *Power and Community* (London: Taylor & Francis, 1994), 71–5; Paul Sendziuk, *Learning to Trust: Australian Responses to AIDS* (Sydney: University of New South Wales Press, 2003), 211–8; Willett, "How We Saved Our Lives," 4–7; Graham Willett, *Living Out Loud: A History of Gay and Lesbian Activism in Australia* (St. Leonards, NSW: Allen & Unwin, 2000), 184–95. Sociologist Jennifer Power provides a comprehensive overview of the campaigns organised by the AIDS Treatment Action Committee, an alliance between AIDS Council of New South Wales, National People Living with AIDS Coalition and ACT UP. See Jennifer Power, *Movement, Knowledge, Emotion: Gay Activism and HIV/AIDS in Australia* (Canberra: ANU E Press, 2011), 119.
6. Abigail Groves, "A Time to Be Loud and Furious: AIDS Activism in Australia," *HIV Australia* 12, no. 2 (2014): 17.
7. Mark Klempner, "Navigating Life Review Interviews with Survivors of Trauma," *Oral History Review* 27, no. 2 (2000): 67–83; Wendy Rickard, "HIV and AIDS Testimonies in the 1990s," in *Oral History, Health and Welfare*, eds. Joanna Bornat, Robert Perks, Paul Thompson, and Jan Walmsley (London: Routledge, 2000), 235.
8. Selma Leydesdorff et al., "Introduction," in *Trauma: Life Stories of Survivors*, eds. Kim Lacy Rogers, Selma Leydesdorff, and Graham Dawson (New Jersey: Transaction Publishers, 2004), 12.
9. Lex Lageman, "AZT on Trial: The Benefits and the Risks," *Sydney Star Observer*, July 8, 1988, 10, 13.

10. Stephen Allkins, interview with the author, 6 August 2014, Northern Rivers.
11. David A. Cooper et al., "Zidovudine in Persons with Asymptomatic HIV Infection and CD4+ Cell Counts Greater Than 400 Per Cubic Millimetre," *New England Journal of Medicine* 329, no. 5 (1993): 297–303.
12. Trials for people with HIV who did not exhibit any physical symptoms began in Australia in 1988.
13. "AZT: Close to 90 Percent Still Alive One Year Later," *Sydney Star Observer*, August 7, 1987, 3.
14. Ibid. *Campaign* reported that forty people from across NSW, Queensland and Victoria were selected to undergo the six-month treatment, "Drug Trials in Australia," *Campaign*, April 1987.
15. Douglas D. Richman et al., "The Toxicity of Azidothymidine (AZT) in the Treatment of Patients with AIDS and AIDS-Related Complex," *New England Journal of Medicine* 317, no. 4 (1987): 192–7.
16. "No AZT Till '87," *Sydney Star Observer*, October 31, 1986, 6; Adam Carr, "AIDS Drugs, a Year After AZT," *OutRage*, January 1988, 38–9.
17. "Australian Increase," *New Scientist*, November 26, 1987, 29.
18. "More AZT—But Not Yet," *Sydney Star Observer*, October 30, 1987, 1; "Anderson Concerned by 'Unnecessary Testing'," *Sydney Star Observer*, October 30, 1987, 3.
19. "More AZT—But Not Yet," *Sydney Star Observer*, 1.
20. July 1991, Professor Peter Baume was commissioned to conduct an inquiry to seek improvements in Australia's drug evaluation system. The review listed 164 recommendations, all of which the government accepted. Peter Baume, *A Question of Balance: Report on the Future of Drug Evaluation in Australia, Commissioned for the Minister for Aged, Family and Health Services, the Hon. Peter Staples* (Canberra: Australian Government Publishing Service, 1991); Paul Nicoll et al., *Drug Evaluation by the Therapeutic Goods Administration: Department of Health and Family Services* (Canberra: Australian Government Publishing Service, 1996); Power, *Movement, Knowledge, Emotion*, 111–44.
21. One particularly notable example is his involvement in the large scale "Australian Response to AIDS" Oral History Project. See Ross Duffin interview with James Waites, 19–23 September 2009, The "Australian Response to AIDS" Oral History Project, National Library of Australia, TRC 6131.
22. Ross Duffin, interview with the author, July 16, 2014, Sydney.
23. Ross Duffin, "Best of Times and Worst of Times," in *Through Our Eyes: Thirty Years of People Living with HIV Responding to the HIV and AIDS Epidemics in Australia*, ed. John Stanley Rule (Sydney: National Association of People with HIV Australia, 2014), 22–7.

24. Ross Duffin, interview with the author.
25. "The Year That Was," *Sydney Star Observer*, December 25, 1987, 6.
26. Alessandro Portelli, *The Death of Luigi Trastulli and Other Stories: Form and Meaning in Oral History* (Albany: State University of New York Press, 1991), 26.
27. "AZT: Close to 90 Percent Still Alive One Year Later," *Sydney Star Observer*, 3; "Call for More AZT Funds," *Sydney Star Observer*, July 24, 1987, 7.
28. Laetitia Hattingh, John Low, and Kim Forrester, *Australian Pharmacy Law and Practice*, Second (Sydney: Elsevier Australia, 2013), 160–4.
29. Medicare came into effect under the Hawke Labor Government on 1 February 1984. For a history of Medicare and Medibank, see Anne-Marie Boxall and James Gillespie, *Making Medicare: The Politics of Universal Health Care in Australia* (Sydney: University of New South Wales Press, 2013).
30. "Quota Is Immoral," *Sydney Star Observer*, 7; Robert Ariss, *Against Death: The Practice of Living with AIDS* (Amsterdam: Gordon and Breach, 1997), 168.
31. Norman Booker, *Strengthening the Community, ACON & the HIV Epidemic in NSW* (Sydney: ACON, 1995), 32.
32. Ibid., 34.
33. Ibid.; "ACON Launches New 'Easier Access' AIDS Drugs Scheme," *Sydney Star Observer*, May 31, 1991, 1.
34. ACT UP Sydney, Submission to Peter Baume enquiry, 20 May 1991, ACT UP/Sydney—Records, 1987–1993, MLMSS 5948, State Library of New South Wales.
35. Groves, "A Time to Be Loud and Furious," 17–8.
36. Ross Duffin, interview with the author.
37. Megan Hutching identifies these as crutch words. Megan Hutching, "The Distance Between Voice and Transcript," in *Remembering: Writing Oral History*, eds. Anna Green and Megan Hutching (Auckland: Auckland University Press, 2004), 169.
38. Ross Duffin, interview with the author. My italics.
39. Thomas Parker, interview with the author, 13 July 2014, Brisbane.
40. Dallas Buyers Club traced Ron Woodroof's actions from 1985 until 1987. America's Food and Drug Administration approved the use of zalcitabine, or dideoxycytidine (ddC) five years later in June 1992.
41. Thomas Parker, interview with the author, 13 July 2014, Brisbane.
42. David Polson, interview with the author, 18 June 2014, Sydney.
43. Geoff Anderson, interview with the author, 9 August 2014, Brisbane; Tony Creighton, interview with the author, 30 July 2014, Sydney; Mark Tietjen, interview with the author, 27 August 2014, Sydney.

44. ACT UP Sydney, Flyer advertising an AIDS Drug Trials and Treatments Public Meeting, 1991, ACT UP/Sydney—Records, 1987–1993, MLMSS 5948, State Library of New South Wales.
45. Robert Ariss, "The Time for AZT Is Now," *OutRage*, April 1990, 12; Power, *Movement, Knowledge, Emotion*, 134.
46. Ariss, *Against Death: The Practice of Living with AIDS*, 89–90; Lex Lageman, "AZT on Trial: The Benefits and the Risks," *Sydney Star Observer*, July 8, 1988, 10, 13; "Taking Part in Drug Trials," *Sydney Star Observer*, November 14, 1986, 5. Other scholars state that people participated in trials for financial incentives, and to educate and empower themselves: Roberto Abadie, *The Professional Guinea Pig* (Durham: Duke University Press, 2010), 91–119.
47. David Polson, interview with the author.
48. Andrew Carr asserts that as Lipodystrophy was first related to HIV in 1999 and is almost exclusive to patients receiving antiretroviral therapy, it is likely a side effect of antiretroviral medication. Andrew Carr, "HIV Lipodystrophy: Risk Factors, Pathogenesis, Diagnosis and Management," *AIDS* 17 (2003): S143.
49. David Polson, interview with the author.
50. Virginia Berridge, "AIDS and Patient-Support Groups," in *Medicine in the Twentieth Century*, eds. Roger Cooter and John Pickstone (Amsterdam: Overseas Publishers Association, 2000), 693.
51. Greg Tillett, "Bicentennial AIDS," *Sydney Star Observer*, October 17, 1986, 4.
52. Ibid.
53. It became known as the Ankali Project in May 1985. Booker, *Strengthening the Community*, 13.
54. Louis McCallum, "Volunteer Support," in *AIDS in Australia*, eds. Eric Timewell, Victor Minichiello and David Plummer (Sydney: Prentice Hall of Australia Pty Ltd., 1992), 265; Power, *Movement, Knowledge, Emotion*, 70; Jeffrey Weeks et al., "Community Responses to HIV and AIDS: The 'De-Gaying' and 'Re-Gaying' of AIDS," in *Sexual Cultures: Communities, Values and Intimacy*, eds. Jeffrey Weeks and Janet Holland (New York: St. Martin's Press, Scholarly and Reference Division, 1996), 162.
55. Peter B. Todd, "AIDS: Burn-Out, Insidious and Devastating Toll," *Campaign*, July 1987, 27–8.
56. Damien Roberts, interview with the author, 5 August 2014, Northern Rivers.
57. Ibid. Italics indicate emphasis in Damien's voice.

58. Michelle Grimshaw, *An Anthology of Mourning Rituals Utilised by Gay Men in Response to AIDS Related Deaths* (Melbourne: National Centre for HIV Social Research, 1992), 4.
59. New South Wales Property (Relationships) Legislation Amendment Act, Act No. 4 (1999), an amendment to the De Facto Relationships Act (1984); Human Rights and Equal Opportunity Commission, *Same-Sex: Same Entitlements. National Inquiry into Discrimination against People in Same-Sex Relationships: Financial and Work-Related Entitlements and Benefits* (Sydney: HREOC, 2007), 69.
60. "Sydney Day Centre," *Sydney Star Observer*, July 8, 1988, 5.
61. Victor Day, interview with the author, 28 August 2014, Sydney.
62. Ibid.
63. Ibid.
64. Ibid.
65. Alessandro Portelli, *The Battle of Valle Giulia: Oral History and the Art of Dialogue* (Wisconsin: The University of Wisconsin Press, 1997), 9; Penny Summerfield, *Reconstructing Women's Wartime Lives* (Manchester: Manchester University Press, 1998), 26.

CHAPTER 8

Coping with Death

Tim Alderman lost his first friend to an AIDS-related illness in 1986. He had met Andrew when they both worked in Numbers, a store in Darlinghurst that sold books, pornography, and sex toys. Andrew's death was "just dreadful. It's not that he wasn't treated well, it was just that nobody knew anything about HIV. Nobody knew anything."[1] The lack of information and knowledge meant anyone who went into the hospital with an AIDS-related illness "was treated a little bit like a guinea pig." On one occasion, Tim noticed Andrew's hospital gown was unfastened, exposing a "whole row of puncture marks down his back where they'd been doing lumbar punctures on him." Tim and their friends visited Andrew in the hospital for the final time on Christmas Day in 1986. They brought him new bed sheets carefully wrapped in festive paper and sat with Andrew who insisted "I'm not going to die today." Tim received the fateful call from the hospital several hours later: "true to his word, he didn't die on Christmas day he died on Boxing day" at the age of twenty-four. For Tim and many others who lived through the epidemic, "unfortunately, it was just the start of it."

The HIV and AIDS epidemic decimated gay male populations around the world. After Australia's first reported AIDS-related death occurred in Melbourne in 1983, the death toll continued to rise, peaking at 738 deaths in 1994 alone.[2] All the men who participated in this study lost lovers, partners, friends, and colleagues. Many witnessed their entire peer group die in less than two decades. Most of these men had relocated to inner city Sydney across the late-1970s and early-1980s in pursuit of a

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0_8

vibrant gay social scene. Yet they soon found themselves attending endless funerals and mourning countless friends' deaths.[3] Despite the continual deaths, in July 1994 the *Sydney Star Observer* reported that "the gay and lesbian community remains 'emotionally strong, caring and united.'"[4] Existing histories echo this assessment. They demonstrate how scores of gay men collectively and publicly grieved by attending the annual AIDS Candlelight Memorials and the unfolding of the AIDS Memorial Quilt.[5] These public events provided attendees with a valuable forum to mourn the loss of large numbers of people who died from HIV and AIDS-related conditions. Such public commemorations, however, only took place once a year.[6] An emphasis on public rituals, while important, does not account for the diverse ways HIV-positive gay men dealt with the insurmountable losses in their private, everyday lives.

This chapter investigates how HIV-positive gay men dealt with others' deaths both within and outside of the existing support networks and public commemorations that activists established. It examines narrators' memories of attending Candlelight Memorials, the use of humour as a coping strategy, the value of frequenting nightclubs as outlets to cope with their grief, and their memories of attending—or avoiding—countless funerals. Most of the men who participated in this study upheld public representations of community solidarity. They depicted themselves as part of a gay community that persevered despite the insurmountable losses they collectively faced. The same coping mechanisms that helped some, however, marginalised others. Together, their personal accounts extend historical understandings of both public and private grieving rituals and reveal the impact of death on those who endured such losses.

Activists' decisions to establish public commemorations are located in a broader shift towards acknowledging the value of grieving that had been underway in Australia across the latter half of the twentieth century.[7] Public responses to death in Australia evolved from mid-twentieth century tendencies to restrain grief to "a late twentieth-century consensus that we can articulate grief, that it is desirable and necessary to do so and that we *need* to grieve."[8] Nevertheless, a level of silence around death and grief appears to have prevailed both outside and within Sydney's gay community. In 1993, the *Sydney Star Observer* reported that the social stigma attached to grieving meant that some gay men were hesitant to talk openly with counsellors about the extent to which they were impacted by others' deaths.[9] In response to such silence, the Ankali Project established the Coping with Multiple Loss Support

Groups at the Albion Street Centre. These groups, one for HIV-positive people and another for those who were HIV-negative, offered attendees with “a safe place to tell your story”.[10] Such explicit efforts to facilitate open discussions about grief and death reflect activists’ and counsellors’ acknowledgment of the value of grieving. Yet they also reveal that some gay men, especially those isolated from the gay community, continued to have few avenues through which they could articulate their grief. Gay men were often considered “disenfranchised grievers” in a society that rarely acknowledged their intimate relationships and the losses they endured.[11]

All the men who participated in this study discussed highly sensitive and intimate topics. These included being diagnosed with a terminal illness, experiencing opportunistic infections, and for many, anticipating their own untimely deaths. Some recalled being subjected to sexual assault and other forms of violence. Nevertheless, interviewees only became visibly upset when they recounted memories of losing close friends or partners across this period. This topic also generated more silence and more laughter than that which emerged during any other part of the interviews. Interviewees’ raw emotions can be partly attributed to the magnitude of death these men faced in a concentrated period. Writing about the “parallel epidemic of grief” as a result of HIV and AIDS, Gail Bigelow and Jeremy Hollinger argue that the grief associated with enduring multiple losses defies “traditional understanding[s] of bereavement.”[12] They suggest that common stages of grieving include initial shock, followed by suffering, and then recovery or adjustment.[13] This process varies according to several factors including the individuals and their relationships to the deceased. The important point is that the countless deaths meant these men did not have the emotional space to deal with each loss as it occurred. Brian Mitchell conceded that the multiple deaths meant “you never really deal with them, you just sort of put it away and you just try to move on because you just can’t deal with it.”[14]

The AIDS Candlelight Memorial

Many narrators understandably struggled to talk about times when they witnessed their entire peer groups deteriorate, attended multiple funerals a week, and read numerous death notices in the *Sydney Star Observer*. Their prevailing grief was particularly clear when they recounted attending the AIDS Candlelight Memorials. In Sydney, the annual AIDS Candlelight Memorials involved a silent procession from Green Park to either Hyde Park or the Sydney Domain, a distance just short of two kilometres. Following the procession, the names of those who had died that year were publicly announced. These two rituals, while both elements of the same event, generated significantly different emotional reactions from the men in this study. Several respondents emphasised the importance of the AIDS Candlelight Memorials as markers of community solidarity. Yet they exclusively referred to the procession. The reading of the names was a notable silence.

Public commemorations served an important political purpose at a time when the broader stigma attached to HIV and AIDS meant that the general public rarely acknowledged the deaths the gay community endured.[15] The numerous panels of the AIDS Memorial Quilt and the multiple names that were read aloud at the annual Candlelight Memorials paid tribute to specific individuals while reflecting the sheer number of people who had succumbed to the virus.[16] These memorials aimed to remedy the notable absence of any national acknowledgment of the large number of gay men who died across the early-1980s. In May 1993, the Melbourne-based gay magazine *OutRage* highlighted the significance of the annual AIDS Candlelight Memorials in Australia. It reported "there's a need to memorialise our losses, to create an occasion when we can safely let down our defenses and remind the world what's happening to us. So this year, again, the vigils will be held."[17] Phil Carswell, the founding president of the Victorian AIDS Council, echoed this observation during an interview for the Australian Response to AIDS Oral History Project the following month. He proclaimed, "I don't see any reason why our grief is not acknowledged and institutionalised, mainstreamed if you like, into and alongside other days of national mourning."[18] Public memorials therefore not only provided individuals with a forum to grieve but also asserted that these lives were valuable and worth remembering.

Such widespread discussions about the political objectives of the Candlelight Memorials, however, often overshadow the emotional significance these events held for attendees. They were a poignant demonstration of community solidarity. In May 1984, Carswell and Tom Carter, a well-known nurse at the Melbourne Communicable Diseases Centre, converged by candlelight in Melbourne's City Square. Their meeting is now widely regarded as Australia's first Candlelight Memorial.[19]

The following October, one thousand people reportedly marched by candlelight through Sydney city to Parliament House. Once there, they observed a minute of silence in remembrance of those who had died from AIDS-related conditions. Two years later, the *Sydney Star Observer* reported that a Candlelight Memorial would be held in Sydney on May 25 to coincide with those organised across America, Europe and in New Zealand.[20] ACON's then-president Don Baxter anticipated that the event would provide "a ceremonial way to remember our friends, to highlight the reality of AIDS in all our lives, and to show care and support for our friends."[21] The annual Candlelight Memorials gained momentum across the late-1980s and into the following decade. The increasing influence and attendance at the memorials across the early-1990s correlated with a heightened death rate.[22] Organisers of Sydney's 1993 Candlelight Memorial expected five thousand people to attend.[23] This was a considerable increase from two thousand marchers the previous year.[24]

The Candlelight Memorials were by no means exclusive to the gay community. Anyone affected by the epidemic, their supporters, and members of the wider public were encouraged to attend. Yet the vigils held particular significance for gay men living with HIV or AIDS. Writing in a 1993 edition of the *Sydney Star Observer*, HIV-positive activist Andrew Morgan depicted the event as a marker of community solidarity amidst the public hostility that many had encountered by that time.[25] Morgan asserted that gay men with HIV or AIDS faced distinct losses. He cited low self-esteem, neglect by medical staff, alienation from family members, and misrepresentation in the mainstream press. Consequently, he lobbied those "who are in a position that allows us to make this public statement of who we are can represent those who are closeted and isolated with their HIV infection as a result of social and institutional intolerance."[26] Not all activists agreed that simply attending the Candlelight Memorials would do justice to the emotional anguish that the epidemic had caused. That same year, gay activist Peter Blazey proposed that the Candlelight Memorial include a "two minute long elephant-like trumpeting of rage and grief."[27] He posited that this scream would be particularly cathartic for those who had endured physical symptoms of HIV or AIDS, the emotional challenges of having the virus, and "all the things that this vile, fucking disease means for those who have it."[28] The scream would ostensibly provide HIV-positive gay men with an outlet to express their rage at the virus. Although it did not eventuate in any formal capacity, the suggestion reflects the distinct value that the Candlelight Memorial held for those who were living with HIV or AIDS at that time.

As mentioned, although several narrators recalled that they regularly attended the AIDS Candlelight Memorials, they almost exclusively focused on the procession. It was an important demonstration of camaraderie in the face of the virus that threatened their lives. Franc Hancock recounted particularly enriching memories of the first procession he attended. He had "gone from discovering I was gay and not knowing where I belonged, to finding a community to fit into, and then the community all started to die. And I suddenly started to find myself alone again."[29] Considering his grief and isolation having lost most of his friends to HIV and AIDS, he found the processions to be "uplifting seeing how many people were there, all as one. And because we all had candles we were identifiable as part of the group. Yeah, it was uplifting."[30] Along similar lines, Adrian Eisler's participation in the AIDS Candlelight Memorial further ingrained his sense of community solidarity. He noted, "I can remember walking down Oxford Street, and I can remember going into Hyde Park, you know in this—just an overwhelming sense of community grief and the outpouring of sorrow at the loss of so many beautiful people."[31] These men sought solace in their memories that they were members of a unified community. Public commemorations reminded them that while they mourned countless deaths, they were not mourning alone.

Yet of the five men who offered detailed descriptions of attending the annual processions, none mentioned nor alluded to the public reading of the names that followed. This silence is telling. The reading of the names threatened the safe memories they had composed about being part of a community that solidified during this period. It served as an explicit reminder of how the epidemic ravaged their peer groups. The reading was therefore absent from nearly all the interviews. David Polson's account is the sole exception. David proclaimed that the Candlelight Memorials were "horrible." He shared vivid memories of his shock and anguish at being confronted by the names of friends and acquaintances, some of whom he had not realised were HIV-positive.[32] Hearing others' names being announced amplified David's concerns about his own mortality. He considered "oh it's gonna be my name read out next year."[33] David's emphasis on the emotional pain of hearing others' names read aloud offers a glimpse into why other interviewees might have repressed or preferred not to discuss these memories. As I will discuss, despite the pain the event causes, David continues to attend the public commemorations as a sign of respect to both those who died and to those who lived through the epidemic. His emphasis on the ongoing significance of the Candlelight Memorials meant that he was perhaps better placed to evaluate the lasting importance of these public events.

Such silences regarding death emerged across several of the interviews. Many respondents provided detailed accounts of one or two close friends who died across the late-1980s and 1990s. Their memories of other friends' deaths, however, became subsumed into brief discussions about attending endless funerals and experiencing decimated social networks. The few detailed descriptions they offered about individuals' deaths illustrate the important role that each man played in their lives. Their testimonies also indicate how they were, and how they continue to be affected by each loss. The significance of this silence was particularly evident in Tim's narrative.

Tim was born in Sylvania, a suburb south of Sydney city. While he acknowledged the tendency to view childhood through "rose tinted glasses," he enjoyed an idyllic, "typical suburban growing up where you weren't really supervised all that much." Tim moved to Melbourne in his early-twenties and, with support from the Catholic group "Acceptance," he embraced his sexuality and came out at the age of twenty-five. He returned to Sydney three years later in 1982. Tim's recall of living in inner city Sydney generally melded with histories of HIV and AIDS activism. He described the successful fundraisers for people with HIV and AIDS that took place at the Oxford Hotel, a popular gay bar on Oxford Street. In this respect, "ghettoisation has its advantages because you can concentrate everything into one area, and Darlinghurst is still considered the target area of HIV in Sydney." In the early-1990s, Tim facilitated peer groups at ACON and served as a volunteer and then as a paid research officer with PLWHA. He was therefore closely involved with the HIV and AIDS cause.

Twenty-five minutes into the two-and-a-half-hour interview, Tim offered a detailed account of the first time he lost a friend to AIDS-related causes. As outlined in the opening of this chapter, his friend Andrew died on Boxing day in 1986. Although Tim conceded that Andrew's death was only the start of the devastation that HIV and AIDS would cause, he did not mention death again until over ninety minutes later.[34] Two hours into the interview, he described losing another close friend in the 1990s. At this point, he explained:

> Between ’86 and ’96, woah, the death rate was … I’ve skirted around that haven’t I? Wasn’t that convenient? The number of deaths, the number of funerals, and watching the decimation of your own social circle, watching the decimation of the scene, you go to so many funerals it was never-ending. At one stage it just went on and on and on.[35]

Tim’s response to his sudden realisation that he had “skirted around” discussing death suggests that it was not a deliberate omission. Rather, it was a particularly devastating and emotionally painful part of the epidemic that he had subconsciously repressed in the interview until that moment. Tim later reinforced the reason for his omission when he stated: “I shouldn’t talk about that; it always upsets me.”[36] The raw emotions that talking about others’ deaths generated provide a possible explanation as to why Tim and other interviewees emphasised their positive memories of a community that mobilised across this period. Discussions about community solidarity might have helped them to cope with their difficult memories of facing such unimaginable losses. The ways in which interviewees repress difficult or painful memories of trauma is a familiar idea among oral historians.[37] Narrators’ memories of grieving individual friends continued to be painful and may have been “unsafe” for them if they discussed each in detail during the interview.

Narrators’ emotional pain of recounting others’ deaths also provides a possible explanation as to why so few men in this study mentioned the AIDS Memorial Quilt. This was somewhat surprising considering the public attention the Quilt has garnered.[38] The unfolding of the Memorial Quilt served a similar purpose to the reading of the names at the annual Candlelight Memorials. Both rituals paid tribute to the individuals who had died as a result of HIV or AIDS. Designing and sewing a cloth panel to add to the Quilt reportedly provided many people with emotional comfort and closure.[39] None of the men I interviewed, however, recalled being involved in this process. Their memories of the Quilt were therefore restricted to viewing it once unfolded. In February 1993, the *Sydney Star Observer* acknowledged the emotional trauma that some individuals experienced at the unfolding. National co-ordinator of the Quilt Project, Terry Thorley, reportedly observed instances when people “have walked in the door and seen the size of the quilt and it is just like a cannonball has hit them in the chest even before they get to the first panel.”[40] Adrian Eisler attested to the emotional trauma of viewing the AIDS Memorial Quilt: “when you’ve seen like a football field laid out of all these quilts, it's so distressing in a sense to realise there's a whole generation that's been wiped out."[41] In this regard, the Quilt appears to have generated the same raw emotions as the reading of the names. Unlike the procession where these men were able to see the large number of people who were still alive, the reading of the names and the unfolding of the Quilt served as a vivid reminder of how HIV and AIDS had decimated their community.

The interviews revealed a stark contrast between attending the public procession of the Candlelight Memorials and the silence regarding the reading of the names. Narrators emphasised the emotional value of attending the processions and the affirmation they achieved by walking through the city alongside others whose lives were also affected by the epidemic. Despite the endless deaths, they were not grieving alone. On the contrary, the reading of the names and the AIDS Memorial Quilt served as explicit reminders of the extent to which the epidemic had decimated their community. They were both a notable silence across nearly all the interviews. The community solidarity that narrators described experiencing at the Candlelight Memorials was instrumental in helping them to cope with their grief. Yet these commemorations were held once a year. Narrators, therefore, had to devise other strategies to deflect some of their emotional pain in their everyday lives.

Coping with Grief

Narrators described the use of humour as a particularly popular coping strategy to help them to deflect their grief across the 1980s and 1990s. Scholars of trauma and resilience are familiar with the use of humour to deal with catastrophic events or experiences.[42] Humour not only helped these men to deal with the insurmountable losses they faced but also to solidify their sense of community with other gay men who were affected by the epidemic. This was most clear in Ross' testimony:

> We had this extraordinary sick humour, I mean we couldn't relate to it now, but it was really perverse. But it was this way of surviving. You get the old *Talkabouts* there are some examples of it, [laughs] it's really shocking if you read it now. I did some of it, it's like "oh my goodness!" But it was a coping mechanism.[43]

Humour not only helped these men to cope with the grief of enduring multiple losses. By publishing in *Talkabout: Newsletter of People Living with AIDS*, Ross and other authors used humour to foster a sense of community and strengthen the bonds they shared with others who were also living with HIV at that time. *Talkabout* was established in 1989. The use of humour on a public platform was perhaps particularly important considering the heightened death-rate over the following few years. Ross' repetition that people would no longer be able to relate to their use of humour reveals the struggle to articulate the coping mechanisms he and others utilised, especially at a time when significantly fewer people are dying from HIV and AIDS-related causes.

While the use of humour helped men like Ross to cope with their grief across the 1980s and 1990s, the enduring pain of living through this period also manifested in his laughter. Ross laughed from the moment I entered his home. This did not appear to be nervous laughter. On the contrary, Ross seemed particularly buoyant and friendly. The significance of his laughter, however, became apparent when he continued to laugh intermittently throughout the ninety-minute interview. Ross perhaps anticipated the interview, which explicitly focused on HIV-positive gay men's intimate lives, may uncover highly personal and potentially painful memories. Ross was acutely aware of my research objectives. On one occasion he abruptly ended his discussion about the structure of HIV and AIDS organisations by stating "let's get back to the personal stories."[44] Although Ross has both written and publicly spoken about his role as an HIV and AIDS activist across the 1980s and 1990s, this oral history study perhaps focused on his intimate experiences more than most other forums in which he has participated.[45] It generated a different kind of remembering and retelling that to which he was accustomed. Ross was conscious of the significance of his laughter. At the end of the interview he confessed, "I laugh a lot to cover up 'oops! It's a bit messy here!'"[46]

While humour helped several HIV-positive gay men to cope with their grief, such coping strategies came at the expense of others. The use of humour had an adverse effect on Thomas. He interpreted such humour as a form of persecution against people with HIV or AIDS. Thomas moved to Sydney in the early-1980s in pursuit of a gay community and a vibrant commercial scene. He shared particularly nostalgic memories of "outrageous" parties and unforgettable friendships. His testimony reveals a clear contrast between the gay community he initially embraced upon arriving in Sydney and that which he experienced during the epidemic. Thomas explained, “when you did go to parties, people would make jokes about it. Gay people. And, um, that was kind of seen as being okay. And I didn’t think so.”[47] Thomas subsequently removed himself from the nightclub scene that had been central to his sense of identity in the preceding years as a “country boy” straight out of high school.

Teardrops on the Dance Floor

Sydney’s commercial scene that had flourished during the gay liberation movement of the 1970s provided an important outlet for many gay men to cope with the magnitude of death they collectively faced across the following two decades.[48] These men articulated their grief in a way that marked a continuation with gay community life prior to the epidemic. Although, as Chapter 2 outlined, many gay men stopped going to bars and nightclubs with the onset of HIV and AIDS, others sought solace in these venues. In 1993, Michael Glynn, the founder of the *Sydney Star Observer* reported, “I suspect our grief and our coming to terms with the desolation upon us has been buried in the ‘keep on partying’ attitude.”[49] Another commentator, playwright Campion Decent argued, “The gay and lesbian community like to party. And most people you talk to will tell you grief is locked away somewhere within the party-hard equation.”[50] That same year, the Candlelight AIDS Memorial organising committee and ACON’s HIV Support Project co-hosted a dance party at a local gay nightclub, the Midnight Shift, to follow the annual Candlelight Memorial.[51] While the gay scene had provided a space for gay men to embrace and celebrate their new-found sexual freedom in the 1970s and early-1980s, for many, it transformed into a medium through which they could articulate their grief over the following decades.

Ross placed particular emphasis on the significance of nightclubs. He partied with nurses who worked at St. Vincent’s Hospital in Sydney, which reportedly treated half of the entire Australian population with HIV and AIDS across the late-1980s.[52] These nurses were “some of the best people to go out with.” He explained, “they’d have these horror weeks and then they’d go out and party and they would party hard. I don’t know how they survived!”[53] Nightclubs also provided Tim with an outlet through which he could temporarily evade being confronted by the deaths of numerous friends. Tim participated in “gutter drag” between 1986 and 1990. This involved wearing a dress and a wig but maintaining his facial hair. The persona he adopted at that time, Cleo, was a form of "escapism."[54] Gutter drag was "a good way of [sighs] not avoiding the issue but at least for two hours, three hours it wasn't happening. You were away from it, and you were really enjoying yourself."[55] The commercial scene held particular relevance for those who were living with HIV. Across this period, men reportedly sold their belongings, claimed life insurance policies, and used their savings to travel and relish what many believed to be their final few moments. For these men, frequenting nightclubs was perhaps part of this broader effort to enjoy their lives before their bodies succumbed to the virus.

The value of nightclubs as an outlet for gay men to express their grief at losing numerous friends also featured in Greg Iverson's life story. The epidemic decimated Greg's entire friendship group and he left Sydney in 2002 after his last friend from the 1980s and 1990s died. Greg's memories of continuing to frequent nightclubs across this period provided him with the affirmation that he was part of a community that solidified in response to the deaths they collectively endured. He asserted that the epidemic "brought our community together, just so close, the gay community back then *became* closer because of this."[56]

Greg's memories of the strategies he employed to cope with the deaths of numerous friends were shaped by his role as an actor in *The Death of Kings*, a verbatim reading about the epidemic in Sydney. The reading premiered on World AIDS Day in December 2013. The cast performed again in July 2014 to coincide with the Twentieth International AIDS Conference in Melbourne. I interviewed Greg the following month. He explained that upon reading the script, he identified that some of the lines in the play were direct quotes from one of his close friends. Consequently, he felt a close personal connection with the reading. On several occasions throughout the interview, Greg quoted lines from *The Death of Kings* to articulate his memories of attending so many funerals that "I just can't cry anymore" and reading countless obituaries in the *Sydney Star Observer*. The significance of the reading became especially clear when I asked Greg whether he continued going to nightclubs and attending parties in the 1980s and 1990s. He promptly responded:

> Oh My God, yes! Even more so because of what we were facing. Again, I'm gonna refer back to this play [laughs]. Um, you know it was those

> days of, you know, "dance parties, ecstasies, Madonna," you know, "Mardi Gras, the Sleaze Ball, we had a ball we did it all," that's one of the poems in the play, "and the next day it was the slap of that door." And that poem's about a nurse, it was written by a nurse who worked in Seventeen South in St Vincent's. It's a wonderful piece, a lovely poem. You know, "the slap of that door" is referring to the doors of the hospital that you used to go through. But it's true. I don't know if because of what we were—how black it was over there made us party even harder over here to sort of block all that out. Perhaps that was part of it.[57]

The juxtaposition between the "slap of that door" and the vibrant "dance parties"—as featured in the poem, "An Afternoon Shift" by David Crawford—reveals the extent to which the nightclubs offered Greg and others with an outlet to temporarily evade the devastation and emotional turmoil that the epidemic caused in their daily lives.

Not all narrators, however, sought solace in the nightclubs during this period. Steven Berveling asserted that the gay nightclub scene in Sydney severely declined with the onset of HIV and AIDS. He reflected that "even whilst you're out, the mood wasn't there. Which is hardly surprising because there's this huge death sentence that's happening all over the community. And it had a huge impact. An enormous impact."[58] As I have mentioned, Steven was diagnosed with HIV in 1996. He recalled that he was extremely cautious about contracting HIV and refrained from going to bars and nightclubs if he had any visible cuts that he feared would expose him to the virus. His recall of a depleted nightlife in the 1980s and early-1990s therefore partly reflects his acute fear of contracting HIV at that time.

The HIV and AIDS epidemic decimated gay men's social networks across the late-1980s and early-1990s. The nightclubs offered many of these men with an important outlet to deflect some of their grief. They were able to temporarily avoid dealing with the losses they endured. By emphasising the value of nightclubs, they were able to affirm that they were part of a community that strengthened with the onset of the epidemic. Nevertheless, these men were ultimately unable to escape having to confront the ongoing deaths they faced. The seemingly endless funerals served as constant reminders of the devastating toll the epidemic was taking on their community.

Funerals for "The Living"

For many of the men in this study, the countless funerals were some of the most unforgettable and agonising parts of the 1980s and 1990s. They served as ever-present reminders that the epidemic was decimating their community. Steven Berveling's assessment that "in your twenties and thirties you don't go to lots of funerals, and we were going to lots of funerals" encapsulates how these young men were forced to confront death on a regular basis, decades before any of them should have been expected to do so.[59] For some, the funerals proved to be too emotionally devastating. They subsequently stopped attending funeral services and rather established new memorials and social gatherings to commemorate their friends. These memorials helped them to achieve the emotional closure that they could not manage at funerals. Specifically, gay men's grief at losing friends and partners was sometimes exacerbated by attending funeral services where they felt unwelcome by the deceased's family.[60] Instances when funeral services were conducted without any mention of the deceased's sexuality, or any acknowledgment of his partner or gay friends, are also well documented.[61]

Considering the emphasis that several of the interviewees placed on community solidarity, some men appeared to feel guilty for avoiding funerals. For these men, the oral history interviews became a forum to explain, and perhaps justify these decisions. Mark and Jamie were particularly forthcoming regarding their resistance to conventional funeral services. Mark worked for the Bobby Goldsmith Foundation from 1990 until 2003. He lost countless clients to the virus across the early-1990s and initially attended each client's funeral as a "sign of respect." Like many others who found the seemingly endless funerals too emotionally taxing, Mark eventually stopped attending. He justified his decision to do so by asserting, "funerals are for the living."[62] Jamie cited similar reasons. He recalled that he avoided funeral services, especially ones that were organised by the deceased's relatives as they "are about those who are left living" and "I don't control my mouth."[63] Both men lost numerous friends and acquaintances to HIV and AIDS-related causes. By emphasising that these funerals were less about the person who had died than they were about providing others with a forum to mourn, Mark and Jamie were able to affirm that they had paid these men due respect.

Emotional burn out was another main reason some narrators stopped attending funerals. Ross continued to attend funerals until HAART was introduced in 1996. He recalled that while funerals were highly attended in the 1980s, "you'd go to funerals in the '90s—and I went to most funerals of close friends—and there'd be ten people there you know because people just got completely burnt out."[64] Others, however, argued that they were not able to attend funerals as they simply did not know they were being held. Unlike Ross, Brian Mitchell did not recall any sustained contact with the gay community or HIV and AIDS organisations. Although he was involved in ACT UP in the early-1990s, he left after activist Bruce Brown died and he felt he no longer related to the group. Brian did not have access to the same information about funerals as men who were engaged in these networks. He recalled that the stigma attached to HIV or AIDS in the 1990s meant "there wasn't much publicised and you didn't know that their funeral was gonna be next week or whatever, so it just was all very quiet."[65] An examination of the numerous death notices that were published in the *Sydney Star Observer* across this period supports Brian's claim. While the newspaper published individuals' names, dates of death, and small personal messages, very few included the funeral details.

The magnitude of death, coupled with the emotional drain of attending conventional funeral services, led many gay men to devise creative and non-conventional ways to commemorate their friends. In January 1996, *Campaign* reported that "the gay community has had so much to grieve in the age of AIDS and has found many ways to express their sadness and celebrate the legacy of lost lives."[66] This involved creating new items to be displayed at the ceremony or buried with the coffin. Others took this further and created new rituals altogether. Thomas attested that these memorials were especially important as they departed from the traditional Catholic funerals to which he was accustomed: "I'm from a religious background so when there's a funeral it's at the church with the priest, and you know, all the family."[67] He continued, "people created their own ceremonies for celebrating their friend's life or having a wake to get together to commiserate. So yeah, I guess it was breaking down the traditional funeral rites as well, for me anyhow."[68] Gay men's memories of establishing new events to commemorate their friends' lives are located in a broader cultural shift towards changing funeral practices that was underway in Australia at that time. Historian Pat Jalland argues that the early-1980s witnessed a growing demand for funerals that were not conducted by clergy.[69] Such changes are illustrated by the multiple editions of *Ceremonies for Today* (1979, 1984 and 1992), authored by

Dally Messenger III, the co-founder of the Civil Celebrant Movement in Australia.[70] These guidebooks “emphasised that a life-centred funeral aimed primarily to celebrate the life of the deceased, which [Messenger] thought traditional services often failed to do.”[71]

Such memorials provided friends with a forum to meet and collectively grieve in a way they felt reflected the deceased’s life. Thomas, however, recalled a particularly confronting farewell when he attended a party hosted by Tropical Fruits, a GLBTIQ community group in the Northern Rivers region of New South Wales:

> The scene actually became really macabre, and there were parties where the ashes of someone who died from AIDS was sprinkled on the dance floor. But you know, ashes aren’t really ashes, there’s bits of bone. And so you were dancing on the dance floor and crushing someone’s bones under your feet at these parties. I just found that a bit too much and yeah, a lot of people did.[72]

These memorials were not always organised by the individual’s friends or family members. Rather, many gay men with HIV or AIDS who anticipated their deaths had an active role in planning how they would be commemorated. When I returned to this event at the end of the interview, Thomas elaborated:

> I didn’t really know the guy but he was a friend of a friend. So yeah, he wanted his ashes scattered on the dance floor. So people were dancing and crunching on his bones while they were dancing. And that was what he wanted, and that was how we sent him off. But yeah, I guess it broke down stereotypes a bit about ceremonies for when you die.[73]

Thomas’ testimony signals an important shift within the gay community whereby planning funerals helped some men to cope with what they perceived as their impending deaths. He candidly explained, “people spent a lot of time planning their funerals. Like, today everyone’s planning their weddings. But yeah, topics of conversation were, ‘so what are you—what’s your funeral?’ You know, ‘where do you wanna be buried?’”[74] Thomas’ repetition that the deceased man “wanted” his ashes on the dance floor reveals the value some of these men placed on fulfilling others’ final wishes.

This is not to suggest that people always received the farewell they wanted. Thomas conceded that although he had consciously planned his funeral, his parents would have likely organised a Catholic service where his friends would be made to feel unwelcome. In response to such issues, *Campaign* published advice from a funeral director in Sydney who encouraged people to appoint a friend or partner as the executor of their will to ensure they receive the farewell they desire.[75] This added precaution would ostensibly ensure that their wishes would be carried out as planned. Yet, this was not always the case. Another participant explained that although he was appointed as the executor of his late ex-partner's will, he felt forced to succumb to the family's demands for a religious service. Some men reportedly protested at funerals that they felt did not pay due respect to the deceased. The *Sydney Star Observer* published one man's account of a pallbearer who wore bright pink socks with bells that jingled as he walked up the aisle in response to the "silent conspiracy" from the deceased's family.[76]

These accounts reveal that some interviewees believed that funerals were not only for but also created by "the living." These men established memorials to grieve their friends, many of which departed from traditional funerals which rarely acknowledged the deceased's partner, sexuality, or gay friends. Non-conventional memorials served two important primary purposes for those living. They enabled individuals to gather with others who were enduring similar grief, and they helped some gay men with HIV or AIDS to come to terms with what they perceived as their inevitably early deaths.

Existing histories that centre on public commemorations, namely the Candlelight Memorial and the AIDS Memorial Quilt, depict a community that mobilised to collectively mourn those who died from HIV and AIDS-related causes. These commemorations served an important purpose. They provided a community with a forum to grieve, paid tribute to those who had died, and sent an important political message that these individuals' lives were valuable and worth remembering. Such public events were held once a year. The oral history interviews provide an opportunity to consider how HIV-positive gay men grieved both within and outside of the annual public events that activists had established. Most narrators composed their accounts to uphold representations of community solidarity. They presented pride in the knowledge that they were members of a distinct group that mobilised amidst the insurmountable level of death they faced. In addition to public events, interviewees recalled using humour and nightclubs to deflect their grief. These coping strategies, while vital to many, marginalised others. Death, therefore, led some men to remove themselves from the gay community. The oral histories reveal the diverse ways gay men coped with death across the 1980s and 1990s, and how they continue to deal with this grief in their present lives.

Notes

1. Tim Alderman, interview with the author, 29 October 2014, Brisbane.
2. National Centre in HIV Epidemiology and Clinical Research, *HIV/AIDS and Related Diseases Annual Surveillance Report 1997* (Sydney: National Centre in HIV Epidemiology and Clinical Research, 1997), 29, 30, 35.
3. Dennis Altman, *The End of the Homosexual?* (Queensland: University of Queensland Press, 2013), 118; Robert Reynolds and Shirleene Robinson, "HIV/AIDS, Loss and the Australian Gay Community," in *Legacies of Violence: Rendering the Unspeakable Past in Modern Australia*, ed. Robert Mason (New York: Berghahn, 2017), 162–82.
4. Philippe Cahill, "Survey Shows Strength in Community," *Sydney Star Observer*, July 1, 1994, 6.
5. Paul Sendziuk, *Learning to Trust: Australian Responses to AIDS* (Sydney: University of New South Wales Press, 2003), 222; Graham Willett, *Living Out Loud: A History of Gay and Lesbian Activism in Australia* (St. Leonards, NSW: Allen & Unwin, 2000), 192–5.
6. Other public memorials were also established in Sydney from the mid-1990s onwards. These include the Sydney Park AIDS Memorial Grove in 1994, followed by the AIDS Memorial Bell in 2003. See Paul Ashton, Paula Hamilton, and Rose Searby, *Places of the Heart: Memorials in Australia* (Melbourne: Australian Scholarly Publishing, 2012), 28.
7. Joy Damousi, *Living with the Aftermath: Trauma, Nostalgia and Grief in Post-War Australia* (Cambridge: Cambridge University Press, 2001), 3; Pat Jalland, *Changing Ways of Death in Twentieth-Century Australia* (Sydney: University of New South Wales Press, 2006), 365.
8. Damousi, *Living with the Aftermath: Trauma, Nostalgia and Grief in Post-War Australia*, 3.
9. Campion Decent, "Good Grief," *Sydney Star Observer*, February 5, 1993, 24.
10. Campion Decent, "A Place to Tell Your Story," *Sydney Star Observer*, February 5, 1993, 24.
11. Nathan R. Kollar, "Rituals and the Disenfranchised Griever," *Liturgy* 9, no. 2 (1990): 73.
12. Gail Bigelow and Jeremy Hollinger, "Grief and AIDS: Surviving Catastrophic Multiple Loss," in *Bereavement: Client Adaptation and*

Hospice Services, eds. Donna Infeld and Nadine R. Penner (New York: Routledge, 2012), 83.

13. Ibid., 84. For scholarship regarding "stages" of grieving, see Dixie L. Dennis, *Living, Dying, Grieving* (Massachusetts: Jones & Bartlett Learning, 2008), 101–11; Elisabeth Kübler-Ross and David Kessler, *On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss* (London: Simon & Schuster UK, 2005), 7–25; Therese A. Rando, *Grief, Dying and Death* (Illinois: Research Press, 1984).
14. Brian Mitchell, interview with the author, 10 June 2014, Sydney.
15. Despite the significant numbers of gay men that died as a result of the HIV and AIDS epidemic across the 1980s and 1990s, these deaths were not always acknowledged by the wider public: Judith Butler, *Precarious Life: The Powers of Mourning and Violence* (London: Verso, 2004), 34–5; Ann Cvetkovich, *An Archive of Feelings* (North Carolina: Duke University Press, 2003), 5; Deborah Lupton, *Moral Threats and Dangerous Desires: AIDS in the News Media* (London: Taylor & Francis, 1994), 125; Jennifer Power, *Movement, Knowledge, Emotion: Gay Activism and HIV/AIDS in Australia* (Canberra: ANU E Press, 2011), 147; Tamsin Wilton, *EnGendering AIDS: Deconstructing Sex, Text and Epidemic* (London: Sage, 1997), 17.
16. Robert Ariss, "Re-inventing Death: Gay Community Memorial Rites in Sydney, Australia," in *Gay Perspectives II: More Essays in Australian Gay Culture*, ed. Robert Aldrich (Sydney: Department of Economic History with the Australian Centre for Gay and Lesbian Research, 1993), 279; Jennifer Power, "Rites of Belonging: Grief, Memorial and Social Action," *Health Sociology Review* 18, no. 3 (2009): 262.
17. "Vigil," *OutRage*, May 1993, 40.
18. Phillip Carswell interview with Adam Carr, 6 June 1993, The "Australian Response to AIDS" Oral History Project, National Library of Australia, TRC 2815/36.
19. Power, *Movement, Knowledge, Emotion*, 145–6; Sendziuk, *Learning to Trust*, 222.
20. "Sydney to Join World AIDS Vigil," *Sydney Star Observer*, May 15, 1987, 1.
21. Ibid.
22. "AIDS Death Toll Reaches 2, 517," *Sydney Star Observer*, June 11, 1993, 3.
23. "Huge Turnout Expected for Candlelight Memorial," *Sydney Star Observer*, May 14, 1993, 5.
24. "Chronology: 1992," Sydney's Pride History Group, available online http://camp.org.au/90s/36-1992.

25. Andrew Morgan, “Carrying the Torch on May 23,” *Sydney Star Observer*, May 14, 1993, 5.
26. Ibid.
27. Peter Blazey, “Grief Queens and Primal Screams,” *OutRage*, July 1993, 50.
28. Ibid.
29. Franc Hancock, interview with the author, 4 August 2014, New South Wales.
30. Ibid.
31. Adrian Eisler, interview with the author, 23 May 2014, Macquarie Park.
32. David Polson, interview with the author, 18 June 2014, Sydney.
33. Ibid.
34. Tim Alderman, interview with the author.
35. Ibid.
36. Ibid.
37. Lynn Abrams, *Oral History Theory*, Second (Oxon: Routledge, 2016), 93; Alistair Thomson, “ANZAC Memories: Putting Popular Theory into Practice in Australia,” in *The Houses of History: A Critical Reader in Twentieth-Century History and Theory*, eds. Anna Green and Kathleen Troup (Manchester: Manchester University Press, 1999), 240.
38. The political importance of the Memorial Quilt is well acknowledged. For a history of the AIDS Memorial Quilt in Australia, see Ainslie Yardley and Kim Langley, *Unfolding: The Story of the Australian and New Zealand AIDS Quilt Projects* (Ringwood, VIC: McPhee Gribble, 1994); Power, *Movement, Knowledge, Emotion*, 145–58.
39. Carswell interview with Adam Carr.
40. Decent, “Good Grief,” *Sydney Star Observer.*
41. Adrian Eisler, interview with the author, 23 May 2014, Macquarie Park, Sydney.
42. Linda D. Henman, “Humour as a Coping Mechanism: Lessons from POWs,” *Humour: International Journal of Humour Research* 14, no. 1 (2001): 88; Kami A. Kosenko and Lance S. Rintamaki, “Forms, Functions, and Foibles of Humour Used in AIDS Service Organisations,” *JANAC* 21, no. 1 (2010): 40; Margaret Mitchell, “Gallows Humour,” in *Encyclopedia of Death and Dying*, eds. Glennys Howarth and Oliver Leaman (Oxon: Routledge, 2001), 203–4.
43. Ross Duffin, interview with the author.
44. Ibid., 16 July 2014, Sydney.
45. As the previous chapter outlined, Ross was revising a chapter about his experiences during the epidemic at the time of the interview: Ross Duffin, “Best of Times and Worst of Times,” in *Through Our Eyes: Thirty Years of People Living with HIV Responding to the HIV and*

AIDS Epidemics in Australia, ed. John Stanley Rule (Sydney: National Association of People with HIV Australia, 2014), 22–7.

46. Ross Duffin, interview with the author.
47. Thomas Parker, interview with the author, 13 July 2014, Brisbane.
48. The title was inspired by one of the panels on the AIDS Memorial Quilt which reads “Mr Cha Cha Heels. Teardrops on the dancefloor.” This panel is often cited to illustrate how the Quilt contained personal messages about individuals from those that mourned them. Yet it also encapsulates one of the most important coping mechanisms that interviewees recalled. Details: Marc Felshaw. 1963–1991. Mr Cha Cha Heels. Teardrops on the Dancefloor.
49. Michael Glynn, “I Am a Long Term Survivor,” *Sydney Star Observer*, February 5, 1993, 25.
50. Decent, “Good Grief,” *Sydney Star Observer*.
51. “Huge Turnout Expected for Candlelight Memorial,” *Sydney Star Observer*, May 14, 1993, 5.
52. Anne-Marie Whitaker, *St Vincent’s Hospital 1857–2007: 150 Years of Charity, Care and Compassion* (Alexandria, NSW: Kingsclear Books, 2007), 140.
53. Ross Duffin, interview with the author.
54. Tim Alderman, interview with the author.
55. Ibid.
56. Greg Iverson, interview with the author, 31 August 2014, New South Wales.
57. Ibid.
58. Steven Berveling, interview with the author, 17 July 2014, Sydney.
59. Ibid.
60. Kerry Bashford, “Rituals of Loss,” *Campaign*, January 1996, 19.
61. Grimshaw, *An Anthology of Mourning Rituals Utilised by Gay Men in Response to AIDS Related Deaths*, 4–5. See also AIDS Funerals. Documentary. Australia: ABC Compass, 2001.
62. Mark Tietjen, interview with the author, 27 August 2014, Sydney.
63. Jamie Richards, interview with the author, 2 September 2014, Tasmania.
64. Ross Duffin, interview with the author.
65. Brian Mitchell, interview with the author, 10 June 2014, Sydney.
66. Bashford, “Rituals of Loss,” *Campaign*.
67. Thomas Parker, interview with the author.
68. Ibid.
69. Jalland, *Changing Ways of Death in Twentieth-Century Australia*, 298.
70. Ibid. Messenger also wrote a history of the Civil Celebrant Movement: Dally Messenger III, *Murphy’s Law and the Pursuit of Happiness:*

A History of the Civil Celebrant Movement (Melbourne: The International College of Celebrancy, 2012).

71. Jalland, *Changing Ways of Death in Twentieth-Century Australia*, 299.
72. Thomas Parker, interview with the author.
73. Ibid.
74. Ibid.
75. Bashford, "Rituals of Loss," *Campaign*, 20.
76. Decent, "Good Grief," *Sydney Star Observer.*

CHAPTER 9

Life as Lazarus, 1996

Elliot Davidson led an envious lifestyle. He had established a successful career as a flight attendant, was well-paid, travelled the world, and received generous annual leave. An HIV-positive diagnosis in 1988 brought this life to a crashing halt. Like many others in his situation, the thirty-one-year-old believed he would encounter the same untimely death that befell so many others. Several people encouraged him to get his affairs in order, enjoy a final trip overseas, sell his belongings, and essentially prepare to die. Elliot heeded such advice. He resigned from his job, left Sydney for Queensland in pursuit of a warmer climate, and "basically sat around and waited to die. And waited, and waited, and waited. And went on the Disability Support Pension, and waited, and waited."[1]

But Elliot did not die. He survived long enough to see the introduction of HAART in 1996. Unlike many of the other men I interviewed, whose reduced physical strength and psychological health mean they are forced to continue to live on the Disability Support Pension, Elliot was able to re-enter the workforce. His ability to do so partly reflects the effectiveness of antiretroviral medication. Yet, Elliot's position at the time of the interview does not account for the emotional challenges that living with HIV, especially having survived through the 1980s and 1990s, entailed. He recalled his reaction to the introduction of medication in 1996:

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0_9

> All of a sudden, the death rate that had been going up from HIV just plummeted. And people were living rather than dying. And so then we had a whole paradigm shift and people were saying "oh well" – you know, after a couple of years people were saying "oh, now you've got an opportunity to live a bit longer and so you've gotta work out what you're gonna do, instead of dying from HIV you'll be living with HIV." And I'm going, "you gotta be shitting me! You've just been telling me for the last years that I've gotta get my house in order and get ready to die. Now I've done all that and I'm ready to go, and now you're telling me I've gotta get ready to live! How am I supposed to do that? I've resigned from my job that I loved and everything." And living on the pension is impossible! So ugh – I know 'cause I've tried it – you know, getting further and further into debt and all that sort of stuff, so there's all these challenges, and you go, "what the hell is going on? Is this someone's idea of a bad joke?"[2]

Elliot's anger does not appear to be directed at the possibility of living with HIV. Rather, it reflects the challenges that he anticipated life with HIV would entail. By the mid-1990s, Elliot had lost numerous friends to HIV and AIDS-related conditions. He had also resigned from his job and had struggled to live on a Disability Support Pension. He anticipated that living with HIV as a chronic condition would be both emotionally and economically challenging, if at all possible.

Elliot's testimony sheds light on the varied responses to the introduction of HAART in 1996. Antiretroviral medication has undoubtedly saved numerous lives and entirely transformed the experience of living with HIV. HIV is rarely considered the death sentence it once was. 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 rebuild their lives, peer groups, relationships, emotional health, physical strength, and careers in ways that they did not anticipate. The interviews revealed narrators' efforts to articulate the personal challenges they faced to adapt to life with HIV as a chronic condition while acknowledging that they are among the few who survived the epidemic. Their personal struggles with HIV from the mid-to-late-1990s are often silenced by suggestions that, unlike many, they are "lucky" to be alive.[3]

The End of AIDS?

In July 1996, approximately 15,000 participants convened in Vancouver for the highly anticipated Eleventh International AIDS Conference with the theme "One World, One Hope." The Conference is a watershed moment in international and Australian histories of HIV and AIDS. It was at this event that researchers first publicly reported the success of clinical trials that tested the effectiveness of combination therapy and protease inhibitors for treating the virus.[4] This treatment regimen, known as HAART, delayed the progression from HIV to AIDS. It transformed HIV from a terminal illness to a chronic condition that could be managed by taking antiretroviral medication. The reported success of HAART aroused much-needed hope among clinical researchers, activists, and other people living with HIV or AIDS. In the months that followed the conference, studies revealed that the virus had reduced to "undetectable. levels" in eighty percent of patients taking the medication.[5] These medical developments were celebrated as a revolution. *Science* magazine lauded the new medication as the "breakthrough of the year."[6] It reported that researchers "seldom uttered the words 'AIDS' and 'hope' in the same sentence. Today, those terms have become inextricably linked in the minds and hearts of researchers and patients alike."[7] Some media commentators went further and suggested that the introduction of HAART signaled the "end of AIDS" entirely.[8]

Although HAART was introduced in 1996, public discussions about the possibility of living with HIV, rather than dying from HIV and AIDS-related conditions first emerged over a decade earlier. As Chapter 4 outlined, from 1984 to 1988 the *Sydney Star Observer* published advice from psychologist Peter Todd who urged readers to adopt a positive mindset to survive longer with HIV.[9] Such ideas gained momentum with the PLWHA movement of the late-1980s and 1990s. In 1991, the *Sydney Star Observer* announced the establishment of the Long-Term Survival Working Group in Sydney.[10] The group aimed to provide members with information about treatment, support lifestyle changes, liaise with long-term survivor groups in America, and to help participants rebuild their self-esteem.[11] That same year, some medical researchers started to refer to HIV as a "chronic illness."[12] Such discussions are a testament to increasing understandings that the virus did not always result in death. Effective antiretroviral medication was not widely available at that time. Adopting a positive outlook was therefore considered pivotal to prolonging one's life by reducing stress and limiting the impact the virus had on their bodies.

Public discussions about the possibility of living with HIV as a chronic illness were also based on individuals' optimism about medical developments. Ross Duffin was heavily involved in transforming Australia's drug approval process in the late-1980s. He maintained that by 1988, "all the activists around the world knew that mathematically combinations were the only way it was going to be treated."[13] Members of ACON, with which Ross was employed, were particularly attuned to the effectiveness of combination therapies at that time. In September 1988, the *Sydney Star Observer* published advice from the Education Program Manager of ACON, Don Baxter. He proclaimed, "I'm confident medical authorities in San Francisco will announce this year various combination drug therapies which will change AIDS from being a terminal illness to a chronic disease."[14] Combination therapies started to be trialled in Australia four years later in 1992, although HIV remained a terminal condition until the introduction of protease inhibitors in 1996.[15] While Ross was attuned to discussions about the possibility of living with HIV as a chronic illness that had been underway since the late-1980s, the introduction of HAART in 1996 generated a significant upheaval in his life. He asserted, "in many ways, people experienced the notion of getting a life back as another crisis. It's like 'what the fuck do I do now?' Many people found it incredibly difficult, just bizarre."[16]

Although several media outlets eagerly anticipated the "end of AIDS" activists and some other people living with the virus were considerably more sceptical about the effectiveness of the new treatment.[17] Many gay men who were diagnosed with HIV in the 1980s and early-1990s had learned to devise their own health regimes in lieu of effective treatment. These involved regularly exercising, eating a balanced diet, and taking natural remedies to relieve stress and to support their immune systems. They were hesitant to begin any treatment regimen that they felt might further jeopardise their health. Some interviewees' resistance to starting HAART was also influenced by the adverse physical side effects many had encountered or witnessed others endure as a result of taking AZT the previous decade. They were conscious of the health risks associated with taking treatment. Some refrained from starting HAART until they felt it was pertinent to their survival. As I have mentioned, Scott Martin lived with HIV for twenty-nine years before he started taking treatment. Although he was offered HAART in the late-1990s, Scott resisted medical intervention until his health drastically declined and he developed AIDS in 2013. Along similar lines, John Whyte lived with HIV for sixteen years before his body succumbed to a host of other illnesses including giardia and microsporidia. Although he was diagnosed with HIV in 1984, he did not start treatment until 2000, four years after HIV became a chronic illness. Such cases illustrate that while combination therapy was available, and its success was being reported around the world, not all people with HIV shared this excitement but rather remained wary of medical intervention. It is also important to note, however, that unlike most of the men who feature in this chapter, Scott and John did not experience physical symptoms for several years—or decades—after they were diagnosed with HIV. They were both in a stronger position to resist medication than those whose health declined much earlier.

Other interviewees asserted that they had rejected their terminal diagnoses from the outset, and the introduction of HAART in 1996 had little significance to their life expectancies. This was most apparent in David Polson's account. David stated that "I was worried, I was fearful, I was terrified, but at the same time I thought 'no, bugger this. I'm not going to die from this.'"[18] David was diagnosed with HIV in 1984, although he did not exhibit any physical symptoms of HIV or AIDS-related conditions for several years. David lost numerous close friends to the virus. He appears to have composed memories of this period that attribute his survival to his ability to adopt a positive mindset, rather than to the success of medical intervention. In doing so, David affirmed that he is not alive out of "luck." Rather, he made himself more active in his narrative of survival.

Even after HAART was introduced in 1996, some interviewees continued to perceive HIV as a terminal illness.[19] They stated that they did not start medication because they simply did not know it existed. Wayne Oldrey maintained that he was unaware of the treatment until his health depleted in 2001, five years after it became available. At that point, he was "sick of life" and felt "if this is dying, I'm ready for it." He was working extensive hours, felt exhausted, and had started to become forgetful. Despite his low T-cell count of forty, his doctor advised him not to worry as "we can fix this these days." He was offered HAART and noted that: "all of a sudden it's like, the realisation is 'oh shit! So, this means I'm not gonna die now. Well, I'm thirty-one and I haven't made any long-term plans. I've got no savings … and I probably should let mum and dad know at this stage.'"[20] Along similar lines, Richard Mcdonell was unaware of the medical developments until his health deteriorated and he needed to start treatment. He explained that "there was no big announcement" that the medication had been developed.[21] As I have mentioned, many interviewees kept updated about new treatments through the gay press, other periodicals including *Talkabout: Newsletter of*

People Living with AIDS and the *National AIDS Bulletin*, and from friends with HIV or AIDS. Men like Wayne and Richard who were not closely engaged in these networks, however, did not have access to this information. They primarily relied on their doctors for updates about medication, and mainly did so when their health had declined.

The Lazarus Syndrome

The introduction of HAART in 1996 completely changed the course of HIV and AIDS. Patients taking this treatment appeared to make such rapid and drastic improvements that this process was labelled the "Lazarus Syndrome" after the Biblical figure that Christ raised from the dead.[22] The name encapsulates the transformation whereby patients taking the treatment appeared to immediately return from a state of near-death. For some of the men who participated in this study, however, the relief of being able to survive with HIV was soon surpassed by the challenges of dealing with the debilitating physical side effects of various antiretroviral medications. The issues that people with HIV or AIDS encountered while taking HAART surfaced at the International AIDS Conference in 1998. Since 1985, the International AIDS Conferences provided important platforms for clinicians, scientists, public health workers, social science researchers and people living with HIV and AIDS to discuss central issues and developments about the virus.[23] The conference that took place in 1998 was the first time the International AIDS Society had gathered since HAART was introduced two years prior. Presenters reported on the severe physical side effects patients endured. Patients had also struggled to adhere to arduous treatment regimens, and some had developed a resistance to certain medications.[24] For these patients, then, the new medication had not necessarily fulfilled the promise of transforming HIV into a chronic "manageable" condition.

Despite issues with medication, for some interviewees, the benefits of taking treatment outweighed their memories of having to deal with the severe physical side effects including intense nausea and diarrhoea. This was especially the case for Steven Berveling and Greg Iverson. These men were hospitalised in 1996 and 1997, respectively. The introduction of HAART therefore came at a critical moment for both men, and they both attributed their survival to being able to start treatment almost immediately after their health declined. As Chapter 6 outlined, Steven seroconverted in 1996 at which point his health had deteriorated to the extent that doctors had booked a space for him at the morgue in two days' time. He reflected, "to this day, and we're now, what? Eighteen years on? I catch myself out in the car, raising my fist in the air and going 'I'm alive!' And it's pretty good."[25] Greg also attested to the value of medical developments. Greg was diagnosed with HIV in 1984. He lived with the virus for thirteen years before his health drastically declined in 1997. He lost a lot of weight and "looked like death warmed up."[26] At the time of the interview, Greg was employed with an HIV and AIDS organisation in Melbourne. His role involved supporting people who had recently been diagnosed with HIV. He often reassured them that "you have nothing to worry about. With the treatments today, you have the same life expectancy as anybody else in his world. All you have to do is take a pill a day. You can live with it."[27] Both Steven and Greg endured severe physical side effects from antiretroviral medication. Greg was also forced to change his combination every twelve months as he developed a resistance to numerous medications. The arrival of HAART at a crucial moment in their lives perhaps explains why side effects did not feature prominently in their testimonies. The silence also likely reflects narrators' present acknowledgement that the same treatment that is keeping them alive might also be damaging their overall health. Steven reconciled his understanding that "the medication may cause a deep disharmony problem in my body that manifests itself in X years' time and causes me to die" by conceding "I'm gonna die anyway, so those things happen."

The extent to which narrators' memories of enduring the debilitating physical side effects of numerous treatment regimens are marginalised amidst broader narratives that celebrate the effectiveness of HAART was particularly evident in Mark's account. In response to my question regarding whether he noticed any physical changes after he started taking combination therapy in the mid-1990s, he conceded:

> Look, what we tend to forget is then we had side effects. It's probably a – I've been on I think the same combination now for about ten years, which has absolutely no side effects I'm aware of. But you know they all had side effects. But I mean, and people used to grumble and moan about the side effects. And again, I would always say "yeah look, you know, you have a bit of diarrhea, it's either that or die." You know, "look what it's doing for us."[28]

Mark's acknowledgment that the side effects are something "we tend to forget" is telling. On two other occasions during the interview, Mark stated that he had forgotten the physical side effects he endured until he started to recount them during the interview. Although he dismissed the side effects as simply “a bit of diarrhoea,” his experiences with medication were considerably more daunting. From the late-1990s, he experienced lipodystrophy and had dermal fillers injected into his face to improve his physical appearance and to limit the likelihood of being identified as an HIV-positive person. Lipodystrophy is a particularly common and well-recognised side effect of antiretroviral medication.[29] It is characterised by one’s body fat shifting from their limbs to their abdomen and to the back of their neck. He perhaps suppressed such discussions in an effort to cope with the difficult memories of dealing with the highly visible and identifiable physical side effects of medication.

Adrian’s life story reflects both the challenges of dealing with the physical side effects of antiretroviral medication in the late-1990s and the difficulty of articulating these memories nearly two decades later. In June 1995, Adrian started to develop what he perceived as a series of winter colds. Over the next few weeks, his health rapidly declined and he had to be taken into Concord Hospital in a wheelchair. He conceded, “I was sick, but I didn’t realise how sick I was.”[30] Adrian’s health had deteriorated to the extent that he had developed AIDS and he was on the “verge of dying” from pneumocystis pneumonia. He had a T-cell count of fifteen and his doctor suggested he had unknowingly been living with the virus for nearly a decade. He was “almost at deaths door, completely unaware.” Adrian remained in hospital for several weeks and reflected on “that awful period” as the beginning of his journey with HIV and AIDS, “where they managed to save my life, but I had to then confront everything that flowed from that.” Nevertheless, Adrian appeared to struggle to articulate his enduring problems with antiretroviral medication while acknowledging that he is one of the few who survived the epidemic. This was particularly apparent as it was over ninety minutes into the three-hour interview before he even alluded to the physical side effects of antiretroviral medication. He explained, “next year will be my twentieth anniversary of living with HIV/AIDS, and I’m still – hopefully still around. But there’s been quite a cost as you’ll find out.” On another instance, he cautioned that his life with HIV “hasn’t been all plain sailing as you’ll find out.” By that point in the interview, Adrian had described being diagnosed with an AIDS-defining illness, losing so much physical strength that he could not stand up to take a shower, and being denied superannuation under his employers’ “AIDS exclusion clause." I was therefore well aware that his experiences had not been "smooth sailing." Such signposting suggests Adrian was conscious that others might have had more challenging experiences than that which he endured. At the same time, he was ready to give voice to the severe challenges he faced while taking treatment.

It was over two hours into the three-hour interview before Adrian discussed the physical side effects of antiretroviral medication in further detail. He described the degradation he felt when he started taking treatment in the mid-1990s: "[severe diarrhoea] was not just embarrassing, but so socially isolating […] of course you feel terribly weak, dirty and whatever." The impact of dealing with the unseen physical side effects was compounded by the visible physical changes he faced. This included lipodystrophy, and he noted that he has a "buffalo hump" because of the medication. Consequently, "a lot of us feel we've now been disfigured."

Adrian's perception that he is fortunate to be alive and his subsequent struggle to articulate the physical challenges he faces are also based on his faith in recent medical developments. The interview took place four days before he was scheduled to start a new treatment regimen that involved taking a single pill each day. His testimony reflects a tension between feeling fortunate to be alive and in a position in which HIV occupies a decreasing role in his life, and his awareness that he will continue to deal with the ongoing physical side effects of past medications:

> The notion of going to a once a day pill next week with hopefully none of those side effects, you can imagine how [inhales deeply] how much I'm looking forward to that. But it's still not gonna take away the buffalo hump, it's still not gonna reduce my lipid profile, but then again people say, "well shut up. You're still alive so what are you whingeing about?"

Adrian's deep inhale underscores the paradox of eagerly anticipating his new treatment regimen while acknowledging that medication has irreversibly damaged his health. His final reflection, however, reveals the extent to which the challenges he faces are marginalised amidst perceptions that, unlike many people who were diagnosed with HIV as a terminal illness and died before medication became available, he is fortunate to be alive.

Tim was considerably more forthcoming than other interviewees when he discussed the severe physical side effects he endured. Most interviewees perceived HAART as pertinent to their survival. On the contrary, Tim felt that starting the new treatment regimen was unavoidable considering his body's dependence on antiretroviral medication by the mid-1990s. His horrific experiences with taking AZT the previous decade meant he was perhaps in a stronger position to critique medication than those whose health had declined as a result of the virus rather than treatment. Tim was diagnosed with HIV in 1985, but did not experience any physical symptoms until he started taking AZT three years later. He initially resisted starting AZT due to the negative reports he had read in the gay press. Nevertheless, he eventually succumbed to his doctor's pressure to start the treatment in 1988, and he concluded: "the big mistake of my life was allowing her to trick me into going onto AZT, because the moment when I started to go on AZT was the single point where all my problems started."[31]

The oral history interview focused specifically on individuals' personal accounts. It facilitated open discussions about the severe challenges Tim faced when he started taking treatment. The "problems" that Tim identified with AZT included peripheral neuropathy, severe nausea, and diarrhoea. More significantly, however, he felt that starting AZT meant his body was dependent on medication. He explained, "there was no knowing what would happen if you did go off, so if you did go off the drugs maybe you would die."[32] Consequently, Tim continued to participate in a number of trials for antiretroviral medications, including Stavudine (d4T), ddI and ddC across the late-1980s and early-1990s. Tim's narrative, therefore, reveals that he did not necessarily choose to start HAART in 1996. Rather, he felt it was unavoidable considering his body's dependence on antiretroviral medication.

Tim's health rapidly deteriorated in the mid-1990s. He was admitted to Prince Henry Hospital in Sydney with chronic anaemia and Cytomegalovirus Retinitis, a viral inflammation of the eye, among other medical conditions. Tim was made acutely aware of the extent to which his health had deteriorated when his doctor informed him that his T-cell count had declined to ten. The average T-cell count of an adult is between 500 and 1200. A T-cell count of less than 200 classified someone whose illness had progressed from HIV to AIDS. Tim asserted that upon his hospitalisation, "it was on for young and old" to keep him alive. He continued:

> When I was put into Prince Henry I thought "two weeks." You know, "you've got two weeks." And that's how sick I was it's like, "you've got

> two weeks to go." But because they put me on the combination therapy so quickly it almost overnight reversed everything – viral load testing had also come in, so they were testing my viral load which was like right up through the ceiling. But within about two weeks after starting me on the combination therapy my CD4 count had started to rise, and my viral load had come right down. So what I had assumed was going to happen – that I was going to die – didn't happen. And I had no idea of the baggage that was going to come with it [laughs]. But when I finally got out of Prince Henry […] my life was clinics and doctor's appointments. That's all my life consisted of for about the next eighteen months.[33]

The first part of Tim's account melds with depictions of people with HIV or AIDS who experienced the "Lazarus Syndrome" with the introduction of HAART. Tim's health had depleted to the extent that he expected to die within a fortnight of being admitted to hospital. On the contrary, however, he made a remarkable improvement within this time frame. Tim's transformation from a state of near-death to one where his T-cell count started to increase is a testament to the effectiveness of the antiretroviral medication.

Tim's recall of his hospitalisation, however, took a clear turn when he stated that he "had no idea of the baggage" associated with starting HAART. His account signals a clear departure from existing understandings that antiretroviral medication enabled numerous people with HIV or AIDS to promptly rebuild their lives.[34] The process Tim underwent from almost dying, to living with HIV as a chronic condition was considerably more drawn out than the "Lazarus Syndrome" suggests. Although the medication effectively treated his HIV, Tim's assertion that his life comprised clinic appointments and taking treatment reveals that his health remained a primary concern across this period. Tim spent the next eighteen months visiting doctors, especially eye specialists to treat and monitor his Cytomegalovirus Retinitis. He had also experienced Wasting Syndrome, a common HIV or AIDS-related illness that causes extreme and rapid weight loss. He, therefore, spent considerable time with doctors and nutritionists to devise strategies to regain his weight and physical strength. Tim's short laugh, as indicated in the extract, reflects the irony whereby antiretroviral medication saved his life, but he then had to deal with severe side effects and countless clinic appointments. It meant that for Tim, HIV had not necessarily become a manageable condition.

The strain of enduring severe physical side effects was amplified by the arduous treatment regimens which meant that Tim, among others, had to structure their lives around taking medication.[35] He recalled that across the mid-to-late 1990s:

> We had massive amounts of tablets to take because you weren't just taking tablets to control your CD4 counts and whatever, you were also taking all these prophylaxes for Candida, and for a whole raft of other problems that you get at that particular stage. When your CD4s were under five hundred, back in those days, you could come down with a whole raft of other problems. So you were on this massive amount of pills to handle that. So you were on massive amounts of pills for your AIDS condition, you're on massive amounts of pills for your prophylaxes. 'Cause you're on so many pills you're getting all these side effects. Diarrhea being the most chronic of them. So you're on massive amounts of pills to try to control diarrhea, to try to control nausea … the actual AIDS drugs themselves came with a whole raft of things you had to do. You had to take them eight hours apart, so you'd have to do stupid things like get up at two o'clock in the morning to take a dose of pills.[36]

Tim's memories of such intrusive treatment regimens not only reflect the impact of HIV in the 1990s, but he continues to experience some of the physical side effects of antiretroviral medication that he took in the late-1990s. These include peripheral neuropathy, and he has since lost his vision in one of his eyes. Tim's emphasis on what "we" had to do at that time reflects his understanding that his personal experiences with medication are representative of that which others in his position endured. In this regard, his testimony not only offered insight into his personal reflections but also a commentary on the broader side effects of treatment that many HIV-positive gay men experienced with the introduction of HAART. While the treatment was effective in improving both the quality of life and life expectancies of people with HIV or AIDS, the shift from dying to living with HIV was not immediate, nor straightforward.

Living with HIV

While Elliot and Ross found the news that they would survive with HIV to be confronting, medication had remarkable benefits for many of the men in this study. It enabled others to alleviate the stigma attached to the virus. They were no longer dying from a terminal illness but living with a chronic condition. Thomas Parker was considerably more optimistic about the shift from living with HIV as a terminal to a chronic illness. It provided him with the confidence to leave an abusive relationship. At the same time, however, Thomas' realisation that he would survive forced him to confront the grief he had accumulated over the previous years.

Thomas made contact with me two months before the interview.[37] The period between an interviewee making contact and participating in an interview was rarely longer than two weeks. Thomas therefore had more time than others to reflect on the life history he would to tell. He was particularly aware that an interview that focused on his intimate experiences would likely arouse difficult memories of the 1980s and 1990s. Before the interview began, he warned me that he might become upset, in which case he would excuse himself from the room and take a few moments alone. The interview that followed marked a direct contrast to that which he anticipated. He fondly reflected on his decision to move to Sydney after finishing high school, detailed his involvement in amateur theatre productions, and recounted memories of attending parties and frequenting nightclubs on Oxford Street. At one point he exclaimed: "Oh, it's nostalgic thinking about those times!"[38]

Emphasising his positive experiences might have been a way to cope with the emotions that difficult memories of the 1980s and 1990s generated. Although Thomas discussed the value of community support, he had also internalised guilt for being gay and having HIV. He attributed such guilt to his Catholic upbringing. Thomas described himself as a "good Catholic boy" during high school, a time when he had little idea about homosexuality. For Thomas, the Catholic Church's persecution of homosexuality amplified the impact of being diagnosed with HIV in the late-1980s. He explained, "I'm from a religious background and yeah, 'God gave me AIDS to punish me for being gay,' you know. And that's kind of what I get from my family. And that's what I believed myself as well."[39] Thomas' guilt for having HIV was compounded by his lack of familial support during this critical period. He explained that although he is from a large extended family, he was ostracised by other family members who disapproved of his sexuality. He reflected on his low self-esteem before 1996:

> It was really hard to meet new people and make new friends. And it was hard – I ended up with a dickhead boyfriend because I had issues with my

> self-esteem and … I didn't think … I didn't think I deserved it or, I don't know how to explain it. But I just felt like an outcast, you know. I felt diseased.[40]

Thomas' assessment that he had a "dickhead boyfriend" was a significant understatement. He described living without electricity when his former boyfriend spent their money on drugs and gambling and alluded to the physical abuse he endured. Thomas' pauses indicate his struggle to express whether he felt he "deserved" to be in that situation. It reflects the extent to which he had internalised the stigma attached to the virus and the impact of his subsequent sense of isolation.[41]

The introduction of HAART in 1996, and especially the possibility of living longer, provided him with both the confidence and the impetus to end his relationship. It helped him to alleviate some of the stigma and guilt he had internalised and he explained, "it was not a healthy relationship and it was really not until the medication started working and I started feeling more confident about a future that I actually left that relationship."[42] The shift to living with HIV as a chronic illness, however, was not an entirely liberating experience. Thomas' previous understanding that he would die from HIV or AIDS-related causes shielded him from the trauma of losing countless friends in such a concentrated period. His realisation that medication was effective and that he would likely survive meant he then had to confront the accumulation of grief he endured over the preceding years. He explained:

> HIV's a problem, but it doesn't mean it's your only problem. So I had some, yeah just a bit of a bizarre thing happen and I kind of lost the plot, I kind of went a bit crazy at the end of '99. And they didn't know what was wrong with me. Uh, I had a good doctor here at the AIDS Medical Unit, and they talked about AIDS-related dementia, where you can get HIV in the brain and it can do funny things to you. I don't really know; it was also I think the trauma of living through that time. And, I cope with difficult situations, which I had through the '80s and '90s, but as soon as the medication started working and as soon as everything seemed like it was going to be okay, that's when I lost the plot. So, I'm not sure but I had so many friends die. I think it was just an accumulation of grief.[43]

The "bizarre thing" was in reference to discrimination in his workplace, and Thomas explained that he had been denied promotions and annual leave on the basis of his HIV-positive status. This was the catalyst for an emotional breakdown. AIDS-related dementia is one of the many neurological conditions associated with HIV and AIDS that can manifest in depression, confusion, and irritability. Yet Thomas' understanding that his breakdown was due to the accumulation of grief he had experienced complicates depictions of the success of medication and offers a glimpse into some of the lasting emotional impacts of the epidemic.

HAART has completely transformed the experience of living with HIV, which is now considered a chronic condition. Celebratory narratives that solely focus on the success of medication, however, leave little room to consider the impact the introduction of combination therapy had on individuals' private lives. While some interviewees' relief at surviving overshadowed their memories of the side effects of medication, others had particularly vivid memories of intrusive treatment regimens and debilitating—and often embarrassing—physical side effects they endured. Extreme nausea and severe diarrhoea, among other health issues, meant that HIV had not necessarily become the manageable condition that some press reports claimed. Furthermore, many of those who were diagnosed with HIV as a terminal condition had to face the challenge of rebuilding their lives after believing they would die. These men had witnessed their peer groups deteriorate, had been encouraged to leave work, and had few employment prospects. Their testimonies offer insight into the nuances in HIV-positive gay men's experiences of living with the virus across the mid-to-late 1990s. For some of these men, the struggles of living with HIV as a chronic condition are marginalised by their perceptions that, unlike many, they were lucky to have survived the epidemic.

Notes

1. Elliot Davidson (pseudonym), interview with the author, 28 October 2014, Sydney.
2. Ibid.
3. Adrian Eisler, interview with the author, 23 May 2014, Macquarie Park, Sydney.
4. Medical researchers asserted that combination therapy had potential neurological benefits, and patients had less chance of developing a resistance to medication than they did with monotherapy: Demetrius James Porche, "One World. One Hope. XI International Conference on AIDS," *JANAC* 7, no. 5 (1996): 94–6.

5. Nathan L. Linsk and Sharon M. Keigher, "Of Magic Bullets and Social Justice: Emerging Challenges of Recent Advances in AIDS Treatment," *Health & Social Work* 22, no. 1 (1997): 70–4.
6. Michael Balter, "New Hope in HIV Disease," *Science* 247, no. 5295 (1996): 1988–91.
7. Ibid., 1988.
8. James Gillett, *A Grassroots History of the HIV/AIDS Epidemic in North America* (Washington: Marquette Books LLC, 2011), 151.
9. "AIDS—The Psychological Aspects," *Sydney Star Observer*, July 12, 1984, 3, 5; "Positively Healthy," *Sydney Star Observer*, June 10, 1988, 8.
10. Cameron Mahoney, "Long Time Survival," *Sydney Star Observer*, June 28, 1991, 9.
11. Ibid.
12. Leon Eisenberg, "There's No Quick Fix for AIDS," *Australian and New Zealand Journal of Psychiatry* 25, no. 3 (1991): 314–21.
13. Ross Duffin, interview with the author, 16 July 2014, Sydney.
14. "Hope in New AIDS Drugs? ACON Urges Early HIV Antibody Tests," *Sydney Star Observer*, September 16, 1988, 1; Balter, "New Hope in HIV Disease," 1988.
15. "A HIV/AIDS Timeline Emphasising the Australian/New South Wales Perspective," The Albion Centre, available from http://www.acon.org.au/wp-content/uploads/2015/04/History_of_HIV_5th-Edition.pdf, 18.
16. Ross Duffin, interview with the author.
17. Gillett, *A Grassroots History of the HIV/AIDS Epidemic in North America*, 111–2.
18. David Polson, interview with the author, 18 June 2014, Sydney.
19. Although trials for HAART began in 1995, the medication did not become widely available until 1996.
20. Wayne Oldrey, interview with the author, 8 August 2014, Gold Coast.
21. Richard McDonell, interview with the author, 23 July 2014, Melbourne.
22. David France, "Holding AIDS at Bay, Only to Face 'Lazarus Syndrome,'" *New York Times*, October 6, 1998, D7; Richard L. Sowell, Kenneth D. Phillips, and Jean Grier, "Restructuring Life to Face the Future: The Perspective of Men After a Positive Response to Protease Inhibitor Therapy," *AIDS Patient Care and STDs* 12, no. 1 (1998): 34; Mary Tucker, "Revisiting the 'Lazarus Syndrome'," in *A History of AIDS Social Work in Hospitals: A Daring Response to an Epidemic*, eds. Barbara I. Willinger and Alan Rice (Binghamton, NY: The Haworth Press, 2003), 255.
23. Gillett, *A Grassroots History of the HIV/AIDS Epidemic in North America*, 62–3. As Chapter 3 outlined, the 1988 conference was the first to provide a public platform for the voices of those with HIV or AIDS.

24. Lars Kallings and Craig McClure, *20 Years of the International AIDS Society, HIV Professionals Working Together to Fight AIDS* (Geneva, Switzerland: International AIDS Society, 2008), 29.
25. Steven Berveling, interview with the author, 17 July 2014, Sydney.
26. Greg Iverson, interview with the author, 31 August 2014, Melbourne.
27. Ibid.
28. Mark Tietjen, interview with the author, 27 August 2014, Sydney.
29. Andrew Carr, "HIV Lipodystrophy: Risk Factors, Pathogenesis, Diagnosis and Management," *AIDS* 17 (2003): S143.
30. Adrian Eisler, interview with the author, 23 May 2014, Macquarie Park
31. Tim Alderman, interview with the author, 29 October 2014, Brisbane.
32. Ibid.
33. Ibid. Viral load testing was introduced in 1996.
34. Colin Macilwain, "Better Adherence Vital in AIDS Therapies," *Nature* 390 (1997): 326.
35. Eric Mykhalovskiy, Liza McCoy, and Michael Bresalier, "Compliance/Adherence, HIV, and the Critique of Medical Power," *Social Theory & Health* 2, no. 4 (2004): 323.
36. Tim Alderman, interview with the author.
37. Thomas is located in Brisbane. I planned to travel there in July 2014, and the interview was therefore delayed.
38. Thomas Parker, interview with the author, 13 July 2014, Brisbane.
39. Ibid.
40. Ibid.
41. Scholarship on internalised stigma outlines how individuals who have been stigmatised by their friends and family members due to their illnesses are less likely to access alternative support networks, despite the value that these networks may hold. See Rachel S. Lee, Arlene Kochman, and Kathleen J. Sikkema, "Internalized Stigma Among People Living with HIV-AIDS," *AIDS and Behavior* 6, no. 4 (2002): 317.
42. Thomas Parker, interview with the author.
43. Ibid.

CHAPTER 10

Bearing Witness to the Epidemic

John Whyte first contacted me in May 2014. He had read an advertisement for this study and was eager to be involved. John was housebound with "the worst 'flu' I've ever had" but explained, "if you thought I may have something to contribute I'd be happy to engage with you."[1] This response was common, and most of the men I interviewed stated that they participated in this study to contribute to documenting a history of HIV and AIDS in Sydney. John's next email marked a clear shift in tone. He disclosed his distinct personal motivations for offering to participate in the study: "I would be most happy to become part of your research, in part because no medical person that has crossed my path in the last ten years has been the slightest bit interested in why I continue to survive."[2] John's comment on "why" rather than "how" he continued to survive reflected his mindset at the time of the interview. He had experienced "complete treatment failure" with anti-depressants and believed he was "untreatable." He anticipated the interview would provide "a fantastic opportunity to share and have recorded my personal experiences."[3]

John was born in Dannevirke, a rural town in the Manawatu-Wanganui Region of New Zealand in 1947. He had spent "seven of the most fantastic years a kid could have" on the Royal New Zealand Air Force Base in Ohakea where his father was stationed. His family then moved to Wellington and John became one of the foundational students at Tawa College in 1961. As a teenager, he started to experiment with one of his "incredibly good looking" peers and visited the beats during

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0_10

his commute to school. After finishing high school, John was accepted into the New Zealand Police Training School, which was then located in the Trentham Military Camp. His career was short-lived however, and he was pressured to leave the police force after he and another male officer were found asleep together in the barracks after a night out drinking. John insisted the situation was "absolutely totally completely innocent" but "they weren't ready to see that." While most men in similar situations "just vanished into the ether," John refused to leave Wellington and secured a job with a company that assembled car radiators. He moved to Queensland several years later in 1971, married a woman in 1975 or 1976, and the couple relocated to Sydney at the end of the decade. They separated "very amicably" shortly afterwards when John's doctor, whom he credits as one of the first openly gay doctors in Sydney, cautioned him, "she's got her whole life in front of her and you're not going to enhance it at all."[4]

John was well accustomed to recording his life experiences. When his parents were still alive, he regularly sent them cassette tapes of him speaking about his life. This was much easier than writing letters, "I used to sit down, hit the 'record' button, and in the end I could just blabber on for thirty minutes or longer without taking a breath [laughs]. It became easy." One day in the early-1990s, John sent his parents "this fatal cassette" where he informed them he had been HIV-positive for ten years. John's comfort with being recorded became clear during the four-hour interview. He openly discussed his memories of frequenting house parties with other gay men in New Zealand and exploring his sexuality. He also expressed his anger at former employers, his conflict with his neighbours, his struggle to survive on a pension, and his prevailing grief having lost all his close friends, his partner, and his parents. He also maintained that his health had improved due to his careful diet, rather than any medical intervention. In this regard, he presented himself as in control of his survival, despite feeling as though he continued to be failed by doctors and by some HIV and AIDS organisations that "certainly haven't done anything to help me."

John's frustration with a lack of an engaged audience was a consistent theme throughout the interview. He explained, "you're the first person that's ever been vaguely inquisitive about my experiences," and "not a single doctor I knew or had anything to do with was the slightest bit interested in how I was managing to still be alive." He returned to this topic at the end of the interview. In response to my question about how he felt after discussing his life in such depth, John promptly replied:

> I was really, really looking forward to it because as I said, nobody's ever been the vaguest – once I racked up twenty years, nobody, no doctor anywhere has ever been vaguely interested in how I managed to get to the twenty-year marker, and thirty years, and still … Couldn't care less, don't wanna know.

John's frustration was partly due to his remarkable story of survival. He explained that he was one of the first people to be diagnosed with HIV when the test came to Australia. He then lived with the virus for sixteen years before his health declined, he developed giardia and microsporidia among other opportunistic infections, and he felt compelled to start treatment. For John, however, having his personal travails overlooked by doctors suggested that his survival and the struggles he continued to endure with HIV were no longer relevant. Considering the broader silence, John perhaps participated in this study for the affirmation that his personal memories of the 1980s and 1990s were significant and meaningful. Despite the sensitive and emotionally difficult topics that John covered, he appeared to be particularly cheerful at the end of the interview and exclaimed, "it's been a fun afternoon!"

John died in August 2015, thirteen months after the interview. I was informed of his death by a member of the HIV Outreach Team who, with permission from John's family wanting to "support her thesis work," showed me the note that John had written before his death from cancer. When I spoke with John's sister via email, she reinforced her support for my study and her enthusiasm for helping to add John's story to the historical record. She explained that she and her siblings "had always told him that he had defied so much medically during his life and his story was worth using in someone's research. Naturally, we were excited that he had been able to do this."[5]

John's testimony raises important questions about the perspectives of men who are living in the aftermath of an epidemic that left many, without resources, fighting for their lives. The interviews took place eighteen years after HAART was introduced in Australia. In the interim, deaths from HIV and AIDS-related conditions plummeted. People started living longer and healthier lives. For many, the epidemic had been "over" for more than a decade. Yet John's testimony serves as a striking reminder that the epidemic is by no means over for those who survived. These men have lived through an event so traumatic and incomprehensible that some could only compare it to a war.[6] Yet they expressed frustration that the broader community treats HIV and AIDS as issues from the past without considering the impact on those who are still dealing with the pain of what they experienced.

This chapter explores narrators' motivations for participating in this study. Stephen Allkins and Lloyd Grosse attested to an increasing interest in their public responses to the epidemic. Recently released documentaries and oral history projects reaffirmed their pride that they were members of a gay community that proactively responded to the threat of HIV and AIDS. With the exception of Ross, however, none of the other interviewees had access to the audience and level of public acknowledgement they described. David Polson, Jamie Richards, and Tony Creighton expressed particular frustration that they felt ignored in public discussions about HIV and AIDS. Their personal testimonies appear to be suppressed at a time when HIV has been "normalized."[7] Some scholars have identified this period as "post AIDS," whereby HIV and AIDS are no longer considered to occupy a dominant role in gay men's lives.[8] Considering the broader public silence, narrators sought to give voice to an experience that they believe has been forgotten.

Narrators' enthusiasm about participating in this study reveals the importance of bearing witness to the HIV and AIDS epidemic.[9] Bearing witness involves individuals relaying their personal—and often traumatic—experiences to others.[10] Psychiatrist Dori Laub identifies this process as one of "reexternalization."[11] The narrator reconsiders and often changes the meaning they had previously ascribed to an event. It becomes, as oral historian Mark Klempner argues, "drained of some of its toxicity."[12] While oral historians are attuned to the potential risks associated with interviewing people about traumatic experiences, many also acknowledge how individuals may benefit from talking about difficult memories in oral history interviews. Alistair Thomson attests to the importance of remembering and recounting the past in oral history interviews, which "helps people feel good about themselves because they are listened to, and because they are able to represent themselves in positive ways."[13]

Re-gaying HIV and AIDS

From the early-1990s, Australian activists started to raise concerns that they were essentially being written out of the history of the HIV and AIDS epidemic. Their anger was particularly pronounced after the

December 1990 observance of World AIDS Day. The theme "Women and AIDS" addressed the increasing rates of HIV and AIDS among heterosexual women. While commentators in the gay press acknowledged the importance of this issue, they argued that the primary focus on women came at the expense of gay men. Specifically, the *Sydney Star Observer* condemned officials who launched World AIDS Day and Counteraid, the latter a major fundraising event whereby celebrities staffed store counters to raise money for HIV and AIDS. They felt officials failed to acknowledge the significant contributions that gay men and lesbians had made to the HIV and AIDS cause.[14] The same edition published the article, "World AIDS Day: Where Were the Gay Men?" The author, a writer and activist named Paul Paech, prophesied that "the absolutely incredible response of most gay men to the catastrophe of AIDS will simply be ignored."[15] He continued:

> Damn it all! They're trying to rewrite our history already! Let's get one thing straight about World AIDS Day and it's something that no politician, no medico, no health department bureaucrat, no editor, no clergyman, indeed, no man, and no woman should ever be allowed to forget. In Australia, AIDS has been a disease of gay men.[16]

Australian activists' anger at what they perceived as an increasing *in*visibility of gay men was also based on their concerns that gay men would be neglected in the national response to the epidemic and would be deprived of adequate funding. This was particularly alarming considering HIV and AIDS-related deaths peaked in the early-1990s. The epidemic was by no means over for gay men. Journalist Larry Galbraith addressed these issues in his report on Australia's Fourth National Conference on AIDS in 1990.[17] The event took place two years after the Third National AIDS Conference whereby a group of people publicly identified as HIV-positive. Considering the history of the conference, it is perhaps not surprising that Galbraith attested to an increasing number of delegates who identified as living with HIV or AIDS. Yet he also denounced the "growing invisibility of gay men […] no time or attention was given to the special needs or issues faced by gay men, who are still by far the largest group directly affected by AIDS."[18] Galbraith's criticisms are located in a broader shift towards what some Australian and international gay activists termed the "homosexualization" or "de-gaying" of HIV and AIDS across western countries.[19] De-homosexualization involved implementing strategies to combat the epidemic without referring to gay men, despite them remaining the group most affected by the virus across this period. Some gay activists had initially supported this shift as it destigmatised the virus by downplaying the connection between HIV and gay men.[20] Yet de-homosexualization also had an adverse effect. It led to decreased recognition and support for gay communities across several countries.[21]

Some activists' fears that gay men would essentially be written out of histories of HIV and AIDS does not appear to have eventuated as they expected. The ways in which gay activists across western countries galvanised in response to the epidemic has been memorialised in numerous international and Australian theatre productions, films and oral history projects. Public interest in gay men's responses to HIV and AIDS was also displayed through the launch of public exhibitions. These included *HIV and AIDS 30 Years On: The Australian Story*, *David McDiarmid: When You See This Remember Me*, and *Transmissions: Archiving HIV/AIDS—Melbourne 1979–2014*. The latter two were organised to coincide with the Twentieth International AIDS Conference that was held in Melbourne in 2014, the same year I conducted the interviews.[22] In addition to public exhibitions, international and Australian documentaries demonstrate how members of marginalised groups—namely gay men and sex workers—mobilised in the face of the deadly virus.[23] Such public representations of activists' achievements reinforced ideas that gay men were part of a community that was on the frontlines of the epidemic. It depicted them displaying an almost unparalleled level of community solidarity.

Some of the activists in this study, however, asserted that such public interest in their experiences across the 1980s and 1990s has been a more recent development. Lloyd Grosse has participated in numerous oral history interviews and delivered guest speeches about his involvement in the HIV and AIDS cause across the 1980s and 1990s. When I met Lloyd for the interview, he informed me that Stephen Allkins had phoned him earlier that morning to encourage him to participate in this study. Lloyd and I had already arranged an interview by that point. Nevertheless, their conversation appears to have reinforced Lloyd's understanding that there is a renewed public interest in their collective experiences with HIV and AIDS. He addressed such recognition during the interview and stated:

> It's funny that we're starting to get interest back into our experiences. Like, people like me and Allkins have unique perspectives on how this movement was born, and how it moved, and how it created leaders, and how it created enemies. And we're now in a position where … [sighs] that stuff doesn't exist anymore. And so there's been a resurgence in interest in what our experience was.[24]

Lloyd's observation that there was an increasing interest in his and other activists' experiences was tempered by his frustration that he felt a significant part of their history is lost. He expressed disappointment that "no one seems to remember Shop Until You Drop," a fundraising event that started as Counteraid.[25] He also joked that younger members of the current HIV and AIDS movement have not engaged with him and other activists from his generation as "they probably think we're all dead."[26] For Lloyd, then, the oral history interview created a platform for him to articulate his role in a history, and in a movement, which he believes younger generations have been unable to replicate.

Stephen echoed Lloyd's assessment that there was an increasing awareness of the value of his and other activists' memories of the HIV and AIDS epidemic. Previous chapters have outlined Stephen's close involvement in the gay community, especially with the gay commercial scene through his forty year career as a DJ. While he witnessed fractures and divisions within the gay community once friends became visibly unwell, he also maintained that the threat of the virus "politically charged" gay men in Sydney who continued to thrive amidst seemingly endless deaths and backlash from the wider public. Stephen also attested that it was over a decade after the introduction of HAART in 1996 before he felt as though he was able to speak about the epidemic, and more importantly, that others were willing to listen:

> The pills hit, and people just went "let's never speak of it again." And I thought it would be for a minute so that we can take a breath and recover, and they literally didn't. And it's only since *Rampant* came out that I started seeing people like Lost Gay Sydney, the Gay and Lesbian Archives , the Pride History Group, and you. There are all of these people coming out of the woodwork to record our history.[27]

In recent years, Stephen has gained access to various avenues through which he can discuss his memories of living with HIV across this period.

Since the Lost Gay Sydney Facebook page launched in 2012, it has provided a forum for people to share photographs, newspaper clippings, and anecdotes about living in Sydney from the 1970s to the early-2000s. The existence and popularity of the site reinforced his perception that there is an entire community who have distinct memories to share.

Stephen's narrative reveals the importance of having a platform to publicly bear witness to the epidemic. This was most apparent when he spoke of participating in the 2007 Australian documentary, *Rampant: How a City Stopped a Plague*. The immense value that Stephen placed on featuring in *Rampant* became clear when he identified viewing the documentary as the start of his emotional healing from the trauma of the preceding years:

> You live through the crisis that was AIDS and you move through it, and by the end of it nobody wanted to talk about it so you just felt shut down. You became irrelevant. Everything you'd gone through, it felt like you were almost irrelevant. Or it never happened. And so I'm processing that in my head and Victoria [Midwinter Pitt] calls me about the documentary. And then I do the interview and then she shows me the documentary, and it just brings back this flood of everything I thought but you felt like you were making it up 'cause you see a whole society of people that just don't have that in them.[28]

Rampant was the first documentary that traced the history of the HIV and AIDS epidemic as it had unfolded in Sydney across the 1980s and 1990s. It encapsulated several important themes that have prevailed in Australian histories of HIV and AIDS. The documentary emphasised how the epidemic galvanised members of Sydney's gay community, sex workers, injecting drug users, doctors, and politicians. In doing so, it paid due respect the many people who worked together to promptly establish peer-based preventative education. *Rampant* also provided Stephen with a particularly safe version of this shared history. It reinforced his pride that he was part of a community that mobilised to provide a distinct and exceptional response to HIV and AIDS.

Rampant was also significant as it was the first indication to Stephen that the silence he felt suppressed discussions about HIV and AIDS had finally been lifted. Although he initially traced this silence to when "the pills hit" in 1996, a closer examination of his life story suggests that he felt discussions about the virus were suppressed from the late-1980s.

Earlier in the interview, Stephen recounted one instance when he visited a close friend who was dying from an AIDS-related illness. He recalled that their mutual friends, all of whom were at least ten years his senior, forbade him from mentioning HIV or AIDS. They feared any explicit discussions about the virus would upset their friend. Stephen remembered a particularly tense visit. He felt that "I couldn't talk to him because I'd been told not to talk to him [about AIDS] by the adults."[29] For several years after the introduction of HAART, HIV and AIDS appear to have remained issues that he felt he was prohibited from discussing.

Stephen may have also participated in this study to contribute to documenting the history of a community that provided an effective and incomparable response to the threat of HIV and AIDS. As was the case with Lloyd, Stephen felt that younger generations have been unable to replicate the level of activism that he and others established. He attributed this to inherent differences between his generation of activists and those who grew up under John Howard's prime ministership, which produced "a whole society of people that just don't have that in them."[30] He continued, "if we were like people were—back then, the way they are now—when AIDS hit, we would've crawled under a rock. We would've said 'it's our fault,' we would've said 'we're awful people.'"[31] Lloyd and Stephen were involved in a distinct kind of activism at a time when large numbers of gay men were dying. They were motivated by a level of anger that is perhaps expressed in different ways at a time when HIV is no longer considered a terminal illness. Together, their testimonies reveal the importance of having a platform to articulate their memories of the 1980s and 1990s. They sought to give voice to an experience that many felt has been forgotten. Yet, very few men I interviewed have been invited to speak about the epidemic in such public platforms. Other narrators' testimonies reveal both the lasting impact of the HIV and AIDS epidemic and the frustration at having their experiences silenced by a lack of an engaged audience.

Silenced Survivors

The introduction of HAART in 1996 marked a clear shift in the lives of people living with HIV. It enabled them to move away from the virus that had monopolised the gay community's focus for nearly two decades.[32] This move was addressed in a 1996 edition of *OutRage*.[33] The HIV-positive author recounted a conversation with someone he identified as a "prominent gay community member," who reportedly stated that "Not for HIV-positive people of course, but for the rest of us, by and large, [the epidemic is] over: no one's interested anymore, they have lives to live."[34] Ross Duffin described a similar response. Since 1982, Ross had campaigned tirelessly for the rights of people living with HIV. When combination therapy became available, "I thought 'okay, I've gotta get out of here! I've gotta get away from living inside my disease! […] I have another life!'"[35] A desire to move on from the epidemic is understandable. For nearly two decades, these young gay men had dealt with constant deaths and endless funerals while facing their own mortalities. The introduction of HAART offered them an opportunity to rebuild their lives in ways they never expected.

While some found this shift liberating, others raised concerns that the threat of HIV and AIDS and the lives lost during the epidemic would be forgotten. Three years after HAART became available in Australia, the Australian Federation of AIDS Organisations launched the campaign: "Getting Our Lives Back in Focus." It questioned, "As time moves on and our perspectives and priorities change, how do we make sure that HIV/AIDS doesn't go completely out of focus?"[36] In spite of such direct efforts to ensure people remained mindful of the virus, for many, the epidemic does indeed appear to have gone out of focus. The drastic decrease in reports about HIV and AIDS in the mainstream press across the late-1990s and early-2000s is a testament to the declining public interest in the epidemic.[37] Trevor Cullen, a professor of journalism with an emphasis on media reports about HIV and AIDS, identifies this decline as "HIV fatigue," whereby readers had been saturated with stories about suffering and death.[38] He notes "why should journalists be bothered about drawing attention to a disease that is acknowledged as nothing like the deadly plague it was predicted to be in the 1980s and '90s.'[39] The urgency and hysteria with which the Australian mainstream press reported the epidemic in the 1980s are well documented.[40] The marked decrease in press reports from the late-1990s suggests that HIV and AIDS was no longer considered the "good story" it was during this earlier period.[41]

Several narrators attested to the declining public interest in the lives of people with HIV. Thomas Parker noted, "my brother, I told him, and I told him it wasn't a problem, and this is probably in the early-'90s. So even today he thinks it's not a problem."[42] Thomas' enthusiasm for participating in this study was clear from our initial correspondence. While he acknowledged the interview might raise painful topics, he welcomed an opportunity to share his personal accounts about life with HIV. His enthusiasm suggests that despite contemporaneous social research into the experiences of HIV-positive gay men, he had not yet found an audience with whom he could discuss his memories of the 1980s and 1990s. He was also willing to bear the emotional issues that talking about the epidemic might generate if it meant he had a platform to discuss living with HIV. Geoff Anderson made a similar observation about the silence that he felt suppressed discussions about HIV in his family. He stated, "to be quite honest, I think my brother might have forgotten. My brother can be self-absorbed."[43]

Narrators' enthusiasm for the study can be understood as a reaction against the broader public silence they felt suppressed discussions about living with HIV. Some men appeared to participate in the oral history interviews in an effort to assert that their memories continue to be meaningful and worth discussing. David's current role as a motivational speaker influenced his determination to ensure that his and others' memories of the epidemic are acknowledged. His company, titled "Survival Power," focuses on how he adopted a positive mindset to prevail after he was diagnosed with a terminal condition at the age of thirty. For David, however, the low attendance at the annual AIDS Candlelight Memorials reflected the declining public interest in the people who lived and lost their lives during the height of the HIV and AIDS years:

> Bit by bit the candlelight parades dropped off. I went this year to one and it was held in ACON. It was lovely, but it was very small. Hardly anyone came which is very sad […] People have moved on. People aren't dying. There are tablets to take. I hate to say it but the HIV community's been forgotten. The general community's moved on, they're not affected by it anymore. So, and they … have forgotten the people of the past. I know it's an awful thing to say but I think it's pretty obvious because no one's coming to the memorials.[44]

Across the late-1980s and 1990s, AIDS Candlelight Memorials were practiced around the world. They involved a silent procession followed by a public reading of the names of those who had died from HIV or AIDS-related conditions. By the 1990s, the Candlelight Memorials reportedly attracted tens of thousands of people across Australia.[45] While annual Candlelight Memorials continue to be held in Sydney, they are now hosted in smaller venues which range from bars on Oxford Street to the Eternity Playhouse Theatre in Darlinghurst. The year before I conducted the interviews, a total of sixteen people attended Sydney's Candlelight Memorial.[46] The AIDS Memorial Quilt is another significant public commemoration that is rarely visible. The Australian Quilt was displayed in full for the final time in Sydney's Darling Harbour Convention Centre in 2002; six years after the final unfolding of the Quilt took place in Washington, DC.

The public's apparent lack of interest in HIV and AIDS and subsequent decisions to bypass the Candlelight Memorials is only one interpretation. Steven Berveling suggested it was also influenced by individuals' desires to move on from the pain they endured during those critical years. Discussions about the Candlelight Memorials raised difficult memories for Steven. In response to my question about whether he attended these events, he responded:

> Yes … and …. the hard bit was always walking past the hospice with the HIV patients at the window … that hard bit gets combined with – I'm gonna say "the fact" – that the boys would hang out and stay alive for Christmas or for Mardi Gras or for their birthday and drop dead one or two weeks later.

While he attested to the importance of the Candlelight Memorials in the 1980s and 1990s, he explained, "we know that it was really horrible, and we would really like that to be remembered. But that doesn't mean that we have to flagellate ourselves constantly about how terrible that was."[47] For men like Steven, then, attending Candlelight Memorials could potentially impede his desire to overcome the trauma that the epidemic caused.

Documenting History

Dominant histories that almost exclusively focus on the public achievements of HIV and AIDS activism can potentially deny others the space to articulate their distinct personal accounts of the 1980s and 1990s. Several of the men in this study explained that they wanted to be involved in order to contribute to documenting a history of HIV and AIDS in Sydney. These men were conscious that they were among the few who survived the epidemic. They depicted themselves contributing to the broader gay community by providing rare insight into the lived experiences of gay men with HIV or AIDS during this period. This motivation was likely influenced by the advertisement, which stated: "help create history by sharing your stories!" Some narrators appeared to seek and achieve composure by affirming that they had distinct memories to share, and that these accounts are currently missing from existing understandings of Sydney's HIV and AIDS epidemic. Of the twenty-five interviewees, Jamie and Tony placed most emphasis on how their decisions to participate in this study were a form of altruism. At the same time, however, focusing on altruism was a relatively safe narrative. It masked their complex personal reasons for participating in this study.

Jamie asserted that he participated in an interview to alleviate some of the survivor guilt he had internalised.[48] Jamie had lost numerous friends to HIV and AIDS-related causes and he was well aware that he is among the few surviving gay men who were diagnosed with HIV in the 1980s. Jamie's determination to document his life experiences was clear from the beginning of the interview. He had kept diaries throughout his childhood and teenage years and had plans to write his memoir. He explained:

> I've outlived everybody that I know of. So I think you do develop, I think I have a good case of what's called "survivor's guilt." I mean, I've known a lot of beautiful, wonderful people that have passed away from it. And then I still – call it a "self-esteem thing" or something – but then I think "what the fuck am I still around for?" That's why I don't want to waste it, I don't wanna sort of be stuck in a cemetery somewhere, and people go "oh fucking thirty years with AIDS and shit, and kept all those diaries but no one else can read them!" [Laughs] It's in my writing. "That would have been interesting."[49]

"Survivor guilt" among gay men who lived through the HIV and AIDS epidemic is well acknowledged.[50] Individuals who survived until the introduction of effective medication simultaneously felt relieved about their prospects of survival and grief for the deaths of others.[51] They also reportedly internalised feelings of guilt and "unworthiness," and questioned why they survived while their friends and partners died.[52] These men understood their survival as an opportunity that many other gay men with HIV or AIDS were denied. By speaking on behalf of others, and testifying to the horror of the epidemic, Jamie was able to achieve affirmation that he had not "wasted" his survival. His plans to write his memoir enabled him to assert that he survived as he still has something tangible to offer society.

Jamie emphasised his altruistic motivations and asserted that others would benefit from learning about his personal experiences of living with HIV. He was particularly frustrated at younger gay men whom he felt were unaware of the trauma that Sydney's gay community collectively endured across the 1980s and 1990s and have become complacent about their risks of HIV and AIDS. Rising rates of infection among younger gay men were particularly confronting.[53] In this regard, "it's like we had World War One and then, you know, everyone forgets everything and then you start again with World War Two."[54] Jamie's determination to ensure that something positive may result from his experiences became especially clear when he explained his desire to visit Positive Living Centres and share his story with younger people who have recently been diagnosed with HIV. He exclaimed: "I've got twenty-six years' experience, ask me a question!" This imperative was directed at HIV and AIDS organisations whom he felt he could help by sharing his personal story. By mentoring younger gay men, he would be able to achieve validation that his suffering was not in vain. At the time of the interview, however, Jamie's plans had not yet materialised. The life narrative he told, at least in part, reflected his frustration that others appeared to be uninterested in his memories of survival.

Jamie's emphasis on his feelings of survivor guilt was also a relatively "safe" and publicly accepted narrative. His plan to revisit his diary entries and write his memoir also appears to be based on his desire to confront his traumatic past experiences. During one of our first phone calls to organise a date and time for the interview, Jamie confided that he had contracted HIV when he was sexually assaulted as a teenager. He returned to this point during the interview and offhandedly remarked that he had "survived rape, incest, and drug abuse."[55] He later conceded that it was these difficult memories that deterred him from reading his diary entries and writing his memoir. He explained, "when I start reading stuff from when I was fourteen, fifteen, my head just gets flooded—nah I can't deal with it! [Laughs] Put it away for another ten years."[56]

Jamie's nonchalance when recounting these events is a distinct "trauma signal."[57] Oral historians argue that survivors of trauma often struggle to articulate their memories as there is no language that adequately conveys their traumatic experiences.[58] Naomi Rosh White identifies such trauma as “unspeakable truths.”[59] She maintains that silence can protect speakers who might fear being disbelieved or pitied by listeners.[60] This is especially important considering oral history interviews sometimes mimic therapy sessions. While oral historians are cautious that interviewers rarely provide the emotional follow-up that therapists offer, Jamie perhaps perceived such distance as an advantage.[61] His decision to mention sexual assault both over the phone and during the interview suggests that it was a relatively “safe” context for him to revisit and to potentially confront these memories. Yet he did not elaborate on these experiences. The parameters of the oral history interview perhaps offered him the space to both acknowledge these traumatic experiences but also to withdraw from this discussion if it became too emotionally painful.

The oral history interviews appeared to provide Elliot Davidson with a similar forum to confront his highly intimate and painful memories of the epidemic within particular boundaries. I ended each interview by asking narrators to tell me how they felt after speaking about their lives. Elliot promptly replied:

> Weird. A little bit. Because I don’t go there very often. And I don’t know why. Well I do know why … ’Cause it’s painful. Because it’s still painful […] If I’m honest, if I’m really honest I still think there are parts of that whole period that I was in Sydney from ’79 to ’91 that are unresolved for me. And I just file them. It’s filed away somewhere, and I don’t go there very often.[62]

As I have mentioned, several of the men who participated in this study have previously told variations of their life histories to counsellors, friends, or to larger groups of strangers through their roles as public speakers. But others have not. Elliot did not mention telling his life history in any other context. His account is a testament to the value of life story interviews to uncover how individuals remember and reflect on the impact HIV and AIDS had on their private lives across this period. While the interview provided him with a reasonably safe forum to revisit these highly intense experiences, it did not delve into the realms of memory and trauma that a discussion with a counsellor or a therapist may.

At the same time, however, Elliot resisted being compartmentalised into a history that centred on his experiences during the epidemic.[63] At the very end of the interview, he stated that there were many things about his life that he had not discussed during the two-hour interview. He had only told me the "tip of the iceberg."[64] An interviewee cannot be expected to recount their entire life in a single interview. Nevertheless, explicitly stating that there was more to his life story than what he had disclosed perhaps helped Elliot to maintain ownership of his stories. His personal memories were only accessible through his voice. Oral historians maintain control by not only selecting participants and guiding the interviews, but also by interpreting the voices and deciding on how they appear in future publications.[65] In this regard, Elliot's interview offers a glimpse into narrators' enthusiasm but also their caution about potentially losing authority when they project highly personal and intimate memories onto the public arena.

As I have mentioned, all the men in this study were self-selected. They were enthusiastic to share their personal experiences of living with HIV and to contribute to writing a history of the epidemic as it unfolded in Sydney. Their accounts reveal the myriad ways in which gay men's intimate experiences of living with HIV or AIDS across the 1980s and 1990s are not always represented in public narratives that predominantly focus on political and community-based responses to the epidemic. Aboriginal gay men are particularly underrepresented in existing histories of HIV and AIDS in Australia. Tony Creighton addressed this absence. Tony was one of two Aboriginal men who participated in this study. He was particularly candid regarding his experiences with racial discrimination within the gay community and simply stated: "if you're black, you're fucked."[66] Tony's testimony indicates that he participated in this study to highlight the experiences of some Aboriginal men and address what he perceived as an omission in public portrayals of gay men with HIV in Sydney. He proudly outlined the social events he had co-organised for Aboriginal gay men. These included the dance parties "Black Out" and "Black Pearls." Tony had also worked with the AFAO Indigenous Project in 2005 to develop an educational booklet titled *HIV and Us* and regularly attended ACON's Ngalawi Djardi "Sit and Yarn" Health Retreat, an annual retreat for Aboriginal and Torres Strait Islander people with HIV. At the end of the interview, Tony screened a fifteen-minute documentary he had created. The documentary, titled "Black and Out" included interviews with Aboriginal gay men, some of whom spoke of their experiences with racism in the gay commercial scene.

This was not the first time Tony had shared his personal story. In 2007, he openly identified as HIV-positive during an interview for an article that was published in the Sydney-based gay and lesbian periodical, *SX News*. His image featured on the cover of the magazine, and while it was “very disconcerting seeing yourself on a cover” he immediately “grabbed fifty copies because I thought I’m only going to be on a cover once.” He then sent some of these copies to old friends to inform them of his positive status. He provided me with a signed copy at the end of the interview. Tony was also employed as a guest speaker for Positive Life NSW from 1998 until 2008. Over the course of a decade, “I went everywhere; lots of schools, funny kids, but even after a while you get sick of telling the same story over and over.”[67] After a five-year hiatus, Tony once again shared his story during an interview for the Lesbian and Gay Life Stories national oral history project in October 2013.[68] I interviewed Tony several months later. Tony expressed pride in being able to offer a comprehensive history of gay Sydney. Throughout the interview, he paid close attention to reciting the names of well-known individuals, addresses where he had lived, and specific dates. At one point he remarked that “you’re getting the gay history of Sydney!”[69] Tony also traced the establishment of the *Sydney Star Observer*, the development of ACON, the Australian Labor government’s proactive response to the epidemic, and the beginning of ACT UP in New York.

At the end of the interview, Tony provided me with eleven CDs which contained documentaries about HIV or AIDS that were televised across the early-1980s and 1990s. This was not a spontaneous decision. He had transferred various video cassettes onto CD in preparation for the interview. Among the short clips was one which Tony proudly described as the first ever televised report about HIV and AIDS in Australia. The day after the interview, I received sixteen emails from Tony, all of which contained links to video clips or documentaries on YouTube that he felt accurately represented aspects of the history of gay Sydney. Tony once again made contact the following week to offer me another three CDs. When I arrived at his home to collect them, he handed me a further ten CDs, all of which he had transferred from video cassettes. This exchange reveals the enthusiasm with which Tony contributed to documenting a history of HIV and AIDS. That same year, he also donated copies of the CDs to the Australian Lesbian and Gay Archives in Melbourne.

Tony’s desire to add his personal story to histories of HIV and AIDS was especially clear three days after the interview. He sent me an email that included scanned obituaries of several men he knew who died across the 1980s and 1990s. These obituaries were originally published in the *Sydney Star Observer*. During the interview, he had briefly mentioned the pain of opening the newspaper and reading the countless death notices, some of which were accompanied by photographs. He elaborated on the practical importance of obituaries via email: "when you wandered around, you saw people and then they 'disappeared,' the obituaries started to remind everyone who had died."[70] He continued, "the ones I kept were people that I knew, and the last two images were some men I had slept with."[71] Tony's desire to contribute to documenting Sydney's gay history is also illustrated in his decision to pass on these obituaries to me, someone who was recording the history. Tony died in June 2015, less than a year after we met for the interview. His decision to participate in this study raises various questions, especially regarding whether he knew his death was nearing, and whether his impending death motivated him to document his history in this way. Tony was also an avid music listener and had asked a friend to ensure his family would not discard his record collection after his death as "I couldn't cope with that." Perhaps his decision to offer the CDs was part of this effort to ensure his collections would continue to be valued after he died. Although this cannot be certain, it is important to consider that the oral history interview not only provided insight into these men's intimate experiences. They reveal that these men had very individual and significant personal motivations for participating in this study. Their motivations reflect the implications of feeling overlooked in existing accounts.

This chapter considered the various factors that motivated men to participate in this study. Recent years have seen an increasing interest in activists' experiences of the epidemic. As Stephen's and Lloyd's accounts illustrate, interviewees placed significant value on having their memories of this period acknowledged. Few of the men who participated in this study, however, had access to such public affirmation. Many of these men felt that wider society has moved on, and essentially forgotten the traumas that they collectively endured across the 1980s and 1990s. By sharing their personal histories, these men were able to both contest and extend existing understandings of their collective experiences as gay men with HIV across the 1980s and 1990s. They asserted that their pasts are significant, valuable, and above all, worth remembering. Most of these also men cited altruistic motivations for participating in this project. They acknowledged that they are among the few who survived the epidemic and asserted that they participated in this study in an effort to help to document the history of HIV and AIDS as it unfolded in Sydney. Their focus on altruism helped these men to mask more specific, private reasons for participating in this study. These included their desires to revisit and bear witness to traumatic past events and painful memories. Their testimonies also revealed that public representations of the HIV and AIDS epidemic in Australia do not always convey narrators' memories of this period. They, therefore, sought to give voice to an experience that many felt has been forgotten.

Notes

1. John Whyte, email message to the author, 28 May 2014.
2. Ibid.
3. John Whyte, email message to the author, 1 June 2014
4. John Whyte, interview with the author, 17 June 2014, Sydney.
5. Rosemary Whyte, email message to the author, 29 August 2015.
6. Robert Reynolds and Shirleene Robinson, "HIV/AIDS, Loss and the Australian Gay Community," in *Legacies of Violence: Rendering the Unspeakable Past in Modern Australia*, ed. Robert Mason (New York: Berghahn, 2017), 162.
7. James Gillett, *A Grassroots History of the HIV/AIDS Epidemic in North America* (Washington: Marquette Books LLC, 2011), 61.
8. Gary Dowsett and David McInnes, "Post AIDS: Assessing the Long Term Social Impact of HIV/AIDS in Gay Communities," XI International Conference on AIDS, Vancouver, 1996; David McInnes, "Professionally Gay: The Workforce of Gay Male Educators," *AFAO/NAPWA Education Discussion Paper* 2, no. 6 (2000/2001): 1–17; Eric Rofes, *Dry Bones Breathe: Gay Men Creating Post-AIDS Identities and Cultures* (New York: The Haworth Press, 1998), 75.
9. Roger Hallas attests to the importance of bearing witness to HIV and AIDS through queer films and videos. Roger Hallas, *Reframing Bodies: AIDS, Bearing Witness, and the Queer Moving Image* (Durham: Duke University Press, 2009), 4–5.
10. Ibid., 10.
11. Dori Laub, "Bearing Witness, or the Vicissitudes of Listening," in *Testimony: Crises of Witnessing in Literature, Psychoanalysis and History*, eds. Shoshana Felman and Dori Laub (New York: Routledge, 1992), 69.
12. Mark Klempner, "Navigating Life Review Interviews with Survivors of Trauma," *Oral History Review* 27, no. 2 (2000): 72.
13. Alistair Thomson, *Anzac Memories: Living with the Legend*, Second (Melbourne: Monash University Publishing, 2013), 240.

14. "World AIDS Day: Why?" *Sydney Star Observer*, December 14, 1990, 14.
15. Paul Paech, "World AIDS Day: Where Were the Gay Men?" *Sydney Star Observer*, December 14, 1990, 35.
16. Ibid.
17. Larry Galbraith, "Conference of the Visible," *Sydney Star Observer*, August 24, 1990, 14.
18. Ibid.
19. Robert Ariss, *Against Death: The Practice of Living with AIDS* (Amsterdam: Gordon and Breach, 1997), 21; Gregory M. Herek and John P. Capitanio, "AIDS Stigma and Sexual Prejudice," *American Behavioral Scientist* 42 (1999): 1131.
20. Dennis Altman, "Dehomosexualization," in *AIDS in the World*, eds. Jonathan M. Mann, Daniel J.M. Tarantola, and Thomas W. Netter (Cambridge: Harvard University Press, 1992), 388–9. See also Cindy Patton, *Inventing AIDS* (New York: Routledge), 117–8.
21. Altman, "Dehomosexualization," 388–9.
22. The exhibition, *HIV and AIDS 30 Years On: The Australian Story* was held at the Powerhouse Museum in Sydney from November 2012–August 2013.
23. Some particularly notable documentaries include: *Transmission: The Journey from AIDS to HIV*. Documentary. Directed by Staffan Hildebrand. Sweden: Face of AIDS, 2014; *United in Anger: A History of ACT UP*. Documentary. Directed by Jim Hubbard and Sarah Schulman. New York: Jim Hubbard, 2012; *How to Survive a Plague*. Documentary. Directed by David France. New York: Sundance Selects, 2012; *We Were Here*. Documentary. Directed by David Weissman and Bill Weber. USA: David Weissman, 2011.
24. Lloyd Grosse, interview with the author, 27 August 2014, Sydney.
25. *Shop Until You Drop*. Documentary. Directed by John Moyle. Australia: University of Sydney TV Service, 1991.
26. Lloyd Grosse, interview with the author.
27. Stephen Allkins, interview with the author, 6 August 2014, Northern Rivers.
28. Victoria Midwinter Pitt was the director of *Rampant: How a City Stopped a Plague*.
29. Stephen Allkins, interview with the author.
30. Ibid.
31. Ibid.
32. Dennis Altman argues that HIV and AIDS pushed other issues off the agenda. 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), 309.

33. "We Deserve To Live—Again," *OutRage*, July 1996, 35.
34. Ibid.
35. Ross Duffin, interview with the author, 16 July 2014, Sydney.
36. Michael Hurley, "As Time Moves on and Our Perspectives Change, How Do We Make Sure That HIV/AIDS Doesn't Go Completely Out of Focus?" *OutRage*, January 1999, 78–9; "Getting Our Lives Back in Focus," *OutRage*, March 1999.
37. D. Lupton, S. Chapman, and W. L. Wong, "Back to Complacency: AIDS in the Australian Press, March–September 1990," *Health and Education Research* 8, no. 1 (1993): 5–17.
38. Trevor Cullen, "Health Communication Theories: Implications for HIV Reporting in Asia and the Pacific," *Asia Pacific Media Educator* 19 (2009): 101.
39. Trevor Cullen, "HIV/AIDS: 20 years of Press Coverage," *Australian Studies in Journalism* 12, no. 1 (2003): 65.
40. Robert French and Ross Duffin, *Mossies Could Spread AIDS: An Annotated List of Media References on AIDS, 1981–1985* (Sydney: Gay History Project, 1986); Deborah Lupton, "Archetypes of Infection: People with HIV/AIDS in the Australian Press in the mid-1990s," *Sociology of Health and Illness* 21, no. 1 (1999): 37–53; Deborah Lupton, *Moral Threats and Dangerous Desires: AIDS in the News Media* (London: Taylor & Francis, 1994).
41. Writing in 1992, Rosalie Aroni asserted, "[t]here is no doubt in the minds of media workers that HIV/AIDS is a 'good story'." Rosalie Aroni, "Looking at the Media," in *AIDS in Australia*, eds. Eric Timewell, Victor Minichiello, and David Plummer (Sydney: Prentice Hall of Australia Pty, 1992), 125–7.
42. Thomas Parker, interview with the author, 13 July 2014, Brisbane.
43. Geoff Anderson (pseudonym), interview with the author, 9 August 2014, Brisbane.
44. David Polson, interview with the author, 18 June 2014, Sydney.
45. Jennifer Power, "Rites of Belonging: Grief, Memorial and Social Action," *Health Sociology Review* 18 (2009): 261.
46. One exception was the International AIDS Candlelight Vigil held in Melbourne's Federation Square in July 2014, which reportedly attracted thousands of attendees. The vigil was held was held to coincide with the 20th International AIDS Conference in Melbourne, which provides an explanation for the particularly high attendance rate.
47. Steven Berveling, interview with the author, 17 July 2014, Sydney.
48. Psychoanalyst William G. Neiderland has provided one of the most widely recognised discussions of "survivor guilt." See William G. Neiderland, "The Problem of the Survivor," *Journal of Hillside Hospital* 10 (1961): 233–47.

49. Jamie Richards, interview with the author, 2 September 2014, Tasmania.
50. For a selection of such studies, see José Catalán, "Psychological Problems in People with HIV Infection," in *Mental Health and HIV Infection: Psychological and Psychiatric Aspects*, ed. José Catalán (London: UCL Press, 1999), 21–41; Walk Odet, *In the Shadow of the Epidemic: Being HIV-Negative in the Age of AIDS* (Durham: Duke University Press, 1995), 21.
51. D.E. Brashers et al., "'In An Important Way, I Did Die': Uncertainty and Revival in Persons Living with HIV or AIDS," *AIDS Care: Psychological and Sociomedical Aspects of AIDS/HIV* 11, no. 2 (1999): 212.
52. Ibid.; Boykin, Fred F. "The Aids Crisis and Gay Male Survivor Guilt," *Smith College Studies in Social Work* 61, no. 3 (1991): 249.
53. The Kirby Institute, *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia*, *Annual Surveillance Report 2015.* Sydney: The Kirby Institute for Infection and Immunity in Society, 2015, 33.
54. Jamie Richards, interview with the author.
55. Ibid.
56. Ibid.
57. Gadi BenEzer, "Trauma Signals in Life Stories," in *Trauma and Life Stories: International Perspectives*, eds. Kim Lacy Rogers, Selma Leydesdorff, and Graham Dawson (London: Routledge, 1999), 29–44.
58. Lynn Abrams, *Oral History Theory*, Second (Oxon: Routledge, 2016), 122; Naomi Rosh White, "Marking Absences: Holocaust Testimony and History," *Oral History Association of Australia Journal* 16 (1994): 12.
59. White, "Marking Absences: Holocaust Testimony and History," 12.
60. Ibid.
61. Wendy Rickard, "Oral History-'More Dangerous Than Therapy'? Interviewees' Reflections on Recording Traumatic or Taboo Issues," *Oral History* 26, no. 2 (1998): 42; Alistair Thomson, "Anzac Memories: Putting Popular Theory into Practice in Australia," in *The Houses of History: A Critical Reader in Twentieth-Century History and Theory*, eds. Anna Green and Kathleen Troup (Manchester: Manchester University Press, 1999), 243.
62. Elliot Davidson (pseudonym), interview with the author, 28 October 2014, Sydney.
63. Such resistance is not uncommon in interviews. Catherine Kohler Riessman, "Analysis of Personal Narratives," in *Handbook of Interview Research*, eds. Jaber F. Gubrium and James A. Holstein (Thousand Oaks: Sage, 2001), 695.
64. Elliot Davidson, interview with the author.
65. Alessandro Portelli, *The Death of Luigi Trastulli and Other Stories: Form and Meaning in Oral History* (Albany: State University of New York Press, 1991), 56.

66. Tony Creighton, interview with the author, 30 July 2014, Sydney.
67. Ibid.
68. Tony's account is published in: Robert Reynolds and Shirleene Robinson, *Gay and Lesbian, Then and Now: Australian Stories from a Social Revolution* (Carlton, VIC: Black Inc., 2016), 84–104.
69. Tony Creighton, interview with the author.
70. Tony Creighton, email to the author, 3 August 2014.
71. Ibid.

CHAPTER 11

Conclusion

Over fourteen years, the virus that is now known as HIV went from being an unidentified yet frightening and deadly disease to a chronic condition that could be managed by taking antiretroviral medication. Narrators' 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. They reveal how HIV-positive gay men navigated issues around disclosure, divisions within the gay community, monitoring physical symptoms of HIV and AIDS-related conditions and the severe side effects of medication, and losing countless friends while considering they may face the same untimely and prolonged deaths that they had witnessed others endure. This book engaged with these men's subjective accounts to complicate existing histories that predominantly focus on HIV and AIDS activism. It revealed, for the first time, both the impact that HIV and AIDS had on these men's private lives across this critical period and how these men make sense of their experiences nearly three decades later.

The testimonies of the twenty-five narrators who feature in this book illuminate the nuances in existing historical investigations into the HIV and AIDS epidemic in Australia which predominantly centre on the positive aspects of activism. Activists worked with—and at times, against—the government to establish what some historians have identified as a world-leading response to the virus. These activists challenged oppression and publicly "came out" as HIV-positive, mobilised to educate others about preventative measures, lobbied government officials to gain

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0_11

faster access to potentially lifesaving medication, and established organisations to provide emotional and practical support for those who were dying from AIDS-related conditions. The significance of their achievements cannot be overstated. These individuals provided an exceptional response to a devastating situation. They exhibited an incredible level of resilience and perseverance in the face of a virus that threatened their lives. The emphasis on activists' accomplishments is not limited to scholarly discussions. Popular representations of the epidemic, including recently released films, documentaries, and public exhibitions, also memorialise Australia's proactive and effective response to the threat of HIV and AIDS.

Such public acknowledgement of activists' endeavours provided some of the narrators, namely those who were closely involved in these political networks and organisations, with dominant stories on which they could draw to articulate their involvement in the HIV and AIDS cause. This was most clearly illustrated in interviews with Lloyd Grosse, Ross Duffin, and Stephen Allkins. These men were heavily involved in HIV and AIDS activism, and predominantly told accounts that melded with these histories. They described challenging oppression by publicly disclosing their HIV-positive status and providing valuable support to others afflicted by the virus. Memories of community solidarity served an important purpose in these narrators' present lives. Such memories helped to sustain some of these men through their more recent frustrations at feeling separated from the same HIV and AIDS organisations they had helped to develop. They depicted themselves as among the few who established a distinct level of activism from which younger generations of gay men, and especially those living with HIV, currently benefit. These public actions, however, are only one part of the history of HIV and AIDS in Australia.

Some narrators' close involvement in HIV and AIDS activism also meant that they had a repertoire of well-told anecdotes that reaffirmed this dominant version of the history of the epidemic. The interviews took place twenty-six years after gay men with HIV or AIDS started to publicly disclose their positive status. In the interim, several interviewees have shared their experiences by featuring on current affairs television programs, newspaper articles, and as guest speakers for the Positive Speakers' Bureau. Men who were heavily involved in activism have also provided particularly detailed accounts of their lives in oral history interviews with Sydney's Pride History Group and as part of the Australian

Response to AIDS Oral History Project that is based at the National Library of Australia in Canberra. They had therefore composed accounts of the 1980s and 1990s that centred on their public actions. Narrators' emphases on their accomplishments perhaps reflect their efforts to establish positive meaning from an event so traumatic and incomprehensible that some argue is akin to war. They conveyed how a community mobilised to support one another through the losses, challenged medical professionals and asserted themselves as active agents in their health care, and readily adopted safe sex strategies in an effort to save their own lives and those of other gay men.

At times, however, these publicly acknowledged stories also suppressed narrators' more intimate and raw memories of the HIV and AIDS epidemic. These included the severe social ramifications of public disclosure and the emotional trauma of being involved in efforts to gain faster access to unapproved antiretroviral medication across the late-1980s and early-1990s. This silence was not limited to activists. Most narrators struggled to articulate memories that departed from dominant depictions of community solidarity and empowerment across this period. Narrators' more intimate memories only started to surface as the interviews progressed, or upon gentle probing.

The public emphasis on HIV and AIDS activism also tends to overshadow narrators' memories of experiencing fractures within the gay community. While the gay community proved to be a vital source of support for many people with HIV or AIDS across this period, the immense fear that the threat of the virus generated meant that some men who displayed visible symptoms felt forced into isolation. Others faced rejection from potential sexual partners once they disclosed their HIV-positive status. These instances threatened their understandings that they were members of a community that mobilised to support one another across this critical period. Nearly all the men I interviewed recalled encountering discrimination from the wider public, doctors, and from some family members. Nevertheless, most men placed particular emphasis on the discrimination they faced from other gay men. It was these encounters that appeared to be particularly painful. The lasting impact of being rejected by other gay men may be based on interviewees' expectations that other gay men would be more understanding, more compassionate, and more empathetic. It can also be a result of histories that depict the gay community as one which mobilised and solidified. These public representations placed such expectations on other gay men that many recalled they did not always, or perhaps could not, fulfill.

Existing histories also tend to overshadow the voices of those who felt isolated from other gay men in Sydney even before the onset of HIV and AIDS. The HIV and AIDS epidemic appears to have exacerbated their perceptions that they were on the fringes of this community. They did not have access to the level of support that appeared to be vital to others. While men like Steven Jottileb sought support from others he had met in the mental health system, several other interviewees including John Whyte and Victor Day did not appear to have other social or support networks on which they could draw. They were eager to document their experiences in an oral history interview. They described primarily dealing with HIV outside of the support networks and organisations that have been a major part of Australia's response to HIV and AIDS.

The life stories revealed that existing histories that predominantly centre on activists' public actions do not always represent the experiences of HIV-positive gay men who have been living with the virus since the early-1980s. Rather, these histories have the potential to overshadow and at times marginalise the voices of those who were not involved in these endeavours. The lives and memories of HIV-positive gay men who felt isolated from the wider gay community and rarely had access to support networks and organisations are particularly underrepresented in such discussions. Yet it is these voices that lead us towards a deeper and more complex understanding of how the virus permeated the lives of those who were most affected. The oral history interviews I conducted explicitly aimed to engage with the respondents' personal memories to unravel the impact that the once deadly and highly stigmatised disease had on their private lives. The interviews, therefore, provided these men with a unique platform to narrate their pasts in ways that both aligned with and departed from dominant histories of HIV and AIDS. Given this approach, narrators gave a much-needed voice to topics that are usually silenced.

Bibliography

Interviews

Adrian Eisler (born London, 1954), interview with the author, 23 May 2014, Sydney.

Brian Mitchell (pseudonym, UK, early-1950s), interview with the author, 10 June 2014, Sydney.

Damien Roberts (pseudonym, country NSW, 1967), interview with the author, 5 August 2014, Northern Rivers.

David Polson (Christchurch, 1954), interview with the author, 18 June 2014, Sydney.

Elliot Davison (pseudonym, South Australia, late-1950s), interview with the author, 28 October 2014, Brisbane.

Evan Richardson (pseudonym, Western Australia, early-1970s), interview with the author, 20 November 2014, Sydney.

Frank Hancock (Sydney, 1953), interview with the author, 4 August 2014, Northern Rivers.

Geoff Anderson (pseudonym, Sydney, late-1950s), interview with the author, 9 August 2014, Brisbane.

Greg Iverson (Sydney, 1960), interview with the author, 31 August 2014, Melbourne.

Howard Clarke (pseudonym, country NSW, early-1950s), interview with the author, 29 July 2014, Sydney.

Jamie Richards (Sydney, 1972), interview with the author, 2 September 2014, Tasmania.

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0

John Whyte (Dannevirke, 1947), interview with the author, 17 June 2014, Sydney.

Lloyd Grosse (Sydney, 1965), interview with the author, 27 August 2014, Newtown.

Mark Tietjen (Gisborne, New Zealand, 1956), interview with the author, 27 August 2014, Sydney.

Richard McDonell (Melbourne 1964), interview with the author, 23 July 2014, Melbourne.

Ross Duffin (Melbourne, 1956), interview with the author, 16 July 2014, Sydney.

Scott Martin (pseudonym, Sydney, late-1950s), interview with the author, 17 July 2014, Sydney.

Stephen Allkins (Sydney, 1960), interview with the author, 6 August 2014, Northern Rivers.

Steven Berveling (Netherlands, 1957), interview with the author, 12 July 2014, Sydney.

Steven Jottileb (regional NSW, 1956), interview with the author, 29 August 2014, Sydney.

Thomas Parker (pseudonym, Queensland, mid-1960s), interview with the author, 13 July 2014, Brisbane.

Tim Alderman (Sutherland Shire, 1954), interview with the author, 29 October 2014, Brisbane.

Tony Creighton (Sydney 1963), interview with the author, 30 July 2014, Sydney.

Victor Day (pseudonym, New Zealand, 1955), interview with the author, 28 August 2014, Sydney.

Wayne Oldrey (southern Sydney, 1970), interview with the author, 8 August 2014, Gold Coast.

Email Correspondence

John Whyte, email message to author, 19 June 2014.

Thomas Parker, email message to author, 30 June 2014.

Tony Creighton, email message to the author, 3 August 2014.

Victor Day, email message to the author, 21 August 2014.

Other Interviews

Michael Glynn interview with Larry Galbraith, 3 December 1995, Pride History Group.

Phillip Carswell interview with Adam Carr, 6 June1993, The “Australian Response to AIDS” Oral History Project, National Library of Australia, TRC 2815/36.

Ross Duffin interview with James Waites, 19–23 September 2009, The “Australian Response to AIDS” Oral History Project, National Library of Australia, TRC 6131.

Periodicals

AFAO National AIDS Bulletin.
Weekend Australian.
Campaign.
Daily Telegraph.
Koori Mail.
OutRage.
Sydney Morning Herald.
Sydney Star Observer.
Talkabout: Newsletter of People Living With AIDS (N.S.W.).

ACT UP Documents

ACT UP Sydney, Flyer Advertising an AIDS Drug Trials and Treatments Public Meeting, 1991, ACT UP/Sydney—Records, 1987–1993, MLMSS 5948, State Library of New South Wales.

ACT UP Sydney, Submission to Peter Baume Enquiry, 20 May 1991, ACT UP/Sydney—Records, 1987–1993, MLMSS 5948, State Library of New South Wales.

Official Reports

Baume, Peter. *A Question of Balance: Report on the Future of Drug Evaluation in Australia*, Commissioned for the Minister for Aged, Family and Health Services, the Hon. Peter Staples. Canberra: Australian Government Publishing Service, 1991.

Bollen, Jonathan, Barry Edwards, Gary Dowsett, David McInnes, and Murray Couch. *Understanding the Contexts of Risk-Taking Among Sydney Gay Men: Re-Analysis of Significant Others 1997 Focus Group Data*. Report to AIDS and Infectious Diseases Branch, NSW Department of Health. Sydney: Sociology Department, School of Behavioural Sciences, Macquarie University, 1998.

Callen, Michael. "Surviving and Thriving with AIDS." *Report of the Third National Conference on AIDS*. Canberra: Australian Government Publishing Service, 1988, 662–70.

Carr, Adam. *Keeping It Up: Sustaining Safe Sex in the Second Decade of AIDS*. Sydney: National Centre for HIV Social Research (Macquarie Unit), 1992.

Chapple, Murray, and Sue Kippax. *Gay and Homosexually Active Aboriginal Men in Sydney*. Sydney: National Centre in HIV Social Research, 1996.

Department of Community Services and Health. *Report of the Working Panel on Aboriginals, Torres Strait Islanders and HIV/AIDS.* Canberra: Department of Community Services and Health, 1989.

Feachem, Richard G.A. *Valuing the Past … Investing in the Future Evaluation of the National HIV/AIDS Strategy 1993–94 to 1995–96.* Canberra: Australian Government Publishing Service, 1995.

Human Rights and Equal Opportunity Commission. *Bringing Them Home: Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families.* Sydney: HREOC, 1997.

Human Rights and Equal Opportunity Commission. *Same-Sex: Same Entitlements. National Inquiry into Discrimination against People in Same-Sex Relationships: Financial and Work-Related Entitlements and Benefits.* Sydney: HREOC, 2007.

Jansson, James, David Wilson, and Jo Watson. *Mapping HIV Outcomes: Geographical and Clinical Forecasts of Numbers of People Living with HIV in Australia*. Sydney: National Centre in HIV Epidemiology and Clinical Research, 2010.

Karmel, Peter. "Concluding Remarks." *Report of the Third National Conference on AIDS.* Canberra: Australian Government Publishing Service, 1988, 783–5.

National Centre in HIV Epidemiology and Clinical Research. *HIV/AIDS and Related Diseases Annual Surveillance Report 1997.* Sydney: National Centre in HIV Epidemiology and Clinical Research, 1997.

Nicoll, Paul, Anne Martin, Alan Chapman, and the Australian National Audit Office. *Drug Evaluation by the Therapeutic Goods Administration: Department of Health and Family Services.* Canberra: Australian Government Publishing Service, 1996.

School of Medical Education, The University of New South Wales. *HIV/AIDS Related Discrimination Health Care Worker Project.* Canberra: Australian Government Publishing Service, 1994.

The Kirby Institute. *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia, Annual Surveillance Report 2015.* Sydney: The Kirby Institute for Infection and Immunity in Society, 2015.

Guidebooks

Allen, Yvonne, and Harry Michelmore. *Living and Loving in the AIDS Free Zone.* Sydney: Australian Consolidated Press, 1987.

Bradford, David. *A.I.D.S., Herpes, and Everything You Should Know About V.D. in Australia*, Second. Melbourne: Melbourne University Press, 1985.

Brass, Alister, and Julian Gold. *AIDS in Australia: What Everyone Should Know.* Sydney: Bay Books, 1985.

Callen, Michael. *Surviving AIDS.* New York: HarperCollins, 1990.

________. *Surviving and Thriving with AIDS: Collected Wisdom*, vol. 2. New York: People with AIDS Coalition, 1988.

________. *Surviving and Thriving with AIDS: Hints for the Newly Diagnosed*. New York: People with AIDS Coalition, 1987.

Callen, Michael, and Richard Berkowitz. *How to Have Sex in an Epidemic: One Approach*. New York: News From The Front Publications, 1983.

Clohesy, Mike, and Peter De Waal. *Oppression Upon Reflection*. Sydney: CAMP NSW, 1975.

Galbraith, Larry. *Sydney & Beyond '89*. Sydney: Southpaw Press, 1989.

Gays Counselling Service of NSW. *Sydney Gay Guide*. Sydney: Gays Counselling Service of NSW, 1984.

Rabkin, Judith, Robert Remein, and Christopher Wilson. *Good Doctors, Good Patients: Partners in HIV Treatment*. New York: NMC Publishers, 1994.

Sydney Gay Liberation. *A Gay Liberation Manifesto*. Sydney: Gay Liberation Publications Group, 1972.

Van Reyk, Paul. *Choosing to Die: A Booklet for People Thinking About Euthanasia and for Those Asked to Assist*. Sydney: AIDS Council of New South Wales, 1994.

Memoirs

Conigrave, Timothy. *Holding the Man*. Melbourne: McPhee Gribble, 1995.

Foster, John. *Take Me to Paris, Johnny*. Port Melbourne: Minerva, 1993.

Menadue, David. *Positive: Living with HIV/AIDS*. Sydney: Allen & Unwin, 2003.

Michaels, Eric. *Unbecoming: An AIDS Diary*. Durham: Duke University Press, 1990.

Documentaries

How to Survive a Plague. Documentary. Directed by David France. New York: Sundance Selects, 2012.

Rampant: How a City Stopped a Plague. DVD. Directed by Victoria Midwinter Pitt. Australia: Chapman Pictures, 2007.

Transmission: The Journey from AIDS to HIV. Documentary. Directed by Staffan Hildebrand. Sweden: Face of AIDS, 2014.

United in Anger: A History of ACT UP. Documentary. Directed by Jim Hubbard and Sarah Schulman. New York: Jim Hubbard, 2012.

We Were Here. Documentary. Directed by David Weissman and Bill Weber. USA: David Weissman, 2011.

Television Broadcasts

AIDS Funerals. Australia: ABC Compass, 2001. Television. Australian Lesbian and Gay Archives no. 235.

Does Dracula Have AIDS? & Other Geoffrey Robertson Hypotheticals. Sydney, NSW: Angus & Robertson in association with the Australian Broadcasting Corporation, c. 1987. Television. Australian Lesbian and Gay Archives, no. 79.

"Living with AIDS." *Couchman Over Australia*. Australian Broadcasting Corporation, 1991. Television.

Living with AIDS. SBS and Current Affairs, 1989. Television. Australian Lesbian and Gay Archives, no. 108.

Shop Until You Drop. Directed by John Moyle. Australia: University of Sydney TV Service, 1991. Television.

Speeches

Dowsett, Gary, and David McInnes. "Post AIDS: Assessing the Long Term Social Impact of HIV/AIDS in Gay Communities." Vancouver: XI International Conference on AIDS, 1996.

Justice Michael Kirby. "AIDS—The Quarantine Option—Occam's Razor." Australian Broadcasting Commission, 1991.

Justice Michael Kirby. "Aids—Insights from the Stockholm Conference." Tasmania: Third Australian National Conference on AIDS, 6 August 1988.

Major General William O. Rodgers. "AIDS Policy and Mandatory Testing in the Armed Forces." Paper presented at AIDS and the Health Professional Summit Conference, 28–9 April 1989.

References

Abadie, Roberto. *The Professional Guinea Pig*. Durham: Duke University Press, 2010.

Abrams, Lynn. *Oral History Theory*, Second. Oxon: Routledge, 2016.

Aldrich, Robert. *Colonialism and Homosexuality*. London: Routledge, 2003.

———. "Gay and Lesbian History." In *Gay Life and Culture: A World History*, edited by Robert Aldrich. London: Thames and Hudson, 2006, 7–27.

Altman, Dennis. "Dehomosexualization." In *AIDS in the World*, edited by Jonathan M. Mann, Daniel J. M. Tarantola, and Thomas W. Netter. Cambridge: Harvard University Press, 1992, 388–9.

———. "Legitimation Through Disaster: AIDS and the Gay Movement." In *AIDS, the Burdens of History*, edited by Elizabeth Fee and Daniel M. Fox. California: University of California Press, 1988, 301–15.

———. *Power and Community*. London: Taylor & Francis, 1994.

———. "The Emergence of a Non-government Response to AIDS." In *Social Perspectives in Lesbian and Gay Studies: A Reader*, edited by Peter M. Nardi and Beth E. Schneider. New York: Routledge, 1998, 506–36.

———. *The End of the Homosexual?* Queensland: University of Queensland Press, 2013.

Ariss, Robert. *Against Death: The Practice of Living with AIDS*. Amsterdam: Gordon and Breach, 1997.

———. "Re-inventing Death: Gay Community Memorial Rites in Sydney, Australia." In *Gay Perspectives II; More Essays in Australian Gay Culture*, edited by Robert Aldrich. Sydney: Department of Economic History with The Australian Centre for Gay and Lesbian Research, 1993, 275–94.

Aroni, Rosalie. "Looking at the Media." In *AIDS in Australia*, edited by Eric Timewell, Victor Minichiello, and David Plummer. Sydney: Prentice Hall of Australia, 1992, 125–41.

Ashton, Paul, Paula Hamilton, and Rose Searby. *Places of the Heart: Memorials in Australia*. Melbourne: Australian Scholarly Publishing, 2012.

Atkinson, Robert. "The Life Story Interview as a Bridge in Narrative Inquiry." In *Handbook of Narrative Inquiry: Mapping a Methodology*, edited by D. Jean Clandinin. Thousand Oaks, CA: Sage, 2007, 224–45.

Ballard, John. "Sexuality and the State in Time of Epidemic." In *Rethinking Sex: Social Theory and Sexuality Research*, edited by R.W. Connell and Gary W. Dowsett. Melbourne: Melbourne University Press, 1992, 102–16.

Balter, Michael. "New Hope in HIV Disease." *Science* 247, no. 5295 (1996): 1988–91.

Bayer, Ronald and Gerald M. Oppenheimer. *AIDS Doctors: Voices from the Epidemic: An Oral History*. Oxford: Oxford University Press, 2000.

BenEzer, Gadi. "Trauma Signals in Life Stories." In *Trauma and Life Stories: International Perspectives*, edited by Kim Lacy Rogers, Selma Leydesdorff, and Graham Dawson. London: Routledge, 1999, 29–44.

Bennett, Garrett, Simon Chapman, and Fiona Bray. "Sexual Practices and 'Beats': AIDS-Related Sexual Practices in a Sample of Homosexual and Bisexual Men in the Western Area of Sydney." *Medical Journal of Australia* 151, no. 6 (1989): 309–14.

Berridge, Virginia. "AIDS and Patient-Support Groups." In *Medicine in the Twentieth Century*, edited by Roger Cooter and John Pickstone. Amsterdam: Overseas Publishers Association, 2000, 687–702.

Bigelow, Gail, and Jeremy Hollinger. "Grief and AIDS: Surviving Catastrophic Multiple Loss." In *Bereavement: Client Adaptation and Hospice Services*, edited by Donna Infeld and Nadine R. Penner. New York: Routledge, 2012, 83–96.

Bongiorno, Frank. *The Sex Lives of Australians: A History*. Collingwood, Australia: Black Inc., 2012.

Booker, Norman. *Strengthening the Community, ACON & the HIV Epidemic in NSW*. Sydney: ACON, 1995.

Boxall, Anne-Marie, and James Gillespie. *Making Medicare: The Politics of Universal Health Care in Australia*. Sydney: University of New South Wales Press, 2013.

Brashers, D. E., J. L. Neidig, L. W. Cardillo, L. K. Dobbs, J. A. Russell, and S. M. Haas. "'In an Important Way, I Did Die': Uncertainty and Revival in Persons Living with HIV or AIDS." *AIDS Care: Psychological and Sociomedical Aspects of AIDS/HIV* 11, no. 2 (1999): 201–19.

Brickell, Chris. *Mates and Lovers: A History of Gay New Zealand*. Auckland: Random House/Godwit, 2008.

Brown, Barbara B., and Douglas D. Perkins. "Disruptions in Place Attachment." In *Place Attachment*, edited by Irwin Altman and Setha M. Low. New York: Plenum Press, 1992, 279–301.

Buchbinder, Susan, and Eric Vittinghoff. "Long-Term Non-progressive HIV Infection." In *AIDS Pathogenesis*, edited by Hanneke Schuitemaker and Frank Miedema. Dordrecht, The Netherlands: Kluwer Academic Publishers, 2000, 65–76.

Butler, Judith. *Precarious Life: The Powers of Mourning and Violence*. London: Verso, 2004.

Callen, Michael, and Dan Turner. "A History of the PWA Self-Empowerment Movement." In *Surviving and Thriving with AIDS: Collected Wisdom*, edited by Michael Callen. New York: PWA Coalition, 1987, 288–95.

Carbery, Graham. *A History of the Sydney Gay and Lesbian Mardi Gras*. Melbourne: Australian Lesbian and Gay Archives, 1995.

Carr, Andrew. "HIV Lipodystrophy: Risk Factors, Pathogenesis, Diagnosis and Management." *AIDS* 17 (2003): S141–8.

Carter, David. *Stonewall: The Riots That Sparked the Gay Revolution*. New York: St. Martin's Press, 2004.

Catalán, José. "Psychological Problems in People with HIV Infection." In *Mental Health and HIV Infection: Psychological and Psychiatric Aspects*, edited by José Catalán. London: UCL Press, 1999, 21–41.

Centers for Disease Control and Prevention. "Current Trends Acquired Immune Deficiency Syndrome (AIDS): Precautions for Clinical and Laboratory Staffs." *MMWR Weekly* 31, no. 43 (1982): 577–80.

———. "Current Trends Prevention of Acquired Immune Deficiency Syndrome (AIDS): Report of Inter-Agency Recommendations." *MMWR Weekly* 32, no. 8 (1983): 101–3.

Chatterjee, Koushik. "Host Genetic Factors in Susceptibility to HIV-1 Infection and Progression to AIDS." *Journal of Genetics* 89, no. 1 (2010): 109–16.

Cooper, David A., Jose M. Gatell, Susanne Kroon, Nathan Clumeck, Judith Millard, Frank-D Goebel, Johan N. Bruun, Georg Stingl, Rex L. Melville, Juan Gonzalez-Lahoz, John W. Stevens, A. Paul Fiddian, and The European-Australian Collaborative Group. "Zidovudine in Persons with Asymptomatic HIV Infection and CD4+ Cell Counts Greater Than 400 per Cubic Millimeter." *New England Journal of Medicine* 329, no. 5 (1993): 297–303.

Counter, Mark. "A History of the People Living with HIV/AIDS (PLWHA) Movement in Australia." *Social Alternatives* 15, no. 4 (1996): 25–7.

Crimp, Douglas. "Portraits of People with AIDS." In *Cultural Studies*, edited by Lawrence Grossberg, Gary Nelson, and Paula Treichler. New York: Routledge, 1992, 117–33.

Cullen, Trevor. "Health Communication Theories: Implications for HIV Reporting in Asia and the Pacific." *Asia Pacific Media Educator* 19 (2009): 99–111.

———. "HIV/AIDS: 20 Years of Press Coverage." *Australian Studies in Journalism* 12, no. 1 (2003): 64–82.

Damousi, Joy. *Living with the Aftermath: Trauma, Nostalgia and Grief in Post-war Australia*. Cambridge: Cambridge University Press, 2001.

Dawson, Graham. *Making Peace with the Past? Memory, Trauma and the Irish Troubles*. Manchester: Manchester University Press, 2007.

———. *Soldier Heroes: British Adventure, Empire and the Imagining of Masculinities*. Oxon: Routledge, 1994.

Dennis, Dixie L. *Living, Dying, Grieving*. Sudbury, MA: Jones & Bartlett Learning, 2008.

Devine, Patricia G., E. Ashby Plant, and Kristen Harrison. "The Problem of 'Us' versus 'Them' and AIDS Stigma." *American Behavioral Scientist* 42, no. 7 (1999): 1212–28.

Duffin, Ross. "Best of Times and Worst of Times." In *Through Our Eyes: Thirty Years of People Living with HIV Responding to the HIV and AIDS Epidemics in Australia*, edited by John Stanley Rule. Sydney: National Association of People with HIV Australia, 2014, 22–7.

Duggan, Marian. *Queering Conflict: Examining Lesbian and Gay Experiences of Homophobia in Northern Ireland*. Surrey: Ashgate, 2012.

Edwards, Laurie. *In the Kingdom of the Sick: A Social History of Chronic Illness in America*. New York: Walker Publishing Company, 2013.

Eisenberg, Leon. "There's No Quick Fix for AIDS." *Australian and New Zealand Journal of Psychiatry* 25, no. 3 (1991): 314–21.

Engel, Jonathan. *The Epidemic: A Global History of AIDS*. New York: HarperCollins, 2006.

Field, Sean. "Beyond 'Healing': Trauma, Oral History and Regeneration." *Oral History* 34, no. 1 (2006): 31–42.

———. “Imagining Communities: Memory, Loss, and Resilience in Post-Apartheid Cape Town.” In *Oral History and Public Memories*, edited by Paula Hamilton and Linda Shopes. Philadelphia: Temple University Press, 2008, 107–24.

Fisher, Kate. “Oral Testimony and the History of Medicine.” In *The Oxford Handbook of the History of Medicine*, edited by Mark Jackson. Oxford: Oxford University Press, 2011, 598–616.

French, Robert, and Ross Duffin. *Mossies Could Spread AIDS: An Annotated List of Australian Media References on AIDS, 1981–1985*. Sydney: Gay History Project, 1986.

Gearing, Nigel. *Emerging Tribe: Gay Culture in New Zealand in the 1990s*. Auckland: Penguin Books (NZ), 1997.

Gelber, Katharine. *Speaking Back: The Free Speech Versus Hate Speech Debate*. Amsterdam: John Benjamins Publishing, 2002.

Gillett, James. *A Grassroots History of the HIV/AIDS Epidemic in North America*. Washington: Marquette Books LLC, 2011.

Godwin, John, Julie Hamblin, David Patterson, and David Buchanan. *Australian HIV/AIDS Legal Guide*. Second. Sydney: The Federation Press, 1993.

Gott, Ted. “Where the Streets Have New Aims: The Poster in the Age of AIDS.” In *Don’t Leave Me This Way: Art in the Age of AIDS*, edited by Ted Gott. Canberra: National Gallery of Australia, 1994, 187–211.

Goulden, Terry, Peter Todd, Robert Hay, and Jim Dykes. “AIDS and Community Support Services: Understanding and Management of Psychological Needs.” *Medical Journal of Australia* 141, no. 9 (1984): 582–6.

Goulding, Christina. “Corsets, Silk Stockings, and Evening Suits: Retro Shops and Retro Junkies.” In *Time, Space, and the Market: Retroscapes Rising*, edited by Stephen Brown and John F. Sherry Jr. New York: M. E. Sharpe, 2003, 54–74.

Guy, Laurie. *Worlds in Collision: The Gay Debate in New Zealand, 1960–1986*. Wellington: Victoria University Press, 2002.

Green, Anna. “Oral History and History.” In *Remembering Writing Oral History*, edited by Anna Green and Megan Hutching. Auckland: Auckland University Press, 2004, 1–8.

Green, Gill. *The End of Stigma? Changes in the Social Experience of Long-Term Illnes*s. Oxon: Routledge, 2009.

Grimshaw, Michelle. *An Anthology of Mourning Rituals Utilised by Gay Men in Response to AIDS Related Death*s. Melbourne: National Centre for HIV Social Research, 1992.

Groves, Abigail. “A Time to Be Loud and Furious: AIDS Activism in Australia.” *HIV Australia* 12, no. 2 (2014): 17–8.

Hallas, Roger. *Reframing Bodies: AIDS, Bearing Witness, and the Queer Moving Image*. Durham: Duke University Press, 2009.

Hattingh, Laetitia, John Low, and Kim Forrester. *Australian Pharmacy Law and Practice,* Second. Sydney: Elsevier Australia, 2013.

Henman, Linda D. "Humor as a Coping Mechanism: Lessons from POWs." *Humor: International Journal of Humor Research* 14, no. 1 (2001): 83–94.

Herdman, Elizabeth, and Susan Kippax. *Institutional Discrimination: Critical Ethnography of HIV/AIDS Related Discrimination in a Hospital Setting.* Sydney: HIV AIDS & Society Publications, 1995.

Herek, Gregory M., and John P. Capitanio. "AIDS Stigma and Sexual Prejudice." *American Behavioral Scientist* 42 (1999): 1130–47.

Hodgkin, Katharine, and Susannah Radstone. "Introduction: Contested Pasts." In *Memory, History, Nation: Contested Pasts*, edited by Katharine Hodgkin and Susannah Radstone. New Brunswick, NJ: Transaction Publishers, 2006, 1–21.

Hoefferle, Caroline. *The Essential Historiography Reader*. Upper Saddle River: NJ: Pearson Education, 2011.

Holmes, Katie. "Talking About Mental Illness: Life Histories and Mental Health in Modern Australia." *Australian Historical Studies* 47, no. 1 (2016): 25–40.

Hutching, Megan. "The Distance Between Voice and Transcript." In *Remembering: Writing Oral History*, edited by Anna Green and Megan Hutching. Auckland: Auckland University Press, 2004, 168–77.

Jalland, Pat. *Changing Ways of Death in Twentieth-Century Australia*. Sydney: University of New South Wales Press, 2006.

Jennings, Rebecca. "Lesbians in Sydney." *Sydney Journal* 2, no. 1 (2009): 29–38.

Jones, David W. "Distressing Histories and Unhappy Interviewing." *Oral History* 26, no. 2 (1998): 49–56.

Kaldor, J., A. M. McDonald, C. E. Blumer, D. M. Gertig, J. J. Patten, M. Roberts, C. C. Walker, S. E. Mullins, K. A. Bailey, and J. C. Chuah. "The Acquired Immunodeficiency Syndrome in Australia: Incidence 1982–1991." *Medical Journal of Australia* 158, no. 1 (1993): 10–17.

Kallings, Lars, and Craig McClure. *20 Years of the International AIDS Society, HIV Professionals Working Together to Fight AIDS*. Switzerland: International AIDS Society, 2008.

Kelly, B. D. "Homosexuality and Irish Psychiatry: Medicine, Law and the Changing Face of Ireland." *Irish Journal of Psychological Medicine* 34, no. 3 (2016): 209–15.

Kelly, Jeffrey A. "Stigmatization of AIDS Patients by Physicians'." *American Journal of Public Health* 77, no. 7 (1987): 789–91.

Kerridge, Ian H., and Kenneth R. Mitchell. "The Legislation of Active Voluntary Euthanasia in Australia: Will the Slippery Slope Prove Fatal?" *Journal of Medical Ethics* 22 (1996): 273–8.

Kippax, Sue, R.W. Connell, Gary Dowsett, and June Crawford. *Sustaining Safe Sex: Gay Communities Respond to AIDS.* London: The Falmer Press, 1993.

Kippax, Susan, June Crawford, Mark Davis, Pam Rodden, and Gary Dowsett. "Sustaining Safe Sex: A Longitudinal Study of a Sample of Homosexual Men." *AIDS* 7, no. 2 (1993): 257–63.

Klempner, Mark. "Navigating Life Review Interviews with Survivors of Trauma." *Oral History Review* 27, no. 2 (2000): 67–83.

Kollar, Nathan R. "Rituals and the Disenfranchised Griever." *Liturgy* 9, no. 2 (1990): 71–80.

Kosenko, Kami A., and Lance S. Rintamaki. "Forms, Functions, and Foibles of Humor Used in AIDS Service Organizations." *JANAC* 21, no. 1 (2010): 25–35.

Kramer, Larry. *The Normal Heart*. New York: New American Library, 1985.

Kübler-Ross, Elisabeth, and David Kessler. *On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss.* London: Simon & Schuster UK, 2005.

Laub, Dori. "Bearing Witness, or the Vicissitudes of Listening." In *Testimony: Crises of Witnessing in Literature, Psychoanalysis and History*, edited by Shoshana Felman and Dori Laub. New York: Routledge, 1992, 57–74.

Lee, Rachel S., Arlene Kochman, and Kathleen J. Sikkema. "Internalized Stigma Among People Living with HIV–AIDS." *AIDS and Behavior* 6, no. 4 (2002): 309–19.

Levine, Martin P. *Gay Macho: The Life and Death of the Homosexual Clone*. New York: New York University Press, 1998.

Lewis, Milton James. *Medicine and Care of the Dying: A Modern History.* Oxford: Oxford University Press, 2007.

———. *The People's Health: Public Health in Australia, 1950 to the Present*. Westport, CT: Praeger Publishers, 2003.

Leydesdorff, Selma, Graham Dawson, T.G. Burchardt, and Natasha Ashplant. "Introduction." In *Trauma: Life Stories of Survivors*, edited by Kim Lacy Rogers, Selma Leydesdorff, and Graham Dawson. New Brunswick, NJ: Transaction Publishers, 2004, 1–26.

Lieutenant Colonel Kevin Farrell. "Human Immunodeficiency Virus (HIV) Testing in the Australian Defence Force." *Defence Forces Journal* 94 (1992): 21–3.

Linsk, Nathan L., and Sharon M. Keigher. "Of Magic Bullets and Social Justice: Emerging Challenges of Recent Advances in AIDS Treatment." *Health & Social Work* 22, no. 1 (1997): 70–4.

Low, Setha M., and Irwin Altman. "Place Attachment: A Conceptual Inquiry." In *Place Attachment*, edited by Irwin Altman and Setha M. Low. New York: Plenum Press, 1992, 1–12.

Low, Setha M. “Symbolic Ties That Bind: Place Attachment in the Plaza.” In *Place Attachment*, edited by Irwin Altman and Setha M. Low. New York: Plenum Press, 1992, 165–84.

Luo, K., M. Law, J. M. Kaldor, A. M. McDonald, and D. A. Cooper. “The Role of Initial AIDS-Defining Illness in Survival Following AIDS.” *AIDS* 9, no. 1 (1995): 57–63.

Lupton, Deborah. “Archetypes of Infection: People with HIV/AIDS in the Australian Press in the Mid-1990s.” *Sociology of Health and Illness* 21, no. 1 (1999): 37–53.

———. *Moral Threats and Dangerous Desires: AIDS in the News Media*. London: Taylor & Francis, 1994.

Lupton, D., S. Chapman, and W. L. Wong. “Back to Complacency: AIDS in the Australian Press, March–September 1990.” *Health and Education Research* 8, no. 1 (1993): 5–17.

Macilwain, Colin. “Better Adherence Vital in AIDS Therapies.” *Nature* 390 (1997): 326.

McInnes, David. *Professionally Gay: The Workforce of Gay Male Educators*. AFAO/NAPWA Education Discussion Paper 2, no. 6 (2000/2001): 1–17.

Mitchell, Margaret. “Gallows Humour.” In *Encyclopedia of Death and Dying*, edited by Glennys Howarth and Oliver Leaman. Oxon: Routledge, 2001, 203–4.

Mold, Alex. “Making the Patient-Consumer in Margaret Thatcher’s Britain.” *Historical Journal* 54, no. 2 (2011): 509–28.

———. “Patient Groups and the Construction of the Patient-Consumer in Britain: An Historical Overview.” *Journal of Social Policy* 39, no. 4 (2010): 505–21.

Morgen, Sandra. *Into Our Own Hands: The Women’s Health Movement in the United States, 1969–1990*. New Jersey: Rutgers University Press, 2002.

Mykhalovskiy, Eric, Liza McCoy, and Michael Bresalier. “Compliance/Adherence, HIV, and the Critique of Medical Power.” *Social Theory & Health* 2, no. 4 (2004): 315–40.

Nash, Catherine J., and Andrew Gorman-Murray. “Lesbian Spaces in Transition: Insights from Toronto and Sydney.” In *Planning and LGBTQ Communities: The Need for Inclusive Queer Spaces*, edited by Petra L. Doan. New York: Routledge, 2015, 181–98.

Neiderland, William G. “The Problem of the Survivor.” *Journal of Hillside Hospital* 10 (1961): 33–47.

Newman, Christy, Robert Reynolds, Rebecca Gray, Peter Canavan, John de Wit, Marilyn McMurchie, Ronald McCoy, and Michael R. Kidd. “Surviving an Epidemic: Australian GPs on Caring for People with HIV and AIDS in the Early Years.” *Australian Family Physician* 42, no. 10 (2013): 734–8.

Newman, Christy, Asha Persson, John de Wit, and Michael Kidd. "'We're All on the Same Side': Relationships Between General Practitioners and Their Patients and Peers in HIV Medicine." *HIV Australia* 12, no. 1 (2014): 47–8.

Odet, Walk. *In the Shadow of the Epidemic: Being HIV-Negative in the Age of AIDS*. Durham: Duke University Press, 1995.

Otlowshi, Margaret. "Active Voluntary Euthanasia: A Legal Perspective." In *The Quality of Death: Euthanasia in Australia*, edited by Ian Hunt and Lynda Burns. Adelaide: Centre for Applied Psychology, Flinders University, 1996, 20–59.

Parr, Alison. "Breaking the Silence: Traumatised War Veterans and Oral History." *Oral History* 35, no. 1 (2007): 61–70.

———. *Silent Casualties: New Zealand's Unspoken Legacy of the Second World War*. Auckland: Random House New Zealand, 1995.

Parsons, Talcott. *The Social System*. London: Routledge & Kegan Paul, 1951.

Passerini, Luisa. "Introduction." In *Memory and Totalitarianism*, edited by Luisa Passerini. New York: Oxford University Press, 1992, 1–19.

———. "Women's Personal Narratives: Myths, Experiences and Emotions." In *Interpreting Women's Lives: Feminist Theory and Personal Narratives*, edited by the Personal Narratives Group. Bloomington: Indiana University Press, 1989, 189–97.

Patton, Cindy. *Inventing AIDS*. New York: Routledge, 1990.

Persson, Asha. "Incorporating Pharmakon: HIV, Medicine, and Body Shape Change." *Body and Society* 10 (2004): 45–67.

Plummer, Ken. *Telling Sexual Stories: Power, Change and Social Worlds*. London: Routledge, 1995.

Popular Memory Group. "Popular Memory: Theory, Politics, Method." In *Making Histories: Studies in History-Writing and Politics*, edited by Richard Johnson, Gregor McLennan, Bill Schwarz, and David Sutton. Minneapolis: University of Minnesota Press, 1982, 205–52.

Portelli, Alessandro. *The Battle of Valle Giulia: Oral History and the Art of Dialogue*. Madison, WI: The University of Wisconsin Press, 1997.

———. *The Death of Luigi Trastulli and Other Stories: Form and Meaning in Oral History*. Albany: State University of New York Press, 1991.

———. *They Say in Harlan County: An Oral History*. New York: Oxford University Press, 2011.

———. "What Makes Oral History Different." In *The Oral History Reader*, edited by Robert Perks and Alistair Thomson, Second. Oxon: Routledge, 1998, 32–42.

Power, Jennifer. *Movement, Knowledge, Emotion: Gay Activism and HIV/AIDS in Australia*. Canberra: ANU E Press, 2011.

———. "Rites of Belonging: Grief, Memorial and Social Action." *Health Sociology Review* 18, no. 3 (2009): 260–72.

Porche, Demetrius James. “One World. One Hope. XI International Conference on AIDS.” *JANAC* 7, no. 5 (1996): 94–100.

Rando, Therese A. *Grief, Dying and Death: Clinical Interventions for Caregivers.* Champaign, IL: Research Press, 1984.

Reynolds, Robert. *What Happened to Gay Life?* Sydney: University of New South Wales Press, 2007.

———. *From Camp to Queer*. Melbourne: Melbourne University Press, 2001.

———. “CAMP Inc. and the Creation of the ‘Open’ Homosexual.” In *Australia’s Homosexual Histories*, edited by David L. Phillips and Graham Willett. Sydney, NSW: Australian Centre for Lesbian and Gay Research, 2000, 133–49.

Reynolds, Robert, and Shirleene Robinson. *Gay and Lesbian, Then and Now: Australian Stories from a Social Revolution*. Carlton, VIC: Black Inc., 2016.

———. “HIV/AIDS, Loss and the Australian Gay Community.” In *Legacies of Violence: Rendering the Unspeakable Past in Modern Australia*, edited by Robert Mason. New York: Berghahn, 2017, 162–82.

Richman, Douglas D., Margaret A. Fischl, Michael H. Grieco, Michael S. Gottlieb, Paul A. Volberding, Oscar L. Laskin, John M. Leedom, Jerome E. Groopman, Donna Mildvan, Martin S. Hirsch, George G. Jackson, David T. Durack, Sandra Nusinoff-Lehrman, and The AZT Collaborative Working Group. “The Toxicity of Azidothymidine (AZT) in the Treatment of Patients with AIDS and AIDS-Related Complex.” *New England Journal of Medicine* 317, no. 4 (1987): 192–7.

Rickard, Wendy. “HIV and AIDS Testimonies in the 1990s.” In *Oral History, Health and Welfare*, edited by Joanna Bornat, Robert Perks, Paul Thompson, and Jan Walmsley. London: Routledge, 2000, 227–48.

———. “Oral History—‘More Dangerous Than Therapy’? Interviewees’ Reflections on Recording Traumatic or Taboo Issues.” *Oral History* 26, no. 2 (1998): 34–48.

Riessman, Catherine Kohler. “Analysis of Personal Narratives.” In *Handbook of Interview Research*, edited by Jaber F. Gubrium and James A. Holstein. Thousand Oaks: Sage, 2001, 695–711.

Ritchie, Donald A. *Doing Oral History*, Third. Oxford: Oxford University Press, 2015.

Robinson, Peter. *The Changing World of Gay Men*. New York: Palgrave Macmillan, 2008.

Robinson, Shirleene. “Responding to Homophobia: HIV/AIDS, Homosexual Community Formation and Identity in Queensland, 1983–1990.” *Australian Historical Studies* 41, no. 2 (2010): 181–97.

Robinson, Shirleene, and Emily Wilson. “HIV/AIDS and Gay Community Print News Media in 1980s Australia.” In *Out Here: Gay and Lesbian Perspectives VI*, edited by Yorick Smaal and Graham Willett. Melbourne: Monash University Publishing, 2011, 88–103.

———. “Working Together? Medical Professionals, Gay Community Organisations and the Response to HIV/AIDS in Australia, 1983–1985.” *Social History of Medicine* 25, no. 3 (2012): 701–18.

Rofes, Eric. *Dry Bones Breathe: Gay Men Creating Post-AIDS Identities and Cultures*. New York: Haworth Press Inc., 1998.

Rubinstein, Robert L., and Patricia A. Parmelee. “Attachment to Place and the Representation of the Life Course by the Elderly.” In *Place Attachment*, edited by Irwin Altman and Setha M. Low. New York: Plenum Press, 1992, 140.

Ruthchild, Carp. “Don’t Frighten the Horses! A Systemic Perspective on Violence Against Lesbians and Gay Men.” In *Homophobic Violence*, edited by Gail Mason and Stephen Tomsen. Sydney: The Hawkins Press, 1997, 1–14.

Sendziuk, Paul. *Learning to Trust: Australian Responses to AIDS*. Sydney: University of New South Wales Press, 2003.

Silverstein, Charles, and Edmund White. *The Joy of Gay Sex*. New York: Crown Publishers, 1977.

Silverstein, Charles, and Felice Picano. *The New Joy of Gay Sex*. London: GMP Publishers, 1993.

Summerfield, Penny. “Culture and Composure: Creating Narratives of the Gendered Self in Oral History Interviews.” *Cultural and Social History* 1 (2004): 65–93.

———. “Dis/composing the Subject: Intersubjectivities in Oral History.” In *Feminism & Autobiography: Texts, Theories, Methods*, edited by Tess Coslett, Celia Lury, and Penny Summerfield. London: Routledge, 2000, 91–106.

———. *Reconstructing Women’s Wartime Lives*. Manchester: Manchester University Press 1998.

Sarre, Rick, and Stephen Tomsen. “Violence and HIV/AIDS: Exploring the Link Between Homophobic Violence and HIV/AIDS as a ‘Gay Disease.’” In *Homophobic Violence*, edited by Gail Mason and Stephen Tomsen. Sydney: The Hawkins Press, 1997, 77–90.

Shilts, Randy. *And the Band Played On*. London: St Martin’s Press, 1987.

Solomon, George F., Lydia Temoshok, Ann O’leary, and Jane Zich. “An Intensive Psychoimmunologic Study of Long-Surviving Persons with AIDS. Pilot Work, Background Studies, Hypotheses, and Methods.” *Annals of the New York Academy of Sciences* 496 (1987): 647–55.

Sowell, Richard L., Kenneth D. Phillips, and Jean Grier. “Restructuring Life to Face the Future: The Perspective of Men After a Positive Response to Protease Inhibitor Therapy.” *AIDS Patient Care and STDs* 12, no. 1 (1998): 33–42.

Thompson, Paul. “Introduction.” In *Oral History, Health and Welfare*, edited by Joanna Bornat, Robert Perks, Paul Thompson, and Jan Walmsley. London: Routledge, 2000, 1–20.

———. “The Voice of the Past: Oral History.” In *The Oral History Reader*, edited by Robert Perks and Alistair Thomson, Second. Oxon: Routledge, 1998, 25–31.

Thompson, Sue. “Hate Crimes Against Gays and Lesbians: The New South Wales Police Response.” In *Homophobic Violence*, edited by Gail Mason and Stephen Tomsen. Sydney: The Hawkins Press, 1997, 132–46.

Thomson, Alistair. *Anzac Memories: Living with the Legend*, Second. Melbourne: Monash University Publishing, 2013.

———. “Oral History.” In *Australian History Now*, edited by Anna Clark and Paul Ashton. Sydney: NewSouth Publishing, 2013, 73–89.

———. “Memory and Remembering in Oral History.” In *The Oxford Handbook of Oral History*, edited by Donald A. Ritchie. New York: Oxford University Press, 2011, 77–95.

———. “Four Paradigm Transformations in Oral History.” *Oral History Review* 34, no. 1 (2007): 49–70.

———. “Anzac Memories: Putting Popular Theory into Practice in Australia.” In *The Houses of History: A Critical Reader in Twentieth-Century History and Theory*, edited by Anna Green and Kathleen Troup. Manchester: Manchester University Press, 1999, 234–48.

———. “A Past You Can Live With: Digger Memories and the Anzac Legend.” *Oral History Association of Australia Journal* 13 (1991): 12–8.

———. “Anzac Memories: Putting Popular Memory Theory into Practice in Australia.” *Oral History* 18, no. 1 (1990): 25–31.

Thomson, Alistair, Michael Frisch, and Paula Hamilton. “The Memory and History Debates: Some International Perspectives.” *Oral History* 22, no. 2 (1994): 33–43.

Tucker, Mary. “Revisiting the ‘Lazarus Syndrome.’” In *A History of AIDS Social Work in Hospitals: A Daring Response to an Epidemic*, edited by Barbara I. Willinger and Alan Rice. New York: The Haworth Press, 2003, 255–62.

Walker, Geoffrey. “Australia’s Response to AIDS: The Law and the Policy Issues.” In *Legal Responses to AIDS in Comparative Perspective*, edited by Stanislaw Frankowski. The Hague: Kluwer Law International, 1998, 169–220.

Wallack, Joel J. “AIDS Anxiety Among Health Care Professionals.” *Hospital Community Psychiatry* 40 (1989): 507–10.

Ware, Cheryl. “‘Time To Speak Out’: The 1980s Australian Gay Press and Personal Accounts of Living with HIV.” *Journal of Australian Studies* 41, no. 4 (2017): 472–86.

Weeks, Jeffrey, Peter Aggleton, Christopher McKevitt, Kay Parkinson, and Austin Taylor-Laybourn. “Community Responses to HIV and AIDS: The ‘De-Gaying’ and ‘Re-Gaying’ of AIDS.” In *Sexual Cultures: Communities,* *Values and Intimacy*, edited by Jeffrey Weeks and Janet Holland. New York: St. Martin's Press, Scholarly and Reference Division, 1996, 161–79.

Wherrett, Richard. "Introduction." In *Mardi Gras! True Stories*, edited by Richard Wherrett. Melbourne, VIC: Penguin Books Australia, 1999, 1–7.

Whitaker, Anne-Marie. *St Vincent's Hospital 1857–2007: 150 Years of Charity, Care and Compassion*. Alexandria, NSW: Kingsclear Books, 2007.

White, Naomi Rosh. "Marking Absences: Holocaust Testimony and History." *Oral History Association of Australia Journal* 16 (1994): 12–8.

Graham Willett. "How We Saved Our Lives: The Gay Community and the Australian Response to AIDS." *HIV Australia* 12, no. 3 (2014): 4–7.

———. *Living Out Loud: A History of Gay and Lesbian Activism in Australia*. St. Leonards, NSW: Allen & Unwin, 2000.

Williamson, Charlotte. *Towards the Emancipation of Patients: Patients' Experiences and the Patient Movement*. Bristol: The Policy Press, 2010.

Wilson, Emily. "'Someone Who Is Sick and in Need of Help': Medical Attitudes to Homosexuality in Australia, 1960–1979." In *Homophobia: An Australian History*, edited by Shirleene Robinson. Sydney: The Federation Press, 2008, 148–71.

Wilton, Tamsin. *EnGendering AIDS: Deconstructing Sex, Text and Epidemic*. London: Sage, 1997.

Wotherspoon, Garry. *City of the Plain: History of a Gay Sub-Culture*. Sydney: Hale and Iremonger, 1991.

———. *Gay Sydney: A History*. Sydney, NSW: NewSouth Publishing, 2016.

———. *Making a Difference: A History of Positive Life NSW*. Sydney: Positive Life NSW Incorporated, 2009.

Whittaker, Andrea M. "Living with HIV: Resistance by Positive People." *Medical Anthropology Quarterly* 6, no. 4 (1992): 385–90.

Yardley, Ainslie, and Kim Langley. *Unfolding: The Story of the Australian and New Zealand AIDS Quilt Projects*. Ringwood, VIC: McPhee Gribble, 1994.

INDEX

C. Ware, *HIV Survivors in Sydney*, Palgrave Studies in Oral History,
https://doi.org/10.1007/978-3-030-05102-0