



# How Gay Men Prepare for Death

## The Dying Business

Peter Robinson

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The Dying Business

BY

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United Kingdom – North America – Japan – India  
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# CONTENTS

<i>List of Tables</i>	<i>vii</i>
<i>Acknowledgements</i>	<i>ix</i>
Introduction	1
1. Affective and Intimate Lives	11
2. Wills and Beneficiary Decisions	39
3. Managing Physical and Mental End of Life	61
4. Euthanasia and Afterlife Beliefs	87
5. Funeral Plans	109
Conclusion	127
<i>Appendix 1: Research Instruments</i>	<i>133</i>
<i>Appendix 2: Participants' Biodata, 1, 2, 3</i>	<i>137</i>
<i>Index</i>	<i>143</i>

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# LIST OF TABLES

## Appendix 2

1.	Work, relationships, children, family $n = 43$	137
2.	End-of-life documents, instructions, $n = 43$	139
3.	Education, Occupation, Income, Assets, Superannuation/Pension, $n = 43$	141

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# INTRODUCTION

There are three characteristics of ethnographic description: it is interpretive; what it is interpretive of is the flow of social discourse; and the interpreting involved consists in trying to rescue the ‘said’ of such discourse from its perishing occasions and fix it in perusable terms.<sup>1</sup>

The research for this book focused on gay men’s end-of-life plans and experiences, or how they prepared for death. While conceived before the outbreak of Covid-19, it was conducted during the worst of the pandemic in England, New Zealand and North America. The Australian interviews were held face to face in 2019 and before its outbreak in early 2020. As explained below in the section on methodology and sample, the international interviews were made possible using the Zoom online conference platform.

Until almost six weeks before the manuscript was due to be sent to the publishers, the title of the book was intended to reflect this literally and was to be *Gay Men’s End of Life Plans and Experiences*. When I realized, however, that while end of life fairly accurately described the focus of my research, a more precise description of what the book covered was the title that it has now, namely, *How Gay Men Prepare for Death: The Dying Business*.

## BIBLIOGRAPHICAL NOTE

Gay men’s end-of-life experiences is a fairly recent and emerging field of research. Early work has been done in Australia, Canada, England and the USA in the field of social work and the disciplines of law and sociology where the focus has tended to be on the end-of-life experience. Almost all publications that included the

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1 Geertz, C. (2017, 1973) *The Interpretation of Cultures: Selected Essays* with a foreword by R. Danton (New York: Basic Books), p. 22.

experiences or concerns of gay men were from research on the broad LGBT populations.<sup>2</sup>

Stand-alone studies on gay men's end-of-life were few in number and very little work has been undertaken on the end-of-life plans and experience of international cohorts of only gay men. As the chapter outlines (below) make clear, this book concentrated on the plans and experiences of an international sample of gay men in relation to their will-writing and beneficiary decision-making; advance-care decisions and power-of-attorney appointments; euthanasia and afterlife beliefs; and their funeral plans. Each chapter begins with a short summary of the relevant literature.

A central argument in most of the work on queer end of life was the tension between choosing family members or partners or friends to take on legal and health-care responsibilities in the last stage of life. Early US research emphasized the importance of friends and the family of choice for ageing gays and lesbians who were likely to experience social isolation because of broken ties with their family of origin.<sup>3</sup> Later English research showed that when writing wills, older lesbians and gays tended to choose between children, friends, siblings,<sup>4</sup> or make mixed choices, while a study of the end-of-life preparations of LGBT Canadians found a preference for family members over friends for end-of-life discussions and decision makers.<sup>5</sup> Australian research noted how advance care or power of attorney provided LGBT people with instruments that avoided the default of family of origin as end-of-life decision makers.<sup>6</sup> And preliminary analysis of the

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2 Almack, K., et.al. (2010) 'Exploring the Impact of Sexual Orientation on Experiences and Concerns about End of Life Care and on Bereavement for Lesbian, Gay and Bisexual Older People' in *Sociology*, 44(5): 908–924; Monk, D. (2011) 'Sexuality and Succession Law: Beyond Formal Equality' in *Feminist Legal Studies*, 19: 231–250; Monk, D. (2016) "'Inheritance Families of Choice?' Lawyers' Reflections on Gay and Lesbian Wills' in *Journal of Law and Society*, 43(2): 167–194; Seelman, K.L., et.al. (2019) 'Motivations for Advance Care and End-of-Life Planning among Lesbian, Gay, and Bisexual Older Adults' in *Qualitative Social Work*, 18(6): 1002–1016; Westwood, S. (2021) *Regulating the End of Life: Death Rights* (Milton Park: Routledge).

3 Knauer, N.J. (2010) 'Gay and Lesbian Elders: Estate Planning and End-of-Life Decision Making' in *Florida Coastal Law Review*, XII: 168, 174.

4 Westwood, S. (2015) 'Complicating Kinship and Inheritance: Older Lesbians' and Gay Men's Will-Writing in England' in *Feminist Legal Studies*, 23: 181–197.

5 de Vries, B., et.al. (2020) 'Advance Care Planning among older LGBT Canadians: Heteronormative Influences', *Sexualities*, <https://doi.org/10.1177/1363460719896968>

6 Hughes, M. and Cartwright, C. (2015) 'Lesbian, gay, bisexual and transgender people's attitudes to end-of-life decision-making and advance care planning', in *Australasian Journal on Ageing*, 34(Supp. 2), 39–43.

beneficiary decisions of a select group of 18 participants from the full data set used in this book showed a distinct preference for family of origin over chosen family.<sup>7</sup>

One obvious reason for the interest in findings that confirm the privileging of family over friends is that from the 1980s the chosen family was regarded as an alternative to the family of origin either completely or when the latter was not accepting of gay family members' sexuality preferences,<sup>8</sup> and, before that, the long history of the gay couple, which 11 participants from this study regarded as their family, and which existed outside the traditional structure of the family of origin. In summary, then, the general assumption that queer people were more inclined to form families of choice and that the family-of-choice idea was widespread also in the general population was not supported by a lot of queer end-of-life research and the research for this book.

## METHODOLOGY AND SAMPLE

The data for this book came from interviews with a sample of 43 gay men aged 40 and older. The majority of participants were recruited from five countries with relatively advanced queer cultures, namely, Australia, Canada, England, New Zealand and the USA. Some had been interviewed for my previous work on gay ageing and gay men's working lives and retirement, and so this was their second interview.<sup>9</sup> In addition, two men were recruited from Germany and Hong Kong. The participant who was living in Germany at the time of interview was a North American expatriate who was instrumental in assisting me make contact with the group of men from California who took part in the research. I had intended to recruit a larger cohort from Hong Kong but whether because the topic was unappealing – at least one of the Chinese-Australian gay men that I consulted in the early phase of the research said that raising matters concerning death and the transfer of property might be regarded as offensive – or because Hong Kong was unsettled because of

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7 Robinson, P. (2022) 'Gay Inheritance Decisions: Family of Choice or Family of Origin?' in S. Brunn and M. Blidon (eds.) *Mapping LGBTQ Places and Spaces: A Changing World* (Springer eBook, <https://doi.org/10.1007/978-3-031-03792-4>), pp. 711–723. The smaller sample was based on a preliminary data set of interviews with 18 participants whose transcripts were available at the time of writing (January 2021).

8 Monk "Inheritance Families", p. 168; Weston, K. (1997) *Families We Choose: Lesbians, Gays, Kinship* (New York: Columbia University Press), p. 27.

9 Robinson, P. (2013) *Gay Men's Relationships across the Life Course* (Basingstoke: Palgrave Macmillan); Robinson, P. (2017) *Gay Men's Working Lives, Retirement and Old Age* (Basingstoke: Palgrave Macmillan).

civil disorder in 2019 and the Coronavirus pandemic in 2020, only one gay Hong Kongese asked for an interview.<sup>10</sup>

Traditional qualitative research techniques were used. Firstly, notice of the intention to conduct the research on gay men's end of life and a call for potential interviewees were sent out to gay community groups in Australia, Hong Kong and North America. Secondly, in England and New Zealand, I contacted networks of colleagues and friends to alert them to the research and asked them to disseminate a notice advertising it. To optimise the variety of end-of-life accounts, potential interviewees were purposively recruited through gay community groups and professional and social networks.

In Australia, notices were advertised with Aleph, a social support group for GLBTI Jews in Melbourne and The Country Network, a social support group for gay and bisexual men living in rural and regional Australia as well as at the Australian Lesbian and Gay Archives, Homo Histories Conference, Canberra, November 2019 and the National Tertiary Education Union's Queer Conference, January 2020. In England, recruitment proceeded almost entirely as a result of the help of Mr Rehan Kularatne as well as through an advertisement placed in *London Review of Books*, October 2020–May 2021. In North America, assistance to publicise the research came from Mr Eric Jannke and also from support groups in and around California including Let's Kick Ass in Palm Springs; PALS in the desert; HIV and aging (*sic*) research group as well as via an advertisement placed in *New York Review of Books*, May–December 2021. Thirdly, when potential respondents expressed an interest in being interviewed, they were sent a copy of the plain-language statement and consent form.<sup>11</sup> Once the signed consent form was returned and a time and date agreed upon, the interview was held and recorded.

I encountered more problems recruiting interviewees for this research than for any previous research. It is hard to know if this was because in the minds of many people, priests, doctors or lawyers are the only appropriate experts on death and end-of-life, and that it is not the domain of historians or sociologists. Wills are very personal documents, and often only discussed with a person's partner and lawyer and perhaps also whoever was nominated as executor and power of attorney. The prospect of discussing the details of such

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10 As an indication of the level of distress Hong Kongese experienced in 2019, more than 600,000 Hong Kong residents were expected to apply for British resettlement: Graham-Harrison, E. (2020) 'UK Government has "underestimated takeup for resettlement scheme"', *The Guardian*, <https://www.theguardian.com/world/2020/dec/12/uk-government-underestimates-takeup-hong-kong-resettlement> accessed 12 December 2020.

11 See Appendix 1.

a document with a stranger, therefore, and in the context of ‘end-of-life’ might account for some of the difficulties that I experienced in recruiting interviewees, for no matter how relaxed or at ease contemporary society might appear to be with death, it is still a taboo topic, as are will-writing and inheritance. In some countries and among some classes, the latter are topics of the utmost secrecy and certainly not to be shared with strangers, let alone a stranger who is also a researcher.

I have written elsewhere about the problems of recruiting in a foreign land and how letters or emails of introduction can open previously closed doors in local gay communities.<sup>12</sup> No matter how sociable gay life appears online (for example on Grindr or Gay Romeo) or face-to-face (in clubs, bars, sex venues) researchers from ‘out of town’ must first establish their bona fides and acquaint themselves with the local culture and social institutions before they can hope to recruit potential interviewees. Like an anthropologist wishing to study the inhabitants of a location where they are not known, ground work is required to establish trust with the people they wish to study before the first interview can take place. And as anthropologists know also, despite the heartache of rejected invitations to interview, location is so very useful for what it reveals about cross-national similarities or differences in the data. In the case of this research whether, for example, it can show if the experience of being a gay man and preparing end-of-life documents in The Australian Capital Territory is similar to or different from that of a gay man living in England or British Columbia or if a case can be made for the existence of shared experience of an international western gay habitus.

All interviews with participants living in Australia took place before the onset of the Covid-19 pandemic in Australia and were recorded face-to-face on a digital recorder. Interviews in England, New Zealand and North America were held during the Covid-19 pandemic, 2020–2021 and took place using the Zoom online conference platform. They were orally recorded (not visually) and later transcribed. All interviewees were asked if they would give permission for the oral recordings to be deposited in perpetuity with the La Trobe Library, Melbourne.

Pseudonyms were used in the book to protect the identity of the participants. In the case of interviewees who participated in my previous research,<sup>13</sup> the pseudonyms used then were used again in this book, so readers who have copies of my previous published research and the interviewees themselves would be able to track connections across time. Interviewees’ correct age at the

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12 Robinson *Gay Men’s Relationships*, pp. 24–30.

13 Robinson *Gay Men’s Relationships*, pp. 21–34.

time of interview were used together with their country of residence, also at the time of interview.

Central to the chapters that follow are aspects of the dying business of the 43 gay men, their accounts of how they were planning to prepare for their own death, in the writing of wills, appointing of attorneys, musings on their funeral plans. The interviews are a snapshot of the preparations that these men were making for their own death at some point in the future. In answering the set of questions that I devised in the hope of gaining some insight into their thinking, they behaved as all interviewees do: some kept to the topic, others strayed off topic, but all drew on their memory of the decisions that they had made about how they hoped to die and sometimes their experience of being with others who had already died.

## CHAPTER OUTLINES

The dying business that is explored in this book has practical aspects. These are explored in sequence beginning with Chapter 1. Broader theoretical questions are explored in each chapter as they arise.

### Chapter 1: Affective and Intimate Lives.

This gives some of the background to decision-making by examining the nature of relationships that the participants had formed in the context of greater acceptance of queer relationships and marriage equality legislation as well as their birth families and current families. It describes how many were in couple relationships and of these what proportion were in common-law (or de facto) relationships, civil partnership, civil union or were gay married as a means of understanding in later chapters their beneficiary decisions, appointment of executors and powers of attorney.

### Chapter 2: Wills and Beneficiary Decisions.

The focus of this chapter is on will-writing and decisions concerning beneficiaries. Particular attention is paid to whether participants preferred family members, partners or friends when choosing executors and beneficiaries and their reasons for doing so. Motivation for benefactions such as altruism and social solidarity are also considered.

### Chapter 3: Managing Physical and Mental End of Life.

Decisions concerning advance care and power of attorney are investigated in this chapter. A relatively new end-of-life instrument, the advance care was in practice in most of the jurisdictions from which the participants were drawn, as was the long-established legal instrument, power of attorney or its

equivalent. Again the focus is on the extent to which participants chose family members over partners or friends to manage their advance care or act at their attorney.

#### Chapter 4: Euthanasia and Afterlife Beliefs.

Participants were prompted towards the end of the interview to discuss beliefs concerning euthanasia on the one hand and life after death on the other hand, and thus the focus of this chapter. Their views on euthanasia are examined in the context of assisted suicide and dying with dignity services and for what they reveal about end-of-life suffering and the notion of the ‘good death’.

#### Chapter 5: Funeral Plans.

The final chapter discusses what participants’ views were on how they planned or expected to have their bodies disposed of after death and whether they preferred burial to cremation or the bone crusher. Implicitly in recounting their views on what sort of funeral they wanted or whether they wanted one at all, the participants revealed something about how they regarded their life’s worth.

A theme that kept recurring when I was examining the participants’ decisions about the writing of wills, appointing of attorneys, or when they were musing on their funeral plans was the power that lived experience had in shaping their understanding of the present and their future. In the case of the men interviewed for this book, often it was an experience of the end of life of someone close to them, a friend, a parent or a partner, that shaped their understanding and might have influenced their decisions concerning what their own death might look like and how it might occur.

Having accepted what historian Philippe Ariès argued – that death which was once tame, is now wild and can terrify us<sup>14</sup> – I was intrigued to find that those who had witnessed the death of someone close to them, who had borne witness, to use the religious phrase, seemed to be able to learn from that experience of death, to banish fear and to think about, conceive and plan for their own with greater strength of mind. And that practice based on such an understanding, as was revealed time and again in interviews with participants, reinforced in my mind the truth of anthropologist Clifford Geertz’s argument – stated in the quotation at the head of this Introduction – that ethnographic description consists in rescuing ‘the said’ from its perishable state and setting it down for our perusal, after the event.

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14 Ariès, P. (1991) *The Hour of Our Death*, trans. H. Weaver (New York: Oxford University Press), p. 28; Ariès, P. (1975) *Western Attitudes toward Death: From the Middle Ages to the Present*, trans. P. Ranum (Baltimore: The Johns Hopkins University Press), p. 13.

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*Spaces: A Changing World* (Springer eBook, <https://doi.org/10.1007/978-3-031-03792-4>), pp. 711–723.

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Westwood, S. (2021) *Regulating the End of Life: Death Rights* (Milton Park: Routledge).

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## AFFECTIVE AND INTIMATE LIVES

The traditional family . . . is clearly losing the monopoly that it for so long enjoyed. Its quantitative significance is declining with the spread of new lifestyles which do not usually aim at living alone but seek ties of a different kind: for example, cohabitation without a marriage certificate or without children; a single-parent family, ‘conjugal succession’ or a same-sex partnership; weekend relationships and part-life companionship; living in more than one household or between different towns. So, more and more intermediate forms, before, alongside and after the family, are appearing on the scene: these are the contours of the ‘post-familial family’.<sup>1</sup>

### INTRODUCTION

This chapter examines the families in which participants grew up – their family of origin and then the families they themselves formed as adults – that is, their current family. And secondly, it examines their relationship status, that is, whether they were single or in a couple relationship. The overwhelming majority were born and raised in nuclear families and two grew up in extended families.

When describing their current family, more than half referred only to their birth family, about one quarter cited their couple relationship as their family, and a relatively small number said that they had formed a ‘family of choice’. In terms of relationship status, a substantial majority ( $n = 29$ ) were in couple relationships from 1 or 2 years to more than 40 years, and 14 were single, ranging from between 1 or 2 years at the time of interview to those who had

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1 Beck-Gernsheim, E. (2002) *Reinventing the Family: In Search of New Lifestyles*, trans. P. Camiller (Cambridge: Polity Press), p. 10.

been single all of their adult life.<sup>2</sup> As shown below, participants' relationships included a variety of forms – from common law (or de facto) to civil union, civil partnership and marriage.

In order to give some context before discussing these findings, the next two sections provide a brief outline of the principal features firstly of households and family and how these contributed to understanding the household or family settings of gay people and secondly of the couple relationship and its bearing on those that gay people established for themselves.

## HOUSEHOLD AND FAMILY

Two terms that sociologists and historians frequently use when examining domestic accommodation arrangements in human settlements are household and family. The term 'household' is used to describe a range of different domestic accommodation settings including solitaries, nuclear families and extended families. As the name implies, 'solitaries' refers to a single-person household,<sup>3</sup> while the ubiquitous nuclear family refers to the arrangement where a conjugal couple and their children live together under one roof. The extended family, meanwhile, can comprise different generations related by birth, more than one married couple from the same generation,<sup>4</sup> or, in earlier times, include farm workers or servants unrelated by birth to other household members.<sup>5</sup> It is used also to describe accommodation arrangements where two siblings or two relations of another sort live together.<sup>6</sup>

Because of its ubiquity and persistence, a brief word about the nuclear family is called for here. Sociologists and historians maintain that from the beginning of the modern period, that is, the sixteenth century in Europe, its principal features have been as the approved site for sexual relations between adults,<sup>7</sup> for

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2 See Appendix 2.

3 Wall, R. in collaboration with Rodin, J. and Laslett, P. (eds.) (1983) *Family Forms in Historic Europe* (Cambridge: Cambridge University Press), pp. 2, 47.

4 Sennett, R. (1992) *The Fall of Public Man* (New York: W.W. Norton & Company), p. 177.

5 Wall, *Family Forms*, pp. 45, 128–129, 212.

6 Wall, *Family Forms*, pp. 128–129.

7 Elias, N. (2000, 1939) *The Civilizing Process: Sociogenetic and Psychogenetic Investigations*, trans. E. Jephcott with some notes and corrections by the author and edited by E. Dunning, J. Goudsblom and S. Mennell, Revised edition (Oxford: Blackwell Publishers Ltd), p. 138; Muchembled, R. (2008) *Orgasm and the West: The History of Pleasure From the Sixteenth Century to the Present*, trans. J. Birrell (Cambridge: Policy Press), p. 24.

the reproduction and care of children,<sup>8</sup> the transmission of property through inheritance,<sup>9</sup> the care of the elderly and avoidance of loneliness<sup>10</sup> and the creation of identity and a ‘shield of privacy’.<sup>11</sup> As the quotation at the head of the chapter suggests, however, the nuclear family is now one of many household types that exist and are available to people in advanced western societies, for, as its author Beck-Gernsheim argued, increased individualization in advanced western societies has been seen as the cause of rising divorce rates<sup>12</sup> increased acceptance of single parenting, same-sex coupling in many forms, and living alone.

### Household or Family Settings of Gay Men

Gay men’s involvement in household or family formation has included roles as varied as: husbands and fathers in heterosexual relationships including marriage; co-parenting as partners or single men with lesbian couples or heterosexual couples; anonymous sperm donors in artificial insemination programmes; and finally, as partners themselves in couple relationships.

As husbands and fathers, there are early examples of gay men and lesbians marrying in 1960s in order to pass as heterosexual married couples,<sup>13</sup> of men with same-sex preferences marrying in order to provide heirs, secure transfer of property or for social status or who married because of social pressure but then separated from their wives or de facto partners and came out later in life.<sup>14</sup> In the last instance, depending on the age when they separated from their previous wife or female partner, they could themselves establish their own household – also known as a blended family or a family of choice (see below) –

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8 Stone, L. (1977) *The Family, Sex and Marriage in England 1500-1800* (London: Weidenfeld & Nicolson), pp. 21–22.

9 Simmel, G. (1999, 1895) ‘On the Sociology of the Family’, trans. M. Ritter and D. Frisby in M. Featherstone (ed.) *Love and Eroticism* (London: SAGE Publications), p. 289; Shorter, E. (1976) *The Making of the Modern Family* (London: William Collins Sons & Co. Ltd), p. 15.

10 Stone, *Family, Sex and Marriage*, pp. 21–22.

11 Shorter, *Modern Family*, pp. 205, 5; Ariès, P. (1973, 1960) *Centuries of Childhood* (Harmondsworth: Penguin Books), pp. 397–398.

12 Beck, U. and Beck-Gernsheim, E. (2008) *Individualization: Institutionalized Individualism and Its Social and Political Consequences* (London: SAGE Publications), pp. 94–96.

13 Dank, B. M. (1971) ‘Coming Out in the Gay World’, in *Psychiatry*, 34: 180–183.

14 Plummer, K. (1995) *Telling Sexual Stories: Power, Change and Social Worlds* (London: Routledge), p. 153; Robinson, P. (2008) *The Changing World of Gay Men* (Basingstoke: Palgrave Macmillan), pp. 30–31.

with a male partner and children from their previous heterosexual relationship and/or their partner's previous heterosexual relationship.

The co-parenting arrangement is a relatively more recent development occurring when two same-sex attracted couples agree to be co-parents, that is, when a lesbian couple and a gay couple between them conceive and give birth to a child.<sup>15</sup> Whether or not the two couples and their progeny are living together under the same roof, the family they create could be known as an alternative family or family of choice (more below).

While artificial (or alternative) insemination might or might not be used for co-parenting, it has itself a long undocumented history as a means of parenting and fatherhood, perhaps as long as the history of insemination. In more recent times, there is evidence both of an alternative insemination boom in the USA in the 1980s and also documented evidence of its practice from the 1930s in the USA.<sup>16</sup> Adoption and foster parenting are other family options for gays and lesbians.<sup>17</sup>

While anthropologists and historians might possibly categorize them as comprising households, couples who live together without children or other relatives are regarded also as constituting a family and, in doing so, are similar in some ways – but not for inheritance purposes – as two siblings living together under one roof. As is shown below, at least one participant said that he regarded his husband and himself as a family.

As well as the everyday parenting experiments just outlined, there is a slightly more formalized family type known as the 'family of choice', which is peculiar to gays and lesbians. The term was first coined in San Francisco in the 1980s to denote an alternative family type comprising, 'friends, lovers, or children, in any combination'.<sup>18</sup> By the late 1990s, the term as well as the idea behind it had become part of an accepted family form among historians of sex and sexuality, with an equivalent status among same-sex people as that which applied to the birth family: 'For many non-heterosexuals the term "family"

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15 See discussion below in Family of Choice section of 57-year-old participant's account of his and his partner's experience of raising their son and co-parenting with a lesbian couple.

16 Regarding date of first report of artificial insemination, no mention was made of it in a detailed study of gay and lesbian life in the San Francisco Bay area in the late 1960s: Bell, M. P. and Weinberg, A. P. (1978) *Homosexualities: A Study of Diversity Among Men and Women* (Melbourne: The Macmillan Company of Australia). For reference to alternative insemination boom in 1980s and evidence of one woman's views on it from 1930s, see Weston, K. (1997) *Families We Choose: Lesbians, Gays, Kinship* (New York: Columbia University Press), pp. 167–168; lesbian baby boom, USA, pp. 168–169.

17 Weston, *Families We Choose*, p. 167.

18 Weston, *Families We Choose*, p. 27.

embraces a variety of selected relationships that includes lovers, possibly ex-lovers, intimate friends, as well as blood relatives, and is as real as the family of origin'.<sup>19</sup>

## THE COUPLE RELATIONSHIP

The couple relationship is not only, when conducted on its own and without children, one of the many family or household forms but also, when the couple lives under one roof with children related by birth, the central feature and at the heart of the nuclear family. From the middle of the twentieth century, when changes in contraception, divorce, education and employment liberated women from the dominant male culture,<sup>20</sup> and began to upset gendered assumptions about the private and public spheres, alternatives to the fixed, idealized and relatively permanent form of the couple relationship as marriage became more available.

These alternatives included, for example, the common-law or de facto relationship, successive relationships, also known as serial monogamy, or co-existing relationships in the form of polyamory. Despite the alternatives to it, marriage did not lose its attractiveness, however, as is evident in the high rates of remarriage that continue to counter-balance high rates of divorce.<sup>21</sup> The image that 'family' offers is still one of the emotional security for the raising and caring for children as well as other advantages in the form of a reduced fear of abandonment and greater security for making long-term financial commitments in, for example, property and private transport.<sup>22</sup> Data on domestic violence, however, suggest that the image of the family as source of emotional security is not always the case in reality,<sup>23</sup> and the data on

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19 Weeks, J. (2000) *Making Sexual History* (Cambridge: Polity Press), p. 219.

20 Muchembled, R. (2008) *Orgasm and the West: The History of Pleasure From the Sixteenth Century to the Present*, trans. J. Birrell (Cambridge: Polity Press), p. 34.

21 Beck and Beck-Gernsheim, *Normal Chaos*, pp. 171, 175.

22 Cherlin, A. J. (2004) 'The Deinstitutionalization of American Marriage', in *Journal of Marriage and Family*, 66: 855.

23 Sardinha, L. and Nájera Catalán, H. E. (2018) 'Attitudes Towards Domestic Violence in 49 Low- and Middle-Income Countries: A Gendered Analysis of Prevalence and Country-Level Correlates', in *PLoS One* 13(10): e0206101. <https://doi.org/10.1371/journal.pone.0206101> accessed 15 November 2022.

marital satisfaction suggested that men continue to find marriage more advantageous than do women.<sup>24</sup>

Sociologists such as Bauman, Beck and Beck-Gernsheim, Giddens, and Sennett argue that growing commercialization and individualization in advanced western countries has transformed intimacy into an exchange relationship,<sup>25</sup> such that there is a growing number of people who no longer marry as couples once did, that is, for life and in order to pass on wealth or property, but in the hope of attaining a very personal goal of finding themselves.<sup>26</sup> The function of the couple relationship, as formalized in marriage or less formally as ‘a relationship’,<sup>27</sup> must now provide in some settings for the emotional and sexual needs of each partner and endures only for as long as it continues to meet the needs of both partners.<sup>28</sup> Critics of this new style of relationship with its ‘use-by date’ observe that while it could suit middle-class, urban, professional people without children, it would not suit couples who want to raise children.<sup>29</sup>

### Gay Couple Relationships

Slightly less than two millennia before the political agitation for same-sex marriage in the late twentieth century, there were examples of formalized same-sex unions in ancient Rome that were roughly comparable to heterosexual marriage in that they were, ‘publicly recognised ... entailing some change in status for one or both parties’.<sup>30</sup> There is evidence also of same-sex

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24 Regarding men’s happiness in marriage, see: Dobrowolska, M., et.al. (2020) ‘Global Perspective on Marital Satisfaction’, in *Sustainability* 12(21): 8817. <https://doi.org/10.3390/su12218817> accessed 15 November 2022.

25 Bauman, Z. (2001) *The Individualized Society* (Cambridge: Polity Press), pp. 156–157; Beck and Beck-Gernsheim, *Normal Chaos*, p. 7; Giddens, A. (1991) *Modernity and Self-Identity: Self and Society in the Late Modern Age* (Cambridge: Polity Press), pp. 88–89; Sennett, *The Fall*, pp. 8–10.

26 Beck and Beck-Gernsheim, *Normal Chaos*, p. 172.

27 Giddens, A. (1992) *The Transformation of Intimacy: Sexuality, Love and Eroticism in Modern Societies* (Cambridge: Polity Press), p. 58.

28 Bauman, Z. (2001) *The Individualized Society* (Cambridge: Polity Press), pp. 156–157; Giddens, *Modernity and Self-Identity*, pp. 88–98.

29 Cherlin, ‘The Deinstitutionalization’, p. 858.

30 Boswell, J. (1995) *The Marriage of Likeness: Same Sex Unions in Pre-Modern Europe* (London: Harper Collins), pp. 80–7.

marriage ceremonies conducted with the approval of the church in Medieval Europe and until the sixteenth century.<sup>31</sup>

During the HIV-AIDS epidemic of 1980s and 1990s, the frequently documented experience of the next of kin taking precedence over a dying man's partner at his end of life underlined the importance of formalizing gay couple relationships and added impetus to movements in favour of same-sex marriage that had already begun with the lesbian baby boom and early experiments in gay parenting.<sup>32</sup> Before the passing of same-sex marriage legislation in advanced western countries, the changes mentioned in the previous section – which were already taking place in heterosexual couple relationships – meant that from the 1990s there appeared to be very little or no difference between relationships conducted by heterosexuals or homosexuals.<sup>33</sup> Gay common-law (or de facto) relationships had existed since the late 1980s: in Denmark, for example, registered partnerships – equivalent to marriage for same-sex couples<sup>34</sup> – were introduced in 1989.<sup>35</sup> Marriage equality was legalized between 2004 and 2017 in the countries the men lived who were interviewed for this book, often in stages, namely with the passing of legislation to legalize registered partnerships or civil unions and then later with the same for same-sex marriage.<sup>36</sup>

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31 Boswell, *Marriage of Likeness*, pp. 262–264.

32 Chauncey, G. (2004) *Why Marriage? The History Shaping Today's Debate Over Gay Equality* (Cambridge, MA: Perseus Books Group), p. 3; Hekma, G. (1999) 'Same-Sex Relations Among Men in Europe, 1700–1990', in F. X. Elder, L. A. Hall and G. Hekma (eds.) *Sexual Cultures in Europe: Themes in Sexuality* (Manchester: Manchester University Press), pp. 99–100; Weston *Families We Choose*, pp. 168–175.

33 Weeks, *Sexual History*, p. 214.

34 Reid, K., de Waal, M. and Zimmermann, R. (2015) 'Intestate Succession in Historical and Comparative Perspective', in Reid, et.al. (eds.) *Comparative Succession Law: Volume II: Intestate Succession* (Oxford Scholarship Online), p. 503. <https://doi.org/10.1093/acprof:oso/9780198747123.001.0001>.

35 Bech, H. (1997) *When Men Meet: Homosexuality and Modernity*, trans. T. Mequit and T. Davies (Cambridge: Polity Press), p. 270.

36 For dates when registered partnership or civil union were introduced in Canada, United Kingdom, New Zealand and when same-sex marriage was legalized in all states of the USA, see: Reid, de Waal and Zimmermann, 'Intestate Succession', p. 503; for account of the passing of marriage equality legislation by the Australian federal government, see: Zimmerman, T. (2022) 'Menace, Brinkmanship, Joy: How Marriage Equality Made It Through Australia's Parliament', in *The Guardian*. <https://www.theguardian.com/commentisfree/2022/nov/15/menace-brinkmanship-joy-how-marriage-equality-made-it-through-australian-parliament> accessed 15 November 2022.

Controversies associated with the campaign for same-sex marriage legislation included resistance from conservatives who disapproved of its challenge to their view of the immutable nature of marriage as the bedrock of traditional society,<sup>37</sup> as well as from GLBT activists and scholars who were concerned that same-sex marriage would set up a hierarchy of relationships, normalizing and valorizing marriage and that it would strengthen the impulse to homo-normativity.<sup>38</sup> Scholars argued also that the public debates did not allow for a more detailed investigation of contemporary relational arrangements.<sup>39</sup>

Gays, lesbians and their supporters who favoured same-sex marriage argued that its legalization would bring them improved tax, inheritance, next-of-kin, and insurance benefits,<sup>40</sup> greater impetus for monogamy and permanence in relationships, that is, ‘enforceable trust’, and security for those who wanted to have children, as well as an opportunity for the symbolic and material celebration of their union and greater opportunity for personal growth.<sup>41</sup> It has been argued also that the passing of marriage equality legislation was for ‘non-heterosexual communities’ a final step away from an identity focus to a focus on intimacy,<sup>42</sup> that is, that marriage equality legislation occurred in many advanced western countries because the gay liberation movement had succeeded in establishing citizenship equality and thus prepared its way. The next section examines the data on participants’ family settings. And the section after that discusses their relationship status.

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37 Frew, C. (2010) ‘The Social Construction of Same-Sex Marriage in Australia: Implications for Same-Sex Unions’, in *Law in Context*, 28(1): 78, 84.

38 Homonormativity is a term first used to describe the dominant values of western, gay culture by Lisa Duggan in her 2003 work, *The Twilight of Equality? Neo-liberalism, Cultural Politics, and the Attack on Democracy* (Boston: Beacon Press).

39 Donovan, C. (2004) ‘Why Reach for the Moon? Because the Stars Aren’t Enough’, in *Feminism and Psychology*, 14: 24, 25–28; Herdt, G. (2009) ‘Gay Marriage: The Panic and the Right’, in G. Herdt (ed.) *Moral Panics, Sex Panics: Fear and the Fight Over Sexual Rights* (New York: New York University Press), pp. 174, 191–192; Stacey, J. (2004) ‘Marital Suitors Court Social Science Spinsters: The Unwittingly Conservative Effects of Public Sociology’, in *Social Problems*, 51: 1, 135.

40 Nussbaum, M. C. (1999) *Sex and Social Justice* (New York: Oxford University Press), p. 201.

41 Cherlin, ‘The Deinstitutionalization’, pp. 851, 853–854, 857.

42 Weeks, J., Heaphy, B. and Donovan, C. (2001) *Same Sex Intimacies: Families of Choice and Other Life Experiments* (London: Routledge), p. 164.

## PARTICIPANTS' FAMILY SETTINGS

This section is devoted firstly to the family background of the participants, that is, the type of family in which they were raised and is referred to as the family of origin; and secondly the type of family that they themselves established, which is referred to here as their current family. Between each of these is a sub-section devoted to an examination of the stories of a small group who experienced family estrangement. All participants were asked the same question, namely, 'Would you briefly tell me the story of your family relationships?' And their answers provided the data for this section of the chapter.

Family of origin is the family into which they were born or in the case of adopted children the family into which they were brought and then raised. Current family could include any members of their remaining family of origin and any family that they themselves created with children who they or their partner/husband fathered when in a previous relationship with a female or adopted, or the family which they created as a matter of choice – their family of choice – comprising, as mentioned above, friends, siblings and others designated family members.

Family estrangement is not peculiar to gays and lesbians but frequently occurs if parents or other family members refused to accept their sexuality. Earlier research suggested that difficulties with family members was a relatively common experience for gay men from the Baby Boomer generation, namely those who came out following the injunction to do so during the gay liberation era.<sup>43</sup> About a fifth of the sample recounted stories of uneasy, unhappy or traumatic relations with their family of origin or other family members, from whom they were estranged.<sup>44</sup> Whether or not family estrangement influenced decisions concerning wills and beneficiaries is discussed in the next chapter.

## Participants' Family of Origin

Almost all participants referred to their family of origin when telling the story of their family. The vast majority were born and grew up in a nuclear family. A small handful had experience of extended-family-life and blended-family-life, and one man was adopted by his older brother and sister-in-law when his

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43 Robinson, *Changing World*, pp. 46–52.

44 Eight participants or slightly less than one fifth of the sample were estranged from their family of origin or family members.

parents died. In the following section, the participants' accounts are discussed of their experience of various types of families of origin, that is, the nuclear family, the blended family or the extended family.

### *Nuclear Family*

A participant with an uncommon experience of nuclear-family-life was the oldest in the sample, 88-year-old Atticus from California. And it was he whose oldest brother and sister-in-law adopted him as their child after the death of his parents:

I was the last one of the seven . . . My mother was in her 40s when I was born. She passed away when I was three years old and my father six months later . . . I was then adopted by my oldest brother who was 21-years old. He had been married a year and found out that his wife could not have children. He was actually placed [as] my legal guardian and then within a couple of years they legally adopted me. My brother and sister-in-law became my mother and my father and I treated them as such my whole life.

The remaining 39 participants who were born and grew up in nuclear families had these characteristics: two had no siblings and were an 'only child'; 11 were the youngest child; nine were the oldest child; one was the first born of triplets; and two came from large families where they had seven or more siblings. Aside from mention of their siblings, other features of family relations that arose in the interviews were, in order: parents' relationships, both harmonious and troubled; divorce and re-marriage; relations with nephews, nieces and cousins. Participants' focus on these experiences of the nuclear family tended to support one of the arguments made in the previous section on the principal roles of the nuclear family, namely, for the reproduction and care of children and as the approved site for sexual relations between adults.<sup>45</sup>

### *Blended Family*

There were two men with experience of blended families: one from the Australian Capital Territory (ACT) who was in his 80s and one from England in his 50s. The older gave a short account of three stepsisters who lived abroad and the second of affectionate family relations which continued after his parents divorced and remarried: 'I am very lucky to have two step-sisters and

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45 Shorter, *Modern Family*, p. 205.

their related-extras and a stepmother because Dad remarried . . . There is very happy energy in visits to . . . where the rest of the family still lives' (Ellis, 56, London).

### *Extended Family*

The two men who grew up in extended families were from the ACT and both were in their 70s. The first, Edward (aged 77) explained that his father, who was illegitimate, had been brought up by his great-grandmother and that then Edward's grandmother was influential in his own upbringing as a child in Queensland:

My maternal grandmother was very important and like a lot of grandmothers actually kind of brought me up. You know, she'd read to me in the afternoons or actually I'd read to her because I knew what the story was and I remembered it and she went off to sleep.

Like many Queensland families, Edward's family took in US servicemen during World War II.<sup>46</sup> And these he remembered for the positive effect that their presence in the family home had for his self-confidence: 'We had Americans sleeping on the veranda and that was Queensland. There were people everywhere and I was accustomed to adults talking with me and I talking with them'.

For the second man who grew up in an extended family, it was also the feminine influence of the additional relative who shared his parents' house with them that he remembered. In his case, it was his mother's cousin whose affection he recalled when describing his family relations: 'My mother's cousin lived with us. She was a single lady . . . loving and caring and . . . a surrogate grandmother because of her kindness' (Lewis, aged 74, ACT).

In both cases, the men found in their extended family something akin to, 'a sharing, a mutuality, a kind of protection often unknown to persons in a nuclear family'. And not the 'oppressive chains' which Sennett and Cobb argued can occur elsewhere and at other times in extended families.<sup>47</sup>

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46 For US presence in Australia during World War II, see Macintyre, S. (2004) *A Concise History of Australia*, 2nd ed. (Port Melbourne: Cambridge University Press), pp. 192–196.

47 Sennett, R. and Cobb, J. (1993, 1972) *The Hidden Injuries of Class* (New York: Alfred Knopf), p. 107.

## Estrangement

Family estrangement can take many forms and occurs for a variety of reasons. In the sample of men interviewed for this book, eight were estranged from family members. Some were estranged from their entire family, a slightly smaller number from their parents, while a handful from their siblings. Homophobia was often but not always the cause of the estrangement. All were in their 50s and their accounts varied from stories of intense estrangement to relatively casual experience of the same.

Where the experience was intense, it occurred because of their parents' refusal to accept the men's' sexuality and all had to leave home once their parents knew that they were gay. The pain that some experienced from their estrangement could be explained by the emotional exclusivity which it has been argued is fostered in the nuclear family: 'its members feel that they have much more in common with one another than they do with anyone else on the outside—that they enjoy a privileged emotional climate they must protect from outside intrusion, through privacy and isolation'.<sup>48</sup>

The first man with experience of intense estrangement was an Australian expatriate who lived in Europe and left his family home after the death of his mother.

I knew from age 17 that my family would not be looking after me. I knew very clearly. It was the death of my mother . . . when I realized that the other three surviving members of my family stuck together like glue and that my connection to the family was actually my mother. In the years later, they realized that. They realized that they [had] created the triage that I was not a part of and I was the younger sibling. (Damien, aged 52, England)

Later in the interview, Damien explained that the homophobia of his father and his brother-in-law was the reason for his estrangement. Recalling memories of Christmases when his mother was alive and he was a teenager, he related how his brother-in-law would make homophobic jokes associating homosexuality with paedophilia and then recalled how, when as an adult and with a long-standing male partner, he came out to his father: 'It did not go well because my brother and sister did not want that and tried to stop me repeatedly'.

A New South Welshman with experience of fairly intense estrangement was Christopher (aged 52). His family belonged to a fundamentalist religious organization that rejected homosexuality. Brought up in a sect that forbade contact

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48 Shorter, *Modern Family*, p. 205.

with the outside world, he decided at 19 to excommunicate himself in order to protect his parents from the scandal and ostracism:

When I excommunicated myself, I stayed at the family home with my mother for another couple of years [until] I decided ... to jump on a plane and go to the other side of the world and create a new life and find myself.

After returning to Australia, his family situation deteriorated when his brother removed him as their father's executor and replaced him with his wife. When Christopher objected, his brother and sister-in-law took the case to court:

And brought it all forward knowing full well that I could not get any legal help. I tried everything. I could not get legal aid because legal aid said that it was out of their parameter. I needed a barrister and a lawyer and could not do that, whereas my brother had it all because it was paid for from my father's bank account.\* They slayed me in there.

[\* Being an executor and with the support of the family's solicitor, Christopher's brother was able to draw on their father's assets to fund the court case.]

While he was able to continue seeing his father, the conflict with his brother and sister-in-law seriously affected Christopher's mental health reviving memories of previous traumas associated with his religious upbringing. He has since recovered and is now actively involved in publicizing the practices of homophobic religions.

The remaining men whose experience of estrangement was more casual still had limited association with their families of origin. In the case of two men – Gideon, aged 70 from New South Wales and Anton, aged 45 from England – their parents' divorces caused estrangement from one of their parents and some of their siblings, while others were estranged from a parent or a sibling who could not accept their homosexuality or their male partner. In the case of the final example – of having no relations with family members – no reason was given other than a peripatetic childhood:

Blood relatives ... have never been an important part of my life. I moved around quite a bit as a child, living in rural areas in Australia, and so close relationships never really developed. (Johann, aged 52, England)

These eight men, whose family relations were broken or non-existent for various reasons, comprised a unique group. Because of the centrality of kinship in the decisions that people make about bequests and inheritance,<sup>49</sup> the

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49 Bourdieu, P. (1992) *The Logic of Practice*, trans. R. Nice (Cambridge: Polity Press), pp. 165–168.

beneficiary decisions that they made are compared in Chapter 2 with those that others made whose relations with their family of origin were continuing and/or relatively harmonious.

### Participants' Current Family

As mentioned, participants were asked to briefly tell the story of their family relationships. When doing so, more than half referred to their family of origin (also known elsewhere as birth family), slightly less than a quarter said that their couple relationship was their family, and a small group referred to theirs as a family of choice. In the following section each family type is discussed in order.

#### *Family of Origin*

In the stories told by those who referred to their family of origin as their current family,<sup>50</sup> it was noticeable that none in a couple relationship made mention also of his same-sex partner. Solely focusing on the family of origin could suggest that feelings of shame about a gay relationship or a very strict understanding of family, which, in the case of the men aged 55 and over, had been shaped four or five decades earlier, did not or could not include in it a place for a same-sex partner. Noticeable also was that the single men who focused on the story of their family of origin could have been omitting any reference to their place in another person's family of choice, again because of a strict understanding of family.

My suspicion is that the reason any mention of same-sex partner was omitted from their family story could be explained by an understanding of family shaped by dominant images, in the case of those over 55, accumulating from decades earlier. In the interviews with those in couple relationships and those who were single, I allowed the participants to relate the story of their family relations without interruption. The question of what if anything was omitted from their family stories might have been resolved had I asked the men in couple relationships whether they regarded their partner as part of their family and the single men if they belonged to someone else's family of choice.

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50 Twenty-seven participants regarded their family of origin as their current family.

*Couple Relationship*<sup>51</sup>

Those who said that they and their partner comprised their family came from all five deciles represented by the sample.<sup>52</sup> And their understanding of couple as family included a man in his late 80s who had had two relationships of 17 years each and a third and possibly final relationship which ended after 29 years when his partner died.

As well, there was a man in his mid-60s who because he had ‘no surviving biological family’ regarded his partner and himself as his family, and three men in their 50s whose views are represented here by Jonathon from England (aged 53) who said that in addition to his family of origin: ‘I think of [my partner] and me as a family’.

*Family of Choice*

A small group spoke of family of choice when speaking about their current family.<sup>53</sup> Some used the term itself during their interview while others used synonymous phrases such as, ‘logical family’, ‘second family’ and ‘family of friends’. Four were from North America and one from New Zealand and they were aged in their 50s, 60s and 70s. Only one participant had created with his civil-union partner and a lesbian couple a family of choice that included a child, which in their case was conceived by them.

By contrast to the previous sections on participants’ current family, a fairly detailed account is provided here of the experiences of a comparatively small group of men. And the reason being that they represented a relatively new social experiment and challenge to the dominance of the heterogeneous family of origin.<sup>54</sup>

North American participants used logical family and other synonymous terms when speaking of their family of choice. Their views are represented here by this account from Joel (aged 74) from California:

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51 The argument in this section concerning the couple relationship as a family type is slightly different from one that I made elsewhere, largely because here it relies on the full and complete sample, see: Robinson, P. B. (2022) ‘Gay Inheritance Decisions: Family of Choice or Family of Origin?’, in S. Brun and M. Blidon (eds.) *Mapping LGBTQ Spaces and Places* (Switzerland: Springer), pp. 711–722. <https://doi.org/10.1007/978-3-031-03792-4>.

52 The 11 participants who regarded their couple relationship as their family were aged 40, 50, 60, 70, 80.

53 Five participants said that they belonged to a family of choice.

54 For more on family of choice as social experiment, see Weeks, *Sexual History*, pp. 216–220.

I have my family here, my family of friends. I do not have a partner at this time and am not sure if I want or care to have one at this point. I do have a housemate and his boyfriend who are here, who are at least part of the [social] bubble in terms of the Virus thing [Covid-19]. I have lots of friends from . . . [a social support] group and some from the bowling, some of them from the . . . tea dance. My favourite activity with my family of choice is the tea dance on Sunday afternoons, which is not held at this point. I consider myself blessed with a pretty tranquil and understanding biological family and a very deep, happy, joyful friend-family here.

While not supplanting or replacing his family of origin, it is clear from this account that Joel's family of choice enhanced his social life especially during the social restrictions and personal privations of the Covid-19 pandemic.<sup>55</sup>

Two men with definitive examples of a family of choice were Toby (aged 64) from Canada and Carter (aged 57) from New Zealand. Each has a slightly different version. Toby explained how his family began with his spouse:

We are in a common-law relationship and we have an extended family that includes . . . one of my representatives [with enduring power of attorney] and we have other really good friends. [My partner] and I have also been heavily involved in LGBT refugee resettlement and we have been responsible for the resettlement of gay young men to Canada and we have a number of people like that in our family network.

After his partner, Toby populated his family of choice with others, namely the people whom he had appointed as his representatives,<sup>56</sup> as well as young men that he and his partner had assisted escaping violent homophobia in the Third World and were committed to looking after for the long term:

We are in the process . . . of settling another couple of guys from Africa. One is 19 and one is 23. They are fairly young compared to some of the other people we have helped who have been in Canada for six years.

Elaborating on his and his partner's relations with the young asylum seekers, he explained as follows:

We don't consider them sons or anything, they are just part of our family. We do not feel that we have to give them the standard family names. It does not matter. They are part of our family. And I know in fact that all of the feelings are mutual and how we would define ourselves.

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55 <https://www.who.int/emergencies/diseases/novel-coronavirus-2019> accessed 20 April 2022.

56 The Canadian term, 'representative' roughly equates to power of attorney and guardian in Australia and some other jurisdictions.

Toby and his partner's decision not to use 'standard family names' strongly suggested that they believed that close affective support can exist *without* formalized family-relationship terminology. It could be argued, therefore, that avoiding the conventional nomenclature that is used to designate relationships in the traditional family was at the core of the original understanding of and rationale for family of choice.

Carter's experience reflected another early understanding of family of choice, for with his partner and a lesbian couple they together conceived and raised a son, all five together forming a family: 'He and I have an 18-year-old son with a lesbian couple based in Melbourne. He is our son. The mothers would count as family'. Like some other similar families of choice where urban professionals were involved,<sup>57</sup> Carter's family practices were carefully regulated:

Because the mothers of our son are based in . . . [Australia] they are less integrated and are not going to regular family dinners here in [New Zealand]. Prior to Covid [-19] hitting, either [my partner] or I would make sure we were in . . . [Australia] on average each five or six weeks to see our son . . . and move into that family home with [his two mothers] . . . We have had an arrangement since [our son] was born where we have Christmases on a three-year cycle. We have one in Melbourne with his one set of grandparents, one in New South Wales with another set of grandparents and always every third year of the cycle one Christmas in . . . [New Zealand] and the mums come over. The mums are always over for important family events.

A common feature in co-parenting arrangements such as Carter and his partner have with their son's mothers is that time spent with each set of parents is agreed on and scheduled so that everyone knows in advance accommodation and social arrangements including visits and family focussed celebrations such as Christmas, Passover or Diwali. Given the geographical separation with which this family of choice must contend, arrangements such as Carter sketched would be possible only for couples with relatively high disposable incomes and flexible working hours.

While other researchers have queried the prevalence of the family of choice,<sup>58</sup> and while this research suggests that it is not a widespread understanding or practice among the gay men interviewed for this book, their accounts suggested a commitment to an alternative family form. And because of its rejection of the traditional family and relationship model and the ideological and practical appeal

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57 For an example of the highly regulated co-parenting arrangements made by some professional gay and lesbian couples, see Robinson, *Changing World*, pp. 145–148.

58 See for example: de Vries, B., et.al. (2020) 'Advance Care Planning Among Older LGBT Canadians: Heteronormative Influences', in *Sexualities*. <https://doi.org/10.1177/1363460719896968>.

of being able to choose who are your close, intimate family members, the family of choice might yet persist and become more common.

One reason for the relative scarcity of the chosen family as a family form could be that, as a result of gay and lesbian experimentation with surrogacy, adoption and foster parenting and, since the 1990s, the increasing legalization of gay marriage, together with declining homophobia in some metropolitan centres of advanced western countries, gay-family formation now more strongly mirrors the heterosexual family norm and that gays and lesbians could see less need for the family of choice. The extent to which the change suggested by this preference was reflected in participants' decisions concerning their wills, other end-of-life instruments, and beneficiary decisions is discussed in Chapters 2 and 3.

#### PARTICIPANTS' RELATIONSHIP HISTORY AND STATUS

All participants were asked the same question, namely, 'Would you briefly describe your relationship status?' And their answers provided the data for this section of the chapter.

Of the 43 men in the sample, 29 were in common-law (or de facto) relationships or had been in one at some point, most often before formalizing their relationship by civil union, civil partnership or gay marriage or becoming single.<sup>59</sup> At the time of interview, 14 were single, eight were gay married, six were in civil unions or civil partnerships, and eight were formerly married or had previously been in a civil union or civil partnership. Of those who were fathers, four had children from a previous heterosexual relationship and as mentioned one had a child by surrogacy with his male partner and a lesbian couple.<sup>60</sup>

In summary, the most frequent relationship type was a common-law (or de facto) relationship, followed by single men and then men who were gaily married or in a civil union or civil partnership. The principal narratives used to describe or explain their relationships are discussed in order.

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59 Cohabitation: in Australia the term de facto relationship is used for two people, gay or straight who have been cohabiting as a couple for 2 years or more (Section 4AA, Family Law Act 1975, Commonwealth of Australia). In other jurisdictions, the equivalent term is common-law partnership. In Canada, for example, a common-law partnership is said to exist when a couple has been cohabiting for 12 months or more, see: <https://www.canada.ca/en/immigration-refugees-citizenship/corporate/publications-manuals/operational-bulletins-manuals/permanent-residence/non-economic-classes/family-class-determining-spouse/assessing-common.html> accessed 2 October 2021.

60 See Appendix 2.

## Common Law, de facto

As mentioned, 29 or the vast majority of participants were in or had had experience of common-law or de facto relationships.<sup>61</sup> All of those who were married or in civil unions or civil partnerships had previously been in common-law or de facto relationships with the partner that they then married or joined in civil union or civil partnership. And, with the exception of three men who had been single all their adult life, the majority of men who were single at the time of interview had at some time been in a common-law or de facto relationship.

Included in those with common-law or de facto relationships was a group of men who had no intention of entering any kind of legal arrangement and their views are represented here by the following extract from interview with Toby (aged 64) from Canada:

We are not married and we never will be because for many years we weren't allowed to be and we didn't feel that it was for us. We know a lot of people who are married and are happily married but also, I know a few people who are unhappy and are into their second relationships or are single . . . After living together for decades, we just don't see the point. I am still not sure why people get married [*Laughs*]. It just makes life so complicated . . . not just for gay people but for straight people as well . . . It makes life so difficult.

By comparison, another group of affluent participants, who as young men had been opposed to gay marriage, were now contemplating it for 'tax reasons'. Their views are represented here by extracts from the interviews with two participants in their 50s.

We have been together for . . . [29 years] never decided to get married, although we're thinking about it now because of tax situations. *Could you tell why marriage is financially beneficial for a couple like you?* Before we didn't look at it, but because we have been talking to estate planners and we are trying to re-do our will, they say that if you get married, then there are the tax advantages . . . We don't really believe in marriage as an institution . . . see it as a heteronormative institution and as we fought for rights to be [who we are] so like why join the normal society, do what the norms tell you? But again, like I said, if you get tax advantages [*Laughs*] that's a different story. (Eric, aged 59, Hong Kong)

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61 For purposes of this research and book, the phrase, common-law relationship referred to a relationship where a couple has requested and been granted common-law status for their relationship and the term, de facto referred to the legal status that is assumed to attach to a couple relationships of 2 years' or more duration.

Like other gay men of his generation, the doubts that Eric and his partner held concerning gay marriage seem to have been influenced by the feminists' arguments from the 1960s and the 1990s.<sup>62</sup> They queried the social institution and its suitability for gays and lesbians. But, also like many financially secure men from their generation, its appeal in the 2020s appeared to lie in the improvement that being married would make to their disposable income, which sentiment the second participant echoed albeit with a certain degree of reluctance:

We've been together about 21 years. With the discussion about marriage, we have more than a slight point of difference . . . [but] I think we ultimately will get married. It's unfortunate [but] we'll be getting married for pragmatic tax reasons. My earlier reason for not getting married was that [their homophobia meant] I could never share it with my family . . . Also, I saw the complexity of the gay community in the 1990s and what could be regarded as the "elastic edges" of what a relationship can be and those elastic edges felt a little bit incompatible with the institution of marriage. (Damien, aged 52, England)

Damien's family relations, which were discussed in the section above on estrangement, soured when his father, sister and brother-in-law excluded him after the death of his mother. Their rejection, together with what he observed of gay relationship practices – the so-called 'elastic edges', which in the 2020s might also be known as polyamory – influenced his views on gay marriage until, that is, his partner's growing awareness of the 'pragmatic tax reasons' for marriage.

### *Single*

The group of 14 who were single at the time of interview included two participants in their 50s and one in his 70s who had been single all their adult life. Although they were not asked to explain their single status, among the reasons that they provided were that relationships could be messy, the ubiquity among their friends, both straight and gay, of people locked in what they regarded as unsupportive or damaging relationships, and that previous experiences in their family of origin meant that it was hard for them to develop or conceive of a supportive relationship with prospective partners.

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62 For discussion of the reasons that men from this generation gave for opposing gay marriage, see Robinson, P. (2013) *Gay Men's Relationships Across the Life Course* (Basingstoke: Palgrave Macmillan), pp. 127–143.

The remaining participants who had had some experience of relationships described those that were both relatively short but also as long as 10 years and, in the case of one man aged 70, of more than 25 years' duration and which came to an end when his partner died. When these men spoke about their single status, a common theme was the importance of friendship to them, which is represented here in the extracts from interviews with two who were in their 70s and one who was in his 40s.

I consider friends more important than a one-on-one relationship with a partner or husband, now in my life. If I was given the choice of living alone in the woods with my love and not being able to socialize with friends, I would choose not having the partner and being able to socialize with friends as a higher priority for me. (Joel, aged 74, California)

I figured out somewhere along the line that maybe “the relationship” that everybody talks about wasn't who I was meant to be. I seem to have a gift for friendship. Being intensely physically intimate with somebody for 35 years, I can't imagine [*Laughs*]. I have friends . . . and I always thought that my talent was friendship, maybe not being a lover. And that is fine. You could do a lot worse. (Harvey, aged 74, North Carolina)

My “ex” and I are very close and we do spend traditional family time together . . . In a way, we have a sort of dispersed family life, which I think suits both of us quite well—when Covid [-19] isn't around. I have a very busy life, a very good group of close friends who I love spending time with and I have a busy job. (Anton, aged 45, England)

All three were unequivocal in their belief in the value of friendship. In the case of Joel from California, he preferred the company of friends to the idealized ‘cottage in the woods’ with partner, while Harvey from North Carolina was convinced of his ‘gift for friendship’ and did not regret the absence of a couple relationship. At 45, Anton had a busy social life and a busy job. His ex-partner was still part of his social life and like both Joel and Harvey seemed unperturbed that he was a single gay man. In Chapter 2, the single men's commitment to friendship is examined again in light of the extent to which they included friends as beneficiaries in their wills.

### Gay Married

The eight gay-married participants had all previously been in common-law or de facto relationships with their partner. They were aged in their 50s, 60s and 70s and were from Australia, England and North America. Among the reasons that they gave for getting married were firstly because it had been legalized and

was permitted, secondly to ‘upgrade’ a civil union or civil partnership, and thirdly because doing so assisted the participant’s partner:

We did not think about getting married at first but when the marriage for men came in here, we decided to do it. We got married in March 2019 . . . [and] by then, we had been together for nine years and we realised that we were committed. The bond between us is very close. (Rowan, aged 71, England)

We got into a civil partnership together in 2008 . . . and then when the law changed in the UK to enable gay marriage, we basically did an “upgrade” but the main occasion was the civil partnership. That is when we had the party, that is when we had the photographs. The upgrade was a bureaucratic exercise. It was a pretty ordinary day; it was formalising something [*Laughs*]. We thought that as people had gone to such a lot of trouble to make gay marriage happen it would be a bit dismal not to show willingness and do it [*Laughs*]. For us, the key thing was the civil partnership, that was the joint commitment, the public declaration of relationship stage. (Wade, aged 66, England)

We were married in San Francisco . . . after it became legal through the entire United States. We did it as a practical reason. He got a job with [the corporation] in New York and he said that it would just be easier in terms of the moving and all the relationship with [the corporation] if we got married. And I said, “Sure. That makes sense”. And so, we got married. *Some of the upper levels of the corporate west are quite liberal and progressive*. Yes. Definitely. It was amazing the whole relationship with [the corporation] when we got married. It was just taken as a matter of course that I was going to make decisions because he did not want to deal with the move and those technicalities, and they just dealt with me. (Dorian, aged 70, New York State)

As gay marriage is normalized, it is likely that the proportion of gay married men will increase in interview samples such as the one recruited for this research. A common theme in the three extracts was how its availability made marriage such an easy step for the men to take. Dorian’s experience was instructive because it underlined the speed with which corporations sometimes adapt to a certain type of social change such as in his case granting partner status and privileges to gay couples in line with or ahead of legislative change in jurisdictions where they conduct business.<sup>63</sup>

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63 For more on privileges enjoyed by gay corporate professionals, see Robinson, P. (2017) *Gay Men’s Working Lives, Retirement and Old Age* (Basingstoke: Palgrave Macmillan), pp. 87–88, 96, 104, 150.

## Civil Union, Civil Partnership

All six participants who were in a civil union or civil partnership had previously been in common-law or de facto relationships and provided two principal reasons for making a civil union or civil partnership. The first was because they wanted to formally recognize a long-standing relationship and the second for practical reasons, which – as in the case of two men with de facto or common-law relationships who said that were contemplating marriage – concerned tax or other financial and property matters. These are represented here in extracts from the interviews with two men who lived in England.

We are civil partnered, so we have formal, legal connection . . . [and got] it fairly soon after it became permitted. But . . . we have never gone the final hog and gone in for marriage partly because we cannot quite see the difference; in fact, we do not want to confuse matters . . . We have been together for 35 years [and] we always called ourselves partners and termed ourselves partners to third parties who needed to know. (Kieran, aged 67, England)

From this extract, it is fairly clear that neither Kieran nor his partner wished to marry because they were content with calling and referring to each other as ‘partner’ and did not want to adopt or have to use the term, ‘husband’.

The second man was brought up in Australia when his parents emigrated from England in the 1960s. Returning to the country of his birth with his Australian-born partner, he reluctantly agreed to a civil partnership. In the following extract, his very serious reservations about it are made clear, as well as a preference – unheard in the marriage-equality debate in Australia – to eliminate marriage and give all relationships an equal status.

We have a civil partnership which we performed in the UK for extremely pragmatic reasons: to avoid inheritance tax. I am not a great fan of marriage, the institution, and my unpopular and controversial opinion about marriage equality is that the Marriage Act should be rescinded . . . It’s always been about property and property rights and property law. In the last 150 years, it’s been conflated with romantic love. They are not the same thing. There are all sorts of perks with this institution of marriage, principally related to property and money. True equality would be [to] get rid of this stupid, anointed institution, treat everybody, regardless of their partnership status . . . on a level playing field about their money, about their property, about their rights and who they want to leave it to. (Donovan, aged 55, England)

## Formerly Married or Civil Partnered

Most of the seven in this group had previously been married to women. The one exception was a man in his 40s from London who had separated from his previous civil-union partner of slightly less than 10 years. Those previously married to women consisted of three in their 70s, two in their 60s and one in his 80s. They represented a sub category of same-sex attracted or bisexual men about whom much has been written and who married in the decades before the decriminalization of homosexuality and came out when it was safe to do so.<sup>64</sup>

If Swedish research on same-sex marriage and divorce is any guide, it could be reasonable to expect that, as more gay men from the countries represented in this study are gay married or enter into gay civil unions/partnerships, they are just as likely to experience similar relationship permanence as heterosexual couples.<sup>65</sup> In other words, rates of separation or divorce in gay marriages or civil unions/partnerships could over time mirror those for heterosexual marriage or civil union/partnership.

## CONCLUSION

The findings from this chapter contribute to observations already made about the nature of gay friendship and relationships and gay men's level of interest in taking advantage of the opportunity to marry that came with the introduction of marriage equality in many advanced western societies.<sup>66</sup> They provided new insights also into the families that gay men came from and that they themselves created, one of the most notable of which was that, while the data revealed a variety of family forms – both in family of origin and in current family forms – they showed that only quite a small minority from the sample had created chosen families.

In this sample, the principal family form was the family of origin and more than half the participants referred to it as their current family, while slightly less than a quarter said that their couple relationship was their family. And, as mentioned, a fairly small group said that they belonged to a family of choice.

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64 Robinson, *Changing World*, pp. 29–31; Robinson, *Life Course*, pp. 83–7.

65 Kolk, M. and Andersson, G. (2020) 'Two Decades of Same-Sex Marriage in Sweden: A Demographic Account of Developments in Marriage, Childbearing, and Divorce', in *Demography*, 57(1): 147–169. <https://doi.org/10.1007/s13524-019-00847-6> accessed 17 November 2022.

66 See Robinson, *Changing World*, pp. 115–152; Robinson, *Life Course*, pp. 37–82, 100–144.

In terms of their relationships, the most frequent relationship type was by far the common-law (or de facto) relationship, followed at some considerable distance by those who were not in a couple relationship, that is, the single men, and then three comparatively small groups who were gaily married, those who were separated or divorced from their wives, partners or husbands, and then those in a civil union or a civil partnership. As kinship is central to the decisions that people make about bequests and inheritance,<sup>67</sup> it is reasonable to assume that participants' current family relations and relationship status will have some bearing on their beneficiary decisions, and these are examined in the next chapter.

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<sup>67</sup> Bourdieu, *Logic of Practice*, pp. 166–167.

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## 2

# WILLS AND BENEFICIARY DECISIONS

The inheritance system of any society (and it clearly may be more or less ‘systematic’) is the way by which property is transmitted between the living and the dead, and especially between generations. It is part of the wider process whereby property relations are reproduced over time (and sometimes changed in so doing), a process that I speak of as devolution.<sup>1</sup>

### INTRODUCTION

In this introduction, the general purpose of wills is first discussed followed by a short examination of gay men’s use of wills. The rest of the chapter has two sections. The first section deals with wills and how participants wrote their own will. The second section concerns beneficiaries and participants’ beneficiary decisions.

Transfer of property was the principal purpose of a will. From the Fourteenth Century in Europe, it had an added important purpose for large landowners, which was to ensure that estates were not divided between multiple heirs and that under the practice of primogeniture the first-born male heir inherited the great bulk of the estate and titles.<sup>2</sup> Associated purposes of

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1 Goody, J. (1976) ‘Introduction’, in Goody, J., J. Thirsk and E. P. Thompson (eds.) *Family and Inheritance: Rural Society in Western Europe, 1200–1800* (Cambridge: Cambridge University Press), p. 1.

2 Boswell, J. (1989) *The Kindness of Strangers: The Abandonment of Children in Western Europe from late Antiquity to the Renaissance* (London: Allen Lane The Penguin Press), p. 271.

wills were to provide for the correct disposal of an individual's property when they died<sup>3</sup>; and to provide also for the surviving partner,<sup>4</sup> other heirs, as well as benefactions to charities, educational and religious organizations.<sup>5</sup> The last purpose, that is for 'pious bequests', was between the Twelfth Century and Eighteenth Century in Europe as important if not more important than the transfer of property and according to Ariès their chief rationale.<sup>6</sup>

During the HIV-AIDS epidemic in the West (c. 1980–2000), will-making had a special significance for gay men. Many of those diagnosed with HIV experienced a degree of social death when ostracized and their plight ignored during the worst years of the epidemic.<sup>7</sup> For them and for other gay people who were excluded by their family or whose relationship was not recognized, the writing of a will in the years before marriage equality was a vital means of firstly affirming their relationship and secondly doing their best to ensure that partners received their inheritance according to the wishes of the deceased person.<sup>8</sup>

Some survivors suffered further distress if, after their deceased partner's funeral, his family stepped in to dispose of their joint property as, in some cases, the existence of a will would not prevent the family from doing so:

Gay men suddenly forced to write wills found themselves in even greater jeopardy, since families often claimed that AIDS-related dementia had incapacitated their sons and invalidated the wills, even when couples had taken elaborate steps to certify mental health at the time of signing.<sup>9</sup>

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3 Sawyer, C. and Spero, M. (2015) *Succession, Wills and Probate* (London: Taylor and Francis Group), pp. 1–7.

4 Thompson, E. P. (1976) 'The Grid of Inheritance: A Comment', in Goody, Thirsk and Thompson (eds.) *Family and Inheritance*, pp. 342–343.

5 Baker, C. and Gilding, X. (2011) 'Inheritance in Australia: Family and Charitable Distributions From Personal Estates', in *Australian Journal of Social Issues*, 46(3): 273–289, pp. 274–275.

6 Ariès, P. (1991) *The Hour of Our Death*, trans. H. Weaver (New York: Oxford University Press), pp. 190–191.

7 Bersani, L. (1988) 'Is the Rectum a Grave?' in D. Crimp (ed.) *AIDS: Cultural Analysis, Cultural Activism* (Cambridge, MA: The MIT Press), pp. 197–222; Shilts, R. (1987) *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York: St Martin's Press); Watney, S. (1988) 'The Spectacle of AIDS', in Crimp *AIDS: Cultural Analysis*, pp. 71–86.

8 Monk, D. (2016) "'Inheritance Families of Choice?'" Lawyers' Reflections on Gay and Lesbian Wills', in *Journal of Law and Society*, 43(2): 167–194.

9 Chauncey, G. (2004) *Why Marriage? The History Shaping Today's Debate Over Gay Equality* (Cambridge, MA: Perseus Books Group), p. 100.

Unrelated to the role of will writing during the HIV-AIDS epidemic and to changes that gay marriage legislation has had on gay relationships, a second reason why gay men's will-writing practices were important is that, according to some US research, they were more likely to live solitary lives and so to die intestate.<sup>10</sup> While there is evidence to show that this can be the case in countries such as England, France and the USA, gay men's dying intestate is, however, less likely in Australia and New Zealand where rates of intestacy are generally lower.<sup>11</sup>

## WILLS AND WILL ADMINISTRATION

To examine how gay men understood and made use of wills, it was firstly necessary to establish whether participants for this research had a will and if they had revised it recently. In order to establish this, all were asked the same question, which was: 'Do you have a will and have you revised it often in the last ten years?' Secondly, as it is general practice in the administration of a will for the testator to nominate an executor to carry out his/her wishes, it was necessary to establish who participants chose for their executor and why. And in order to establish this, all were asked the same question, namely, 'If you have a will, who did you choose as your executor and why?' For the purpose of the discussion below, an executor was understood to be a person who could be trusted and the testator could rely on to take care of his/her affairs after death.

Slightly more than 80% of the sample had a will, almost all of whom had revised it at least once in the previous 10 years and appointed an executor.<sup>12</sup> The eight who did not have a will were at risk of intestacy. This relatively small number was in line, however, with other research on intestacy in Australia and New Zealand showing smaller rates here compared to intestacy

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10 Knauer, N. J. (2010) 'Gay and Lesbian Elders: Estate Planning and End-of-Life Decision Making', in *Florida Coastal Law Review*, XII: 163–215.

11 Reid, K., de Waal, M. and Zimmermann, R. (2015) 'Intestate Succession in Historical and Comparative Perspective', in Reid et.al. (eds.) *Comparative Succession Law: Volume II: Intestate Succession* (Oxford Scholarship Online), pp. 442–512. <https://doi.org/10.1093/acprof:oso/9780198747123.001.0001>.

12 Thirty-five participants had wills. For data used in this chapter, see Appendix 2.

rates in other similar developed economies.<sup>13</sup> Will revision and choice of executor are examined in the next two sections.

### Will Revision

Five principal reasons were given for changing wills. The first two were each cited by about one third of those who had revised their wills, and these were changed relationship status and changed material circumstances. The remaining three reasons were used by relatively small groups of between four and six participants in each case: travel or relocation; health or illness; and finally, fine tuning decisions about heirs or the distribution of assets. The importance of changed relationship status for will revision could be explained by the fact that slightly more than two thirds of the sample ( $n = 29$ ) were in couple relationships and these ranged from between 1 or 2 years to more than 40 years. Fourteen were single at the time of interview and had been single from between 1 or 2 years to all of their adult life.

#### *Changed Relationship Status*

Slightly more than one third with wills revised them because of changes to their relationship – as a result of civil union, civil partnership or marriage, death, separation or divorce, or simply because they had decided to live together. Their accounts are discussed in order.

Six participants cited civil union, civil partnership or marriage as the reason for revising their will. All were in long-term relationships. For those in Australia, getting married meant that a new will had to be written, for, as Roland (aged 50) explained, a person's previous will becomes invalid at marriage:

To the best of my knowledge, when you become married it invalidates all previous wills really automatically. The lawyer told us that as soon as you get married, all your previous wills are immediately under law invalidated.

Others who revised or wrote a will when they married or civil partnered included: Wade (aged 66 from Brighton): 'it was all of a sudden and there was civil partnership and we did wills'; and Warren (aged 50 from Perth): 'We

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13 Vines, P. (2022) 'What Happens If You Die Without a Will?', in *The Conversation*. <https://theconversation.com/what-happens-if-you-die-without-a-will-186384> accessed 11 Aug 2022; Reid, de Waal and Zimmermann 'Intestate Succession'.

wrote them just before we got married. We had them written legally with a lawyer . . . I never had a will before that and I have not revised it’.

The one exception among the men in long-term relationships who had revised their wills in the last 10 years was Dorian from New York State (aged 70). While the others wrote new wills when they married or civil partnered, Dorian did not decide to revise his previous will, which predated his relationship of 25 years, until after Donald Trump was elected president of the USA in 2016. Concerned at the possibility of a conservative turn in US politics and to protect his partner after his death, he set up a trust and wrote a will, as he explained:

One of the reasons I did a trust is because it was during the Trump Administration and we had a conservative supreme court and had no idea what the future was going to be and I wanted to make sure that when I passed away—and I am 20 years older than my partner and am obviously going to be passing away before he does—that he would be protected and he would have everything that I wanted him to have without any legal issues if [in the event] our marriage was dissolved legally because of strange things that can happen in the United States. He was going to be protected.

Dorian’s decision was to protect his partner’s inheritance rights in the event of same-sex equality being struck down by a conservative supreme court. As it turned out, his fears and concerns were not ill-founded. In the legal opinion that he wrote in 2022 when the US Supreme Court revoked the right to abortion in that country, justice Clarence Johnson forecast that the court could reconsider previous decisions to allow contraception in marriage, decriminalize homosexuality, and permit same-sex marriage.<sup>14</sup>

A smaller group explained that they revised their wills because of death, separation or divorce. The oldest in the sample, Atticus (aged 88 from California) said that he re-wrote his will after the death of his partner of 29 years and because of other changed circumstance (mostly financial, discussed below). Another told of changing his will when he and his husband divorced, and a third man that he also revised his will when he separated from his previous boyfriend.

Two men revised their wills after their partners moved in with them. The first was in his 70s and from the Australian Capital Territory (ACT): ‘I have a will and it has been revised . . . probably within the last few years . . . Around about the time we moved in together, I think we both looked at our wills and

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14 Greve, J. E. (2022) ‘Contraception, Gay Marriage: Clarence Johnson Signals New Targets for Supreme Court’, in *The Guardian*. <https://www.theguardian.com/world/2022/jun/24/clarence-thomas-roe-gay-marriage-contraception-lgbtq> accessed 15 July 2022.

revised them' (Fabian, aged 74). And the second, aged 40, did something similar: 'it was probably about six months, maybe a little bit more than that after [partner] moved in with me. So, if I'm getting my timeline straight, that's probably what it was closest to' (Damon, ACT). Both revised their wills when, like so many others, their couple relationship and future together was more certain.

### *Changed Material Circumstances*

Twelve participants or just over one third with wills revised them when their material circumstances changed. In most cases, participants' changed material circumstances occurred when they acquired property or changed their property ownership arrangements such as a couple agreeing to joint ownership after marriage, civil union or civil partnership, moving in together, or relocating.

Three men noted that they first wrote a will when they acquired property. 'When I began to accumulate a humble amount of assets, I thought ... "Be sensible and have a will"', said Donovan (aged 55) from England. And Mason (aged 60) from California explained that he and his partner wrote a will for the same reason and in similar circumstances: 'We ... had one done probably in the early-1990s once we had enough assets to care about'. Ethan (aged 58, England) observed also that he believed that the connection between writing a first will and acquiring property was fairly common among single gays: 'Like a lot of single gay men, I did not get around to doing a will until relatively recently ... because I did not become a property owner until I was nearly 50'.

Two men in their 50s had slightly unusual property experiences. The first was born into a wealthy family and the second had acquired property in different countries over the course of his working life. Each had a novel story to tell about writing and revising wills.

US citizen Randolph (aged 57) was living in Germany at the time of interview and provided this brief history in answer to the question on writing and revising his will:

I have had a will since the day I turned 18. It had been drafted well in advance because of the family I grew up in. I had significant assets at that time. Yes, I had my first will at 18 and have more or less maintained one since. I no longer have any assets because my father disinherited me.

For Randolph, it was the loss of what appeared to be a considerable inheritance that meant that he had to write quite a different will from those

that he had had since 18. His current will was important to him because it included details of which friends were to receive which of his belongings:

I made a new one back in March which is, I was reflecting, highly detailed because ... there is no cash but there are a lot of things which have value and I don't want those things to go to my mother or my sister so therefore I have to have a will. *Would they be paintings and carpets and things like that?* Yes, paintings, carpets, furniture, jewellery. I have a set of silver which miraculously is worth something like eighty thousand dollars. Who knew? [Laughs].

The loss of the inheritance that he had grown up expecting to receive on the death of his father was painful and life changing, not least because of his HIV-positive status:

It is terrible because by then I was in my late-40s, my life decisions had been made. I did not expect to live into my late-40s but I was relieved that, since I had, at least I would be well cared for in my later years, which, of course, is exactly what this is all about. That is no longer the case and this is an interesting ride for me.

As mentioned in the previous section, he changed his will when he divorced his husband. He did so again prior to his interview (August 2020) because of concerns about the Covid-19 global epidemic.

Will-writing complications for Damien (aged 52, England) related to assets that he held in a number of different jurisdictions:

In the last ten years, I have revised ... [my will] twice and the biggest revision was in the last 12 months. There is the added complexity of living in three countries. I have got assets in the UK, Switzerland, and Australia, so you need a will in all three countries.

He was in his own words, 'not rich': 'We are not talking about multi-millions here; this is just where the assets are'. His intention was, however, to simplify where possible the arrangements that he had to make to ensure that his affairs were well organized in the context of different jurisdictions' legal requirements:

There is a requirement in Switzerland that if you have got a living parent, automatically 50 per cent goes to a living parent. And you have to foresee that. That law is changing in a year and a half. There are these quirks in each country. In the UK, there is inheritance tax; in Australia there isn't. You have to navigate all of that.

*Travel or Relocation*

Travelling caused one participant to reflect on the effect of not having a will in the event of an accident: ‘I remember I was travelling somewhere, jumped on a plane and thought, “What if the plane goes down?” so I quickly drafted a will’ (Carter, aged 57, New Zealand). Others revised their wills when they relocated because the change of residence often meant living in a different jurisdiction with different rules concerning wills and intestacy. When Johann (aged 52) and his partner migrated to England from South Australia, for example, both wrote new wills:

We have wills, both in Australia and in the UK, and they were fairly regularly revised. They probably changed three times in that ten-year period, or at least twice, I would suggest. *Do you remember any event that caused you to revise your will?* The most recent was moving here and having to do a new UK one. I forget the details of why we needed to but that then meant that we had to make some adjustment to the Australian one to refer to that or something. I can’t remember. That was three years ago we got the UK one and updated the Australian one.

*Health or Illness*

More than 70% or the vast majority of interviews were held in 2020 and 2021, that is, during the initial phase of the Covid-19 global pandemic in the West, of which more than half were held between February and November 2020, which was arguably the worst stage of the virus’s spread.<sup>15</sup> Given these facts, it was a little surprising that only three participants referred to the threat that Covid-19 posed to life as the reason for revising their will. Aged between 57 and 70, their views are best represented here by the following explanation from Emmett (aged 70, England), who was interviewed in May 2020:

Partly because of the Covid-19 outbreak and in common with many other people we are remaking the will at the moment. We are just about to contact the lawyer to make the revisions because, obviously, given our age and the state of the disease, it is a wise thing . . . to revise it.

The sample included a total of five men who were HIV positive (aged 57–68), two of whom revised their wills for health reasons. One referred to his

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15 Thirty-one interviews were held in 2020 and 2021. Of the 17 that were held between February and November 2020, 10 were with participants aged 60 and older and three with men who were HIV positive. See Appendix 2.

possible vulnerability to Covid-19 infection because of his HIV status, while the other explained his decision to revise his will in light of his improved mental health:

I really went off the rails after I got HIV, was in a bad way. I didn't care about living anymore and I didn't care about anything. I did own property and I did have money and I did have a successful business and I lost everything. But over the last year, I rebuilt my life and I feel for the first time in my life quite content and happy, which is really lovely. I will make a will because I see it is important to do. (Christopher, aged 52, New South Wales)

### *Fine Tuning*

A small group regularly revised their wills. In all cases, they did so in order to alter the distribution of belongings or personal possessions among friends, relatives or charities, as shown in the following extracts:

I have revised it three times in the last eight years. I have set out distributions as per percentage to charities and friends. *Was there any particular reason you revised it three times in eight years?* I just wanted to fine-tune it and make sure it was distributed accordingly to those organisations or persons in particular. (Lewis, aged 74, ACT)

I do revise it. I do not frequently revise the main body but I have a large addendum of bequests of individual items from my considerable collection of clutter. I do revise that every now and again. (Rowan, aged 71, England)

I did my first will in 2013 and I have revised it five times since then, partly because testators had died or things have changed, generally only tweaking, not major changes. (Ethan, aged 58, England)

### Choice of Executor

All 35 participants who had a will had appointed an executor at the time of interview. In a small number of cases where trusts had been set up, a person was appointed, usually a trustee, with an equivalent responsibility to carry out the testator's wishes. Executors were drawn from four principal categories: family member(s); the partner; a professional person; or friend(s).

In some cases, participants chose executors from more than one category. For example, a small number appointed as executors a family member and their partner. In one or two cases, executors were chosen from three

categories, often the partner together with a professional person and a family member or friend(s). In some instances, the family member or friend was a useful, practical choice for the added reason that they were also a lawyer.

Reasons for choice of executor tended to focus on trust and also the practical and personal purpose of being able to rely on the person(s) to take care of the testator's affairs after death, whether these included disposal of their body, funeral arrangements, distribution of legacies, the winding up of financial affairs, with or without the assistance of anyone holding the testator's power of attorney.

### *Family Member*

More than half those who chose a family member to be their executor nominated a sibling, followed by those nominating a niece, nephew or both, and then by one participant only who chose one of his children.<sup>16</sup> Unless the sibling was a professional person also, almost no explanation was provided, or possibly thought necessary, for choosing a sibling as executor, perhaps because of the obvious blood connection.

In the case of nieces or nephews, however, a number of participants justified their decision on the grounds of what they saw as the sensible benefit of having someone from a generation 'below them':

We decided we wanted people from the next generation to be written down there as well, so it seemed obvious to pick my nephew because I am close to him and his closest niece whom I am quite close to as well. We wanted people from the next generation to make sure that they were going to be around. (Rowan, aged 71, England)

Although it was rarely admitted, some might have found it easier to appoint a niece or nephew as executor because their sibling relationship was broken or not close, as Seth, aged 68, from California intimated in this extract from this interview:

I do have an executor who is my oldest niece. I chose her because I feel like I have been able to maintain the most honest and open conversation about my life [with her] and . . . that she would show compassion to my friends or anyone she might encounter after I have gone.

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16 Of the 14 who chose a family member to be their executor, eight nominated a sibling, five a niece, nephew or both, and one chose one of his children.

The majority of those who chose a family member for executor were in couple relationships,<sup>17</sup> and here most appointed them together with their partner, a professional person, a friend, or all three. For those participants who were single, slightly less than a quarter appointed family members as their executor,<sup>18</sup> their preference being for friend(s) or the professional person or both.

### *Partner*

Of the 24 in couple relationships who had a will, more than two thirds nominated their partner as an executor.<sup>19</sup> The remaining group of less than a third did not explain nor were they asked in the interview to explain why they did not appoint their partner as executor.

Explanations for the choice of partner were sometimes perfunctory, some saying, for example, that it just made sense, was a 'natural' choice, 'to keep it simple' or because of proximity such as Damon (aged 40) from the ACT explained: 'My partner is the first executor because he's here'. Other reasons included familiarity with testator's family or personal trust, as shown in the following extracts from two interviews:

I chose my partner . . . because he is the person I absolutely trust and he has good relations with my family and he will be able to get support from them to fulfil his wishes and my wishes. (Nicholas, aged 72, New South Wales)

My husband is the sole executor of my will because there are very few people in my life that I trust as much as him and I thought it made good practical sense as we've had honest and open discussions about my desires for my estate and what happens to my body after I die. He understands what I need and I would sooner that he did that rather than burden my now two adult children with the hassle of dealing with wills and burials and things. (Harrison, aged 56, Victoria)

As well as trusting his partner, Nicholas's account suggested a level of care and concern for what his partner could need after his death. And Harrison's explanation touched on not only trust but also the practical and personal reasons for choosing his partner, namely being able to rely on his partner to take care of his affairs after death, which lies at the heart of the executor's role.

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17 Of the 14 who appointed a family member to be executor, 11 were in a couple relationship.

18 Of the 14 who appointed a family member to be executor, three were single.

19 Of the 24 participants in couple relationships who had wills, 17 nominated their partner as executor.

When asked about their decision *not* to nominate their partner as executor, participants who were in a couple relationship gave two reasons for the decision. The first was to avoid encumbering or burdening their partner. And the second, given by those who were roughly equal in age, was that appointing a younger friend or a professional person made more sense; the younger friend especially so as they were thought more likely to outlive both partners.

### *Professional Person*

Almost all of those who chose a professional person to be their executor nominated a lawyer.<sup>20</sup> Other choices included, for example, an accountant and a firm of trustees. Principal justifications for nominating a professional person as executor were firstly a belief in their competency and reliability and secondly to avoid burdening family or friends, as shown in the following.

#### *Competency and Reliability*

I have been an executor for three estates and the first two were so badly done. I knew the first person. He was my first relationship for 17 years. I knew him well and because of the way his . . . will was written, it did not carry out his wishes and there was nothing I could do about it. There was a brother who swooped in and made some terrible accusations of loaning him money and things that were not true. I wanted to make sure that mine was well done and that is why I went to lawyers. I went to gay lawyers who understand the situation also. (Atticus, aged 88, California)

#### *Avoid Burdening*

I did not want to put anybody into any trouble, I suppose . . . I think I just thought it was more convenient for everybody and also cheaper . . . to do the whole thing through the public trustee. I do not know if I paid anything at all. (Clive, aged 81, ACT)

My executor on the will is the solicitor who drew it up. Before that, I had one of my best friends, who was a responsible person who I thought would be good for this. I had him as the executor until we moved [to England] and then I changed it to the solicitor because it got more complex when we were in two different countries. He's a lovely friend but he does not deserve that dumped on him [*Laughs*] when I can just pay someone to make it better for us. (Johann, aged 52, England)

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<sup>20</sup> Fourteen chose a professional person as executor, 10 of whom were lawyers.

One participant who was about to revise his will explained that he would choose a professional executor in order to avoid burdening the friends he had previously appointed: ‘I need to revise that partly because I am not quite as close to those friends as I once was and it is a huge burden to put on someone’; and also, because, as he had no children of his own, it made more sense in his view to do so:

I feel I ought to appoint a professional executor because I don’t know what my family situation will be at that time, what friends will still be around. It is a little easier if you have got kids: you can leave everything to the kids and they are the executors. (Anton, aged 45, England)

*Friend(s)*

A similar number chose a friend or friends for their executor as chose a family member or professional person.<sup>21</sup> Friends were chosen firstly for their practical common sense, personal knowledge of the testator, or secondly because they were younger, in much the same way as a family member, often a niece or nephew, could be chosen as executor.

The importance of having an executor with practical common sense and personal knowledge of the testator was underlined in these extracts from interviews:

Among other things, [name of friend] is ‘Miss super-efficient’. No nonsense! Get it done! Problem: fix it! And the other one was this young lawyer [name of friend] who was also of that persuasion . . . [And all] they’d have to do would be to hire a solicitor and get the estate through and, in a few months’ time, go back to the solicitor and the beneficiary. (Edward, aged 77, ACT)

The joint executor for both wills is a friend of ours, who is younger than us, so will survive us, more likely to be *compos mentis* even when we are not. She is ten years younger and she is fiercely well organised and takes no shit from anybody. She is just the sort of person who you would have to organise anything, really. (Wade, aged 66, England)

The . . . [executor] after that is my very close friend. She is the sister I never had, school captain of the girls’ school across the road from me. We’ve been friends since we were like 14. The reason I appointed her and not anyone from my family is because, even though my parents . . . are only in their 70s, I think it would be bit too much for them . . . [and] I know that . . . [she] would do it to within an inch of its life. (Damon, aged 40, ACT)

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21 Fourteen chose friend(s) as their executor.

Wade's justification for his choice of a friend for executor was two-fold. Not only was she a 'non-nonsense' person but also, she was younger than him and his partner. Others, like Kieran (aged 67) from England explained their choice of friend also for reasons of age and youthfulness:

The person is younger than us, very bright, very diligent, newly retired, so has time and knows us very well, knows our state secrets, as it were. I think we feel comfortable, provided he survives, of course, in guiding the process.

Among the small number of those whose current family type was the chosen family, there was no evidence of any preference for choosing friends as executor. The five who had created families of choice appointed family members or partners as their executors. By contrast, the current family type of the 14 participants who appointed friends as executors was the family of origin or the couple, which, taken together with the preference for family members in the group from chosen families, would seem counter-intuitive, that is, that those from chosen families avoided appointing friends while friends were appointed executor by those who regarded the family of origin or the couple relationship as their current family type.<sup>22</sup>

## BENEFICIARIES

This section examines participants' beneficiary decisions, in terms of who they nominated and why they nominated these persons or organizations. All were asked the same questions: 'If you have a will, who are your beneficiaries? Who did you choose and why?' The most common beneficiary choices were (in numerical order): partner; nieces and nephews; charities; siblings; friends; and children. Beneficence was a common theme in the explanations for beneficiary choice given by those who nominated a family-of-origin member, that is, nieces or nephews, siblings, or children. Many who planned to leave assets to family-of-origin members included in the deliberations – which they openly included in their interview – a strong awareness of which family members had 'done well' (almost always in a material sense) and who had not.

This awareness of material success then often formed the basis for beneficiary decisions as family members' perceived neediness was used as the guiding principle for decisions about legacies where, for example, some participants reasoned that family members who were understood to have done well did not need further assistance while those who were regarded as struggling deserved

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<sup>22</sup> See Chapter 1 for discussion of current family types.

the material assistance that their beneficence would provide. Beneficence was a feature also of participants' decisions to nominate their partner as the primary or sole beneficiary of their will.

### Partner

Slightly fewer than two thirds of those with wills nominated their partner as a beneficiary.<sup>23</sup> Most of those who did so nominated their partner as the primary or sole beneficiary and many of these raised also the sensitive matter of which partner would die first and how this would affect distributions from the deceased partner's estate. Secondly, some included provision for previous partners, including in a few cases their former wives, whether because they had been nominated in superannuation accounts or pension funds or from a sense of duty or affection: 'My wife was the beneficiary [of life insurance] and I have maintained her as the beneficiary on that . . . I owed it to her, I felt' (Joel, aged 74, California); 'My former partner is a part beneficiary of my superannuation' (Nicholas, aged 72, New South Wales); 'I do want . . . to give my "ex" a life interest in some of my estate' (Anton, aged 45, England).

In most cases, those in couple relationship planned to leave everything that they owned to their surviving partner: 'My entire estate goes to my partner' (Rowan, aged 71, England); 'In the event of one of us dying, the other gets everything' (Wade, aged 66, England); 'One hundred per cent [goes] to my partner' (Damien, aged 52, England). Only a few felt the need to justify leaving 'everything' to their partner and these included Harrison (aged 56) from Victoria (Australia) who may have felt the need to explain his decision because his children from a previous marriage were also included as beneficiaries: 'To cover off any outstanding debts that might exist with my husband and there should be sufficient superannuation and life insurance to cover that'.

Another participant explained why his partner would not get everything. Jonathon (aged 53) from England said that his husband would get that part of his estate which they together had accumulated 'as a result of our lives together', while another portion, which had been acquired through his family from what their grandfather had left, would go to his brother. This explanation nicely encapsulated the thinking of many which privileged family-of-origin members (or blood-family members) over members of the couple family or the chosen family.

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23 Partners or spouses were included as beneficiaries in the wills of 21.

### Nieces, Nephews

Just under half who had wills chose to nominate their nieces or nephews as beneficiaries.<sup>24</sup> When they explained why they were leaving a legacy to their niece or nephew, participants said either that it would help them ‘get ahead’ or because they had special needs.

Those who wanted to help their nieces and nephews get ahead included some who believed in giving according to need and others who did not distinguish by need. Rowan (aged 71) from England had a pretty clear idea of how his niece and nephews were getting on and had decided to leave more to the niece because his nephews were doing well and she would benefit from his legacy:

I am fairly hard-headed about this. My oldest nephew is doing extremely well working ... [in the USA] making a lot of money and so he does not need a big bequest from me. My gay nephew is civil partnered with a gay actuary who is earning a ridiculous amount. They have a small portfolio of rental properties and they do not need my bequest. But my niece is hoping to buy a flat in the London area so she will need a bit of support.

Nieces and nephews with special needs were cited by a small number of participants and are represented here by this account:

He is on disability [pension] and he is ADHD. He is an apoplectic ... He is wonderful with people ... but he has no judgement at all about people. I think a group-home setting would be great for him or just a caretaker sort of person and I think there are such places here ... When they moved here, which was five years ago, he had a major slip and ... wound up in a hospital. He has been clinically dead twice. It has been bad stuff. Even though he is fine now, and he would not hurt a fly, he is just someone you need to look after or make sure is looked after. (Harvey aged 74, North Carolina)

### Charities

Two fifths of participants with wills left money to charities.<sup>25</sup> None nominated a charity as sole beneficiary and instead included charities with other beneficiaries, namely, their partner, family members or friends. Gay social support services were the most common charity followed by charities that had a social

<sup>24</sup> Nieces or nephews were included as beneficiaries in the wills of 17.

<sup>25</sup> Charities were nominated as beneficiaries in the wills of 14 of the 35 participants with wills.

or cultural focus, and then those with which participants had a personal attachment or association.

Almost half who wanted to leave something to charities specified gay social support services. These included those who wanted to assist LGBT resettlement, PLWHA support services or gay rights organizations. Roland (aged 50) from Victoria included in his will instructions, 'to set up a charity ... to assist homeless LGBTIQ young people' and Johann (aged 52) from England that, 'Forty per cent goes to the Pinnacle Foundation in Australia which is an educational foundation that helps LGBTIQ students with financial support through university and even secondary school if they need it'.

Charities with a social or cultural focus included, for example: The Orchestra of the Age of Enlightenment (Ethan, England); The Art Gallery of South Australia and Adelaide Botanic Gardens (Donovan, England); as well as an educational charity (Anton, England); and mental health organizations (Rowan, England). Those who wanted to leave in their wills funds to benefit bodies with which they had a personal attachment or association included Andrew (aged 75) from Canada who wanted to leave an endowment to the university where he studied; Preston (aged 70) from the ACT who planned to leave a bequest to his parish church; and Kieran (aged 67) from England who wanted to leave, 'a real, solid, transformational legacy' to a charity he had worked for which maintained mediaeval churches.

### Siblings

Siblings were the choice of slightly less than a third of those with wills. Beneficence was a strong factor in decisions made to include siblings as beneficiaries. Participants' reasoning often revealed a clear understanding of family dynamics and which sibling(s) had achieved and which had not. This was then used to explain why some were included and others were not, that is, which siblings were deserving and which were not or had no need of material assistance. In this extract from interview, for example, Damien (aged 52) from England explained why his family were not the 'main beneficiaries': 'Not because there is any ill-will or malice, but I know that they are going to inherit enough from their families'. While Dorian, (aged 70) from New York State explained more precisely why one brother would benefit from his will in a way that his other two brothers would not and why:

I left some tangible things to my other brother who is an attorney who is extremely well-off. He has no need for anything [that] I would leave him, nor do his children because they are going to be receiving from him and his

wife who is well-off and very Republican. Fine! But my other brother, in [a midwestern state] is struggling and he has some health issues and I want to make sure that I would be able to help him. And then also his son as well. He is in [a midwestern state] and that side of the family needs some extra help. My youngest brother, my next brother really does not need help . . . He loves books and I have a huge amount of books [to leave him].

### Friends

Slightly more than a quarter of participants with wills chose friends as their beneficiaries. When explaining their decisions to nominate their friends, they tended to rely on one of three narratives. Friends were mainly chosen as an expression of gratitude for or recognition of the bonds of friendship or an expression of love and affection; in one or two cases as an act of beneficence; and in one or two cases to pass on to them objects that the testator thought they would appreciate.

Benefactions as expressions of gratitude or recognition of friendship were evident in three extracts of interviews:

One friend that we thought we were going to be in a relationship at the time when I was making this will, I have not changed it, and he is a significant beneficiary; the other one for advice that he has provided at different times. (Preston, aged 70, ACT)

I have a very short list of friends I would like to leave a cash bequest to. They have been important part of my life and I am very grateful to them all. Not a fortune but it is [a way of saying] ‘Thanks very much, you have been lovely’. (Donovan, aged 55, England)

That list of friends is largely [from] the last ten years. When you are an expatriate . . . [and] leave a country and for 20 years, there are people who . . . have come to you to make sure that you are OK and checked in . . . and helped me in all sorts of indirect ways. . . . That’s just a reflection of that. (Damien, aged 52, England)

Beneficence or acts of kindness or charity was exemplified best in this extract from the interview with Kieran (aged 67) from England: ‘Various people who I’ve known mainly through work, who I like, but also need the money . . . The individuals are given quite useful sums but they’re not transformational sums’. Among those who had specific belongings in mind, which they wanted friends to have, were two men in their 50s. ‘Personal bequests, of which there are about a dozen, to individual friends of mine, individual items’ (Ethan, aged 58, England). ‘It is a list of friends and this is traditional in my

family actually. I gave objects and things to people who I thought would appreciate them most' (Randolph, aged 57, Germany).

### Children, Grandchildren, Godchildren

Four chose children as their beneficiaries and two chose grandchildren and two their godchildren. The two who chose grandchildren nominated the grandchildren of their deceased partners, none having grandchildren of their own. In the following extract, Quinn (aged 60) interviewed in Victoria in Australia explained how he proposed to honour the promise to his deceased partner:

My house that I own, I have left to my deceased partner's grand-children. I promised him I would [do that]. The house that we lived in was sold, so I took some of the benefit of that, and I think it's only fair that his grandchildren take that benefit.

Of the four nominating their children, three became parents in previous relationships with women. The remaining participant was, with his partner and two lesbians, one of his son's parents. And the son was the chief beneficiary of his will and his partner's will. These four beneficiary decisions were outlined without detail or any need to explain or justify, children being direct bloodline descendants.

The presence in the sample of two who choose to include godchildren as beneficiaries supported Monk's argument that, while doing so was now less common, lawyers interviewed for his research, who had experience with gay and lesbian clients, had noted an increasing tendency for the inclusion of godchildren in their wills. That parents could ask gay or lesbian friends to be godparents because they were (once) unlikely to have children of their own is a convincing, common-sense explanation.<sup>26</sup>

## CONCLUSION

Family members were the most common choice for executor. And of these, siblings were the first choice followed by nephew or niece or both. Friends were the executor choice of only a very small number of participants and were

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<sup>26</sup> Monk "Inheritance Families of Choice?", pp. 184–185.

chosen for their common sense or practical and/or personal knowledge of the testator.

By comparison, beneficiary choice can reflect the whole web of social relationships, including, for example, partners and spouses, family members – from parents, siblings nephews and nieces to godchildren and stepchildren – and friends. Partners or spouses were the most common beneficiary choice followed by nieces and nephews then charities, siblings, friends, and children, grandchildren, and godchildren in that order. Choosing nieces and nephews and siblings before friends suggested a recognition of the primacy of kinship,<sup>27</sup> and a preference for members of family of origin over those who comprised participants' family of choice. It could be argued that the special place given to partners represented a greater acceptance and understanding of spousal rights following the success of marriage equality legislation in the West since the late 1990s,<sup>28</sup> and prior to that the relatively widespread take up of common-law (de facto) relationships among gays and lesbians. Few if any felt the need to explain or justify the primacy given to partners in their beneficiary decisions. It was simply assumed and required no explanation.

In almost all cases, the gift of inheritance was made without any expectation of reciprocation and hardly ever in return for benefits or gains that testators had received from their beneficiaries and so were in a sense distinct expressions of altruism. Underlining many of the decisions were varying expressions of care, beneficence or social solidarity. Evidence of beneficence was found in many decisions to nominate family and friends and, as shown, some participants made very careful decisions based on their knowledge of family dynamics and which relatives had succeeded and which were struggling. When friends were chosen as beneficiaries, decisions were often made to recognize or honour the bonds of friendship, underpinned by degrees of beneficence. Beneficiary decisions to leave money or assets to social or cultural organizations were without doubt material gestures of social solidarity.<sup>29</sup>

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# 3

## MANAGING PHYSICAL AND MENTAL END OF LIFE

I am just trying to picture myself in a hospital bed or at home or a nursing home. In order to feel that life is still worth living, I want to be able to listen to music and read. Those are my two main things. I do play music as well. I am just picturing myself not being able to get to my organ or my piano. (Rowan, aged 71, England)

### INTRODUCTION

This chapter examines participants' decisions to prepare an advance-care plan and/or to appoint a power of attorney so that their end of life can be managed according to their wishes in the event of losing capacity to do so for themselves. With an advance care plan,<sup>1</sup> which is a relatively new instrument for end-of-life planning,<sup>2</sup> individuals can specify which end-of-life procedures they want to do without – for example, being force fed or receiving futile medical intervention – and which friend, family member or other representative should give effect to these wishes. As explained in the next section, an advance care plan may be lodged with an individual's medical practitioner and is morally

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1 An advance care plan can have two parts, an instructional directive and a values directive where the instructional directive (known in the UK as an Advance Decision to Refuse Treatment) specifies those medical procedures from which an individual wishes to be spared and the values directive can consist of more general statements about what matters to them as a functioning human being. See, for example: <https://advancecareplan.org.uk/advance-care-planning/>.

2 According to the New Zealand Ministry of Health, introduction of advance care planning dated from the 1980s: <https://www.health.govt.nz/publication/advance-care-planning-guide-new-zealand-health-care-workforce> accessed 16 January 2023.

but not necessarily legally binding. Advance care or its equivalent was available in all the jurisdictions where the participants lived at the time of interview.

Power of attorney, at its simplest, enables a person to grant another authority to take responsibility for their end-of-life needs and care if and when they lose capacity. Participants' decisions concerning power of attorney were included in the research for this book because in some jurisdictions a person could be granted power of attorney for financial affairs as well as power of attorney for medical and health care, thus dividing the authority to act for the donor's financial and material circumstances from that concerning their body and health. In some cases, a person could appoint an agent to be their financial power of attorney and another to be their medical power of attorney. As explained in the section below, power of attorney (financial) and power of attorney (medical and health care) were available in most of the jurisdictions from which participants were drawn.

#### ADVANCE CARE

The following brief summaries give some idea of the similarities in the practice of advance care and occasional minor differences. In British Columbia, for example, under the Health Care (Consent) and Care Facility (Admission) Act (1996), a person can make an advance directive which is not legally binding that 'gives or refuses consent to health care in the event that the adult is not capable of giving the instruction at the time the health care is required'.<sup>3</sup> In the State of California, meanwhile a person has a 'legal right' to make an 'advance health care directive' to let their family and friends know their 'health care preferences, including the types of special treatment you want or don't want at the end of life, your desire for diagnostic testing, surgical procedures, cardiopulmonary resuscitation and organ donation'. Advice from the website of the California Department of Justice suggested that, as in many other jurisdictions, a directive is not legally binding.<sup>4</sup>

In England and Wales, an 'advance statement' allows a person to 'to make generalized statements' regarding their 'wishes and preference about future treatment and care'. A website drawing on the expertise of the NHS, the National Council of Palliative Care, and Hospice UK made clear that the

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3 For more on British Columbia, see: <https://www2.gov.bc.ca/gov/content/health/managing-your-health/incapacity-planning> accessed 16 January 2023.

4 For California, see: <https://oag.ca.gov/consumers/general/care> accessed 16 January 2023.

advance statement was not legally binding.<sup>5</sup> In New South Wales, an advance care directive consisted of an instructional directive ‘with legally binding instructions’ about the medical treatment the person would consent to or refuse; a values directive; and details of a person’s enduring guardian who was a ‘trusted relative or friend’ and appointed to be the ‘substitute decision-maker’ when the person no longer has capacity.<sup>6</sup> Advance care planning in New Zealand included an advance directive (also known as a living will) where the person specified what sort of care they wanted withheld. Information provided by the New Zealand Health Quality & Safety Commission suggested that an advance directive could be made legally binding.<sup>7</sup>

All participants interviewed for this book were asked the same question on advance care directives: ‘How did or would you frame your values directive and why? How did or would you frame your instructional directive and why?’ Included in the explanatory material that participants received before the interview was a brief description of some of the features of advance care as understood in Australia, England, New Zealand, and North America.<sup>8</sup> When answering the question, the majority began by focusing on the instructions which they thought they would include or had already included in their advance care plan or equivalent advice document, that is, their instructional directives. There are a number of reasons why their answers tended to be quite general or rather vague, for example, whether to be revived or whether to have a life-support machine turned off. Firstly because only a handful had completed an advance-care plan, the remaining participants were only speculating on what they would include if and when they came to write one. Secondly as knowledge of what end of life entails is largely the preserve of hospital staff, priests, social workers and undertakers, it could be argued that very few people know what sort of instructions will be needed to advise medical or nursing staff about what to do in their final days.

In the case of the values directive, participants were asked to consider in general terms what ‘about being a human’ was important to them. While some found it difficult to answer, many followed the written example in the material – ‘being mobile, able to communicate with other human beings’ – and during

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5 For England and Wales, see: <https://advancecareplan.org.uk/advance-statement/> accessed 16 January 2023.

6 For New South Wales, see: <https://www.advancecareplanning.org.au/create-your-plan/create-your-plan-nsw> accessed 16 January 2023.

7 For New Zealand, see: <https://www.hqsc.govt.nz/our-work/advance-care-planning/acp-information-for-consumers/questions-and-answers/> accessed 16 January 2023.

8 See Appendix 1 for explanatory material sent to participants prior to interview.

interview said that physical and cognitive faculties were important to them and so implicitly of value. Many were able to add that they had no wish to exist in a 'vegetative' state or that quadriplegia would be extremely undesirable while some observed that if they lost capacity, it would be difficult for them or someone acting for them to know when it was time to bring their life to an end.

The following section, which chiefly concerns how participants phrased or would phrase their instructional directive and their values directive, begins with an introductory section on how the end-of-life awareness of some was strong because they were more familiar with it from witnessing the death of someone close to them – a family member or friend – or in the course of their working life, or because of its significance for gay men and their families and friendship groups, during the HIV-AIDS epidemic of the 1980s and 1990s.

### End-of-Life Awareness

Slightly fewer than half recalled experiences of the death of a family member, partner or close friend. These people tended to have a clearer idea of what end of life might mean for them and spoke relatively candidly about their own mortality. There was evidence also of a fuller understanding of death and dying in the views of older participants, possibly because of a deeper awareness that comes with age, that is, that, while adults of any age might have a rough idea of their life expectancy, it is arguable that those aged 50 and older will have a more precise understanding of their probable longevity, based on what they have witnessed in their own family, peer group or age cohort.<sup>9</sup>

Being present at the death of someone close, an acquaintance or as part of work or community service was the experience of slightly more than half the sample, the largest group of which comprised those who had had experience of the death of a family member, followed by those who had experienced the death of a friend, then those who experienced death and dying as part of their work, and those who did so during the HIV-AIDS epidemic. These experiences were most often recounted when participants explained what they themselves would prefer at end of life and the decisions that they had made or would make concerning advance care and are examined in the next section.

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<sup>9</sup> Similar to argument of Bytheway, B. (1996) 'The Experience of Later Life' in *Ageing and Society*, 16: 613–624.

*Family*

Mothers were the family member whose dying and death were most often cited followed by fathers, siblings and grandparents. Included in the understandings that participants developed as a result of bearing witness to their mothers' dying and death were that life becomes lonelier as friends die and that they cannot be replaced; that differences of opinion between family members can derail implementation of the dying person's wishes; that losing capacity can sometimes be a blessing. These lessons were evident in the following extracts from three men in their 70s:

I just know ... from my own mother ... that one friend doesn't replace another. You could make other friends but the sense of loss for that friend is simply irreplaceable. [Academic commentator] makes the comparison in different sense. He said that, "If your butcher doesn't give you the meat you want, you can change a butcher". But friends aren't there to serve our interests. It's true for friends but it's even truer for spouses and lovers. (Edward, aged 77, Australian Capital Territory (ACT))

No matter what you write in your advance directive, you can always be faced with something, which we were when my mother was in respiratory arrest and they had to react and they put her on a ventilator ... and she said, "I don't want that". She was 90. Do not allow anyone to have co-durable power of attorneys! With my sister and me, she said, "She's already on it; we can't take her off!" And I said, "She does not want to be on it; we have to take her off!" (Joel, aged 74, California)

In a way, it's much simpler if you lose your mental capacity, these are not decisions you can possibly take. With my mother who had Alzheimer's, she was entirely in the hands of medical professionals and her children; whereas, if you've got your marbles, it's a much more difficult thing to weigh up. (Emmett, aged 70, England)

*Friends*

A small group referred to friends' experiences of incapacity when describing what they would prefer to avoid at their own end of life. In the following examples, participants pointed to the fear that was shared by many in the sample, which was of being 'trapped in their body' and the possibility that, on losing physical functions such as speech, they might still be aware of what was happening around them and the torment that this would entail.

We had a friend who had . . . shrinkage of the frontal lobe and she was clearly conscious of who we were. The only thing you could do with it was to talk to her in the way we did when she was well . . . And the problem with that was, she heard and understood what was being said . . . but couldn't form the words to reply. (Edward, aged 77, ACT)

I have a friend who is 83 now and 95 per cent of her body is useless to her, her kidneys are beginning to shut down but her mind is incredibly still alert and it is distressing for her to live in this body. She . . . is near a decision to tell them to stop all medication. Now, she is still fully cognizant. There is nothing wrong with her mind, there is no Alzheimer's, apart from ageing deterioration, but her body is completely useless to her. (Nicholas, aged 72, New South Wales)

I have known a person who . . . [was] trapped in her body. It is a nightmare, an absolute nightmare. I have no interest in being Stephen Hawking in a chair and tapping. This is not me. (Randolph, aged 57, Germany)

### *Workplace*

For those who were employed in the health sector, dying and death could be part of their everyday work. Three from the sample had such jobs and their workplace experiences had been influential for them. Wade, aged 66 from England, was keenly aware of the extent to which the medical profession can affect a person's chance of a peaceful death:

I know what happens if you fall into the clutches of young doctors in teaching hospitals who will energetically try aggressive treatments for all sorts for good reasons and not-so-good reasons . . . I have seen situations where particularly Christian-informed, palliative-care doctors will try and . . . make everybody feel bad for not going for the idealised hospice alternative idea of death.

Another participant, with no personal experience in health but with knowledge gained from a friend who had worked in the health sector, observed also that medical and nursing staff could impede a person's peaceful departure:

I think the biggest problem as always is to stop the medical profession struggling to keep you alive. A friend of mine worked in hospitals for 55 years and he said, "What you've got to understand is that from the nurses' point of view, they grieve at every death. They don't become immune". This struggle they put up to keep you alive is not some external thing. They feel . . . a kind of commitment to the person. (Edward, aged 77, ACT)

Joel (aged 74) had worked in a hospice for men dying from AIDS and this experience had given him some idea of the quality of death: 'I had 500 patients in hospice. I was not with them when they died but I worked with them and their families, so I have had a lot of experience of what a good death is', which, a little later in his interview he explained as: 'peaceful with dignity'.

In his job as a counsellor, Nicholas (aged 72) had observed the work of medical practitioners and was not convinced by what he called the 'artificial elongation' of life:

I think that sometimes that is the obsession in the medical practice that you must cure people, you can't fail, or that refusal [to accept] that denial, that death is just as much a part of life as birth is, as loss is. We lose everything. That is it! And we have to learn to give it away.

He had witnessed also the slow decline that dementia caused in some people, a situation which he himself had no wish to suffer:

They are quite happy really in a way, but it is terrible for the people who retain a conscious, subjective relationship with them. They are still, Mum, Dad, whatever, but they are not; they have gone. It is not a real problem for them once they are beyond that distress phase in the early stages. They are a happy little body, they sit there, evacuate. I don't think it is good for people, really.

#### *HIV: Gay Familiarity With Death*

Farewelling and bearing witness to the dying and death of friends and acquaintances during the HIV-AIDS pandemic was a marked feature of the lives of many gay men born in the 1940s and 1950s.<sup>10</sup> Given this fact, it was a little surprising that only two interviewees referred to their experience at that time and the effect that this had on thoughts about their own end of life. The sample recruited for this research included six participants who declared that they were HIV positive (three in their 60s and three in their 50s).<sup>11</sup> The two who referred to friends' deaths during the pandemic were not among that group.

It is not a simple matter to explain absences in participants' stories or their reports of past experience but it is possible to suggest three possible reasons for the

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10 Robinson, P. (2008) *The Changing World of Gay Men* (Basingstoke: Palgrave Macmillan), pp. 54–62; Robinson, P. and Geldens, P. (2014) 'Stories of Two Generations of Australian Gay Men Living in the Presence of HIV-AIDS' in *Journal of Australian Studies*, 38(2): 233–245.

11 See Appendix 2.

absence of accounts of friends' deaths from HIV-AIDS as witnessed by those who participated in research for this book. The first possible reason is that because HIV-AIDS was increasingly medicalized from the mid-1990s<sup>12</sup> – the final step in its medicalization being the relatively widespread availability since the 2010s of HIV pre-exposure prophylaxis or PrEP in advanced western economies, either from state subsidized health or on-line sales<sup>13</sup> – it now features much less frequently in public-health campaigns or media coverage. The second reason could be that those from the Baby Boomer generation – who witnessed the greatest loss of friends, work-mates and lovers from HIV-AIDS<sup>14</sup> – continue to be affected by some form of survivor guilt and might be reluctant to revive memories of those dark years. And the third reason could be that, because death itself is so fully medicalized, only health professionals are now usually present at the hour of death,<sup>15</sup> although that would not exclude the presence of close friends or relatives at the bedside of the dying person in the hours or days before their death.

The two men who drew on their experience of death and dying during the HIV-AIDS epidemic when reflecting on their own death were in their 70s at the time of interview and would have been in their early 40s when HIV-AIDS was at its fiercest in cities like London, Sydney, and New York. Dorian, aged 70 from New York State summed up the experience of the two from this sample, and quite possibly many others from his generation: 'I have seen too many people ... [including] lots of people who died of AIDS who I was close to in the 1980s and 1990s, and their life was extended and [was] a life of suffering. And I don't want that'.

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12 Treatment for HIV-AIDS radically changed in the mid-1990s with the development of the protease inhibitor, a new antiretroviral drug and then a regimen of immunomodulating of drugs that people with HIV were prescribed which significantly extended their life expectancy. See Sendziuk, P. (2003) *Learning to Trust: Australian Responses to AIDS* (Sydney: University of New South Wales Press), pp. 217–220.

13 Taylor, J. (2021) *The Guardian*: <https://www.theguardian.com/society/2021/jul/02/gamechanger-hiv-transmission-dropped-90-for-men-taking-prep-australian-study-finds> accessed 22 August 2022; see, for example, this website for on-line purchase of PrEP: [https://prep.health/just-4-steps-to-prep/?hsa\\_acc=9714106491&hsa\\_cam=13056338330&hsa\\_grp=121758021763&hsa\\_ad=527042198782&hsa\\_src=s&hsa\\_tgt=kwd-301285988868&hsa\\_kw=prep+prescription&hsa\\_mt=b&hsa\\_net=adwords&hsa\\_ver=3](https://prep.health/just-4-steps-to-prep/?hsa_acc=9714106491&hsa_cam=13056338330&hsa_grp=121758021763&hsa_ad=527042198782&hsa_src=s&hsa_tgt=kwd-301285988868&hsa_kw=prep+prescription&hsa_mt=b&hsa_net=adwords&hsa_ver=3) accessed 22 August 2022.

14 Robinson, P. (2013) *Gay Men's Relationships Across the Life Course* (Basingstoke: Palgrave Macmillan), pp. 145–64.

15 The loneliness of death and dying in contemporary society was an important argument that Norbert Elias made quite some time ago: Elias, N. (1987) *The Loneliness of the Dying*, trans. E. Jephcott (Oxford: Basil Blackwell), pp. 68–91.

### Instructional Directive

In relation to the advance care directive overall, it was notable that only a handful of participants had completed one or its equivalent and that very few were aware of its existence prior to interview.<sup>16</sup> The next most notable finding was that, of those who were aware of an advance care directive, very few had a clear idea of the sort of instructions that they would need on hand and to put into effect if they wanted to avoid a painful or prolonged illness with little hope of recovery.

While quite a few stated that they had no wish to live out their last days in a 'vegetative' state, fewer were clear about how to write the type of instructions that would be needed in order to avoid it – that is, instructions that would be intelligible to staff in a hospital setting such as, for example, not to have a naso-gastric tube inserted for nutrition or a tracheotomy performed – or how to ensure as much as possible to have a simple or 'good' death where, 'one passes into dreaming and the world vanishes—if all goes well'.<sup>17</sup>

Analysis of participants' answers to the sort of instructions they would write or, in the case of a small group, had already written, revealed four approaches as to how they would like their end of life managed. The first was a preference for euthanasia which was expressed also as simply, 'turn me off'. The second approach, which was strongly qualitatively associated with the first was an unelaborated preference for 'do not resuscitate'. The third was a wish for comfort care with pain relief, which was one of the examples included in the preliminary material sent to participants before interview. And the fourth was for friends to make end-of-life decisions when appropriate. Even though a strong connection could be said to exist between preferences for euthanasia, a pain-free end of life, and do not resuscitate, subtle differences between them are revealed as each is discussed in order.

### *Euthanasia*

Slightly less than a third of the sample expressed some degree of interest in euthanasia, or being 'turned off', if, after an accident or illness, they lost cognitive faculties and were seriously physically incapacitated, that is, were left in what some referred to as a 'vegetative state'. One participant in his early 70s, who had had almost 20 years' experience in HIV-AIDS support, observed

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16 Three participants had an advance care directive or its equivalent.

17 Elias *The Loneliness*, p. 66.

firstly that, ‘death and dying . . . challenge us much more deeply than we think it . . . [will] in our preparation for it’; and secondly in relation to euthanasia: ‘a lot of people think that they would not mind having euthanasia but, when it comes to it, they hang on, they bargain. That is very understandable and very human’; then finally, and here touching on his values, that he had no wish for, ‘anything beyond what is my capacity to be fully alive’.

For the majority, euthanasia was preferable to continuing to live if ‘brain dead’ or in a vegetative state, by which they mostly meant if seriously and irretrievably paralysed. Three referred to British physicist Stephen Hawking, who lived most of his adult life severely paralysed from motor neurone disease, saying that they had no wish to live as he had done. In every case, the end-of-life decision to ‘pull the plug’, ‘turn me off’ or ‘pump up the morphine’ was vaguely left to an unspecified other, the details of which could presumably change if and when the men completed an advance care plan.

It is worth noting that this general wish, expressed by the majority, to avoid a ‘vegetative’ existence tended to overlook the slow decline of ordinary old age when bodily functions gradually cease and people die of old age, the fact of which was strongly emphasized when the death certificate was released of the former Queen Elizabeth II showing that she died of ‘old age’.<sup>18</sup> While participants’ mention of dementia and bodily dignity touched on the slow decline, they were generally more focussed on death as the result of something dramatic or violent, such as an accident or a stroke, rather than simple old age, about which German sociologist Norbert Elias had the following to say:

Many people die gradually; they grow infirm, they age. The last hours are important, of course. But often the parting begins much earlier. Their frailty is often enough to sever the ageing from the living. Their decline isolates them. They may grow less sociable, their feelings less warm, without their need for people being extinguished.<sup>19</sup>

For those who decided not to make an advance care plan and instead proposed to rely on an enduring power of attorney, it is possible that ‘pulling the plug’ or ‘pumping up the morphine’ would be a qualitative decision left to their attorney and possibly in consultation with medical or hospital staff. As a footnote, a number said that they approved of euthanasia but only as long as it was an individual’s personal decision and not made by relatives because they were eager to prematurely inherit the assets of the dying person or by the state.

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18 ‘Queen Elizabeth II’s death certificate says the monarch died of “old age”’, Australian Broadcasting Corporation, <https://www.abc.net.au/news/2022-09-30/death-certificate-of-queen-elizabeth-ii-released/101489296> accessed 30 September 2022.

19 Elias *The Loneliness*, p. 2.

Participants' views on euthanasia that were discussed in this short section are examined in more detail in Chapter 4: Euthanasia and Afterlife Beliefs. The data on euthanasia that were used in Chapter 4 came from the penultimate question in the interview schedule – when participants were asked what thoughts they had about their physical end of life and were prompted to speak about euthanasia and the afterlife – whereas those here were revealed when participants explained their thoughts on the instructional directive.<sup>20</sup>

#### *Do Not Resuscitate*

Those who spoke in favour of instructing hospital staff not to resuscitate them seemed to be expressing a preference for involuntary euthanasia, without actually using the term. Two men in their mid-70s joked about having the acronym, 'DNR' tattooed on their chest; another said that do not resuscitate so that he could 'rather just go' would be preferable to being 'put on a breathing machine'; and a fourth rationalized his choice as follows:

I guess I frame it this way these days . . . that we would not let a dog or a cat suffer; we would put them down. But for human beings, we seem to suddenly revert to different values and keep them alive at whatever cost, however horrible that existence might be for that person. (Gideon, aged 70, New South Wales)

Those who cited do not resuscitate did so in response to the example provided in the preliminary material that they were sent, namely, in the context of 'a catastrophic medical event which did not kill them but left them with no realistic prospect of a decent recovery'. And they often did so together with a wish that they would receive comfort care and pain relief to ease their dying.

#### *Comfort Care and Pain Relief*

Those in couple relationships who preferred comfort care and pain relief emphasized that they had already discussed these decisions with their partners and that both they and their partner were agreed on the course of action at end of life. 'Where there is not a reasonable prospect of recovering an acceptable quality of life', said Wade, aged 65, from England:

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<sup>20</sup> For interview schedule, see Appendix 1.

And both of us as partners would know what that was for each other, we would not seek for anything beyond keeping the person comfortable and pain free. Any care beyond that would be superfluous, if that stage is reached, so no antibiotics if someone gets pneumonia, no blood transfusions, nothing that is going to be intrusive.

Reasons for choosing comfort care and pain relief included a philosophical wish to avoid life prolonging treatment and a visceral desire to avoid a painful death, both of which can be seen in these extracts from two interviews.

Where someone is totally incapacitated and their life is one of survival but it needn't be, and they feel that they are at the end and they are willing to face the end . . . if that's the situation I am in, and there is no practical, physical option, other than just mechanical perpetuation, then I would rather just be allowed to die. (Ellis, aged 56, England)

I don't want to be kept on life support . . . I don't want to splutter to death in agony. But I'm perfectly reconciled to being mortal. I've had a wonderful life, I don't want to die tomorrow, but I don't mind death. Like most people, dying is more of a problem than death. I've never had a fear of death. (Kieran, aged 67, England)

### *Friends to Decide*

A small group said that they would prefer to leave to friends, partners or family members decisions about how their life would be ended. Aware of the weight of such a responsibility, some said that they would leave the decision to friends because they trusted their friends, partners or family members and because they themselves could not face having to make the decision or, in the case of men in couple relationships, because both partners were agreed on a mutual course of action, such as, for example, in the case of Toby, aged 64, from British Columbia and his partner:

We have had multiple conversations. We have shared the documents. We have had a chance to talk about this together and it so happens that we are very similar in our desires . . . and even if I had not written something I would be fairly confident that he would be able to represent me.

Underlying the views expressed here was the common assumption that friends or partners would decide how participants' lives would be ended only when they themselves had lost capacity: 'I would be quite happy to outsource that decision to my partner . . . in the circumstance that I had no hope of regaining function or sentience' (Damien, aged 40, ACT).

Associated with this assumption was an awareness of the dilemma all faced who wished friends, partners or family members to make the end-of-life decision for them, which was how to convey when exactly their life ceased to be worth living or as Harvey (aged 74) explained:

If I lose cognitive function, do I know that I have lost cognitive function? And that is the problem. Somebody else has to be involved in that. I wish there were some way that I could help them from where I am now, but I don't see how I can. I don't see how I can anticipate that event in such a way as to relieve my sisters from having to watch me lose my mind.

Edward (aged 77) captured the practical nature of the dilemma as follows:

At what point do you say, "If I've gone blind, is this the point? And at what point of being blind?" ... Or when I can't work the remote control of the television? But everybody said, "I can't do that now!" ... The person you've made your ... [decision maker] does need some guidance in all of this, otherwise they may think, "Am I doing this too soon or have I waited too long?" But how do you then quantify this? Some people might say it is when I become incontinent or more likely when I can't control my bowels. It becomes those sorts of things, at those moments at which you say once that happens this is the time to tell them, "No more".

A third participant addressed the dilemma similarly but slightly differently:

If it were a series of check boxes, so that in 2021, Donovan said that there were six things he valued in life, how many of them would have to disappear before he would consider the life [that] he is currently living to be no longer worthwhile? The things in life he valued: if he no longer possessed them, does that change his view about end of life and whether it's time to switch him off? I can't really answer that. It's an interesting question that I am going to ruminate over. I am not going to fixate or become obsessed but I found it unusually difficult to answer in a genuinely thoughtful and deep way. (Donovan, aged 55, England)

A man in his 70s thought that he had something approaching a solution of the problem that Harvey, Edward and Donovan outlined above: 'If you trust that person's judgement, then I'm happy to have that person assess the situation, remember what I was like and what I said at the time and take the decision for me if I'm mentally incapacitated' (Emmett, aged 70, England). Trust between two people would seem to lie at the heart of the matter, that is, at the practicability of the advance care directive as a guide for the decision maker who must implement the dying person's wishes.

Those with partners of long standing seemed confident that their partners could be trusted to make the life-and-death decision on their behalf.

I would feel very comfortable about deferring to [partner's] judgement if I was not in a position to exercise my judgement at the relevant time. My preference is for him to exercise judgement at the relevant time rather than my exercising a speculative judgement way ahead of the time based on incomplete information. (Carter, aged 57, New Zealand)

Carter used the phrase, 'speculative judgement' to explain why at the time of interview, or any time before the approach of his demise, he refused to specify what type of decision(s) he would want his partner to take in order to bring his life to an end if he lost capacity – on the grounds that he could not know in advance how medical technology and life-extending capacity would develop between now and then or how he would feel about end of life then. What was central also to Carter's thinking, which other men in couple relationships shared, was that he trusted his partner to know what was appropriate when the time came to bring his life to an end.

Those who expressed a wish for a friend, partner or family member to decide how to end their life when discussing their advance care directives seemed to be suggesting that an enduring power of attorney (medical) would suit their purpose but because of the overlapping and apparent similar purpose of the two instruments, an uncorrected misunderstanding occurred in some interviews where the author might not have made sufficiently clear the distinction between them. As mentioned in the introduction, the two instruments could be seen as similar, but they are not.

### Values Directive

As mentioned, participants were provided with preliminary material to assist them answering a question on advance care directive. The fairly general advice that they received on the values directive was:

the person provides details on what about being a human being and alive is important to them, e.g., being mobile, able to communicate with other human beings in a meaningful way or to go on living no matter what their circumstances.<sup>21</sup>

Because of this advice, it was not altogether surprising that narratives addressing communications and mobility concerns strongly featured in the responses. Slightly more than half the sample referred to dignity of their body, which included mobility, and slightly less than half referred to sentience, referring in this case to the ability to communicate with and understand others.

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21 See Appendix 1.

Three principal narratives were revealed when participants spoke to the values that would inform their advance care directive. These were altruism, dignity, and sentience. Altruism was expressed firstly as the wish to avoid being or creating a *burden* for anyone else and secondly as a wish to avoid any excessive use of *resources* to keep them alive. Dignity referred to participants' wish firstly for their *body* to be treated with dignity – including a preference for mobility, minimal pain and loss of bodily functions, as well as the desire not to have to exist in a 'vegetative' state – and secondly for their *death* to occur with dignity. The third principal narrative was sentience and this referred to a desire to die where possible with the use of all their senses, that is, to die having sight, hearing, and speech and thus be able to communicate and understand before the final moment. The narratives are examined in order in the following section.

#### *Altruism: No Burden*

Wishing to avoid being a burden on others was a focus of the values directive of six participants, who were aged from their early-40s to mid-70s. All used the terms burden, burdensome or the phrase 'being a drag' in expressing this altruistic wish. Harvey, aged 74 said: 'When I feel like I am being a drag on other people, then I don't want to be here', while Ellis (aged 56) explained that in his view any decision to prolong life should depend on the age of the person, the extent of their injuries, as well as to what extent it would burden others:

Because [of] the expense and the burden emotionally and practically on those around you, I am not sure . . . [medical intervention] is worth it. For someone younger or if their mind is active, and they are energetic and they feel that they have the energy and passion to continue living, if that is the case, that is great, and there is the possibility of them being enabled to live an extended life, then I am all for that. But in the circumstances . . . if I am . . . [totally incapacitated] and there is no practical, physical option, other than just mechanical perpetuation, then I would rather just be allowed to die.

Two men in their 40s, both in long-term relationships considered the possible effect on their partner if they were severely incapacitated and needed high-level care. Declan, aged 42, said: 'I do not want to be a burden on somebody else. I do not want their life to be compromised because they have to take care of mine'. And Damon, aged 40, expressed a similar sentiment in the context of what he regarded as quality of life:

I would not want to be in some sort of vegetative state where there was a lot of care needing to be applied because that's not quality of life for me and it

is not quality of life for anyone else either. I am a bit pragmatic like that you know, if there is no quality of life there.

*Altruism: Use of Resources*

When providing well considered reasons for not prolonging their lives if there were little chance of recovery after an incapacitating event, two intellectuals with backgrounds in the Humanities raised the matter of unnecessary use of finite resources. Edward (aged 77) made a connection between the resources that he now required and those which could be required to keep him on life support, arguing that he would not feel entitled to make use of them.

I can convince myself at the moment that I am some use for the amount of resources I use up in the world but if I were laid up in a hospital bed just sucking in more and more medical care and I wasn't ever going to go anywhere, I wouldn't feel entitled to take that around my time of life. If you were 40 or something, you ... [could think] you might come through the other end and this is a downhill slide and you might come out of it but ... we know all the medical expenses are in the last 18 months of life and ... I would not want to use that up.

Carter (aged 57) expanded on the idea of the resources that would be needed to keep him alive on life support, saying that it would be wasteful in his view and included also a strong altruistic wish not to burden his family.

If I were in a vegetative state, I would be indifferent to that at the time. I would be an emotional burden on my family and an environmental burden on the planet and a logistical burden on the health system where there would be many other needs greater than mine as you have described it. I would want those burdens to stop and my family to be able to make the necessary decisions and emotional adjustments and move on as quickly as possible.

*Dignity: Body*

More than half the sample expressed a wish to end their life with dignity, by which most meant that they had no desire to do so immobilized or in a 'vegetative' state or that they preferred to have the use of their faculties and senses to the very end. A small number referred to a more private dignity, that is, being able to perform their own personal care. As mentioned in the section above on euthanasia, many of those interviewed for this research tended to

focus on death as something dramatic – preceded by months, days or hours in a vegetative state – rather than the result of old age, which can be long and drawn out.

The possibility of being immobilized at the end of life raised quite visceral fears. For example, Clive (aged 81) said: ‘there is nothing dignified about being kept alive when you are just a sausage sort of thing’; while, according to Ellis (aged 56), he would, ‘rather just be allowed to die’, if there were, ‘no practical, physical option other than just mechanical perpetuation’. Others, meanwhile, distinguished between levels of physical disability:

If I was totally incapacitated and not able to make my own decisions . . . [that is] if I am hooked up to tubes and everything and I need a machine to help me breathe and that kind of stuff, then basically I am just a vegetable, then I wouldn’t want that kind of life. (Eric, aged 57, Hong Kong)

If I were a quadriplegic and fully paralysed, I don’t think that is quality of life that I would want to have to endure. If I lost a limb, it wouldn’t bother me, I would keep going, I would be quite fine in some ways. (Christopher, aged 52, New South Wales)

On the matter of personal care, views tended to focus on participants’ capacity to attend to their own toileting, as illustrated in these representative extracts from two interviews:

If it gets to the point when you cannot even feed yourself, when you cannot even go to the toilet, you have got to have somebody wipe your bum, I think it is demeaning. I do not want to be in that state. (Fabian, aged 74, ACT)

If you have an inability to toilet yourself, that to me is pretty grim. I . . . [understand] that there are many elderly people who need assistance and they are perfectly happy with that. Maybe I would be too at that stage . . . but sitting here now, that would not be . . . a tolerable quality of life. (Damon, aged 40, ACT)

### *Dignity: Dying and Death*

Slightly less than a quarter of the sample were concerned about the quality of their end of life. Because ‘death with dignity’ is now a widely used euphemism for euthanasia, the phrase can no longer be used in any other way, but it is precisely what participants meant when they said that a ‘vegetative’ state was not ‘quality of life’, as in the case of Fabian, aged 74, who maintained that:

Quality of life sums it up, as I see it. When you see people living in a vegetative state, there is no quality of life. It is almost cruel . . . It is quality of life as opposed to a vegetative state where you cannot do anything, you cannot look after yourself. I do not want to get to that point.

And also, in the case of Nicholas (aged 72) who used tender, humorous examples to describe what quality of life meant to him and why, because he believed in the ‘natural life’ of things including human life, ‘life at any cost’ was not a choice that he would make:

If I cannot be of any use to anybody, if I cannot boss my partner around and have a good time and feel his embraces, if I cannot cook food, what is the purpose of being human? . . . I don’t believe in the unnatural prolongation of life. Everything has a natural life. A piece of music has a natural life and structure to it.

### *Sentience*

The value of sentience was evident in the accounts of those who cited a strong preference for functioning comprehension and communication faculties until the end of life. This was often discussed in reference to the sociability which comprehension and communication enabled as well as the philosophical acknowledgement of the self as a cognitively functioning being.

Among those who cherished their cognitive functions were two men in their 70s and one in his 50s. As well, there is an extract from a participant who was in his 40s and whose account very nicely emphasizes the sociability of communications:

It would probably be cognitive functions because I read all the time. That would certainly be a big blow . . . But everybody I know in my family kept their marbles. My mother, father, aunts and uncles, all of them, they all kept their marbles. I think that is the important thing . . . Fortunately, I spend a lot of time alone and I don’t mind being alone. I have learned how to have a cat and I love my cat. And it’s all good. My friends are the same way. They have lives and they interact with other people. (Harvey, aged 74, North Carolina)

I have had a great life but I do not want it to end where I am sitting in a room, gaga, staring at four walls with no comprehension or understanding, not recognising people. That is not good. Three of my grandparents all lived to a good old age and all basically did have their wits about them. My grandmother was blind but walk into a room and say, “Hello,” and she

knew exactly who you were and she was spot on, sharp as a tack and lived to 93. That is my way of looking at it. (Fabian, aged 74, ACT)

Yes, the loss of cognitive ability, [that is] full ability, not just sight or hearing. We're talking about the ability to understand and comprehend and recognize people. Recognition and [being able to] understand that that is your dear friend or . . . [relative]; the loss of that and no ability to make a connection . . . [would be] an issue. (Damien, aged 52, England)

I would want to communicate . . . Being able to communicate means having people I care about near me and people who to some extent care about me. If I did not think anybody cared about me, I think I would find that quite difficult. (Aiden, aged 42, England)

As mentioned in previous sections, quite a few mentioned the painful dilemma of dementia, which can mean a seemingly trouble-free life for the person with dementia but a less enjoyable experience for friends or family looking on.

## POWER OF ATTORNEY

As mentioned, participants' decisions and views on power of attorney were included in this research because in some jurisdictions a donor can appoint a power of attorney to look after their health care and another to look after their financial affairs if they lose capacity. A brief summary follows. In Canada, power of attorney was specifically to provide authority for another person to manage someone's 'money and property'.<sup>22</sup> By comparison, and in line with practice in most other jurisdictions covered in this book, California had a power of attorney allowing an agent to manage a person's financial affairs and a medical power of attorney for management of their health care if they lose capacity.<sup>23</sup> And so did England and Wales, where there were two types of lasting power of attorney: one for property and financial affairs and another for health and welfare (different processes apply in Northern Ireland and Scotland).<sup>24</sup>

In New Zealand, the term enduring power of attorney (EPA) was used for a person to manage the financial affairs of someone who no longer has capacity

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22 For Canada, see: <https://www.canada.ca/en/financial-consumer-agency/services/estate-planning/giving-power-attorney.html> accessed 17 January 2023.

23 For California, see: <https://californiamobility.com/the-4-types-of-powers-of-attorney-in-california/> accessed 17 January 2023.

24 For England and Wales, see: <https://www.gov.uk/power-of-attorney> accessed 17 January 2023.

and was known as a property EPA; another for health care was known as a personal care and welfare EPA.<sup>25</sup> Power of attorney in the North Carolina was available for a variety of circumstances including to act and look after another person's financial, medical or other personal affairs when they did not have capacity. Among different types was the durable (statutory) power of attorney which is used to appoint someone to look after a person's financial affairs including after incapacitation and medical power of attorney giving an agent power to act on a person's behalf when they themselves are unable to do so.<sup>26</sup> Meanwhile in the Australian state of Victoria, a general enduring power of attorney existed for financial decisions and from 2016 the role of medical treatment decision maker who had quite strong powers to act in the interests of the donor: 'If a medical treatment decision maker consents to treatment, a health practitioner may proceed with that treatment. If the medical treatment decision maker refuses treatment, a health practitioner cannot provide that treatment'.<sup>27</sup>

All participants answered the same question on power of attorney: 'Have you appointed a power of attorney and who did you choose and why?' Whereas the majority did not have an advance care plan, a much smaller number (less than a third) had not appointed a power of attorney. One probable reason for the much lower use of advance care is that it is a relatively new end-of-life instrument. And whereas the question concerning the advance care directive evoked quite detailed answers, the question concerning power of attorney tended to evoke relatively short answers, and possibly for three reasons.

Firstly, its focus was on the person chosen to be the participant's attorney and why they were appointed, secondly because the definition and meaning of advance care were given special attention in the preliminary material sent out prior to interview, and thirdly because power of attorney is a legally binding document. The focus then of this section is on which person participants chose to be their attorney – partner, professional person, relative, friend – and why they chose them, and, where appropriate, what if any details they provided about the sort of health care they would like their attorney to ensure that they received at end of life.

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25 For New Zealand, see: <https://officeforseniors.govt.nz/our-work/promoting-enduring-power-of-attorney/how-to-create-an-enduring-power-of-attorney/> accessed 17 January 2023.

26 For North Carolina, see: <https://eforms.com/power-of-attorney/nc/> accessed 16 January 2023.

27 For Victoria, see: <https://www.health.vic.gov.au/patient-care/medical-treatment-planning-and-decisions-act-2016> accessed 17 January 2023.

Thirty-five participants had written wills and most had appointed attorneys. In a small group with wills who had not appointed attorneys was Quinn, aged 60. In this extract from his interview, he explained why, like some others, he felt it was too early to appoint an attorney and that, because he and his now deceased partner had lived a sheltered life, he had almost no friends from whom to choose if he wanted to appoint one:

Because I think at the moment, I'm completely compos. I don't have any issues with my memory or any of those issues. And still being 60, I don't think I'm that old that I need to . . . Maybe in the future, I will look at that again and see what happens, see how I feel. *If you decide to appoint an attorney, who would you choose?* I haven't got any ideas. That's probably another reason why I haven't done it. I just don't know who I would get to do it . . . [because] as I said, when we lived together . . . we really didn't have a circle of friends that we used to go out and socialise with. There was just us.

Of those who had a will and had appointed an attorney, slightly less than half chose their partner or spouse, five chose a professional person (lawyer or accountant), three a friend, and three their niece or nephew.<sup>28</sup> Among those without a will – and who had therefore not appointed an attorney – the preference was roughly similar: the majority thought that they would appoint their partner or spouse and the minority a family member. When explaining their choice of attorney, interviewees drew on three principal narratives: knowledge and trust; age and authority; and geographical proximity; and these are discussed in order.

### Knowledge and Trust

People whom the majority of participants appointed or would appoint as their attorney were chosen because of their close personal knowledge of the testator and because they were trusted, a similar preference for including friends as decision makers in advanced care instructions (above). Most often they were the partner and occasionally a sibling or a good friend, which, according to Eric (aged 57) who had appointed his partner, 'just seemed the natural thing to do':

If you look at a husband and wife, a man and a woman, you would naturally give your wife or your husband the decision making to do it on your behalf, right?

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28 See Appendix 2 for details of attorneys appointed.

Quite a few in couple relationships had mutual arrangements where, like Eric, they appointed each other as their attorney. Wade (aged 66) observed that, while this was common in heterosexual and homosexual couple relationships, it had an inherent flaw:

If we were in a situation where we were both in the same accident and both unconscious and unable to act in our own interests then we are stuffed, I think. I don't think there is anybody else we have nominated. We have powers of attorney for both those areas and they are both mutual.

Both single men and those in couple relationships emphasized trust as their reason for choice of attorney. Christopher (aged 52) said that he would appoint his cousin: 'Based on some of the medical things that have happened to me ... [she] would be the best one. She's very good. She's quite an astute and particular person'. Meanwhile, Harrison (aged 56) had decided on his husband, also for reasons of trust, which he explained in some detail as follows:

Because we have had those honest and frank conversations about what should happen, should I be incapacitated in any way, he has a very clear understanding about what my wishes would be. And again, I trust him to follow my wishes, as opposed to appointing either a sibling or my children because their judgement would be clouded by our relationship and they will follow their emotional views instead of my wishes.

Harrison had children from his first marriage to a woman and his decision concerning who to appoint as his attorney was considered, and included why, given the nature of his relationship with his children, the choice of his husband was both more practicable and responsible.

Those who had chosen or would choose a friend tended to understand trust slightly differently than the men whose choice was their partner, namely, they judged that they could trust them to do a good job because they were practical and well organized. Preston (aged 70): 'He is a very practical person. He is not gay ... [and] I have a good friendship with him and thought that he would be a suitable person'. And Aiden (aged 42) also emphasized the practicality of the friend whom he planned to appoint: 'It is the sort of thing he would do very diligently, very calmly, and would be quite good at it. He is quite an organized person like that'.

### Age and Authority

Some participants chose or intended to choose attorneys because they were a generation younger or because they had sufficient authority, in the words of

Edward (aged 77) to, ‘stand over the medical profession’. His previous experience of a serious health condition influenced Edward’s approach to end-of-life planning:

When I got the diagnosis from the oncologist, which was the important interview and the explanation of what was happening, I knew from previous discussions I’d had with other doctors leading up to that, that I needed somebody else in the room with me. If it was good news, I wouldn’t hear it properly. If it was bad news, I wouldn’t hear properly either. And I needed someone else who would listen to what was being said properly on both ends and ask the questions that I would have asked had it not been about me . . . [Name of friend] is a trained lawyer although that is not what he does. He just asked and the oncologist was more than happy to answer the questions. He didn’t think he was being put out but you do need somebody who will be there to do that for you.

From his experience and his belief in the need to speak up to the medical profession, Edward said that he needed someone to be his attorney who was both ‘bloody minded’ and younger:

I have got to think of somebody who’s now 40! If, by some terrible chance, I live to be 92 or something, that’s another 15 years. A lot of people die in 15 years . . . [or] they become not capable of doing all the hard things you have to do. It becomes too much for them. You have got to think of somebody who is that much younger.

Emmett, also in his 70s, was aware from word of mouth of the potential difficulties arising in a hospital setting.

Friends we were talking to, who are a couple of weeks ahead of us in this process, they told us that their lawyer said that, even when you are civil-partnered or married, you do need to have somebody with power of attorney . . . Because the hospital won’t necessarily take just the word of your spouse or civil partner, you need to appoint . . . [an attorney] and I gather that you can appoint your partner formally to have a power of attorney . . . so that you give the partner an extra layer of authority . . . Apparently, the health service in England won’t necessarily accept your partner’s view that you should be switched off if you’re seriously ill, so I think we probably will do that. And, if we can appoint each other, we will appoint each other to the medical one probably.

The situation that Emmett described was similar to what many gay men faced during the HIV-AIDS epidemic when partners were passed over and the dying man’s parents had final say about his end of life. Whether it is still the case in the 2020s in the health service in England (and perhaps elsewhere) is conjecture but one that was powerful enough in the case of Emmett and his

partner to influence decisions that they were planning to make in choice of attorney.

### Geographical Proximity

A reliable friend or family member who lived nearby was in the view of some a desirable quality when deciding on who to appoint as their attorney. Californian Seth (aged 68) was pleased because the person he wanted was, ‘a long-term friend who is a couple of years younger than me and lives close by’. Meanwhile, for Ellis (aged 56) the geographical distance from family made choosing an attorney difficult: ‘I don’t live close enough to my blood relatives of the next generation for it to be something to reasonably expect them to do’.

## CONCLUSION

In relation to advance care, it was notable that only a small number had completed a plan or its equivalent or were aware of its existence prior to interview and secondly that, of those who were aware of advance care, only a handful had a clear idea of the sort of instructions that they would need on hand and to put into effect if they wanted to avoid a painful or prolonged illness with little hope of recovery. By contrast, a relatively large number – of slightly more than two thirds of the sample – had appointed an attorney and while the chief reasons given for choice of attorney was that the person was knowledgeable and trusted or young and able to speak with authority, the majority of participants chose their partner or spouse and only a minority a family member, thus reversing the trend that was revealed in the previous chapter of privileging family members over friends as end-of-life decision-makers.

When discussing advance-care arrangements or power-of-attorney appointments, participants often said how they hoped that they would be able to experience a ‘good death’ or at least avoid the opposite, that is, a death that was drawn out, excessively painful, undignified, what French historian Philippe Ariès called the ‘dirty death’.<sup>29</sup> The sort of death that they hoped for was one where they avoided dying in pain, being ‘brain dead’ or relying on a breathing machine, where treatment was prolonged or in the words of one a form of ‘mechanical perpetuation’. Bodily dignity was important, which meant

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29 Ariès, P. (1991) *The Hour of Our Death*, trans. H. Weaver (New York: Oxford University Press), pp. 568–70.

being able to perform their own personal care and not living on in an immobilized state. Being able to avoid total incapacitation or loss of comprehension was important also for those who wished for a good death.

To guard against the distress of the dirty death, both Ariès and Elias observed that the hospital had become the common site for death and that for that reason it was often a lonely experience. 'In the intensive care unit of a modern hospital, dying people can be cared for in accordance with the latest bio-physical specialist knowledge, but often neutrally as regards feeling; they may die in total isolation'.<sup>30</sup> In answer to the question on which many participants reflected, that is, How likely was a good or easy death? Sherwin Nuland argued that, while a good death was to be hoped for, 'by and large, dying is a messy business'.<sup>31</sup>

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Elias, N. (1987) *The Loneliness of the Dying*, trans. E. Jephcott (Oxford: Basil Blackwell).

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30 Elias *The Loneliness*, p. 88.

31 Nuland, S.B. (2014) *How We Die: Reflections on Life's Final Chapter* with a Foreword by P. Kalanithi (London: Penguin Random House), p. 142.

- End of Life Care Planning, California: <https://oag.ca.gov/consumers/general/care>
- Incapacity Planning, British Columbia: <https://www2.gov.bc.ca/gov/content/health/managing-your-health/incapacity-planning>
- Lasting Power of Attorney, England and Wales: <https://www.gov.uk/power-of-attorney>
- Medical Treatment and Planning Act 2016, Government of Victoria: <https://www.health.vic.gov.au/patient-care/medical-treatment-planning-and-decisions-act-2016>
- North Carolina Power of Attorney: <https://eforms.com/power-of-attorney/nc/>
- Nuland, S.B. (2014) *How We Die: Reflections on Life's Final Chapter* with a Foreword by P. Kalanithi (London: Penguin Random House).
- Power of Attorney, Canada: <https://www.canada.ca/en/financial-consumer-agency/services/estate-planning/giving-power-attorney.html>
- Powers of Attorney, California: <https://californiamobility.com/the-4-types-of-powers-of-attorney-in-california/>
- PrEP Health: [https://prep.health/just-4-steps-to-prep/?hsa\\_acc=9714106491&hsa\\_cam=13056338330&hsa\\_grp=121758021763&hsa\\_ad=527042198782&hsa\\_src=s&hsa\\_tgt=kwd-301285988868&hsa\\_kw=prep+prescription&hsa\\_mt=b&hsa\\_net=adwords&hsa\\_ver=3](https://prep.health/just-4-steps-to-prep/?hsa_acc=9714106491&hsa_cam=13056338330&hsa_grp=121758021763&hsa_ad=527042198782&hsa_src=s&hsa_tgt=kwd-301285988868&hsa_kw=prep+prescription&hsa_mt=b&hsa_net=adwords&hsa_ver=3)
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- Taylor, J. (2021) *The Guardian*, <https://www.theguardian.com/society/2021/jul/02/gamechanger-hiv-transmission-dropped-90-for-men-taking-prep-australian-study-finds>

## 4

# EUTHANASIA AND AFTERLIFE BELIEFS

The practice of assisted dying – helping someone take their own life at their request – is regulated in Switzerland and permitted if offered without a selfish motive to a person with decision-making capacity to end their own suffering.<sup>1</sup>

There is no notion, however bizarre, in which people are not prepared to believe with profound devotion, provided it gives them relief from the knowledge that one day they will not exist, provided it gives them hope in an eternal existence.<sup>2</sup>

## INTRODUCTION

This introduction begins with a general outline of euthanasia beliefs and practices and then briefly sketches the afterlife beliefs of the four principal religious traditions, namely, Buddhism, Christianity, Hinduism and Islam. A brief recapitulation follows of the ‘good death’ argument from Chapter 3 and any connections between the notion of the good death that participants raised when speaking about their advance care or power of attorney and then made again when discussing their views on euthanasia in this chapter. Following the Introduction, the chapter has two principal sections. The first section comprises an analysis of participants’ views on euthanasia and the second examines their afterlife beliefs.

Euthanasia and afterlife beliefs are combined in one chapter because in the penultimate interview question, participants were asked if they had any

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1 Chrisafis, A. (2022) ‘Jean-Luc Goddard chose to end life through assisted dying, lawyer confirms’, *The Guardian*, <https://www.theguardian.com/film/2022/sep/13/jean-luc-goddard-chose-to-end-life-through-assisted-dying-lawyer-confirms> accessed 16 September 2022.

2 Elias, N. (1987) *The Loneliness of the Dying*, trans E. Jephcott (Oxford: Basil Blackwell), p. 6.

final thoughts about their physical end of life and were prompted to discuss their views on euthanasia and the afterlife. I mention this here in case any reader wonders why consideration of participants' afterlife beliefs precedes the next chapter with its focus on their funeral plans, as funerals normally have to take place before there is any chance of proceeding to an afterlife.

### Euthanasia

Euthanasia is one of a number of terms used to describe the practice of prematurely bringing about the end of a person's life. Recent scholarly work distinguished between voluntary euthanasia, that is, when a person's life is ended at their request and involuntary euthanasia, which is when their life is ended without their consent or wish.<sup>3</sup> The most obvious example of involuntary euthanasia was the Nazi euthanasia programme in World War II (more below).

Other terms used to describe practices similar to euthanasia include 'assisted dying', which is also known as assisted suicide and can take place with or without the aid of a medical practitioner, as well as the phrase, 'dying with dignity'.<sup>4</sup> The phrase, 'withdrawal of treatment', while not always regarded as euthanasia, is similar and often takes place in intensive-care units. Withdrawal of treatment occurs when machines supporting life are switched off and the person receives no other form of life-supporting treatment.<sup>5</sup>

Assisted suicide is controversial and opposed by those who argue that it can be confused with dying with dignity or because it is often proposed by others who believe that the right to end one's life should not be limited only to those who are at the end of their life.<sup>6</sup> Another unstated reason for opposing assisted suicide might be the existence of the organization known as Dignitas, which has operated in Switzerland since the late 1990s, provides fee-based assisted

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3 Westwood, S. (2022) 'Introducing "Regulating the End of Life: Death Rights"' in S. Westwood (ed.) *Regulating the End of Life: Death Rights* (Milton Park: Routledge), pp. 2–3.

4 See, for example, these websites with details of dying with dignity in Tasmania: <https://www.dwdtas.org.au/> accessed 6 October 2022; and the campaign for assisted dying for the terminally ill in Britain: <https://www.dignityindying.org.uk/> accessed 6 October 2022.

5 Eschun, G.M., et.al. (1999) 'Ethical and Practical Considerations of Withdrawal of Treatment in the Intensive Care Unit' in *Canadian Journal of Anesthesia*, 46: 497–504: <https://doi.org/10.1007/BF03012952> accessed 6 October 2022.

6 The following website for the British 'Dying in Dignity Campaign' includes arguments against assisted suicide and including it in any legislation to legalize dying with dignity: <https://www.dignityindying.org.uk/> accessed 6 October 2022.

dying and since 1998 has helped more than 1,000 people die.<sup>7</sup> The argument that the right to die should *not* be restricted only to the end of life was raised by two participants (Edward, aged 77, Australian Capital Territory; Scott, aged 62, Australian Capital Territory) who believed that individuals had the right to choose the time of their death with or without the approval of the medical profession.<sup>8</sup> Their views are examined in more detail below.

As the hospital has been for some time now the fairly usual setting for death,<sup>9</sup> and therefore also for the practice of euthanasia, a brief account follows of how it is understood by some Australian, British and North American medical researchers. In a 2020 study of British laypersons' attitudes to sedation and euthanasia, a distinction was made between death from terminal anaesthesia, which was referred to as continuous deep sedation (or being kept continuously unconscious), and death from the administration of medication, that is, 'physician-assisted dying'. In their opening paragraph, the authors noted:

The use of sedation in end-of-life care . . . remains controversial. While gradual sedation to alleviate intractable suffering is generally accepted, there is more opposition towards deliberate and rapid sedation to unconsciousness (so-called 'terminal anaesthesia' . . .).

Their research was possibly conducted in the context of the double-effect principle, the meaning of which is that medical practitioners should avoid administering patients with medication to ease pain and suffering if the intention is bring about their death.<sup>10</sup> The researchers seemed therefore to be exploring how laypersons regarded terminal anaesthesia in the context of what they claimed was a general acceptance of gradual sedation.<sup>11</sup>

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7 Gentleman, A. (2009) 'Inside the Dignitas House', *The Guardian*, <https://www.theguardian.com/society/2009/nov/18/assisted-suicide-dignitas-house> accessed 11 January 2023.

8 For discussion of these and similar right-to-die arguments, see: Westwood, S. (2017) 'Older Lesbians, Gay Men and the "Right to Die" Debate: "I Always Keep a Lethal Dose of Something, Because I don't Want to Become an Elderly Isolated Person"' in *Social & Legal Studies*, 26(5): 606–628.

9 Ariès, P. (1975) *Western Attitudes toward Death: from the Middle Ages to the Present*, trans. P. Ranum (Baltimore: The Johns Hopkins University Press), pp. 87–89; Ariès argued that the hospital as the common site for death accelerated between 1930 and 1950.

10 Patterson, J.R. (1998) 'The Rule of Double Effect' in *The New England Journal of Medicine*, 338(19): 1389.

11 Takla, A. et.al. (2021) 'British laypeople's attitudes towards gradual sedation, sedation to unconsciousness and euthanasia at end of life', *PLoS ONE* 16(3): e0247193. <https://doi.org/10.1371/journal.pone.0247193> accessed 4 October 2022.

Sedation and how it is used is a sensitive topic for the medical profession, other health professionals and the public, touching as it does on the double-effect rule and the intentions of medical practitioners when administering sedatives to people in pain at the end of life. A 2018 article distinguished between three types of sedative use: double-effect sedation; parsimonious direct sedation; and sedation to unconsciousness and death. The author argued against sedation to unconsciousness and death – which it could be argued the layperson might have difficulty distinguish from terminal unconsciousness – because it was simply another form of euthanasia, which is illegal in many states of the USA: ‘sedation to unconsciousness and death, in which the clinician’s aim is total unconsciousness, is not justified by the rule of double effect and only seems justifiable if euthanasia is justifiable’.<sup>12</sup>

The distinction that was made in the 2020 study of British layperson’s attitudes to sedation and euthanasia helped in clarifying a definition for euthanasia. Its authors appeared to explicitly understand physician-assisted dying to be euthanasia and terminal anaesthesia to be something else entirely. In their view, perhaps euthanasia was seen to occur when with consent medical practitioners actively intervened to hasten or bring on death and that death that occurred as a result of terminal anaesthesia was not euthanasia or could not yet be included in the definition of euthanasia.

Euthanasia has a controversial history, not least because its practice challenges the central belief of the Judeo-Christian tradition, which is the sanctity of human life. Because it is seen as a gift from God, taking a life is forbidden and severely punished. In the eyes of many believers, euthanasia is still a form of murder.

From . . . [Christianity’s] earliest days . . . Christian theologians asserted that no human being had the right to dispose of life as he or she pleased – only God could decide for death. This belief was elaborated in Church law during the Renaissance, when moral horror at suicide joined prohibitions against infanticide, abortion and contraception; later, capital punishment joined the list. All came to seem the same crime, that of judging when life should end.<sup>13</sup>

Arguments against the legalization of euthanasia included that it was opposed by or caused guilt in medical practitioners, would put pressure on the elderly who were not ill to consent to ‘rational suicide’ as an end-of-life option

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12 Sulmasy, D.P. (2018) ‘The last low whispers of our dead: when is it ethically justifiable to render a patient unconscious until death?’ in *Theoretical Medicine and Bioethics*, 39: 234, 260.

13 Sennett, R. (2006) Introduction, E. Durkheim, *On Suicide*, trans R. Buss (London: Penguin Books), p. xii.

and gradually be extended to non-consensual practice.<sup>14</sup> Despite such concerns about its use, misuse and legality, euthanasia has been unofficially practised since at least the early decades of the Twentieth Century, as is suggested in this account of the final hours of King George V:

‘The King’s life is moving peacefully towards its close, was the final notice issued by George V’s doctor, Lord Dawson, at 9.30pm on the night of 20 January 1936. Not long afterwards, Dawson injected the king with 750mg of morphine and a gram of cocaine – enough to kill him twice over – in order to ease the monarch’s suffering, and to have him expire in time for the printing presses of the Times, which rolled at midnight.’<sup>15</sup>

Its most notorious state-sanctioned practice in recent memory was, however, the Nazi euthanasia programme in World War II. Involving psychiatrists, physicians and nurses,<sup>16</sup> it was designed to remove from German society people whose lives were regarded as worthless: ‘Hitler saw the sick as an economic burden on the healthy and wanted to rid the German race of the “polluting” effect of the “undesirables”’. After military conquests, the programme was extended to occupied countries during the War, including, ‘children in institutions, prisoners of war, hospital patients, as well as concentration camp and extermination camp prisoners’.<sup>17</sup>

Chief among the targets of the Nazi euthanasia programme were the mentally disabled. On German soil, the rationale used to justify their ‘mercy killing’ was the belief that ‘if only the afflicted . . . could understand the misery and worthlessness of their lives, they would not want to live’. In occupied territory, however, no such indulgence applied: ‘Jews, Poles, or Russians in any mental facility were not selected. Regardless of their condition, they were simply killed’.<sup>18</sup>

As mentioned at the outset, ‘assisted dying’ is now one of the more commonly used terms in place of euthanasia – perhaps to signify much the same by another name or perhaps because it avoids the connotation of state-sanctioned ending of life or murder that is associated with euthanasia. In

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14 Powell, M. (2018) ‘Ten non-religious reasons against euthanasia’, *Spectator Australia*, <https://spectator.com.au/2018/02/ten-non-religious-reasons-against-euthanasia/> accessed 29 Sep 2022.

15 Knight, S. (2017) “London Bridge is Down”: the secret plan for the days after the Queen’s death’, *The Guardian*, <https://www.theguardian.com/uk-news/2017/mar/16/what-happens-when-queen-elizabeth-dies-london-bridge> accessed 10 Sep 2022.

16 Burleigh, M. (1994) ‘Psychiatry, German Society, and the Nazi “Euthanasia” Programme’, *Social History of Medicine*, 07(2): 213–228.

17 Weindling, P.J. (2008) ‘The Nazi Medical Experiments’ in Emanuel, E.J. et.al. (eds.) *The Oxford Textbook of Clinical Research Ethics* (New York: Oxford University Press), pp. 21–2, 28.

18 Hilberg, P. (1992) *Perpetrators Victims Bystanders: The Jewish Catastrophe 1933–1945* (New York: Harper Collins), p. 68.

a recent case, the French film maker Jean-Luc Goddard was reported in 2022 to have made use of assisted dying because he was suffering from ‘incapacitating illnesses’ and did not wish to continue living ‘at any cost’.<sup>19</sup> End-of-life decisions such as those taken by the doctor attending King George V and the film director Goddard were possible because of the increased medicalization of death, where, argued the French historian Ariès, ‘the time of death can be lengthened to suit the doctor’:

The doctor cannot eliminate death, but he can control its duration, from the few hours it once was, to several days, weeks, months, or even years. It has become possible to delay the fatal moment; the measures taken to soothe pain have the secondary effect of prolonging life.<sup>20</sup>

While drugs can be used to ease pain and might therefore have the effect of prolonging life, as many have observed, the same pain-soothing measures mentioned in the previous quotation can have the effect also of hastening death and is an example of medically assisted suicide, such as occurred in the case of King George V when his doctor administered the dose of morphine and cocaine.

How and under what circumstances euthanasia is made available in the twenty-first century is fairly important because, according to German sociologists Ulrich Beck and Elizabeth Beck Gernsheim, it is increasingly likely to be seen and possibly practised as a solution for the aged-care problem in advanced western economies. Arguing that the increasing trend towards individualization in the West has had important consequences for ageing populations, Beck and Beck-Gernsheim noted firstly that, as more women entered the work force and domestic gender relations were renegotiated, fewer women would be willing or able to perform care work for elderly family members:

To what extent will the state and society be prepared to create a wide and flexible range of care facilities? ... Medical technology in making life ever longer, seeing it through acute crises and chronic illnesses ... highlights a simple truth: apparatuses can prolong life, but they cannot care for people.

The second consequence they observed was the continuing effect of class on an individual’s experience of old age, which has been apparent for some time in countries like Australia and England: ‘the rich [will] simply purchase good

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<sup>19</sup> Chrisafis ‘Jean-Luc Goddard chose to end life’.

<sup>20</sup> Ariès, P. (1991) *The Hour of Our Death*, trans. H. Weaver (New York: Oxford University Press), p. 585.

and expensive care themselves on the “senior services market”, while the less well-off receive no help because they cannot pay for it’.<sup>21</sup>

As the majority of those from this sample who said that they believed in an afterlife were Christian, it is worth considering the proposition that a connection might exist between viewing euthanasia as a form of murder and a belief in an afterlife. At its simplest, this connection is as follows. Because life is God’s gift, it is precious and must be preserved at all costs.

When life is over, believers are promised an eternal spiritual life. The promise of eternal life is conditional, however, on believers refusing to agree to the premature termination of their mortal life. Such a perceived connection might explain the strength of anti-euthanasia arguments and lobbying from conservative Catholics and other Christians.<sup>22</sup>

### Afterlife Beliefs

Belief in an afterlife has a very long history with roots in ancient civilizations in Egypt and the Middle East as well as in ancient Greece and Rome, ‘mythologised . . . in Hades or Valhalla, in Hell or Paradise’.<sup>23</sup> All four major religious traditions, namely Buddhism, Christianity, Hinduism and Islam, share a belief in life after death.

In the case of Christianity and Islam, it is a belief in resurrection of the soul; in the case of Buddhism a belief in re-birth; and in Hinduism a belief in reincarnation of the something approaching the essence of the person.<sup>24</sup> As well, all four religious traditions share a similar understanding of a paradise or heavenly world where believers progress towards God, union with God or, in the case of Buddhism, to Nirvana, which is understood as, ‘a state of joy, happiness and peace’.<sup>25</sup>

As the second quotation at the head of the chapter suggests, however, the sociologist Norbert Elias viewed a belief in an afterlife as a means of easing

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21 Beck, U. and Beck-Gernsheim, E. (2008) *Individualization: Institutionalized Individualism and Its Social and Political Consequences* (London: Sage Publications), p. 133.

22 The Right to Life is an anti-abortion, anti-euthanasia lobby group with close links to the Catholic Church in Australia, <https://righttolife.com.au/life-issues/euthanasia> accessed 1 October 2022.

23 Elias *Loneliness*, p. 1.

24 Badham, P. (1995) ‘Death and Immortality: Towards a Global Synthesis’ in Cohn-Sherbok, D. and C. Lewis (eds.) *Beyond Death: Theological and Philosophical Reflections of Life after Death* (London: Palgrave Macmillan), pp. 123–124.

25 Badham ‘Death and Immortality’, p. 125.

people's fear about death and the time when they will cease to exist. Other ways of dealing with the fact that life was finite were, according to Elias, to banish any thought of death or to 'look death in the face as a fact of our own existence':

We can adjust our lives, and particularly our behaviour towards other people, to the limited span of every life. We might see it as our task to make the end, the parting from human beings, when it comes, as easy and as pleasant as possible, for others and for ourselves.<sup>26</sup>

### The 'Good Death'

As mentioned in the previous chapter, the idea of the good death was the focus of the work of Ariès and to some extent also that of Elias,<sup>27</sup> who separately argued that, as death had been medicalized, it now most often took place in a hospital, while Ariès independently emphasized that this being so, its timing was largely in the hands of hospital staff. As mentioned as well in the previous chapter, when discussing what they had included or would include in an advance care or hoped an agent with their power of attorney (health care) would provide for their end of life, participants often described the sort of death that they hoped for or hoped to avoid, and in doing so indirectly drew on notions of the 'good death', most often loosely described as a pain-free or gentle death.

In the next section, participants' views on euthanasia are more fully discussed and notions of the good death were again present – expressed, for example, as a death without purposeless agony or pain – even when they held varying opinions on what or which practices or procedures comprised euthanasia. Some understood euthanasia to be equivalent to the withdrawal of treatment, not being resuscitated or palliative care, while others used terminology appropriate to the jurisdiction in which they lived, such as, 'legalized euthanasia' (Victoria, Australia), 'medical aid in dying' (California, USA) and 'medical assistance in dying' (Ontario and Vancouver, Canada).

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<sup>26</sup> Elias *Loneliness*, p. 1.

<sup>27</sup> Ariès *The Hour*; Elias *Loneliness*.

## PARTICIPANTS' VIEWS ON EUTHANASIA

All participants were asked the same question, which was: 'What thoughts do you have about your physical end of life and do you have any beliefs about euthanasia?' With the exception of four, the overwhelming majority were in favour of euthanasia. Some of those in favour referred to their previous experience of witnessing or being aware of its practice, which, except in the few jurisdictions where it had been legalized, was mostly unofficial, or witnessing the death of friends and relatives where euthanasia would have been a kinder option than the dying person was permitted. Among those in favour was a group who had concerns about its practice and the need for safeguards or guidelines.

The next section has three parts. The first looks at the principal reasons participants gave in support of euthanasia. The second examines their previous experience of euthanasia or where in their view it would have been preferable to a friend or relative's lingering death, together with aspects of euthanasia that concerned a group who nonetheless supported it. And finally, the principal reasons given by a small group who did not support or were equivocal about euthanasia.

## Arguments in Favour

Principal arguments in favour of euthanasia were to avoid unnecessary suffering or deteriorated quality of life. Other arguments included participants' belief in their right to choose the time (and place) of their death and the right to end their life.

*Avoid Unnecessary Suffering*

Almost half of those who approved of euthanasia said that they did so because once legalized, its practice would ensure that they (or others) could avoid unnecessary suffering or any marked deterioration in their quality of life when close to death. In most cases, they did not elaborate. The following extracts, however, give some idea of the views that those provided who favoured euthanasia.

There are people, for whom life for a long period of time has, to put it in an extreme sense, given them no joy. And [it is not clear] why that isn't grounds for explaining to people, doctors [that they] don't want to be here anymore ... It's only if you're in extreme physical pain. What I have not

understood about psychological pain, one of my friends explained to me, was on one occasion he was having an episode and he said, “You are just in physical pain. It’s a mental state and I thought in my madness, how can I explain to people how it feels like?” (Edward, aged 77, Australian Capital Territory (ACT))

I am certainly pro-euthanasia. I think it can be quite cruel that people do not have a choice [about] quality of life. We do not let our pets suffer and all the rest of it and yet [with] our nearest and dearest, we say, “Oh, no, you cannot touch it”, so I am very much pro-euthanasia . . . If I ever got to a situation where my quality of life was going to be just yuk, I would rather not be here . . . All this crap from politicians: “Palliative care is so wonderful these days”. Well, it is a load of bullshit. It is good up to a point but there is a point at which palliative care does not do anything. When it gets to the last bit, it is not pleasant, and I am not sure I want to go through that. (Fabian, aged 74, ACT)

I am in favour of euthanasia because of the purposelessness of prolonged agony when death is going to happen . . . Euthanasia, yes, if it came to that, and we both know that. We have both told each other. (Kieran, aged 67, England)

If I had an incurable disease, then I would want to have the right to end my own life. I would not I would not want to prolong it . . . But I mean, it depends on how bad the situation is, right? But yeah, if it’s in a situation where the quality of life is not what I decided it should be, then I would want the assisted suicide. (Eric, aged 57, Hong Kong)

If I am in a situation where I’m not able to have any quality of life, I would like to be turned off. I would like to be able to say [that] I would like to take my life or I would like it to be taken for me if I was in that predicament where I was going to be a complete and utter vegetable and burden to everybody. (Roland, aged 50, Victoria)

A very rare view, as represented in Edward’s extract, was that more needed to be done to understand the extreme distress that mental illness can cause its sufferers and why physical pain is more readily understood as a reasonable argument in favour of changing the law concerning euthanasia but mental pain seems somehow insufficient, as though the pain is not quite real. In contrast, a more common view, as represented in Fabian’s extract, was to compare how pets are treated when suffering a life-threatening illness with how humans are expected to endure a similar illness but without any prospect of the sort of release that veterinarians can provide their patients.

Another common response, such as Kieran expressed, was to argue how unreasonable it seemed to prolong a painful end of life when death was imminent. And finally, quite a few expressed a desire similar to Eric and Roland, which was to be allowed the choice to end their life for their own sake

and the sake of those caring for them, and this is examined in more depth in the next section.

### *Choice and Rights*

For 12 participants, euthanasia was seen as a choice, to which they believed they had a right. In their view, as their life was their own and not a gift from God or any other supernatural being, under certain circumstances, such as extreme pain or with no prospect of recovery from illness, it was their choice when to end it. They were not advocating suicide for petty reasons, however, as Edward (aged 77) from the ACT made clear: 'I don't think people should be allowed to kill themselves because their dog's died. You get a new dog'.

Dorian (aged 70) from New York State saw a simple connection between a possible deteriorating quality of life and the right to choose euthanasia: 'I completely believe in euthanasia. I want to be able to have the choice if I do not have the quality of life to make that decision. And I want to make that decision'. By comparison, Toby (aged 64) from British Columbia hoped that by the time he reached his end of life, the laws in the Canadian province would have changed to allow him to ask for medical assistance in dying in the event that he needed it:

Depending on my state of health when I near the end of life, I may choose to have medical assistance in dying. I hope that the legislation is amended so that people can make that choice. Right now, the legislation is very, very restrictive. You can only have medical assistance in dying for certain kinds of situations and I hope that they expand the inclusion criteria. Right now, you need to have an irremediable and grievous medical condition, whatever that means . . . I hope that they open that up a bit more because if I am suffering a lot and don't have an end in sight, I sure wouldn't mind getting some help to exit.

For a number of participants, having the ability to end their life was a matter of personal rights, and their views are represented here in the following extract:

I've always thought that . . . we should [be able to] decide how we want to die. I've felt that for a long time . . . It is a bit of a minefield but you should be able take your own life when you want to without the interference of the state. I've always been of that position – if I didn't think I had the quality of life I wanted, and it wasn't going to get better. (Scott, aged 62, ACT)

Scott's belief in a person's right to end their life was tempered by a concern for how it would affect friends and family as well as his understanding of how

his mother was faring and her preference not to end her life in a nursing home, a view shared by many participants and their elderly relatives and friends:

But you have to consider the other people around . . . My mother is still at home. She has no intention of going into a nursing home; she's doing all right at the moment.

That ending life should be much like the life lived, that is, a matter over which the individual has the final word, seemed to be the fairly unique view behind the following approach to euthanasia as personal choice:

It is about having agency over your own life. I have enjoyed a high degree of control over my affairs and my life. Some things you cannot control, but only very occasionally have I not been able to do something I want. I find it bizarre that there is this taboo around end of life and somehow this thing called life gets conflated with religion. (Donovan, aged 55, England)

Among other expressions of euthanasia as choice or a matter of personal rights were the following: 'I think it is important for a person to be able to leave when they are ready' (Christopher, aged 52, New South Wales); 'I believe that we should be able to leave this world on our own terms and with dignity' (Warren, aged 50, Western Australia); 'Euthanasia, I think we really ought to investigate as a form of palliative care. I would certainly like to have it available as an option' (Anton, aged 45, England).

### Previous Experience and Concerns

Almost all of those with previous experience of the practice of euthanasia or how it would have benefited the dying spoke of the very personal such as when their parents, children, friends or lovers were dying. In all, slightly less than one third of the sample spoke of their previous experience. And slightly more than a quarter of those who supported euthanasia cited concerns about its practice if it were made legal.

Only one participant had experience of euthanasia. In this case, it was a passive form of euthanasia – when he and his wife gave permission for their son's treatment to be withdrawn:

When my son died, we agreed for it to be switched off because it was clear that if he could be revived – he suicided on his tablets – he would be completely brain damaged and so we just let it happen. (Clive, aged 81, ACT)

Others had emotionally affecting accounts of witnessing the death of parents and friends where they could not request any form of euthanasia to ease

the pain for them. These included Rowan (aged 71) from England who said: 'I have known people with things like motor neurone disease who really could have done with the straightforward ability to request euthanasia'; and Seth (aged 68) from California: 'I have seen a few people who have died of lung issues and that is really hard, that is really difficult'.

Two men briefly described what their parents experienced when dying and how euthanasia would have eased their suffering:

Having seen my mother suffer through dementia and then a long process when her body stopped functioning to when she actually died, I think euthanasia is an appropriate way to end a life that's just a burden to everyone around you. (Harrison, aged 56, Victoria)

My father turned into a vegetable in a terrible hospital with early-onset Alzheimer's . . . I saw both parents and my stepfather suffer needlessly really for the last few years of their lives when everyone around them was sick of them. It was a terrible thing. (Warren, aged 50, Western Australia)

A number of participants were fairly sure that euthanasia was already being practised in countries where it was still illegal. These included Douglas (aged 80) from Victoria who did not support euthanasia but had no qualms about the withdrawal of treatment and Bruce (aged 56) who was from Victoria also and who recounted his father's death:

My father died of leukaemia and he was in a lot of pain . . . He was a doctor. He knew all the doctors in the . . . hospital, he had worked there, so he just said, 'Look, do it for me', and we all knew that. It has been going on for quite some time but quite subtly.

More than a quarter who supported euthanasia raised concerns about its practice if legalized. The principal concerns were firstly that it could be used by unscrupulous relatives or an unsympathetic state to end a dying person's life prematurely, secondly that more humane means of killing were needed and thirdly that vested interests in the health industry were opposed to improving the end of life and making euthanasia available.

Misuse of euthanasia was raised by a small group. Their concerns centred on its misuse by either relatives of the dying person or the state. Questionable motives of relatives concerned Rowan (aged 71) from England who said that while he thought, 'the law on euthanasia is too strict at the moment', he argued for safeguards, 'against pressure from families to push people out to get hold of their estate. That is a serious danger'. A view which Donovan (aged 55) from England echoed: 'It is a fantastic idea but not to be misused, not to be used by greedy relatives that want to bump off grandma to get her house'. Two participants expressed concerns about the overreach of the state. The first said

I believe in euthanasia but not to be decided on by anyone other than me or my agent. I don't want the state to do it if you are becoming too much of a burden. (Joel, aged 74, California)

And the second said that he was concerned about reports that he had read about the potential for euthanasia services to be abused in Holland.

Two men were worried about the means that are at present available for killing those who wish to end their life. Both were in their 40s. The first said: 'The thought of dying in Switzerland in a warehouse on an industrial estate does not fill me with great joy' (Aiden, aged 42, England). The second participant raised a similar point but in the context of changes that were needed, powerfully making the case for doing so now:

I think euthanasia is something that ought to be available and I hope it is available. But I do worry about it because when you think about the American experience, where they are very enthusiastic about killing people judicially, they seem to be unable to do it humanely. I have never really read any discussion as to why that is, and how your experience of Dignitas, which is the end-of-life place, would differ from death row in the States.

I certainly don't want to be in position where I am feeling oxygen-starved or distressed and you do hear stories even about these very well-appointed euthanasia places in Switzerland and elsewhere of things not being easy, and I don't think we should be sweeping that under the carpet. I know it sounds awful to say that we should be researching humane ways of killing people, but if we can do it for animals ... that should be what happens to us. (Anton, aged 45, England)

It is very difficult if not impossible to envisage any government anywhere openly discussing or raising in public how the state itself or private companies should improve the killing services that were provided for those who wished to end their life. If it is true, as Anton suggested, that euthanasia providers were leaving people struggling for breath or in extreme distress in the last moments of their life, there would be a strong argument for publicly discussing how to improve and regulate such killing services.

One participant drew on his understanding of working in the modern health system to explain his concerns if euthanasia were made more easily available to assist in people's end of life. The fears that Toby (aged 64) from British Columbia enumerated mirrored those that German sociologists Beck and Beck Gernsheim claimed had already begun, as mentioned in the Introduction. Drawing on his experience in the Canadian health system, Toby said that he was worried that vested interests in the health industry were opposed to improving the end of life and making euthanasia available. Because of his

conviction, the strength of his argument and its underlining some of the arguments of Beck and Beck-Gernsheim that were mentioned in the Introduction, I have quoted it in full:

In western countries, we still don't have enough people to take care of seniors and our economy is not going to be robust enough to manage to care for all seniors. I am worried about that and I am not sure if that's going to create more pressure for expanded options in medical assistance for dying ... or if people will be left to languish like they have, which has been so obvious with the situation of Covid, where people are under-cared for and warehoused as if they are some kind of disposable chicken in a coop.

Part of my concern about the end of life for me but for others as well, is that there are a lot of vested interests in how that will look ... Physicians are required to do everything possible because otherwise they feel that they are going to end up with a law suit on their hands or someone is going to hold them to account for not doing X or Y. At a certain point, this is doing harm. For an older person, if there is a nice way to exit and the likelihood of improvement is really minimal, they don't ... [extend their life] ...

There are also vested interests in the form of the unscrupulous health-care providers, of which there are many. I am not going to pretend that all doctors and all nurses are wonderful, because they are not. Having worked in the health system, I know there are people that I wouldn't trust. I am just worried that, unless I have a really solid advocate, that decisions could be made, not just for myself but for others as well, that are really not in our own best interest.

Toby's concerns were threefold: that inadequate material conditions might result in more older people choosing euthanasia through sheer despair; that in obedience to their Hippocratic oath, some medical practitioners will prolong life unnecessarily; and that some health care providers also might be tempted to prolong life unnecessarily in order to maximize their profits.

### Equivocal or Opposed

A small group of four participants who were equivocal about euthanasia or did not support it gave two principal reasons for their points of view. The first was that they would rather rely on their personal optimism or will in the face of death and the second that they preferred withdrawal of treatment instead of euthanasia.

In the following extract, Quinn (aged 60) from Victoria recounted his previous experience of serious illnesses. Although he did not explicitly oppose euthanasia, it was not an option that occurred to him at his 'sickest'. And his attitude suggested that, even in the face of another stint of cancer or heart

illness, he never would, preferring to rely on an innate optimism and something suggesting denial:

I haven't thought about . . . [euthanasia]. It has never really worried me so much. Even when I've been at my sickest with cancer and heart problems, I never thought that that was the end of it . . . I'm not a defeatist and I'm not a pessimist. I'm always an optimist so I always think the best outcome, which isn't always good when you know that the worst outcome is what's going to happen and you think . . . "How do you prepare for something if you don't know it's ever going to happen?" I don't know this.

Damon (aged 40) from the ACT held a slightly similar view, which was not based on his own experience but which he arrived at after the death of his grandparents, one of whom had dementia, the other keeping their mental capacity to the end.

In terms of euthanasia, I can't necessarily imagine myself doing it because I am pretty stubborn . . . If I was in massive pain, I would be like, "Just drug me out up and whatever happens, happens". But I want to see how it plays out.

One participant positively objected to euthanasia because it was illegal but said that he would not object to withdrawal of treatment:

As for euthanasia, at this stage, I'd have to say No. I am also aware of facilities to allow people to die without being euthanised. A withdrawal of treatment is not the same as euthanasia, which is a determination to end your life. A withdrawal of treatment can see the same purpose. (Douglas, aged 80, Victoria)

In summary, those with equivocal views about euthanasia or who did not support it were not entirely closed to its possibility at some future point. In Quinn's case would he be more likely to consider it if his optimism failed and for Damon if his will weakened? Meanwhile, Douglas was not opposed to what is known as 'peaceful' euthanasia.

#### PARTICIPANTS' AFTERLIFE BELIEFS

In response to the question, 'What thoughts do you have about your physical end of life and do you have any beliefs about the afterlife?' the majority of participants planned to do as Norbert Elias enjoined his readers to do, and 'look death in the face'.<sup>28</sup> Almost 70% of the sample said that they either did not believe in life after death or did not mention the afterlife in their answer. The remainder said that they

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28 Elias *Loneliness*, p. 1.

either believed in the afterlife, would not discount the possibility of it or believed that the dead lived on in the lives of others. These beliefs are examined in order.

### No Belief in an Afterlife

Those who said that they did not believe in the afterlife comprised one group that was quite certain that there was no life after death and another group that wrestled with the idea, entirely comprising men who had been brought up as Christians, and in the end rejected it. As mentioned, there was a third group that made no mention of the afterlife when answering the question.

Among the quite-certain refusers were atheists and agnostics as well as a handful who, while they did not believe in life after death, found it an enticing idea. Atheists either stated that they had no belief in the afterlife or drew on reason or science to support them. Those who simply stated that they had no belief in life after death included Nicholas (aged 72) from New South Wales: ‘no sense of an afterlife’; Ethan (aged 58) from England: ‘I think we just expire and that’s it’; and Harrison (aged 56) from Victoria: ‘end of life happens . . . I certainly don’t want to live forever’. Those who used reason to support their unbelief in the afterlife included Toby (aged 64) from British Columbia: ‘there is no evidence that such a thing exists, any kind of life after death including reincarnation’; and Roland (aged 50) from Victoria: ‘as science would have it . . . when you are brain dead . . . the ability to do anything is gone . . . That’s the end of life. That’s it. Full stop’.

Five participants found the idea of the afterlife enticing but rejected it. And their views are represented by the following:

I just can’t find it in me to believe it to be true, much as I would love it to be. *It’s something we will only know in the doing.* Indeed! [*Laughs*] . . . and anything we speculate on now can only be a function of what we believe and things in which we believe in this life. By definition, it is unknowable. One would hate to be proved wrong! [*Laughs*]. (Jonathon, aged 53, England)

I do not believe in an afterlife. It would be fantastic if there is and a pleasant surprise if it is. From the knowledge that I have and the understanding I have of the world, my belief is that that does not happen. (Declan, aged 42, Victoria)

Those who wrestled with and then rejected the afterlife beliefs that they had acquired when inducted into Christianity included a participant in his mid-70s who, despite his faith, regarded belief in life after death as a ‘necessary device’ used to influence followers (Andrew, aged 75, Ontario). For him, there was no heaven and no hell. Another man who was in his early 50s said that he had rejected Christianity because of his ‘very religious upbringing’ and therefore could not believe in life after death (Johann, aged 52, England).

## Belief in an Afterlife

A relatively small group of six believed in life after death. Three of these believed in a Christian afterlife, two spoke of a belief in a spiritualism afterlife or in the spirit of the dead living on, and one in Buddhist reincarnation.

The views of the Christians are represented here by Ellis (aged 56) from England, whose belief touched on an understanding of the afterlife as a union with God:

I genuinely believe there is more. We are not encouraged in the Christian faith to enquire as to exactly what form that takes. It is not productive and also why worry? I genuinely believe that we can trust in God's love, that there will be sufficient of what we love and sufficient of who we love and who we have loved that it will be a meaningful experience. I believe very definitely that is the case and that is about as far as it goes.

While the views of those who believed in a spiritualism afterlife or the spirit of the dead living on are represented here:

I am a very strong believer of life after death. I felt the rebirth because in my life I know so many things and I don't know where I learnt them, I just know them. I attributed all this to previous lives and I have done a lot of previous-life experiences with re-birthing, regressions, and hypnotism. That was one of my little side-trips. When I got tired of being a hairdresser, I got into that. That was in the 1980s and I was into that for a long time. (Atticus, aged 88, California)

I have on occasion had a sense of someone's spirit after death. Not a lot of the presence of someone's presence, I mean. I can't be categorical on that but, you know, I'm open to such a notion. I wouldn't be categorical about it. (Clive, aged 81, ACT)

Christopher (aged 52) from New South Wales had been studying Buddhism for two years at the time of his interview. Brought up a Jehovah's Witness, he had had a difficult life after excommunicating himself from the Witnesses, being ostracized by some of his family, and contracting HIV. His belief in the afterlife was as follows:

I never expected to ever become spiritual because anytime anybody talked about spirituality or God, I would run the other way. I don't have such a great view on who God is. I don't agree with or like the way it's been force-fed to people. I believe in some sort of energy or past life and . . . [that] we go through cycles and we learn through cycles and then when we have learnt we can help others in their pathway through their journey to the next realm . . . I feel that this life for me has been resolving some Karmic debt or some Karmic situation from a previous life. That's the way I make sense of it. There is no other way of making sense of it otherwise.

### Afterlife as a Possibility

A small group of about the same size as those who believed in an afterlife said that they were open to the idea of one. Their views are represented by extracts from two men, one in his 60s and one in his 50s.

No real strong beliefs in that way. I am not a particularly religious person. I tend to be fairly practical. It will be a surprise if there is something afterwards [after death]. If not, I won't care [*Laughs*]. (Mason, aged 60, California)

No life after death. Of course, I am not certain about that. I am just completely uninterested in the idea of it. Our life is centred around what we experience now . . . If there is one, that is a bonus. If there isn't one, that's really no surprise. (Donovan, aged 55, England)

### Living on in the Lives of Others

Two participants said that they believed the dead lived on in the lives of others, that is, that the dead remained alive in the memory of the living. Their views are represented in the following extract from the interview with Carter (aged 57) from New Zealand:

We live after death in the sense of the impact we have made on other people's lives. They will carry a bit of me, all going well, for the rest of their lives and in terms of family stories, pass that on to them, so there is a kind of intellectual DNA and spiritual DNA that is passed on through doing your best to live a good life and being a positive force in the lives of others.

Carter's belief was a fairly idealistic one in that he seemed to be saying that the good he did would live on in the lives of others. It is entirely possible also that the bad that people do lives on in the lives of others, as is suggested in the psychological notion of generational trauma, which is gaining more currency.

## CONCLUSION

Almost all the men interviewed for this book supported the introduction of euthanasia. Some argued in favour of euthanasia as a means of avoiding unnecessary suffering or marked deterioration in quality of life when a person was close to death, while a handful made a more radical argument, which was that legalizing euthanasia would permit individuals the right to

decide for themselves when they would like their life to end. A smaller group raised concerns about the possible misuse of euthanasia if it were legalized, citing both long-standing arguments against its misuse by the state or relatives eager to take possession of the dying person's estate and a newer one concerning the extent to which assisted suicide was humanely conducted in commercial facilities that provided 'dying with dignity' services.

As mentioned in this chapter and the previous chapter where euthanasia was discussed, a rarely explicit but fairly clear understanding of the good death underlay participants' views on the matter. None used the phrase but many referred to what they hoped they might experience themselves, which was a peaceful death, one without prolonged agony or pain. And this hope often influenced arguments in favour of euthanasia as did an awareness of how messy death could be which many understood from the personal experience of witnessing the death of family members or friends.

A significant majority either did not believe in an afterlife or made no mention of it when asked. A group of less than a third of the sample believed in an afterlife or were open to the possibility of one. What these could suggest is that gay men were no different in their religious adherence and beliefs than the rest of the population and that as a result of living in, 'a society that has deprived itself of religion and shows little interest in posterity',<sup>29</sup> shared a similar lack of belief in religion.<sup>30</sup>

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29 Lasch, C. (1991) *The Culture of Narcissism: American life in an Age of Diminishing Expectations* (New York: W.W. Norton & Company), p. 209.

30 The most recent Australian census showed a continued increase in the proportion of the population with no religion, from 30.1% in 2016 to 38.9% in 2021; see <https://www.abs.gov.au/articles/religious-affiliation-australia#change-in-no-religion-over-time> accessed 21 January 2023.

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## 5

# FUNERAL PLANS

I've told my lawyer and I've told my oldest son what I wanted for a funeral service. It's not to be in any holy place, it's not to take place in New York City. I don't want a Viking funeral where they put a guy on a boat with treasure and set it on fire. I want it to be on Cape Cod, where I raised my family, and I want to be cremated and my ashes scattered over Barnstable Harbor – Kurt Vonnegut.<sup>1</sup>

## INTRODUCTION

The funeral plans of men interviewed for this book are the focus of this chapter. As explained in the previous chapter, this discussion follows consideration of participants' afterlife beliefs because they were prompted to speak about their views on euthanasia and life after death in the penultimate interview question when being asked for their thoughts on their physical end of life. And as I observed there, I felt the need to explain the chapter order because any progress to an afterlife usually occurs after a funeral.

When the data for this chapter were first assembled, a number of sorting possibilities were considered, that is, a number of categories that could be used for examining and arranging the data. There was material, for example, about participants' religious beliefs, formal and informal; whether or not they wanted a funeral service or a memorial service; what they wanted done with their bodily remains: buried, cremated or donated to medical science; and how detailed were the plans that they had made for their funeral.

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1 Terkel, S. (2002) *Will the Circle be Unbroken? Reflections on Death and Dignity* (London: Granta Books), p. 226.

As many qualitative researchers know, a simple question can evoke a variety of answers, some expected and some not, and just so here when in answer to the relatively simple question, ‘Is there anything else you would like to say about your will and end of life plans? For example, have you included funeral plans with your will?’, participants provided details about their religious upbringing and beliefs, preference for burial or cremation, thoughts about arranging for their cadavers or organs to be donated for the use of the living, and all without additional prompting during the interview.

### FUNERAL PLANS

Funeral is the name given for the burial or cremation of a dead person and the associated religious or secular ceremonies. A funeral traditionally served three functions. The first was to celebrate the life of the dead person; the second for the proper disposal of the corpse, which could take place by burial, cremation or on a pyre;<sup>2</sup> the third was to mark a period of mourning for the dead person, also serving as an act of social solidarity or continuity.<sup>3</sup> It was generally the custom for Christian funeral services to comprise two stages: firstly the body was taken by procession from the place of death – which until the 1950s was often the person’s home, the hospital being much more common nowadays<sup>4</sup> – to the church and secondly again by procession from the church to the grave.

The two-stage funeral procession became more common from the eighteenth century in Europe with the movement to relocate cemeteries for reasons of public health from the centre of towns and cities to their outskirts.<sup>5</sup> French historian Philippe Ariès argued that the transferring of cemeteries to the edge of towns and cities coincided with what he called the secularization of the funeral procession and burials when in France (and elsewhere) cemeteries became the responsibility of municipal bodies and the role of the clergy was

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2 Laqueur, T.W. (2015) *The Work of the Dead: A Cultural History of Mortal Remains* (Princeton: Princeton University Press), pp. 3–9, 527–48.

3 Ariès, P. (1991) *The Hour of Our Death*, trans. H. Weaver (New York: Oxford University Press), pp. 145–146; Griffin, G.M. and D. Tobin (1982) *In the Midst of Life: the Australian Response to Death* (Melbourne: Melbourne University Press), p. 98.

4 Ariès, P. (1975) *Western Attitudes toward Death: From the Middle Ages to the Present*, trans. P. Ranum (Baltimore: The Johns Hopkins University Press), pp. 87–88.

5 Ariès *The Hour*, pp. 491–498.

limited to the funeral service and their presence at the grave was withdrawn, to be filled by that of the undertaker, then the funeral director.<sup>6</sup>

Contemporary funerals can follow the form established after cemeteries were moved out of town in eighteenth-century Europe, namely, where the dead person's body is first transferred from their place of death, although, unless the person is a head of state or government, the transfer is no longer done in procession, and then, after a religious or non-religious service, it is transferred to the grave. In most cases, the dead body is transferred from the place of death to the place of service and then to the grave by firms of funeral directors who prior to 1900 were known as undertakers:<sup>7</sup>

In the towns, there is no way of knowing that something has happened: the old black and silver hearse has become the ordinary gray (sic) limousine, indistinguishable from the flow of traffic. Society no longer observes a pause; the disappearance of the individual no longer affects its continuity. Everything in town goes on as if nobody died anymore.<sup>8</sup>

With the general decline in religious affiliation in the second half of the twentieth century,<sup>9</sup> non-religious funerals became increasingly popular. These could be conducted by secular funeral celebrants, friends of the deceased or the representatives of organizations to which the dead person belonged, such as, for example, Rotary International, sporting clubs or in Australia the Returned Servicemen's League or Legacy. Funeral directors have increasingly taken on the role of conducting non-religious funeral services. One problem with non-religious services was 'to frame rites which say something worth saying and which are not just imitations of church liturgies':

Secular liturgies have little to fall back upon for that depth when the transcendental is excluded by definition. Unfortunately it is just as easy in a non-religious funeral as in a religious one to substitute sentimentality for meaning and triteness for truth.<sup>10</sup>

Gay men had a unique experience of funerals when between 1980 and 1996 at least two generations were directly affected by the AIDS epidemic. During

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6 Ariès *The Hour*, pp. 492, 598–601.

7 Mitford, J. (1998) *The American Way of Death Revisited* (London: Virago Press), p. 148; Ariès *The Hour*, p. 598.

8 Ariès *The Hour*, p. 560.

9 The latest Australian census showed a continued increase in the proportion of people stating that they have no religion, rising from 6.7% of the population in 1971 to 38.9% in 2021; see <https://www.abs.gov.au/articles/religious-affiliation-australia#change-in-no-religion-over-time> accessed 21 January 2023.

10 Griffin and Tobin *In the Midst of Life*, p. 87.

this time, they had a disproportionately high experience of death, mourning, grief and funeral-going as thousands of friends, former partners, and acquaintances died of AIDS and AIDS-related illnesses.<sup>11</sup> In response to the social death which often affected gay men's experience of death and dying during almost two decades, the funerals of men who died of AIDS could take on the form of a 'grand performance', a quiet gathering of close friends and family, or, if unaccepting families organized them, sometimes omitted any reference to the deceased's sexuality or his partner.<sup>12</sup>

In his study of the disposal of the dead, French historian Thomas Laqueur argued that the dead had a power, 'to make communities, to do the work of culture, to announce their presence and meaning by occupying space',<sup>13</sup> illustrating his point with reference to Karl Marx's grave in Highgate cemetery, London and the graves of other socialists and Jews that are situated nearby in the same cemetery. If it is true that the dead 'make communities', how do we make sense of the decisions taken by the men interviewed for this book who decided not to have a grave in a cemetery or special place for the burial of their corpse or cremated ashes and instead, to have their corpse or organs donated for the use of living humans and their ashes scattered 'anywhere'? Do decisions such as these suggest that people who have no wish for their corpse or the ashes of their remains to be buried *are not* or *were not* part of a community or that they have no wish to be part of a group of people like them in announcing their 'presence and meaning by occupying space'?

Although 25 participants or almost 60% of the sample said that they had not yet made funeral plans, they were able when asked to provide some idea about whether they wanted a funeral or details of the sort of funeral that they wanted. Their answers were examined together with those of the minority who had made funeral plans and, in the sections that follow, all are examined under topics which follow the traditional logic for the stages of the funeral, that is, the service – religious or non-religious – and then the disposal of the body, by burial, cremation, or the bone crusher.

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11 Robinson, P. and Geldens, P. (2014) 'Stories of Two Generations of Australian Gay Men Living in the Presence of HIV-AIDS' in *Journal of Australian Studies*, 38(2): 233–245.

12 For autobiographical account of one family's refusal to acknowledge their dead son's sexuality or cause of death, see Conigrave, T. (1995) *Holding the Man* (Melbourne: Penguin Books).

13 Laqueur *Work of the Dead*, pp. 21–22.

## Religious Services

Only slightly more than one-fifth of the sample wanted a religious funeral.<sup>14</sup> When speaking about their decision for a religious funeral, these participants referred either to family precedence or ‘tradition’, that is, to what their parents had done before then or to what they and their partner wished for each other and had decided together.

### *Parents, Family Tradition*

Five participants referred to their parents’ funerals when explaining their preference for a religious funeral. Their accounts are represented here by two men: one in his late-60s and one in his mid-50s. Seth (aged 68) who was from California wanted half of his ashes spread at the AIDS memorial in San Francisco and half of them to be interred in his parents’ plot.

The national AIDS Memorial Grove is in San Francisco at Golden Gate Park . . . [and] has a plaza area [where] they have people’s names engraved in it. It is called ‘Circle of Friends’. It is both living and dead people and I had my name engraved there. It is the only place in the city where you can also spread ashes. I let them [siblings] all know that I want to be cremated and half go to Memorial Grove and half go to my parents’ plot. They are going to take a screw and take out part of the dirt for me [*Laughs*].

Seth was one of the six participants who said that they were HIV positive. And for him, and I suspect many thousands of other gay men in the USA, the National AIDS memorial Grove represents a permanent memorial for the hundreds of thousands of people who died during the HIV-AIDS epidemic in the USA. Within the Grove is the Circle of Friends where the names of those affected by AIDS, living and dead, are engraved in stone.<sup>15</sup>

Ellis (aged 56) from England provided a detailed account of his parents’ funerals when outlining his own wishes for a religious funeral and why he believed it was important for people to make funeral plans, ‘because it reduces the amount of head scratching’ for family and relatives after their death. His father remarried after his parents divorced and according to Ellis, ‘made very firm plans with my stepmother’, which meant that making arrangements was quite straightforward for him and his siblings:

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14 Nine participants said that they wanted a religious funeral service.

15 See: <https://www.aidsmemorial.org/circle-of-friends> accessed 29 October 2022.

The only stuff we had to work out was the stuff you don't usually have the presence of mind to sort out, which is what is going to be read at his funeral, what is going to be said, what are we going to listen to, that kind of thing, and what goes on his headstone. And those are the things that, while painful, are lovely to do. Dad organised together with [stepmother] pretty much everything else: the funeral plan in terms of payment; burial rather than cremation.

His mother, on the other hand, 'didn't really do anything':

She didn't even express an opinion about where she wanted her remains to be. She didn't want to be buried. It wasn't careless, she genuinely didn't care. She said, "It's not me. I'll have gone and I am not fussed. You can chuck me in the bin, if you like, just do not worry about it". But it did mean that in the end we had to go through that thought process because we weren't sure and we wanted to do the right thing. In one way, it was lovely. It was a creative moment and brought . . . us close together . . . the six of us, including my brother-in-law and my sister-in-law.

Together, Ellis and his four siblings and their partners arranged a remarkable funeral for their mother, which began when they met in London and drove some way along the Thames to a point where in his words, 'We ended up throwing Mum in the river' because it is now possible to get a soluble, environmentally clean container made out of compressed sand and salt. In the following account, Ellis explained why the funeral that he and his siblings and their partners devised so nicely suited them and their idea of what their mother would have wanted herself:

It was like an urn but it was a globe shape with a lid and Mum's ashes were placed in that . . . The way it worked out was lovely. Mum would have been tickled and it worked. We are not good at ceremonial, we are always poking fun at each other and it meant that there was a ceremony of sorts, something to remember. It was not mawkish and it was in keeping with Mum's sense of who she was and her sense of humour, but also, it was delicate.

While Ellis's story is a striking example of how children can agree and resolve to honour a mother who left no instructions for her own funeral, it suggests also how the wishes of the deceased can be countermanded by the living, emphasizing as well the common-sense understanding that 'funerals are for the living'.

#### *Partner*

Five mentioned funeral arrangements that they had made together or in consultation with their partner and they are represented here by accounts from

two men, one in his 70s, the other in his 60s. The first, Joel (aged 74) from California explained that he planned to let his ex-partner arrange his service in accord with the latter's religious affiliation:

As far the service itself . . . my ex-partner will probably take control of it. He is a devout Episcopalian. In fact, I converted from Catholicism to Episcopalian when I was with him. Of any church or religion, that is the one I can embrace the easiest.

The second account was provided by Kieran (aged 67) from England and was included in this section because, even though he and his partner had 'enormous difficulties with the faith', they both wanted their remains committed to a churchyard or a cemetery. Each had slightly different plans: Kieran wanted his remains spread in a churchyard and his partner to be buried in a family plot with his deceased parents and sibling:

The idea is to sprinkle the ashes or bury them, whatever the authorities allow, within the churchyard of this church . . . which is a Welsh church, this wonderful, wonderful romantic setting by a river. [Partner] is also doing . . . [something] in a church which has got strong family connections up in [name of county] which is right in the middle of where he was born and lived for the first two decades. We both want to have a conventional, in the best sense, a traditional send-off.

For Kieran, a strong emotional connection with the historical and natural environment was all important when explaining his choice of the location for his remains:

The crows are squawking, it has an incredible sense of wildlife as well . . . and then you go into the church and it has been there for 1000 years and still representing the faith. It has been through the Armada, it has been through the Second World War, it has been through the Norman invasion, it has been through everything and survived.

As was a shared understanding that he and his partner had of church buildings and what they represented in the spiritual, perhaps also mythical landscape of Britain:

We do feel a strong sense that churches represent continuity in the best sense and a sort of faith. We do not want to be associated with the faith, but we respect it, and I think we would like to be allies of it by association, rather than by deep internal belief, which neither of us have.

### Non-Religious Services

Almost twice as many participants said that they preferred a non-religious funeral to a religious one.<sup>16</sup> These comprised a small group of three who had well-developed plans and the remainder who had only sketchy plans or ideas about the sort of service that they wanted including a group of nine who wholly rejected the idea of a religious service, five of whom referred to their Catholic upbringing when explaining their decision.

#### *Well-Developed Plans*

There were three participants with well-developed plans and they were from the Australian Capital Territory (ACT) and England. Their plans included details of the music that they wanted played and the style and nature of the service. The first of three was a man in his early 80s (Clive, aged 81, ACT) who provided a list of the music that he was compiling for his funeral:

I have chosen about an hour, an hour and a half's worth of music, it's all ludicrous anyway. *What music have you chosen?* I can give you the full details if you really want them. I can even play it, to you [*Laughs, walks off, returns with a list*]. There are seven items and they include a passage from Pergolesi's *Stabat Mater* ... and two items with me playing the violin on them ... in a band called 'Mulga Bill's Bicycle Band' ... and the last three are 'Hotel California' by the Eagles, which is a key work as far as I am concerned and then, 'I am a Man of Constant Sorrow' ... from the film, 'Oh Brother, Where Art Thou?' And then there is a big finish ... a passage from Bach's B Minor Mass, which ends with trumpets, played very loud to get the best of the spluttery trumpets at the end is my instruction. I don't know but I have probably put a burden on somebody or other to do [it all]. Maybe I will just go out with 'Hotel California' [*Laughs*].

While Clive was clear about the 90 minutes' of music he would like played at his funeral, he was less sure about its format and said elsewhere in his interview that he was content to leave that and other details of his memorial service to his family and friends.

Donovan (aged 55) from England wanted music also at his funeral service, although his repertoire was less extensive than Clive's:

I have set the sound track for my funeral: Philip Glass piano solo, played by the artist. I want tears! None of this soft-rock rubbish [*Laughs*] ... Being a bit of a control-freak, I did want to choose the sound-track. *Are there hymns?* No! It

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16 Sixteen participants said that they preferred a non-religious memorial or service.

won't be religious at all. We are not religious in the slightest. I think we struck a good note with my dear old Mum's funeral. That was a non-religious funeral and it was fantastic. People still talk about it. It was pitch-perfect.

By contrast to Clive and Donovan, Damien (aged 52) from England wanted his friends to meet in a place which meant a lot to him and had made provision in his will for funds to be made available for them to do so:

I set aside . . . [money] for people to gather in a very beautiful place they will never get to in their lives, a place in Italy and if they were to scatter some of my ashes there [it would be] great. It is general but it is to pay for ten friends to have a week in this place that they just would not get to but it is for them to experience this place that has touched me and make it a funeral. That is the focus; it is a party basically.

Although relatively few in number, those with well-developed funeral plans seemed mainly focused on minimizing the maudlin nature of their memorial service and ensuring that it would be a memorable or uplifting experience for their family and friends.

### *Sketchy Plans*

Explanations that were given for having only sketchy plans or no plan at all tended to centre on the common-sense understanding that 'funerals were for the living', as Eric (aged 57) from Hong Kong explained: 'Frankly I don't care [*Laughs*] I am not around. They can do what they want [*Laughs*]. I did not put anything in . . . my current will'. Others with sketchy plans either reiterated this understanding or provided outlines of how they expected their friends or family to mark their passing informally.

Edward (aged 77) from the ACT drew on the common-sense understanding: 'I could not care less for me because I am not going to be there . . . so I will leave whether to have one to my partner'. When asked about the sort of memorial that he envisaged might take place, he said: 'The normal thing these days . . . is somebody says something and then everybody chips in, sits around, says something'. Others who shared the same common-sense understanding were Aiden (aged 42) from England, who was very clear about his wish for next to nothing to mark his passing: 'I would not want anyone to think I want the Mozart Requiem being played with weeping mourners. I would instruct: simple, quick, send off'; and Harrison (aged 56) from Victoria, who, like many others, was more concerned about his surviving partner:

I have left a clear instruction with my husband to say that . . . [my] funeral is really for the living and not for me. I have no religious concerns. I am not a

believer in any supernatural being ... The funeral ... should be set up in such a way that benefits the people who are left behind and ... whatever it is that they need is what they should get. I don't care at all what happens just to say that whatever they want is what my husband should work with them to achieve.

One of a few from this group who reluctantly agreed to the need for some post-mortem service or celebration was Nicholas (aged 72) from New South Wales. In the following extract, he seemed to suggest that a life well lived with friends and family was preferable to a funeral service or memorial and that he honestly expected nothing more:

I hope that everybody gets to say to me what they want to say to me before I am dead. I don't need people to say things about me, except to celebrate their lives and their lives with me in the way that they want to.

A participant who had sketchy plans only, which when written would probably include a fulsome celebration of his life – along the lines of the services being planned by those already discussed in well-developed plans (above) – was Johann (aged 52) from England. In the following extract, Johann explained that he wanted an ‘after party’ where ‘Cosmopolitans would have to be served [as] that is my signature cocktail’:

“After parties” can be lovely. That aspect of them I really like. It brings this group of people together and hopefully if it is a nice person, it's a nice funeral and those group of people are lovely and often haven't met each other but know of each other because they have been in this person's life. And I get the importance of the after-party and it's a nice, social celebration of that person's life. That bit I fully understand is a good thing.

Emphasizing the importance of a social gathering to celebrate a person's life was Johann's way of distinguishing between what he hoped for himself and what transpired at this father's funeral:

My father's funeral was the most awkward funeral I have ever been to and I could not wait to get out of there. It was horrible. We would have been better not having it. He was not well-liked by anyone and everyone felt this fake sense of needing to console me and things. I did not like him and ... I really wish it had not happened. The only positive [partner] said ... was that at least it ... did a good job of representing what he had been like in life: this ... weird, fake, non-personal funeral. It was just strange.

In a previous chapter,<sup>17</sup> Johann was quoted as explaining that, because his family had moved around a lot when he was young, blood relatives were not

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17 Chapter 1: Affective Lives.

an important part of his life. Elsewhere in his interview, he confessed that his most problematic relationship was with his father – who was possibly responsible for the family having to move around a lot – and in this extract, he seemed to suggest that his family had made a mistake in arranging the ‘weird, fake, non-personal funeral’ for his father, which might have been his way of signifying the level of unresolved feelings that he and others had for his father.

As mentioned, a small group of five referred to their Catholic upbringing when explaining why they did not want a religious funeral service. Four of these rejected any thought of a religious funeral service because of memories of the bad experiences they had had as children in Catholic education systems in Australia, England or the USA.

In New York State, Dorian (aged 70) said that he wanted no religious service ‘whatsoever’: ‘I am a lapsed Catholic and don’t want anything to do with religion when I pass’. Quinn (aged 60) from Victoria was more forthright, drawing an unambiguous connection between his schooling and wish for a non-religious funeral service:

I don’t want a religious service. Unfortunately, that was beaten out of me in school. *Catholic?* The Brothers of St Gerard Majella: a very small group that have since been disbanded by the Vatican.

Two participants who likewise had no wish for a religious funeral were nevertheless aware of possible difficulties that could arise in their families because of their preference. Mason (aged 60) from California said: ‘I don’t want to be buried out of the Catholic church which will be difficult because in my family I have two aunts who are nuns’. Meanwhile, 42-year-old Declan from Victoria anticipated a ‘shit-fight’ if he predeceased his parents and they were unwilling to acknowledge his partner’s role in organizing his funeral, and was the principal reason that he intended to clearly state his wishes when his will was written:

I think we presume a lot of things and I think I have to make those things quite clear [in my will] so that that is easier for everyone in the end. But also, by the same token, I want my parents to go, “Well, as [partner] has been with him for the last four years, [partner] should be making those sort of decisions” . . . But that’s just too much to risk and that is why it is something that I have to do.

A fifth participant who was brought up a Catholic did not however relate memories of bad experiences in the Catholic school system but explained that, despite being ‘quite religious’, he had no wish for prayers or religious celebrants at his funeral:

I was raised by Catholic brothers and nuns until the age of about fifteen and then my parents ran out of money, so I went over to public school which

shocked me terribly [*Laughs*] but nevertheless helped me a lot because it meant I did not end up [becoming] a cleric because I am quite religious . . . I have some anathema about churches, particularly Roman Catholic churches. I don't want strangers talking about me and saying arcane prayers . . . and I certainly don't want clerics incensing over me [*Laughs*]. I don't feel hostile about that, I don't have animosity but I certainly rigorously do not want anything to do with those people, particularly because I think that they have abrogated their moral and spiritual authority totally and completely. (Nicholas, aged 72, New South Wales)

What the sketchy plans suggest is that a significant minority of the sample either accepted the common-place understanding that funerals were for the living and were unconcerned by what took place after their death to celebrate their life or were opposed to any sort of memorial because of their dislike of religion and/or religiosity.

#### Disposing of the Body: Burial, Cremation or the Bone Crusher

The phrase 'bone crusher' which is used in the subheading was not meant to offend readers, referring as it does to the views of a number of participants, one of whom raised the question of how to dispose of the body: 'Do you want to be thrown into a pauper's grave or do you want to be ground up or burnt?' (Edward, aged 77, ACT). In this section, the focus is on participants' thoughts about and advice that they had included in their wills for the disposal of their body.

About half as many said that they preferred a traditional funeral to those who wanted a cremation.<sup>18</sup> And a small group of six said either that they wanted their corpse or organs donated for research or to aid the living or that they really did not care and that their ashes could be thrown 'under a bush somewhere'.

#### *Burial*

Slightly less than a quarter of the sample said that they would prefer or had stated a wish for a burial. Of these, a majority said that they would prefer an alternative burial.<sup>19</sup> The three who wanted a conventional burial referred to some form of family tradition, as shown in the following extracts. 'I want to be buried in the grave-yard where all my family is buried' (Emmett, aged 70, England). 'I've already got a plot for my ashes in a cemetery . . . in the same

18 Eleven participants said that they wanted a burial; 21 said that they wanted a cremation.

19 Of the 11 who stated a preference for burial, eight participants said that they wanted an alternative burial.

church that my family has used for a few generations’ (Carl, aged 58, New Zealand). ‘When my father died, we decided we would get a “fits-three” grave . . . He’s on the bottom, Mum’s in the middle, and there is room for me’ (Donovan, aged 55, England).

Interest in and demand for woodland burials,<sup>20</sup> which can also be known as green burials, seemed to be growing in countries like Australia, England and the USA. When asked about the growth in the green burial movement in the UK, one participant whose partner was a secular funeral celebrant had the following to say:

It is quite niche. It is expensive . . . White, middle-class, slightly alternative-minded people would go for that as an option. It is happening. I am not quite sure how prevalent it is in terms of percentages but I would say that it is steadily growing. But growing more rapidly are secular funerals and DIY funerals where you manage the whole thing yourself because getting a funeral director is very expensive. (Wade, aged 66, England)

While a participant from North America spoke of the personal appeal of so-called ‘body farms’:

If I could go to a body farm, I would sure do that because I am a big environmentalist. I like the idea of those body farms, just nourishing the earth and letting things take their course. It’s not that I am anti-religious or anything; it’s just that I am religious in a different way. *Tell me a little more about the body farm.* Your remains are buried and become the roots of a tree. They plant a tree on top of you. I saw an article in one of the papers last week about these ‘pods’ that they have. I like that idea, it’s a poetic idea.

Others elsewhere emphasized geographical location and a form of relatively modest environmental sustainability, which did not include having their bodily remains converted into effluent,<sup>21</sup> as the main reasons for the appeal of woodland or green burials. ‘I have changed that [his instructions] to have a woodland burial . . . in a delightful woodland setting in a large area set aside for woodland burials’ (Rowan, aged 71, England). ‘A couple of friends have had woodland burials [in] coffins that would very easily decompose and become part of the soil’ (Ellis, aged 56, England). ‘One of those environmental

20 See, for example, this account from *The Guardian* of an alternative funeral in Devon, England: Wollaston, S. (2022) ‘Ditch the hearse, bring the kids, have a picnic: an alternative undertaker’s tips for a better funeral’, <https://www.theguardian.com/lifeandstyle/2022/oct/19/shallow-grave-kids-picnic-alternative-undertaker-funeral> accessed 20 October 2022.

21 For details of processes for converting dead bodies into effluent, see: Kalia, A. (2019) ‘A Greener Way to Go: What’s the Most Eco-Friendly Way to Dispose of a Body?’ in *The Guardian*, <https://www.theguardian.com/lifeandstyle/2019/jul/09/greener-way-to-go-eco-friendly-way-dispose-of-body-burial-cremation> accessed 20 October 2022.

burials where you're put into the ground and have to rot [*Laughs*] would be the most appealing thing for me' (Roland, aged 50, Victoria).

### *Cremation*

Just under half of the participants said that they wanted to be cremated after death. When explaining their choice for cremation, most spoke of where they wanted their ashes left, namely buried or scattered. One or two said that they might reconsider the decision as more information came to light about the environmental impact of cremation – mostly in connection with what they understood to be the large amount of energy required to reduce a corpse to ashes.<sup>22</sup>

Preferred locations for the scattering of ashes varied. Joel (aged 74) from California said that he wanted his remains returned to the east coast USA:

And the ashes scattered in the garden by the church that my main partner and I attended. We are both going to be scattered there. At first, I was going to scatter to the wind but my daughter was very insistent that she needed to have a place. I am not having a gravestone or anything but there is a place that she can go to.

Meanwhile, Dorian (aged 70) said that he wanted his ashes simply, 'scattered in New York'; and Davis (aged 65) from California that, 'I would be cremated and scattered at sea like my Mom. I do not want anyone spending any money'; while unclear where he wanted his ashes to go, Jonathon (aged 53) from England said that he wanted his scattered 'somewhere important to me'. Another participant did not specify a location for them but instead explained who would receive his ashes:

I intend to be taken away immediately – I have spoken to my partner – and cremated . . . My ashes will be given to my partner and half will go to the family and half will remain with him. And that's the arrangement. (Nicholas, aged 72, New South Wales)

Two were not particularly concerned about what happened to their ashes. 'I want to be cremated and I want my ashes tossed' (Randolph, aged 57, Germany). 'Throw my ashes under a bush somewhere would be fine' (Johann, aged 52, Sheffield). And dark humour coloured the thoughts of one of the men in their 40s who related a story that he had heard about, 'the vengeful old queen who said in his will that he wanted his ashes to be flung in the faces of his enemies'!

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<sup>22</sup> Wollaston 'Ditch the hearse'; Kalia 'A greener way to go'.

*Medical Science, the Tip or the Bone Crusher*

A small group of six participants said that they wanted their body or organs either donated to medical science or in extreme cases simply ‘thrown on the tip’. The latter preference, while to contemporary readers might suggest a serious case of low self-esteem, has a long tradition, as French historian Phillippe Ariès explained in his study of changing attitudes to death:

Anonymity [in death] persisted until the eighteenth century . . . The bodies of the poor and of the young children of the rich, who were treated like the poor, were sewn into shrouds . . . and thrown into big, common graves . . . [while] those who drowned in the rivers or were the anonymous victims of disasters . . . [were] left to rot on the dump like animals, executed criminals, or the excommunicate.<sup>23</sup>

The six from the sample canvassed thoughts about the disposal of their body that ranged from having it sent to the blood and bone factory, the fairly standard intention to have it sent to a medical faculty, to throwing it under a bush or into a rubbish bin.

Edward (aged 77) from the ACT planned to include in his will instructions to have his cadaver sent to a university medical school, for reasons of economy:

The main thing is to send the body to the medical school for the dissecting table, partly to avoid something I know [which is that] weddings are one of the great expenses and funerals are a completely unnecessary expense at the other end. I have no idea why people spend money on funerals and gravestones and all of that stuff . . . It is a complete waste of money to start having coffins and all of that.

Aware that not all of the cadaver can be put to use, he noted, ‘that they will want to do something with the left-overs’. And his answer was that many people would want a service of some sort: ‘the relatives are very uneasy about it, so they have these ‘thank-you’ ceremonies’. While arranging to have his cadaver donated to the medical school was his intention at the time of interview, he mentioned also that this was his second option: ‘My view is to send it to the blood and bone factory but I don’t know that they are up to that’.

Other participants who like Edward regarded any fuss about how their body should be disposed as unnecessary included Johann (aged 52) from England whose view included an environmental consideration: ‘I would actually prefer my body to be dumped on a compost heap where it could do some good rather than taking up urban space in a cemetery’; and Warren

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23 Ariès *The Hour*, p. 207.

(aged 50) from Western Australia who reported his partner's view: 'If he could be put in a rubbish bin, he would be happy with that'.

Finally, there was Damon who referred to an episode of the Oprah Winfrey television programme that he had seen when he was 15 and realized that his remains could be converted into an object of material value:

They were talking about death and one of the things they could do and can still do was like when you cremated, they take your ashes and make them into a diamond. And I am like, "That's fabulous", because I immediately thought of like Victorian mourning jewellery. And there is a little part of me that just goes, "I can't think of anything better than being turned into some horrible jewellery that then has to be passed on because this is great-uncle" ... [I know that] you can make conditional gifts, so, part of them getting my estate is conditional on that they accept this tiara, which is written into there. The wording is something like, "As far as is practically possible, I must be made into a diamond and placed into a tiara. And this money is set aside for that". I know it is a semi-terrible thing, but there is a little part of me that is like what a fabulous story for future generations to tell. You have got to set up your pranks in advance [*Laughs*].

As comical or improbable as Damon's thoughts about his remains might seem, a similar proposal was considered immediately after the French Revolution when in 1801 the public servant Pierre Giraud suggested that the ashes of cremated people could be turned into glass and then made into 'commemorative medals'.<sup>24</sup>

## CONCLUSION

The fact that religious or non-religious funeral services were relatively unimportant to those interviewed for this book suggested that they did not consider any form of public ceremony necessary to celebrate or mark their life's end. Many explained their decision in light of the common-place understanding that funeral were 'for the living' or that, as they were not going to be present, they were not particularly concerned about how or whether their life was celebrated or marked. It was not clear, however, if behind this sentiment lay a belief that they did not have a claim, as the French historian Lacquer argued in the case of socialists and Jews in London's Highgate cemetery, 'to announce their presence and meaning by occupying space'.

While there was no evidence to suggest that the men regarded their lives as less worthy or less valuable than those of others, such as heads of state or

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<sup>24</sup> Laqueur *Work of the Dead*, p. 527.

government, senior members of academia, business, finance, media or religion who seemed to require, like the paterfamilias of Victorian novels, to have their lives monumentally celebrated in obituaries in traditional print newspapers like *The New York Times* or *The Times*, could it be that the stigma of sexual outsiders can persist into death and that gay men continue to see themselves as unworthy? Another explanation is that, as that at the time of interview all but three of the sample were likely to die without immediate descendants,<sup>25</sup> did the fact of not belonging to the ‘tree of man’ mean that there was less need for commemoration? A third explanation as to the relative unassuming end that many of the participants envisaged for themselves is that their views represented a type of gay man who was content with his life’s achievements and who had no need for fanfare or pomp to mark its end, and that his achievements in the spheres of the domestic and the intimate were sufficient and would stand alone.

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25 Two of the three were in their 80s, the third was in his 50s and all had children from previous relationships with women. There were no gay fathers in the sample who had with their male partner or husband arranged for children through surrogacy or adoption. See Biodata in Appendix 2.

[lifeandstyle/2019/jul/09/greener-way-to-go-eco-friendly-way-dispose-of-body-burial-cremation](#)

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# CONCLUSION

The curiosity I have is . . . how much of this does have an LGBT dimension and how much of it is what I would believe anyway if I was not gay. And I think somehow that the advantage being gay gave me – as a member of an out[sider] group, particularly in the times of emerging HIV – was that my generation had to be a bit more “on the ball” with these things. I have contemporaries who are straight who really have not thought about this sort of stuff and I would be really interested to know whether gay people generally, from this age group, are more sorted out about with plans and awareness than their more normative equivalents who can just muddle through and think, “Oh, it will all be all right”. (Wade, aged 66, England)

Emerging aspects of the data were how firstly the role of the family and secondly the idea of the ‘good death’ influenced participants’ end-of-life decisions and appointments in thinking about and preparing for death. In relation to family, it was notable that members of participants’ family of origin were often but not always the preferred choice in end-of-life decisions and appointments. And when musing on the sort of death that they hoped for, the idea of the good death often lay behind participants’ preference for a calm, quiet or easy death.

## THE ROLE OF FAMILY

Among the more unexpected findings from this study was that family members rather than friends were more often chosen as beneficiaries. While similar findings were reported in other published research on LGBT end-of-life decision-making,<sup>1</sup>

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1 See, for example: de Vries, B., et.al. (2020) ‘Advance Care Planning among older LGBT Canadians: Heteronormative Influences’ in *Sexualities*, <https://doi.org/10.1177/1363460719896968>; Westwood, S. (2015) ‘Complicating Kinship and Inheritance: Older Lesbians’ and Gay Men’s Will-Writing in England in *Feminist Legal Studies*, 23: 181–197.

they were surprising for two reasons. In the first place, because of the assumed centrality of friendship in the family of choice,<sup>2</sup> a distinct preference for family members over friends suggested that the role of the chosen family was becoming less important in the lives of gays and lesbians. In its heyday, it represented a life experiment for gays and lesbians who wanted to live or try to live outside traditional family structures – and which the widespread introduction of marriage equality legislation could also make redundant. If the chosen family is becoming less common as this and other research suggest, it could be that as gay men age, the family of origin becomes more important to them and they have fewer qualms ‘returning to the nest’. Secondly, the privileging of family members seemed a slightly odd choice given that the common-law (or de facto) relationship was the most common relationship type and that almost a quarter regarded the couple relationship as their family.

Possible explanations for preferring family members over friends as beneficiaries included: (1) that choosing family members was the ‘easy’ option, that is, it required no special thought, was the standard, predictable choice and was unlikely to be challenged or questioned by family or friends; (2) even if more loosely connected or maintained, family relationships might be less likely than friendships to break up and could therefore appear to be a more dependable option, that is, in contrast to family relationships, friendships did not or were regarded as unlikely to last the ‘test of time’. Because both of these explanations are only speculative, further research would help test their validity.

Decisions concerning appointment of executors and power of attorney favoured the traditional as well and could be seen also as the ‘easy option’, that is, they required no special thought and avoided possible dispute or, on the other hand, simply reflected the enduring strength of the couple relationship. In the case of executor, the first choice was partner or spouse followed in equal number for each by family, professional persons, and friends. Slightly against the general trend of favouring family over friends was the fact that equal numbers chose friends for their executor as chose family and that each of these was only slightly less than those who chose partner or spouse. Of those who had a will and had appointed an attorney, just under half chose their partner or spouse and very small numbers chose a friend, professional person, or a niece or nephew.

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2 Weeks, J. (2000) *Making Sexual History*, Cambridge: Polity Press; Weston, K. (1997, 1991) *Families We Choose: Lesbians, Gays, Kinship* (New York: Columbia University Press).

## GAY MEN'S UNDERSTANDING OF THE 'GOOD DEATH'

Participants' beliefs about euthanasia and life after death were central to Chapter 4, while in Chapter 5 their funeral plans was the focus. As these chapters showed, a majority favoured euthanasia, a very small number believed in the afterlife, and almost all participants had some idea of the sort of funeral they wanted, if only about 40% had made funeral plans.

In Chapter 4, a possible connection was suggested between why a belief in an afterlife might help explain the views of those who opposed euthanasia, namely, that a belief in life after death went hand in hand with a belief in the sanctity of life and that this could therefore help to explain opposition to any form of the premature ending of life such as by euthanasia. This possible connection was not considered when the research project was being planned and the interview schedule written. Another possible connection was identified with afterlife beliefs and that was between them and funeral plans. My analysis showed that, while only a very small number of participants said that they believed in life after death, nearly all had views on the sort of funeral that they wanted, which might suggest that those who do not belong to an organization that offers rites to mark death could tend to spend more time considering it and certainly as their own death draws nearer.

The hope of being able to experience a 'good death' was often implicit when participants explained their advance-care arrangements or power-of-attorney appointments and gave their views on euthanasia. None specifically used the phrase, 'the good death' or expressed a hope for one; instead, they expressed a desire to avoid the opposite, that is, a drawn-out, painful or undignified death, which, as mentioned, Ariès called the 'dirty death'.<sup>3</sup> Important for many when considering their own death, were some of the following: bodily dignity by which they meant being able to communicate with other, to toilet themselves, and to avoid immobilization or incapacitation. Not living on in a 'vegetative' state was a frequently used phrase. These hopes often influenced their arguments in favour of euthanasia as did an awareness of how messy death could be, which many understood from the personal experience of witnessing the death of family members or friends, in the case of the latter, memories of friends' deaths during the AIDS epidemic were strong and still influential.

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3 Ariès, P. (1991) *The Hour of Our Death*, trans. H. Weaver (New York: Oxford University Press), pp. 568–570.

Although less than half had made funeral plans, almost all participants had an idea of the sort of funeral that they would like for themselves. Notable among these was an absence of anything grand, grandiose or monumental, and, in Chapter 5, I speculated on the reason for this, drawing on the work of Thomas Laqueur who had observed in the burial plots of Jews and socialists in London's Highgate cemetery announcement of 'their presence and meaning by occupying space'. And I speculated if gays and lesbians might feel less willing to make a similar announcement because they are not part of the hetero-normative structure. Being outside it, and understanding themselves to be outsiders, and with the exception of AIDS memorial cemeteries and gardens, do they feel less part of or less need to claim space for themselves and so announce their presence and meaning?

If there is any truth to this, will a stronger push to announce the presence and meaning of gays and lesbians increase along with their acceptance and the success of their normalization? Another less political explanation for the absence of grand funeral plans in the stories of the men interviewed for this book is that the sample might have comprised a group of relative unassuming participants who were content with their achievements, wishing for no fanfare or pomp to mark their end, and, as I wrote in Chapter 5, that their achievements in the spheres of the domestic and the intimate were sufficient.

In the quotation at the head of the chapter, 66-year-old Wade from England wondered if preparing for death had any special or particular relevance to gay men. As he observed, the AIDS epidemic not only marked his generation of gay men but gave them something of an advantage in that as young men they had to confront death when their friends were dying in the 1980s and 1990s and that this could have given them some remembered familiarity with the business of death. The trauma of the AIDS epidemic aside, the accounts provided in this book strongly suggest that concerns about the business of death are shared by gay and straight populations. As Laqueur argued, all of us find it very difficult to accept or believe that one day we will not be here,<sup>4</sup> and what this book has shown is that preparing for that time is not always easy.

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4 Laqueur, T.W. (2015) *The Work of the Dead: A Cultural History of Mortal Remains* (Princeton: Princeton University Press), pp. 55–58.

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# APPENDIX 1: RESEARCH INSTRUMENTS

## GAY MEN'S END-OF-LIFE PLANS AND PREPARATIONS

### Interview Questions

We begin with four questions about your personal life.

- (1) Briefly tell me the story of your family relationships.
- (2) How long have you been out and how easy has been your gay life?
- (3) Briefly describe your relationship status. Are you single, married, divorced, in a long-term relationship and for how long have you been so?
- (4) Do you have any children? If you do, please explain the nature of your relationship. For example, are they children from a previous straight relationship, the children of your partner or children you and your partner have had together?

Next set of questions concerns your will and asks for more detail than the preliminary questions.

- (5) Do you have a will and have you revised it often in the last 10 years?
- (6) If you have a will, have you appointed an executor? Who did you choose and why? If not, who do you think you would choose and why?
- (7) In some jurisdictions, someone can be appointed to look after a person's medical and financial decisions in the event of their losing capacity to do so themselves. This can be known as enduring power of attorney, medical and financial. Have you appointed an enduring power of attorney medical and financial and who did you choose and why? If not, who do you think you would choose and why?
- (8) In some jurisdictions, someone can be appointed to make lifestyle choices for a person in the event of their losing capacity to do so for themselves, e.g. to arrange meals at home, home visits or to move you into aged-care accommodation. A person with these responsibilities can be known as a Guardian. Have you appointed a Guardian and who did you choose and why? If not, who do you think you would choose and why?
- (9) If you have a will, who are your beneficiaries? Who did you choose and why? If not, who do you think you would choose and why?

- (10) Is there anything else you would like to say about your will and end-of-life plans? [Prompt: funeral plans]

Two final questions concern the end of life.

- (11) What thoughts do you have about your physical end of life? [Prompt: Any beliefs about euthanasia, life after death?]
- (12) Do you have an advance care plan or directive? [Explain if not] How did [would] you frame your values directive and why? How did [would] you frame your instructional directive and why?

END



**Attorneys**

Have you appointed attorneys (financial, medical)

Yes/No

Who are your Attorneys in relation to you?

Spouse/Partner  
 Sibling (sister, brother)  
 Child (daughter, son)  
 Niece, nephew  
 Friend (male, female)  
 Professional person (doctor, lawyer, priest)

**Guardian**

Have you appointed a guardian?

Yes/No

Who is your Guardian in relation to you?

Spouse/Partner  
 Sibling (sister, brother)  
 Child (daughter, son)  
 Niece, nephew  
 Friend (male, female)  
 Professional person (doctor, lawyer, priest)

**Advance Care Directive**

Some jurisdictions provide for an advance care directive where a person specifies what type of treatment they wish to receive in the event of losing decision-making capacity.

It often has two parts, where a person firstly makes an **instructional directive** stating what type of medical treatment they want/do not want, e.g.

if they suffered a catastrophic medical event which did not kill them but left them with no realistic prospect of a decent recovery, would they want to receive:

the full treatment available or only comfort care including pain relief?

invasive surgery or not?

If asked, what would be your instructional directive?

The second part is a **values directive** where the person provides details on what about being a human being and alive is important to them, e.g. being mobile, able to communicate with other human beings in a meaningful way or to go on living no matter what their circumstances.

If asked, what would be your values directive?

END

## APPENDIX 2: PARTICIPANTS' BIODATA, 1, 2, 3

### 1. Work, relationships, children, family $n = 43$

---

<b>Code</b>	<b>Name</b>	<b>Age</b>	<b>Location</b>	<b>Occupation</b>	<b>Relationship</b>
	Atticus	88	California	Hairdresser <b>R</b>	Single, gay widowed
	Clive	81	Australian Capital Territory	Musician <b>R</b>	Single, strgt separated
	Douglas	80	Victoria, Australia	Chemist <b>R</b>	strgt marr + gay de facto
	Edward	77	Australian Capital Territory	Writer/historian	gay de facto; strgt divc'd
	Andrew	75	Ontario, Canada	Historian <b>R</b>	gay common law (de facto)
	Lewis	74	Australian Capital Territory	Pub serv <b>R</b>	gay de facto
	Joel	74	California	Soc wkr; corp exec <b>R</b>	Single, strgt divc'd
	Harvey	74	North Carolina	Academic	Single; strgt separated
	Fabian	74	Australian Capital Territory	Teacher <b>R</b>	gay de facto
	Nicholas	72	New South Wales	Counsellor <b>R</b>	gay de facto
	Rowan	71	England	Academic	gay married
	Preston	70	Australian Capital Territory	Sales <b>R</b>	Single, gay widowed
	Gideon	70	New South Wales	Pub serv <b>R</b>	Single
	Emmett	70	England	Academic	gay civil ptrn'd

*(Continued)*

<b>Code</b>	<b>Name</b>	<b>Age</b>	<b>Location</b>	<b>Occupation</b>	<b>Relationship</b>
	Dorian	70	New York State	NFP consultant	gay married
	Seth	68	California	Vol HIV org; pub serv <b>R</b>	Single; strtg divc'd
	Kieran	67	England	Sec charitable org <b>R</b>	gay civil ptrn'd
	Wade	66	England	Counsellor <b>R</b>	gay married
	Davis	65	California	IT consultant	Single
	Toby	64	British Columbia	Health care mgr <b>R</b>	gay common law (de facto)
	Scott	62	Australian Capital Territory	Teacher	gay de facto; strtg divc'd
	Edwin	61	Victoria, Australia	Clerk	gay de facto
	Quinn	60	Victoria, Australia	Retired (no work details)	Single
	Mason	60	California	IT consultant	gay married
	Ethan	59	England	Clerk	Single
	Carl	58	New Zealand	Mgr glbt NFP	gay de facto
	Randolph	57	Germany	Mgr disability support <b>R</b>	Single
	Eric	57	Hong Kong	HR <b>R</b>	gay de facto
	Carter	57	New Zealand	Academic	gay civil union
	Harrison	56	Victoria, Australia	Gen mgr NFP	gay married
	Ellis	56	England	Product engineer	Single
	Bruce	56	Victoria, Australia	Entrepreneur	gay de facto
	Donovan	55	England	Data analyst <b>R</b>	gay civil ptrnshp
	Jonathon	53	England	HR consultant	gay married
	Johann	52	England	Architect <b>R</b>	gay civil ptrnshp
	Damien	52	England	Mktg consultant	gay de facto
	Christopher	52	New South Wales	Disability pension	Single
	Warren	50	Western Australia	Academic	gay married
	Roland	50	Victoria, Australia	IT engineer	gay married
	Anton	45	England	Judge	Single
	Declan	42	Victoria, Australia	Sales + customer services	gay de facto
	Aiden	42	England	Lawyer	gay de facto; gay separated

*(Continued)*

<b>Code</b>	<b>Age</b>	<b>Location</b>	<b>Occupation</b>	<b>Relationship</b>
Damon	40	Australian Capital Territory	Teacher	gay de facto
Code Name	Age	Location	Occupation	Relationship

Co = couple Ch = family of choice E = estranged from family of origin O = family of origin NFP = not for profit R = retired ^ Family = participants' current family type; see Chapter 1.

## 2. End-of-life documents, instructions, $n = 43$

<b>Code</b>	<b>Age</b>	<b>Will</b>	<b>Executor</b>	<b>Beneficiaries<sup>^</sup></b>	<b>PoA#</b>
Atticus	88	Y	fr; prp	nce, nph, frs, char;	Prp
Clive	81	Y	pub trustee	sp; ch; stp-ch	No
Douglas	80	Y	sp; ch; prp; fr	sp; ch	sp; ch
Edward	77	Y	fr(m); prp	ptr	No
Andrew	75	Y	ptr	ptr	Ptr
Lewis	74	Y	nph, nce	ptr's nce, nph; char, fr	fr(m + f)
Joel	74	Y	sib	g/ch; nce, nph, frs	Prp
Fabian	74	Y	nph, nce	nphs, nces ( $n = 4$ )	nph, nce
Harvey	74	Y	fr(m)	sib(f); nph	fr(m); sib
Nicholas	72	Y	ptr	ptr	Ptr
Rowan	71	Y	sp, nce	sp, nce, char	Sp
Preston	70	Y	fr(m)x2	sib(m)x2, nce, frs, char	frs(m)
Gideon	70	Y	pub trustee	nce, nph, g-ch(m)	Nph
Emmett	70	Y	ptr, prp; fr	ptr(50), nce/nph(30), frs(20)	Prp
Dorian	70	Y	sp; sib; prp	sp(90), sib(m)(10)	Prp
Seth	68	Y	nce	nce, nph	No
Kieran	67	Y	ptr; prp; fr	ptr, sib(f), char, nce	Prp
Wade	66	Y	sp; fr	sp	Sp
Davis	65	No	No	[nce, ptr's nce]	No

(Continued)

Code	Name	Age	Will	Executor	Beneficiaries^	PoA#
	Toby	64	Y	ptr; neph	ptr, nce/neph, frs, char	ptr then nce/neph
	Scott	62	No	[sib(m)]	[ch(f)]	[Unsure]
	Edwin	61	No	[Would not appnt]	[char]	[ptr]
	Quinn	60	Y	sib(f)	gr/ch of dec. ptr	No
	Mason	60	Y	sp, sib, sib's ptr	sp, sib, sib's ptr	sp, sib, sib's ptr
	Ethan	59	Y	fr(m); prp	charity(66); g-ch(f)(33)	No
	Carl	58	Y	sib(m)+prp	sib(m)x2	No
	Randolph	57	Y	fr; prp	frs	No
	Eric	57	Y	sib	sp	Sp
	Carter	57	Y	ptr	ptr then ch	No
	Harrison	56	Y	sp	sp; ch	Sp
	Bruce	56	No	[nph/nce]	[nph/nce]	[ptr then fr(m)]
	Ellis	56	No	[sib(m), nce]	[nph/nce, char]	[sib(m), nce]
	Donovan	55	Y	prp	sp(95), fr(5)	Sp
	Jonathon	53	Y	ptr; sib	ptr, sib, char	No
	Christopher	52	No	[cou]	[ch of cou x 2]	[cou]
	Johann	52	Y	prp	sp, frs, char	sp, f(m)
	Damien	52	Y	sp; fr(f)	sp then f(70), char(30)	Sp
	Warren	50	Y	ptr then ptr's sib(f)	ptr then sibs + ptr's sibs	ptr then ptr's sib(f)
	Roland	50	Y	sp; fr(m)	sp; char	sp; f(m)
	Anton	45	Y	fr; prp	sib(80), frs(20), char(default)	No
	Declan	42	No	[ptr]	[ptr]	[ptr]
	Aiden	42	No	No	[sib(f)bulk; sp]	No
	Damon	40	Y	sp; fr(f)	nce(2)	No
	Code Name	Age	Will	Executor	Beneficiaries^	PoA#

ch = child(ren) char = charity/charities cou = cousin f = female fr = friend g-ch = god-child gr/ch = grandchild m = male nce = niece nph = nephew prp = professional person ptr = partner (for those in de facto or common-law relationships) sib = sibling sp = spouse (for those who were married) stp-ch = stepchild(ren) ACP = Advanced Care Plan PoA = Power of Attorney.

^ Figs in brackets represented approximate percentage distribution to beneficiaries; abbreviations in parentheses represented those who could be participants' beneficiaries if they were to write a will; abbreviations in parentheses were used also to signify participants' most likely choice of executor or power of attorney.

~ = Living will, which is roughly equivalent to an Advanced Care Directive (see Chapter 3).

3. Education, Occupation, Income, Assets, Superannuation/Pension,  $n = 43$ 

<b>Code Name</b>	<b>Age</b>	<b>Education</b>	<b>Occupation</b>	<b>Income AUD*</b>	<b>Assets AUD*</b>	<b>Super/Pension AUD*</b>
Atticus	88	Trade dip 1952	Hairdresser <b>R</b>	NP	NP	NP
Clive	81	Pgrad Dip 1963	Musician <b>R</b>	25K	250K	NP
Douglas	80	Dip 1960	Chemist <b>R</b>	200K	6.5M	4M
Edward	77	BA(Hons) 1965	Writer/historian	26K	500K	Nil
Andrew	75	PhD 1975	Historian <b>R</b>	163.6K	1.36M	129K
Lewis	74	Year 9	Pub serv <b>R</b>	25K	10K	450K
Joel	74	MSW 1998, MBA 1970	Soc wkr; corp exec <b>R</b>	65K	653K	Income
Harvey	74	PhD 1988	Academic	82K	273K	Nil
Fabian	74	BA DipEd 1966	Teacher <b>R</b>	55.3K	400K	483K
Nicholas	72	MCounselling	Counsellor <b>R</b>	36K	900K	350K
Rowan	71	PhD 2002	Academic <b>R</b>	54K	1.75M	Income
Preston	70	BCom 2001	Sales <b>R</b>	60K	2.5M	60K
Gideon	70	BA 1971	Publ serv <b>R</b>	37K	300K	300K
Emmett	70	D.Phil	Academic	NP	2.7M	NP
Dorian	70	BA 1973	NFP consultant	139K	1.6M	NP
Seth	68	BA	Vltr HIV-org; pub serv <b>R</b>	87.5K	340K	235K
Kieran	67	MA 1974	Secry charitable org <b>R</b>	45.3K	1.4M	NP
Wade	66	MSc 2003	Counsellor <b>R</b>	57.5	1.1M	As for assets
Davis	65	Trade dip	IT consultant <b>R</b>	28K	92K	NP
Toby	64	MNurs	Health-care mgr <b>R</b>	113K	NP	NP
Scott	62	BA 2001	Teacher	101K	400K	150K
Edwin	61	Year 12	Clerk	60K	800K	230K
Quinn	60	LLB 2003	Lawyer	80K	3M	Nil
Mason	60	Year 8	IT consultant	131K	1.97M	394K

*(Continued)*

<b>Code</b>				<b>Income</b>	<b>Assets</b>	<b>Super/ Pension</b>
<b>Name</b>	<b>Age</b>	<b>Education</b>	<b>Occupation</b>	<b>AUD*</b>	<b>AUD*</b>	<b>AUD*</b>
Ethan	59	BA 1981	Clerk	56K	698K	NP
Carl	58	BA	Mgr GLBT org	NP	NP	NP
Randolph	57	MA 1988	Mgr disability support <b>R</b>	27.5K	98.5K	Nil
Eric	57	BA 1984	HR <b>R</b>	90K	9M	115K
Carter	57	JD	Academic	177K	3.26K	3.54K
Harrison	56	MBA 2015	Gen-mgr NFP	125K	650K	800K
56Ellis	56	BMus 1986	Product engineer	104.4K	550K	27.K pa
Bruce	56	MBA 1999	Entrepreneur	160K	2M	300K
Donovan	55	PhD 1997	Data analyst <b>R</b>	25K	1M	500K
Jonathon	53	MBA 2001	HR consultant	537K	3.6M	895K
Johann	52	MPlanning 2003	Architect <b>R</b>	25K	700K	126K
Damien	52	MBA 2008	Mktg consultant	203K	4M	1.4M
Christopher	52	BA	Disability pension	23K	20K	Nil
Warren	50	PhD 2010	Academic	140K	500K	500K
Roland	50	BAppSci 1991	IT engineer	98K	500K	280K
Anton	45	LLB 2001	Judge	268K	NP	NP
Declan	42	Dip Bus 1997	Sales + cus services	65K	100K	100K
Aiden	42	LLM	Lawyer	205K	53.5K	321K
Damon	40	BA, BEd 2004	Teacher	132K	600K	160K
Code name	Age	Education	Occupation	Income AUD*	Assets AUD*	Super/ Pension AUD*

NP = not provided R = retired \* Approximate value of participants' income, assets, and funds held in superannuation or pension accounts were expressed in Australian dollars, 2019–2020.

# INDEX

- Acts of kindness, 55–56  
Adelaide Botanic Gardens, 55  
Advance care, 2–3, 62, 79  
    directives, 63  
    plan, 61–62  
Advance statement, 62–63  
Affective and intimate lives, 11  
    civil union, civil partnership,  
        32–33  
    couple relationship, 15–18  
    estrangement, 21–24  
    formerly married or civil  
        partnered, 34  
    household and family, 12–15  
    participants family of origin,  
        19–21  
    participants' current family,  
        24–28  
    participants' family settings,  
        19–28  
    participants' relationship history  
        and status, 28–34  
Afterlife beliefs, 87–88, 93–94  
    afterlife as possibility, 105  
    living on in lives of others, 105  
    participants' afterlife beliefs,  
        102–105  
Age and authority, 81–83  
AIDS epidemic, 130  
Alternative family, 14  
Alternative insemination, 14  
Altruism, 75–76  
Art Gallery of South Australia, The,  
    55  
Ashes, 122  
Assisted dying, 88, 91–92  
Assisted suicide, 88–89  
Australian Capital Territory  
    (ACT), 5, 20–21, 43–44,  
    95–96, 116  
Baby Boomer generation, 67–68  
Benefactions, 56  
Beneficence, 55–56  
Beneficiaries, 52–57  
    charities, 54–55  
    children, grandchildren,  
        godchildren, 57  
    friends, 56–57  
    nieces, nephews, 54  
    partner, 53  
    siblings, 55–56  
Blended family, 13–14, 20–21  
Blended-family-life, 19–20  
Bone Crusher, 120, 123–124  
Buddhism, 87, 93  
Burial, 120–122  
California Department of Justice,  
    62  
Canadian health system, 100–101  
Catholic education systems, 119  
Catholic school system, 119–120  
Catholic upbringing, 119  
Charities, 54–56  
Children, 57  
Chinese-Australian gay men, 3–4  
Choice of executor  
    family member, 47–52  
    friend, 47–52  
    partner, 47–52  
    professional person, 47–52  
Christianity, 87, 93

- Christians, 103–104
- Circle of Friends, 113
- Civil partnership, 32–33
- Civil union, 32–33
- Co-existing relationships, 15–16
- Co-parenting arrangement, 14
- Comfort care, 71–72
- Commemorative medals (from cremated remains), 124
- Competency, 50
- Contemporary funerals, 111
- Continuous deep sedation, 89
- Country Network, The, 4
- Couple relationship, 15, 18, 25
  - gay couple relationships, 16–18
- Covid-19, 1, 5
  - global pandemic, 46
  - outbreak, 46
- Cremation, 122
- Death, 77–78
  - with dignity, 77–78
  - gay familiarity with, 67–68
- Dignitas (organization), 88–89
- Dignity, 75–78
- Dirty death, 84–85, 129
- Disposing of body, 120–124
  - burial, 120–122
  - cremation, 122
  - medical science, tip or bone crusher, 123–124
- Domestic violence, 15–16
- Double-effect sedation, 90
- Durable power of attorney, 79–80
- Dying, 77–78
  - with dignity, 88
- End-of-life decisions, 91–92
- Enduring power of attorney (EPA), 79–80
- Estrangement, 21–24
- Euthanasia, 69, 71, 87–88, 90, 93
  - participants' views on euthanasia, 94–102
- Executor, choice of, 47–52
- Extended families, 12, 21
- Extended-family-life, 19–20
- Family, 12, 15, 64–65
  - of choice, 13–15
  - estrangement, 22
  - role of, 127–128
  - settings of gay men, 13–15
  - tradition, 113–114
- Fee-based assisted dying, 88–89
- Friends, 51–52, 65–66, 83
- Funeral directors, 111
- Funeral plans, 110–124
  - disposing of body, 120–124
  - non-religious services, 115–120
  - religious services, 112–115
- Gay couple relationships, 16–18
- Gay familiarity with death, 67–68
- Gay men, 40, 111–112
  - end-of-life experiences, 1–2
  - household or family settings of, 13–15
  - methodology and sample, 3–6
- Gay rights organizations, 55
- Gay social support services, 54–55
- Godchildren, 57
- Good death, 84–85, 94
  - gay men's understanding of, 129–130
- Grandchildren, 57
- Green burials, 121
- Health care, 79–80
- Health Care and Care Facility Act (1996), 62
- Health Quality & Safety Commission, 62–63
- Health sector, 66
- Hinduism, 87, 93
- HIV, 67–68, 127
- HIV-AIDS epidemic, 40–41, 64, 67–68, 83–84
- Homophobia, 22
- Hospice UK, 62–63
- Household, 12–15
  - settings of gay men, 13–15

- Individualization, 12–13, 16
- Inheritance system, 39
- Islam, 87, 93
- Judeo-Christian tradition, 90
- Legalized euthanasia, 94
- LGBT, 127–128
- Marriage equality, 17
- Medical aid in dying, 94
- Medical assistance in dying, 94
- Medical science, tip or bone crusher, 123–124
- Medical technology, 92
- Medically assisted suicide, 92
- Mulga Bill's Bicycle Band, 116
- National AIDS Memorial Grove, 113
- National Council of Palliative Care, 62–63
- Nazi euthanasia programme, 91
- Nephews, 54
- Nieces, 54
- Non-religious funerals, 111
  - service, 119
- Non-religious services (*see also* Religious services), 115–120
  - sketchy plans, 117–120
  - well-developed plans, 116–117
- Nuclear family, 12–13, 20
- Oprah Winfrey television programme, 124
- Orchestra of the Age of Enlightenment, The, 55
- Ostracism, 22–23
- Pain relief, 71–72
- Palliative care, 96
- Parents, family tradition, 113–114
- Parsimonious direct sedation, 90
- Participants afterlife beliefs, 102–105
  - belief in afterlife, 104
  - no belief in afterlife, 103
- Participants current family, 24–28
  - couple relationship, 25
  - family of choice, 25–28
  - family of origin, 24
- Participants family of origin, 19–21
  - blended family, 20–21
  - extended family, 21
  - nuclear family, 20
- Participants relationship history and status, 28–34
  - Common Law, de facto, 29–31
  - gay married, 31–32
  - single, 30–31
- Participants views on euthanasia, 94–102
  - arguments, 95–98
  - avoid unnecessary suffering, 95–97
  - choice and rights, 97–98
  - equivocal or opposed, 101–102
  - previous experience and concerns, 98–101
- Peaceful euthanasia, 102
- Personal care, 79–80
- Physical and mental end of life, 61–62
  - advance care, 62–79
  - comfort care and pain relief, 71–72
  - do not resuscitate, 71
  - end-of-life awareness, 64–68
  - euthanasia, 69–71
  - instructional directive, 69–74
  - power of attorney, 79–84
  - values directive, 74–79
- Physical disability, 77
- Physician-assisted dying, 89
- Pinnacle Foundation in Australia, 55
- PLWHA support services, 55
- Polyamory, 15–16, 30
- Power of attorney, 2–3, 62, 79, 84
  - age and authority, 82–83
  - knowledge and trust, 81–82
- Pre-exposure prophylaxis (PrEP), 67–68

- Professional person, 50
- Property EPA, 79–80
- Property ownership arrangements, 44
- Pseudonyms, 5–6
- Quality of life, 78
- Rational suicide, 90–91
- Religious services (*see also* Non-religious services), 112–115
  - parents, family tradition, 113–114
  - partner, 114–115
- Religious traditions, 93
- Rotary International, 111
- Same-sex marriage, 17
- Secular liturgies, 111
- Sedation, 90
  - to unconsciousness and death, 90
- Sentience, 75, 78–79
- Serial monogamy, 15–16
- Solitaires, 12
- Speculative judgement, 74
- Terminal anaesthesia, 88–89
- Traditional qualitative research techniques, 4
- Transfer of property, 39–40
- Two-stage funeral procession, 110
- Values directive, 74–79
  - altruism, 75–76
  - dignity, 76–78
  - sentience, 78–79
- Vegetative state, 69–70, 75–77, 129
- Welfare EPA, 79–80
- Wills and beneficiary decisions, 39
  - beneficiaries, 52–57
  - changed material circumstances, 44–45
  - changed relationship status, 42–44
  - choice of executor, 47–52
    - family member, 48–49
    - friend, 51–52
    - partner, 53
    - professional person, 50
    - will revision, 42–47
- Withdrawal of treatment, 88
- Zoom online conference platform, 5

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