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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,¹ which is a relatively new instrument for end-of-life planning,² 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'.³ 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.⁴

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

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.⁵ 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.⁶ 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.⁷

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.⁸ 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

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.⁹

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.

9 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.¹⁰ 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).¹¹ 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

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-1990s¹² – 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 sales¹³ – 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-AIDS¹⁴ – 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,¹⁵ 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'.

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 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 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.¹⁶ 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'.¹⁷

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

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’.¹⁸ 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.¹⁹

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.

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.²⁰

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:

²⁰ 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.²¹

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.

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 be 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'.²² 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.²³ 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).²⁴

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

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.²⁵ 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.²⁶ 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'.²⁷

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.

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: [see: https://www.health.vic.gov.au/patient-care/medical-treatment-planning-and-decisions-act-2016](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.²⁸ 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?

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’.²⁹ 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

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'.³⁰ 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'.³¹

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