Advance Care Planning: What Gives Prior Wishes Normative Force?

NANCY S. JECKER*

Abstract

The conventional wisdom about advance care planning holds that the normative force of my prior wishes is simply that they are mine. It is their connection to me that matters. This paper challenges conventional thinking. I propose that the normative force of prior wishes does not depend exclusively on personal identity. Instead, it sometimes depends on a special relationship that exists between a prior, capacitated person and a now incapacitated person. I consider what normative guidance governs persons who stand in a special relationship, and contrast these with the standard model of respect for autonomy. My conclusion is that advance care planning for individuals who have lost decision-making capacity should incorporate the virtues of prudence and integrity, even when one and the same person ceases to exist, and respect for personal autonomy is no longer relevant.

Keywords: Advance care planning, normative guidance, autonomy, capacity, personal identity, decision-making

Introduction

When I grow old, if I were to experience dementia and lose decision-making capacity, how should medical decisions be made on my behalf? Framing the

* University of Washington, School of Medicine, Department of Bioethics & Humanities. Seattle, Washington 98195-7120, United States. Email: nsjecker@uw.edu.
question in this way, as a concern about my own future self, shapes the way we reason about the problem and may change the answer we give. To begin with, first person framing elicits heightened concern because whatever happens to the future person will happen to me. In other words, I anticipate being in the subjective state of the future person and experiencing directly that person’s pains and pleasures. Their burdens and benefits will be my burdens and benefits. By contrast, when I imagine other people’s futures, I anticipate being an outsider and observer of someone else’s experiences.

First person framing also awakens a sense of personal responsibility. One feels a heightened duty to act or omit acting in certain ways now so that one’s future is more likely to go the way one would like it to go. Even if I do not believe my future is entirely under my control, I may believe that my actions now partly shape it. By contrast, I generally believe I cannot control the futures of others much or at all. Thus, I regard myself as responsible for my future in a way that I do not for other people’s futures.

In addition, first person framing elicits particular feelings and emotions. When it is my future self, I feel a certain way that I do not feel when it is someone else’s. For example, imagine a future person in poor health with a progressive dementia, such as Alzheimer’s. The prognosis for this condition includes reduced cognitive abilities; gradually worsening memory; eventual loss of orientation to place and time; along with personality changes such as combativeness, restlessness and impulsivity. If such things were going to happen to me, I would feel afraid and anxious; if they were imminent for someone else, I may feel compassion and empathy, but not fear or anxiety.

Finally, it is noteworthy that first person framing sidesteps the metaphysical problem of whether a future incapacitated individual is identical with me now. It simply assumes the persistence of one and the same person over time. Rather than wrestling with the problem of whether I survive the loss of memory and personality, first person framing simply takes this for granted.

In this paper I propose that first person framing is roughly the right way to think about decision-making on behalf of a person who loses decision-making capacity. This proposal is not based on showing that a person at some time $t$, prior to dementia, is identical in the strict and philosophical sense to the person who lacks capacity and exists at a later time, $t+1$. Instead, I draw on a looser, but related, notion of personal identity that I call “the narrative self”. A narrative self embodies a type of connection that exists between a successor and predecessor by virtue of sharing objects and physical spaces, standing in the same roles and relationships, and experiencing and interpreting the world through the same physical body. According to this analysis, the ethical
challenge is to understand our ethical responsibilities toward a future incapacitated individual with whom we stand in a special relationship. To address this challenge, I appeal to modified forms of prudence and integrity and show how they can shed light on the ethical duties between predecessors and successors. If the argument of this paper is persuasive, it follows that the question of whether personal identity persists is not a question we must answer in order to address the practical clinical concern of how we ought to make medical decisions on behalf of individuals who lose decision-making capacity.

Two Views about the Persistence of Persons

The conventional wisdom about advance care planning holds that the normative force of my prior wishes is simply that they are mine. It is their connection to me that matters. This view undergirds two opposing positions about the persistence of persons. The first position, which I will call “the two-person view”, holds that in certain cases involving permanent loss of psychological connection and continuity, a prior capacitated self ceases to exist and has no special moral authority over the now incapacitated patient. The second position, which I will refer to as “the one-person view”, holds that, on the contrary, an individual can survive over time despite the absence of psychological continuity and connectedness, and therefore can retain moral authority to make decisions on behalf of a now incapacitated person. According to the one-person view, even though the later person loses capacity for autonomous decision-making, their autonomy can be extended and honoured provided their prior wishes can be known.

The divide between these two positions has been challenging to bridge. Bridging it appears to require nothing less than a full-fledged philosophical account of personal identity across time. If this is right, then in order to settle the practical problem of who should decide on behalf of an individual who loses capacity, we need first to settle what the necessary and sufficient conditions are for a person to continue to exist, and then we may apply these to the case at hand.

To gain insight into why this debate is so intractable, it is helpful to look at it in more detail. Consider the one-person view. Those who defend this view typically rely on some form of empirical analysis, such as the spatial-temporal view, which focuses on the continuity of the body over time. According to this view, b is a continuer of a, just in case b’s properties grow out of, or are causally produced by, or are to be explained by, b’s having earlier had the properties a then had. By contrast, those who support the two-person view often maintain that in the absence of psychological continuity and connectedness, an
individual ceases to exist. Proponents of the two-person account often endorse a different type of empirical analysis, one that appeals to psychological qualities such as memory. According to one formulation, \( b \) is a continuer of \( a \) just in case \( b \) possesses all the memories that \( a \) possessed. In other words, a thread of memory connects the individual over time such that even if \( b \) cannot remember \( a \), \( b \) remembers some prior individual who in turn remembers \( a \). Under conditions where memory is sufficiently disrupted and the thread of memory is irrevocably broken, personal identity does not continue. Moreover, even if we could miraculously restore memory, it might be argued that the restored memories do not arise in the right way if they did not come from having had the experiences that produced the memories. Thus an alternative formulation of the two-person view holds that \( b \) is a continuer of \( a \) just in case \( b \) possesses all the memories that \( a \) possessed, and these memories were caused by having had the experiences that led to the memories.

There is no clear winner in this debate, and both positions face numerous alleged counter-examples (Coburn 1985). For example, the spatial-temporal account associated with the one-person view can be objected to on the basis of cases where we think a body continues to exist but a person does not. For example, some would say that Terri Schiavo’s body continued to exist, but she herself did not when she lapsed into a persistent vegetative state. Or, if you are a believer, you may be convinced that general resurrection cases represent a counter-example to the spatial-temporal view. In these cases, a person is thought to die and rot away, and then at some later point come into existence again, at the General Resurrection. This occurs despite the absence of spatial-temporal continuity. If this is right, it cannot be true of personal identity that it holds only when spatial-temporal continuity holds. Finally, the spatial-temporal view has been rejected on the ground that over time, all of the cells in our body die and are replaced. Thus continuity of the body cannot be a necessary condition for the persistence of persons.

The two-person account also faces challenges. For example, what does it mean for a memory to be caused in the “right way”? Consider a case involving brain rejuvenation. Smith’s brain is diseased; a healthy duplicate of it is made and put into Smith’s head. On the assumptions about the role of the brain usually made, the survivor of this process will be just like a healthy Smith. But will that person be Smith? People differ over the answers to puzzling cases such as this one. If multiple healthy copies of Smith’s brain are made, which one is identical to Smith? Presumably, identity is a one-to-one relationship, such that it is not possible for more than one future person to be identical with Smith.
Challenging the Conventional Wisdom

If we cannot settle the metaphysical debate about the persistence of persons, where does that leave us? While it may at first blush seem that this leaves us without a solution to the practical problem of who should decide on behalf of patients who lose decisional capacity, perhaps there is a third alternative. Although both sides take for granted that the importance of my temporally remote desires is based on the glue of a continuous self, this assumption can be questioned. Moreover, although both sides assume that being rational requires (in part) having coherent, stable attitudes over time, this assumption too can be questioned. Let us examine these assumptions in more detail.

The Glue of a Continuous Self

It might be thought that if a person is one and the same over time, that person is rationally required to coordinate their attitudes at different time slices. By contrast, different persons may hold disparate views and are not subject to the same requirement. To illustrate this point, Hedden (2015) uses the following pair of examples.

**Fickle Frank:** Frank is a physicist who changes his mind constantly and frivolously. At breakfast, he is pretty sure that the Everett multiple universe hypothesis is the right interpretation of quantum mechanics. By mid-morning, he abandons that belief in favour of the Copenhagen interpretation. At lunchtime, he switches camp once again, siding with the de Broglie-Bohm theory. But this does not last, and by afternoon, he is firmly convinced that some sort of hidden variable approach must be right. It is not that he keeps gaining new evidence throughout the day to support different hypotheses. Rather, he simply changes his mind.

**The Frankfurt Physicists:** A major conference on quantum mechanics is being held in Frankfurt. In attendance are proponents of a wide range of interpretations of quantum mechanics. There is a team of researchers from MIT who believe that the Everett multiple universe hypothesis is the best explanation of the available data. Seated next to them is an eminent professor from Cambridge who advocates the Copenhagen interpretation. Further down the row is a philosopher of physics who recently authored a book arguing that the de Broglie-Bohm theory is correct. In all, the lecture hall is filled by advocates of at least a dozen competing quantum-mechanical views.

In the case of Frank, we assume that his mercurial nature is evidence of irrationality, because we assume people are rationally required to coordinate their
attitudes at one time with their attitudes at another time. By contrast, we take for granted that the Frankfurt physicists are not required to do that, because they are different people. We appear to set different standards for intra-personal and inter-personal rationality.

Yet consider a different possible analysis. Perhaps what makes Frank irrational is not that the same person holds different views at different times, but rather that Frank decides impulsively and on a whim to switch his position. If we regard the paradigm of a rational act to be one done for a reason, Frank's flip-flopping qualifies as irrational. By contrast, if startling new evidence were to come to light refuting the Everett multiple universe hypothesis, then we would not call Frank fickle. Instead, we would say he was on solid ground when he shifted mid-morning to the Copenhagen interpretation. Likewise, what makes the Frankfurt physicists rational is not that they are different people but the connection between their beliefs and evidence. For example, we assume that their divergent views are backed by different data, or that they interpret the same data differently. Unlike Frank, who is too irresolute to choose a view and stand by it, the Frankfurt physicists' views are anchored by evidence.

According to this account, what makes a person's beliefs rational is not their relation to the attitudes that the person has at another time. Instead, it is their relationship to evidence. The beliefs one held at a prior time, or will come to hold at a future time, carry no more weight than the beliefs of other people. Both intra- and inter-personal rationality share the same standard, namely, matching the world, in the sense of conforming to the best available body of evidence. If a person's beliefs change rationally, this can only mean that the evidence upon which they rely has changed. Notice that this conclusion has nothing to do with the number of people choosing. Notice too that based on this analysis, we do not have a duty to coordinate our beliefs with beliefs we held in the past. We are justified in changing whenever new evidence comes to light, or old evidence is refuted.

In the case of advance care planning on behalf of a person who loses decisional capacity, this analysis helps to clarify the significance of personal identity across time. Rather than assuming that the best choice for an incapacitated patient is to act in a manner that coheres with a prior capacitated self, one ought instead to think in terms of what the evidence now suggests we should do on behalf of that person. The idea here would be to gather information about such facts as the individual's present quality of life, that is, their present enjoyments and pleasures, experiences of pain and suffering, preferences and goals. We can then consider the impact that different treatment options might have. According to this analysis, normative requirements do not
depend on or make reference to the relation of personal identity over time. Instead, moral requirements are impersonal (Hedden 2015, 452). Once we grasp the evidence, we know everything we need to know to form beliefs and make decisions for an individual.

**What Values Matter When a Person Ceases to Exist**

So far I have made the case that we ought to make decisions on behalf of persons who lose decisional capacity on the basis of evidence related to what would be in the incapacitated person’s best interests. We should do this by considering what we know or can glean about that person’s quality of life and the various factors likely to enhance or hinder it. For example, we should make observations about what it is like to be that person, and try to benefit and avoid harming that individual.

In response it could be argued that this view glosses over an important consideration. In the cases involving Fickle Frank and the Frankfurt physicists, the problem is determining the best interpretation of quantum mechanics. What qualifies as evidence is pretty clearly a set of observations about the world. By contrast, in the case of decision-making for a person who loses capacity, empirical observations alone cannot settle the score. Instead, values related to quality of life enter into the equation, as do other societal and cultural norms. Arriving at a decision about what medical treatment to use or continue on behalf of someone who can no longer speak for themself is not simply a matter of empirical observation, it also requires doing good and avoiding harm, being fair, and perhaps considering what the prior capacitated person would want if they were suddenly lucid and could grasp the situation for themself. The question thus becomes: what values should govern if we assume, for the purposes of argument, that the person at \( t \) and the person at \( t+1 \) are not one and the same individual? It is to this question that I now turn.

Suppose I develop dementia and at some future time, \( t+1 \), I cease to exist. This occurs because even though the individual with dementia continues to exist, I do not survive the loss of psychological connectedness and continuity. Instead, there are two people—the person who has my memories and no longer exists, and the person who lacks my memories and does exist. If this were the case, then the value of respect for autonomy would lose its moral force. Since the person at \( t+1 \) is not identical to me, I would lack the ethical authority to decide for that person on the basis of my values, because these are my values, and may or may not match the values the other person holds. At best, it seems, I may be justified in acting as a surrogate for the future person on the
grounds that I know the future person well, understand her values, and am well-situated to act in accordance with what she would want, were she suddenly lucid and able to speak on her own behalf. However, from a practical standpoint, even my ability to predict the values and desires of the person at t+1 could be challenged. After all, how could I possibly claim to know them? The person at t+1 comes into existence at a future time when I have ceased to exist. Thus, I cannot possibly gather any direct, first-hand evidence about the individual at t+1. It might seem preferable to leave decision-making to contemporaries of the person at t+1; after all, contemporaries are in a position to do what I cannot, namely, make first-hand observations of the future person, talk to her, and advocate for that individual’s interests in real time. If this is correct, it follows that when we adopt the two-person view, the ethical basis for my decision-making authority over the demented individual is undercut. If we accept this conclusion, we might well wonder, what should I do now? If the future demented person is not me, then it appears I have no more reason to serve the best interests of that future person now than I have to serve the best interests of any other person who exists at a future time, t+1.

Yet I submit that this approach does not survive careful scrutiny. Upon reflection, even assuming that the two-person view is correct, we can nonetheless say that I am connected to the person at t+1 and stand in a “relationship” of a special sort with her. I will refer to this relationship as a “special relationship,” although from a strict and philosophical sense, a relationship requires two relata, and according to the two-person view, one of the two persons has ceased to exist. We can characterise the connection by saying that the person who comes into existence at t+1 used to be me. She is my successor, not someone else’s successor. As soon as I depart, she resides in the same place I was in and “takes over” my life. This observation opens the door to many others. My successor perceives and experiences the world in the body that used to belong to me, lives in the home I once lived in, is visited by my friends, belongs to my family, is cared for by my doctor, and even enjoys access to my bank account and all my worldly possessions. On the basis of these kinds of observations, that person and I might be said to stand in a unique and special relationship.

A useful, albeit imperfect, analogy is the connection that exists between me now and the physical remains and worldly possessions I will one day leave behind. I have legal and ethical authority to make decisions about what will happen to such things. For instance, I can prepare a last will and testament, and can choose to dispose of my worldly possessions and bodily remains in whatever manner I see fit. Those who outlive me ought to respect my wishes,
because the objects and body are mine in an enduring way that survives my personal demise. Obviously, the physical remains I leave behind are not identical with me; what I am pointing to is the fact that they are my remains. In the death case, the past person exercises moral authority regarding what happens to her body after death, even though nothing we can do to a person’s body can affect a person who has ceased to exist. The basis for honouring a dead person’s wishes is that the remains and the past person are connected in a special, unique way. To speak metaphorically, we can say that the person has a unique relationship with their corpse, namely: they used to inhabit it.

How can this observation be of help in the present case? It might be thought that even if the future incapacitated person is not me, by virtue of being my successor I have a special stake in that individual’s welfare. Speaking metaphorically, just as I have an interest in what happens to the body I used to inhabit, I have an interest in what happens to the person who takes over my life. In both cases, the moral significance of prior wishes is not based on respect for autonomy, because the assumption is that the future person, like the corpse, is not identical to me. Instead, the moral significance of prior wishes is grounded in the special relationship in which my successor and I stand.

Yet perhaps I am taking this analogy for more than it is worth. After all, in the case of two living individuals, each has a distinct point of view and subjective experience of the world. The person at \( t+1 \) who lacks capacity, is a living being with feelings and experiences that a corpse lacks. Since we would be making decisions about another person, not an object, it seems that the other person’s current subjective experience and point of view matter morally and must take precedence.

Nor can I stake a claim by saying that this person is partly me, or in transition to being not-me. For there can be no temporal overlap between the prior capacitated person and the now incapacitated person. This is because personal identity is an all-or-nothing relationship; it does not admit of degrees. We do not believe, for example, that statements such as “she is your aunt” or “he is the person you married in 1973” admit of degree. Thus, when the demented person who is not me comes into existence, I am gone.

In response, we need to remember that we are talking about a person who lacks decisional capacity. Hence someone else must decide on that person’s behalf. Although a predecessor cannot experience directly the point of view of the incapacitated patient, this is true of any surrogate decision-maker, not just the predecessor. If this fact by itself disqualifies the predecessor who exists at \( t \) from making decisions about a successor who exists at \( t+1 \), then it disqualifies all surrogate decision-makers.
Consider a different analogy. When a person loses decision-making capacity, we typically grant decision-making authority to that person’s spouse, adult offspring, parents or siblings. The ethical basis for this is that such individuals are thought to stand in a special relationship with the incapacitated person. Similarly, it could be argued that we should grant predecessors decision-making authority over their successors. In both cases, we believe that those who stand in a special relationship are well suited to act with the incapacitated person’s best interests at heart, because of their connection and concern for that person. In addition, we expect them to be well situated to know and act upon the individual’s values and preferences because of that unique relationship.

To clarify special relationships further, it is helpful to contrast them with the identity relationship. Although identity is a straightforward, all-or-nothing relationship, it nonetheless exists along a continuum. At one end of this continuum, we say that an individual at time $t$ is identical with an individual at time $t+1$; at the other end, the individual at time $t$ and the individual at time $t+1$ are strangers. In the interstices between we find varying degrees of proximity: a loved one, friend, family member; a fiduciary relationship between physician and patient or teacher and student; cousins; acquaintances; the friend of a friend; someone we see on our daily commute; an individual who lives in a faraway country that we read about on the Internet; a person born in the distant future. What I am arguing is that the relationship of being the “successor of” or “predecessor of” is like a close relationship, and is situated at the same end of the spectrum as a loved one, friend or close family members. DeGrazia (1999), for example, suggests such a view when he notes that agents of an advance directive would “identify with” their successors, even if they were not identical to them. He goes on to characterise the nature of the concern he would have for a successor as “prudential” as opposed to altruistic, noting that even if a person ceases to exist, they may care about the future survivor: “As far as severe dementia is concerned, there may be good reasons to doubt that personhood is all that really matters” (DeGrazia 1999, 390).

**Prudence and Integrity**

If we suppose that a person who experiences dementia ceases to exist due to the loss of psychological continuity and connectedness, then perhaps the normative force of prior wishes must be explained by appealing to values other than autonomy. Prudence and integrity may serve as useful guides in this regard. Prudence requires managing the claims of the self at distinct time slices, and sometimes denying the demands of present time slices with an eye to serving
the welfare of the whole, temporally extended self (Nagel 1979). If we modify prudence and refer not to the self at distinct time slices, but to the self and its successors at distinct time slices, we can draw on prudence as an ethical guide, and interpret it as instructing us to keep a successor’s interests in mind when making decisions now. It would be imprudent, for example, to act in a way that would harm my successor, or to act in a way that my successor has reason to reject. Even though that person is not me, by virtue of the special relationship in which we stand, I consider that person’s interests and values, and I care about what happens to that person.

What more precisely would a modified prudential model look like? To start with, we can say that we feel a sense of responsibility for those we are close to which resembles the responsibility we feel toward successors. Whereas helping a stranger is a good thing to do, it is not obligatory in some cases. For example, I do not have an obligation to donate when a stranger knocks on my door requesting money for a worthy cause. Yet if an aunt I see regularly is ill, I have a duty to respond to her that cannot be discharged by helping another ill person. My duty is to do something for this aunt, for example, visit her at the hospital, phone, or bake a casserole and deliver it to her when she returns home. When someone who is dependent on me is ill, my obligation is still greater. Thus, an infant son or daughter who becomes ill exerts a much greater “ethical pull” than my aunt or a stranger does (Nozick 1983, Sommers 1986). Both my future self and my future successor are similar to the infant in their reliance on me now. For example, both my future self and my successor depend on me now to plan ahead, save for retirement and maintain a healthy lifestyle. Both my future self and my successor could be negatively impacted by actions I take now, such as wracking up debt or smoking cigarettes, because they would suffer as a result of such actions. For these reasons, it is reasonable to think prudently not just about our future selves but also about our future successors.

In the case of my successor, one important way to realise my prudential duty to protect that person’s interests is by means of advance care planning. For example, executing a directive to physicians is a way to prudently plan for a successor’s welfare. Likewise it would be reasonable for a physician caring for a patient who has lost decisional capacity to ask those who knew the prior person how that person would decide if she could be miraculously transported to the hospital and make decisions for her successor. My argument establishes that this type of thought experiment has an ethical basis, irrespective of whether we understand the relationship between the past and present person to be an identity relationship (the one-person view) or a successor-predecessor relationship.
(the two-person view). On either account, the past person’s preferences matter. According to this analysis, personal identity is a sufficient, but not a necessary, condition for prudential concern (McMahan 2002).

**Integrity**

One concern with the above analysis, and with the appeal to prudence more broadly, is the worry that acting on behalf of others may not be rational in the way that self-management is. After all, it serves one’s *self-interest* to protect one’s future selves, but protecting the welfare of third parties does not. Thus, if the future person is not *me*, why should I care, or care as much, about that person? This concern raises far broader questions about the rationality of morality, which philosophers have addressed at length elsewhere (Parfit 1984).

One partial response to this objection is to appeal to the value of integrity (Laden 2009). Integrity, according to one account, requires constructing a story that can unify a person’s life and provide a basis for the special concern that a person has for herself across time. As MacIntyre understands it, the most useful criterion for personal identity is a narrative standard:

*The Narrative Criterion of Personal Identity:* what makes an action, experience, or psychological characteristic properly attributable to some person (and thus a proper part of his or her true identity) is its correct incorporation into the self-told story of his or her life (Shoemaker 2014, MacIntyre 1984, 1989).

According to this account, to be a unified person is not simply a matter of numerical identity, but is more broadly a matter of maintaining integrity through processes of change and disruption. Rather than counting the passive subjects of ongoing experience, this account pays attention to agency. It looks for the deliberate activity of constructing a unifying story, a story that relates various experiences over time to each other and to the larger context of a life.

What might this approach say more specifically about the connection between predecessors and successors? Nagel (1979) offers one answer to this question. Nagel regards temporal distance among time slices of a single person as a model for thinking about interpersonal distance. Thus we motivate concern for temporally distant successors in the same way we motivate concern for much later selves. In both cases, we attempt to step outside the present moment and adopt a standpoint of temporal neutrality. Just as thinking about the connection between beliefs and evidence serves as a model for thinking about both the time slices of Fickle Frank and the disparate views of the Frankfurt physicists, so too prudence and its counterpart, integrity, can serve as models for thinking
about both time slices of one and the same person and time slices of persons that stand in the special relationship of predecessor and successor. By adopting temporal neutrality, Nagel’s account lends support to the special concern for both later selves and future successors.

To motivate Nagel’s account, consider the role that elders and ancestors play in personal identity within certain cultural groups. In traditional Navajo culture, for example, one’s identity is partly constituted by one’s history, not only the personal history of an individual, but also the history of the larger group to which one belongs, such as one’s family, tribe and nation. To be uprooted from that history would be to lose one’s identity in a very real sense, because such history partly constitutes the individual. A person with integrity seeks and finds a unity relation between the individual she is now and the various components of her personal identity over time. In this manner, a person with integrity thinks in terms of her life as a whole, considering its overall meaning and significance.

Yet what exactly does it mean to view a life as a whole? Hawkins (2014) proposes two possible interpretations. First, a person’s life can be viewed as simply a collection of events, and the whole can be viewed as consisting of the sum total of these individual events. According to this view, the value of the whole is equal to the value of the parts added together. A second interpretation is to regard a person’s life as not reducible to the value of the individual events. Instead, the second view maintains that certain properties of the whole, such as its trajectory, thematic unity, or the ordering of events, matter too. The narrative account of the self gains traction when we accept something like the second interpretation, regarding the various stages of life as irreducible to the sum of the parts, and recognizing the parts as comprising a meaningful narrative only when considered as a whole.

Dworkin (1994), for example, expresses the second view when discussing decision-making on behalf of an unconscious patient. He judges that for such a patient, “We worry about the effect of his life’s last stage on the character of his life as a whole, as we might worry about the effect of a play’s last scene or a poem’s last stanza on the entire creative work” (Dworkin 1994, 199). According to Dworkin, the last chapter of a life carries significance by virtue of making an essential contribution to the whole; it represents not just any chapter, but the final one. For this reason, when rendering decisions on behalf of someone who is both demented and happy, Dworkin instructs us to sometimes forego lifesaving treatment when foregoing it is consistent with the prior person’s clearly stated wishes. For Dworkin, the last chapter should connect with the chapters that came before, not merely with the present moment. Hence the best interests of the demented happy individual tell us only part of the story.
An example, discussed widely in the literature (Hawkins 2014, McMahan 2002, Dworkin 1994), involves a patient named Rupina, who develops Alzheimer’s yet turns out to be content most of the time. Previously, Rupina executed an advance directive specifying that she should not receive treatment for any potentially fatal condition, preferring to avoid a situation where her final phase of life was a demented phase. When Rupina develops pneumonia, the question arises whether or not to treat her with antibiotics. Since she is clearly experiencing her life as positive now, what is the significance of her past desires? The narrative account might suggest that Rupina is better off if the prior desire not to have a life with a demented end is satisfied even though this may disappoint Rupina now. Prudence directs us to consider the character of Rupina’s life as a whole, rather than focusing exclusively on what Rupina wants in the present moment. Likewise, integrity directs us to decide in a way that contributes to unifying the different parts of Rupina’s life into a meaningful whole. The desires of the past serve as guides to how Rupina’s life has been set up, and give evidence about what might count as a good ending for the narrative of Rupina’s life. According to this analysis, past desires carry normative force, not because we place more value on the past, or place more value on Rupina when her cognitive capacity was still intact, but instead because it is in Rupina’s best interest (at all points in her life) to have a good ending to the narrative that comprises her life (Hawkin 2014, 524). It is the integrity of the narrative, considered in its entirety, that motivates (modified) prudence and sometimes justifies overriding a person’s present wishes.

**Conclusion**

In conclusion, the approach I am proposing regards a range of considerations as integral to decision-making on behalf of incapacitated persons. First and foremost, the narrative of the patient’s life matters. This includes not only the present moment but also the individual’s history and future. The relevance of these contextual features is that making sound decisions for persons requires framing them in terms of the broader perspective of a life, and attempting to sustain a unity relation among different life stages. I refer to this constructed standpoint as a narrative, and the one(s) who constructs the story as the author(s). Ideally, the leading character(s) and author(s) are one and the same. Unfortunately, sometimes another person must carry on as author even while the leading character continues to exist. When cognitive decline advances, patients may no longer be able to tell their own stories, and may need help crafting them in a way that is true to their life and personal narrative. One noteworthy advantage
of advance care planning is that it allows the leading character to continue to author the story on behalf of a future self or successor who is no longer able to function in that way. Surrogate decision-makers should consider both the wishes of the prior capacitated individual together with evidence about the perspective and needs of the now incapacitated patient. A central goal should be unifying these sometimes disparate perspectives into a narrative whole.

Second, even if cognitive decline results in a person ceasing to exist, prior wishes have normative force due to the special relationship that exists between a predecessor and successor. The successor occupies the same place in the world that the predecessor once occupied. Both individuals belong to the same family, stand in the same roles and relationships, experience the world through the same body, possess the same worldly possessions, wake up and go to bed in the same place. The predecessor and successor are hardly strangers, and the significance of the relationship between them deserves recognition (Jecker 1989). The prior capacitated person has a stake in her successor, and cares about how that person’s life unfolds. The connection between them is not dependent on numerical identity but is instead based on a special relationship.

It is worth noting that if we adopt a narrative account of the self, the principle of respect for autonomy continues to exert normative force alongside the values we associate with special relationships. According to both the one-person and the two-person views, the earlier and later individuals are one and the same in the sense of sharing a single narrative self. Self-determination, so understood, is about making decisions in a way that respects the narrative self, that is, the self-told story of a person’s life. Regardless of whether a person survives severe dementia or ceases to exist, respect for the narrative self remains intact.

Finally, first person framing is roughly the right way to think about decision-making on behalf of patients who lose decisional capacity. The values associated with first person reasoning are prudence and integrity, and these values (in modified form) should guide surrogate decisions. Surrogates should attempt to make decisions in a way that evinces concern for the whole of a person’s life, not just a particular moment in time (prudence). Surrogates should also attempt to decide in a way that unifies the various stages of a patient’s life in a meaningful way (integrity). What is good for the patient is not necessarily the same as what is good at a particular moment. Rather than thinking only in terms of time-relative interests, surrogates should think in terms of the best interests of the whole person. In the last phase of life, we ought to consider what represents a better completion of a life, not just what the person wants now. In all phases of life, we ought to ask what makes sense for the person over time, considering life as a whole.
Acknowledgements

I am grateful to Paul T. Menzel for generous assistance with an earlier version of the paper. A draft of this paper was presented at a workshop on “Dying Well: End of Life Care, Advance Directives, and Physician-Assisted Death” held at The Chinese University of Hong Kong, Centre for Bioethics, 9–10 November 2015. The helpful feedback provided by workshop participants challenged me to think more deeply about these issues.

References