

## MAKING END-OF-LIFE CARE DECISIONS FOR OLDER ADULTS SUBJECT TO GUARDIANSHIP

*Zachary Sager  
Casey Catlin  
Heather Connors  
Timothy Farrell  
Pamela Teaster  
Jennifer Moyer*

*This Article addresses end-of-life decision-making by guardians of older adults. First, the Article presents current definitions of hospice and palliative care and describes several common end-of-life disease trajectories. This background information introduces the diverse contexts in which guardians may find themselves when making end-of-life care decisions. The next section sets forth results of our recent research*

---

Zachary Sager is a palliative care physician and psychiatrist. Dr. Sager is currently an advanced fellow at the New England Geriatric Research Education and Clinical Center (GRECC) at Boston VA Healthcare System, where he focuses on end-of-life care for Veterans with trauma and/or substance use disorders.

Casey Catlin is a psychologist and research coordinator with the Boston VA Research Institute (BVARI). Dr. Catlin led the data collection efforts for three studies reported here. Her dissertation research concerns the assessment of values in older adults.

Heather Connors is a gerontologist and research director at Guardian Community Trust. Dr. Connors' research and education efforts focus on improving guardianship for adults. Guardian Community Trust is a non-profit organization located in Andover, Massachusetts that advocates for guardianship reform through research, education, and an active grant-making program.

Timothy Farrell is a geriatrician with the Division of Geriatrics, University of Utah School of Medicine and the VA Salt Lake City GRECC, as well as the University of Utah Health Interprofessional Education Program. He was the lead author on the American Geriatrics Society position statement on the care of unbefriended adults.

Pamela Teaster is a professor in the Department of Human Development at Virginia Tech and director of the university's Center for Gerontology. Her research focuses on guardianship and elder abuse.

Jennifer Moyer is a geropsychologist with the New England GRECC at the Boston and Bedford VA Medical Centers and a professor of psychology in the department of psychiatry at Harvard Medical School. Her research focuses on guardianship, capacity, and adjustment to illness in older adults.

*focusing on end-of-life care for unbefriended adults subject to guardianship. “Unbefriended” adults are those who lack decision-making capacity, have no advance directive, and have no family or friends to serve as a surrogate decision-maker.<sup>1</sup> As such, professional guardians may be appointed when health care decisions are needed. Making health care decisions for such adults, particularly end-of-life care decisions, can be challenging. Little to nothing may be known about the person’s values prior to guardianship and the patient may be unable to convey his or her wishes and goals to the guardian. The third section provides practical guidance to guardians. We discuss the assessment of values – with some thoughts about what to do when it is not possible to assess values. Finally, we discuss several common end-of-life health care decisions that may confront guardians – a code status change, a do not transfer order, and de-escalating care within an intensive care unit. For these situations, we provide information from the perspective of our interdisciplinary team for the purposes of supporting guardians who face these challenging decisions.*

## I. Introduction

Individual health care decision-making authority is governed by state healthcare and guardianship laws. This Article discusses the process of making decisions on end-of-life health care for adults who (1) have lost decision-making capacity due to an advanced illness, and (2) require a healthcare agent to make decisions but have not previously executed an advance directive, and (3) have no family or friends to serve in the role as next of kin or default surrogate decision maker. Historically, the term “unbefriended” has been used to describe such individuals, and although the term “unrepresented” or simply a description of the situation (e.g., “incapacitated older adult without advocate”) is preferable and considered less stigmatizing, this Article utilizes the term “unbefriended” to refer to this population.<sup>2</sup> It is difficult to find a single word or phrase to characterize this population; an essential element is significant social isolation and typically a lack of historical knowledge about the individual. For these individuals, a professional or “stranger” guardian may be appointed.

Guardians face a tremendous burden in responding to requests for decisions by the healthcare team. For example, the healthcare team

---

1. Pamela B. Teaster et al., *Wards of the State: A National Study of Public Guardianship*, 37 STETSON L. REV. 193, 195 (2007).

2. See Timothy Farrell et al., *AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults*, 65 J. AM. GERIATRICS SOC’Y 14 (2016); see Timothy Farrell et al., *Caring for Unbefriended Older Adults and Adult Orphans: A Survey of AGS Members*, (unpublished manuscript) (on file with the Journal of American Geriatric Society).

may suggest or ask that a person's code status be changed to "do not resuscitate" ("DNR") in the context of the person's current illness stage and in consideration of the likelihood that resuscitation would not be successful or may in fact be harmful. The guardian makes a decision guided by authorities within the scope of state law and based on the person's values.<sup>3</sup> However, state laws may not be entirely specific to the end-of-life situation, and, as a "stranger" guardian, the person's values may be unknown to the guardian (assuming the person subject to guardianship is no longer communicative, for example, if a person is sedated in the intensive care unit). Further, some guardians may be unfamiliar with clinical contexts for end-of-life care which have evolved considerably in recent years.

As a response to this dilemma, this Article provides guidance to guardians who face complex decision-making in the end-of-life care context. Section II describes common end-of-life terminology encountered by guardians in the field, as well as a description of common end-of-life illness trajectories. Section III summarizes recent studies about end-of-life care for "unbefriended" persons subject to guardianship. Finally, we discuss some of the most common and difficult decisions that guardians may encounter caring for these patients, and provide clinical, empirical, and practical recommendations.

## II. The End-of-Life Healthcare Context

### A. Hospice and Palliative Care

Hospice is a term familiar to many people through personal experiences with loved ones or family members. Dame Cicely Saunders, a physician, nurse, and social worker in the United Kingdom opened the first modern hospice facility in a London suburb in 1967; and the first hospice facility in the United States opened in 1974.<sup>4</sup> Originally imagined as a physical space for individuals with a terminal illness to die humanely and comfortably, hospice in the United States is now a broad term applied to both a Medicare benefit and a philosophy of care for

---

3. UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT § 313 (UNIF. LAW COMM'N) (2017).

4. *History of Hospice Care*, NAT'L HOSPICE & PALLIATIVE CARE ORG., <https://www.nhpc.org/history-hospice-care> (last updated Mar. 28, 2016).

individuals with a terminal illness.<sup>5</sup> Introduced as a Medicare benefit in 1982 and subsequently made permanent,<sup>6</sup> hospice as a care model provides services for individuals with a terminal illness and a life expectancy of less than six months.<sup>7</sup>

As a philosophy, hospice recognizes that dying is a normal part of life and aims to restore an individual's dignity while focusing on efforts to improve quality of life and provide comfort.<sup>8</sup> As such, the goals of hospice may stand in contrast to a state's "unqualified interest in the preservation of human life."<sup>9</sup> Hospice is provided in settings across the care continuum, in hospitals and in inpatient units, in nursing facilities, and at home.<sup>10</sup> Patients are cared for by a hospice team consisting of nurses and physicians, advanced practice nurses, social workers, chaplains, aides, and volunteers.<sup>11</sup>

Palliative care is often confused with hospice; though many of the goals align, it differs in several significant ways. Palliative care grew out of the hospice movement, but is not strictly focused on individuals at the very end of life.<sup>12</sup> Instead, palliative care is intended for any individual with a serious life-limiting disease.<sup>13</sup> Palliative care can be offered concurrently with life-sustaining care or may be independent.<sup>14</sup> Palliative care also provides services across the continuum, including in the inpatient, outpatient, nursing facility, and home settings.<sup>15</sup> Cen-

---

5. *Id.*

6. *Id.*

7. *Id.*

8. *Preamble and Philosophy*, NAT'L HOSPICE & PALLIATIVE CARE ORG., <https://www.nhpco.org/ethical-and-position-statements/preamble-and-philosophy> (last visited Mar. 12, 2019).

9. See Rebecca Critser, *Assisted Suicide: Is the Cruzan "Unqualified State Interest in the Preservation of Human Life" a Legitimate State Interest?*, 13 NAT'L ACAD. ELDER L. ATT'YS J. 71 (2017) [hereinafter Crister].

10. *Hospice Care*, NAT'L HOSPICE & PALLIATIVE CARE ORG., <https://www.nhpco.org/about/hospice-care> (last updated Apr. 3, 2017).

11. *Id.*

12. William G. Nelson, *Palliative Care: Putting a Cloak on Cancer*, CANCER TODAY, <https://www.cancertodaymag.org/Pages/Spring2017/Palliative-Care-Putting-a-Cloak-on-Cancer.aspx> (last visited Mar. 12, 2019) [hereinafter Nelson].

13. *Id.*

14. *What is palliative care?*, MEDLINEPLUS, <https://medlineplus.gov/ency/patientinstructions/000536.htm> (last visited Mar. 12, 2019) [hereinafter MEDLINEPLUS] ("Palliative care can be given at the same time as treatments meant to cure or treat the disease.").

15. *Id.*

tral to the mission of palliative care providers is addressing the symptoms that accompany a life-limiting diagnosis like cancer, advanced lung disease, or heart disease.<sup>16</sup> These symptoms often include pain, nausea, breathlessness, and fatigue, or may manifest in emotional, social, or spiritual domains. The breadth of issues present at the end of life lends itself to care being provided by a range of professionals, all possessing the same goal of improving an individual's quality of life.<sup>17</sup>

Palliative care, like hospice, is multidisciplinary. Addressing the social, psychological, and spiritual needs of patients is core to the palliative care mission, and teams often include social workers, therapists, and chaplains.<sup>18</sup> An individual with a life-limiting illness can request palliative care involvement at any point in his or her illness trajectory.<sup>19</sup> Palliative care has been demonstrated to be more effective when provided early, and can potentially provide patients with a longer life in some disease processes.<sup>20</sup>

## **B. Differences Between the Trajectories of Three Common End-of-Life Illnesses**

Despite sharing a common end point, the trajectories of various terminal illnesses look quite different. This has important ramifications in palliative and hospice care, and in the context of the decisions that guardians may be asked to make, as services are tailored towards an individual's goals, values, and disease course.<sup>21</sup> For example, Figure 1

---

16. *WHO Definition of palliative care*, WORLD HEALTH ORG., <https://www.who.int/cancer/palliative/definition/en/> (last visited Mar. 12, 2019) (explaining that palliative care improves the quality of life for patients with life-threatening illness).

17. *Id.* (discussing how palliative care "provides relief from pain and other distressing symptoms").

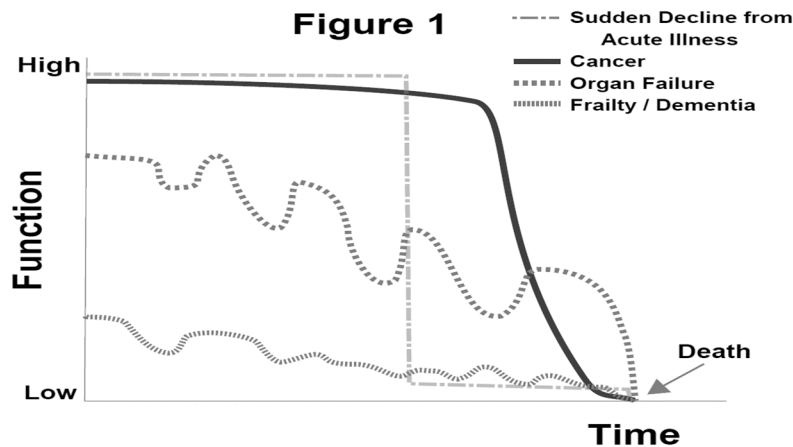
18. *See* MEDLINEPLUS, *supra* note 14.

19. INST. OF MED. OF THE NAT'L ACADS., *DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE* (2015) [hereinafter *DYING IN AMERICA*] ("Palliative care may begin early in the course of treatment for a serious illness.").

20. Jennifer S. Temel et al., *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, 363 *NEW ENG. J. MED.* 733, 733 (2010) [hereinafter Temel et al.].

21. *DYING IN AMERICA*, *supra* note 19, at 10 (explaining palliative care should be consistent with individuals' values, goals, and informed preferences).

provides a visual of the disease trajectories for cancer, dementia, and organ failure, created by the Palliative Care Network of Wisconsin.<sup>22</sup>



These disease classes often have a predictable course, allowing providers and guardians to make certain generalizations about the care and illness trajectory. The following section analyzes these trajectories further.

### 1. CANCER

All forms of cancer combined represent the second leading cause of death in the United States.<sup>23</sup> Indeed, the early pioneers of hospice and palliative care created these specialties to address the pain and suffering of individuals with terminal cancer.<sup>24</sup> Thankfully, earlier palliative care involvement increased access to symptom management and pain control and has improved life for individuals with terminal cancer.<sup>25</sup> In imagining the course of terminal cancer, it is often helpful to view the trajectory along a steady path.

22. Paige Comstock Barker & Jennifer S. Scherer, *Illness Trajectories: Description and Clinical Use* #326, 20 J. PALLIATIVE MED. 426, 426 (2017).

23. NAT'L CTR. FOR HEALTH STATISTICS, *Leading Causes of Death*, CENTERS FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm> (last updated Mar. 17, 2017).

24. See generally Nelson, *supra* note 12.

25. Jennifer S. Temel et al., *Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial*, 35 J. CLIN. ONCOLOGY, 834, 840 (2017).

Oftentimes, individuals are diagnosed after a non-descriptive symptom, like a cough or fatigue, which does not respond to time, antibiotics, or home remedies.<sup>26</sup> Sometimes, a concerning finding is the result of routine screening exams or tests.<sup>27</sup> Next, imaging studies demonstrate a mass, and the individual is soon hurried to an oncologist with treatment options provided to them.<sup>28</sup> Over the coming months and years the individual will undergo regular treatment, like chemotherapy, radiation, surgery, and increasingly, targeted immunotherapies.<sup>29</sup> For individuals with advanced cancer, the American Society of Clinical Oncology recommends referral to interdisciplinary palliative care teams early in the illness course to provide care alongside cancer directed treatment.<sup>30</sup>

Palliative care is involved to help the individual manage symptoms like pain, fatigue, and the emotional burden of a serious illness.<sup>31</sup> During cancer therapies patients will often experience side effects or require time away from work, but frequently are able to continue on with their lives with some degree of normalcy.<sup>32</sup> If initial treatments are not effective, the physician may suggest other treatment options.<sup>33</sup> An advancing cancer may spread to other parts of the body, frequently accompanied with more debility.<sup>34</sup> The spread of cancer often marks an inflection point, whereby the illness trajectory begins to swing steeply downward. Individuals with cancer may become critically ill and enter a phase where death appears imminent. At this point, medical provid-

---

26. *About Cancer: Diagnosis and Staging*, NAT'L CANCER INST., <https://www.cancer.gov/about-cancer/diagnosis-staging> (last visited Mar. 12, 2019) [hereinafter NAT'L CANCER INST.] (describing a symptom that does not go away).

27. *Id.*

28. *Id.* (describing imaging procedures).

29. *Types of Cancer Treatments*, NAT'L CANCER INST., <https://www.cancer.gov/about-cancer/treatment/types> (last visited Mar. 12, 2019) (describing treatments).

30. Chase Doyle, *Concurrent Palliative Care: Recommendations from the ASCO Clinical Practice Guideline*, ASCO POST (Dec. 10, 2017), <http://www.ascopost.com/issues/december-10-2017/concurrent-palliative-care-recommendations-from-the-asco-clinical-practice-guideline/>.

31. *Id.*

32. *Id.*

33. See NAT'L CANCER INST., *supra* note 26.

34. Yousuf S. Zafar et al., *Decision Making and Quality of Life in the Treatment of Cancer: A Review*, 17 SUPPORT CARE CANCER 117, 120–21 (2009).

ers will often recommend hospice care and no longer offer cancer-directed treatments.<sup>35</sup> Sometimes, hospice is offered sooner if cancer treatments prove too taxing, appear ineffective against the spreading of the disease, or if patients request it on their own.<sup>36</sup> With this type of illness trajectory and with the initial period of treatment more focused on cure and maintaining normalcy, it is often hard for patients and providers to discuss goals and personal values early in the disease course.<sup>37</sup> Unfortunately, delaying these important discussions may mean that it is too late once the issue is broached.

While the above describes a stereotypical experience for an individual with cancer, it becomes more complicated when cancer is a new diagnosis added to a preexisting list of other serious comorbid diseases. Cancer can strike at any age, but the median age of cancer diagnoses is sixty-six years.<sup>38</sup> In older and more frail adults, the effectiveness of treatment must be carefully weighed against the potential toxicities, and with decreased room for error.<sup>39</sup> An individual who is already frail would be expected to experience a faster decline with the addition of a new life-threatening illness.<sup>40</sup> For this reason, discussions of care goals are best initiated at the time of diagnosis, or early in treatment before the patient begins to experience significant decline.<sup>41</sup> Further adding complexity to care considerations is the myriad of new cancer treatments. Targeted therapies are often oral medications with few side effects and the potential for miraculous results: slowing or reversing the trajectory of cancer.<sup>42</sup> While these new treatments have led to a shift in the cancer treatment landscape, they also risk instilling such fervent

---

35. *Id.*

36. DYING IN AMERICA, *supra* note 19.

37. Jennifer W. Mack et al., *End-of-Life Care Discussions Among Patients with Advanced Cancer: A Cohort Study*, 156 ANNALS INTERNAL MED. 204, 210 (2012).

38. *Age and Cancer Risk*, NAT'L CANCER INST. (Apr. 29, 2015), <https://www.cancer.gov/about-cancer/causes-prevention/risk/age>.

39. Hans Wildiers et al., *International Society of Geriatric Oncology Consensus on Geriatric Assessment in Older Patients With Cancer*, 32 J. CLINICAL ONCOLOGY 2595, 2601 (2014).

40. See Catherine Handforth et al., *The Prevalence and Outcomes of Frailty in Older Cancer Patients: A Systematic Review*, 26 ANNALS OF ONCOLOGY 1091 (2014).

41. See David Hui et al., *Impact of Timing and Setting of Palliative Care Referral on Quality of End-of-Life Care in Cancer Patients*, 120 CANCER 1743 (2014).

42. *Targeted Cancer Therapies*, NAT'L CANCER INST., <https://www.cancer.gov/about-cancer/treatment/types/targeted-therapies/targeted-therapies-fact-sheet#97> (last updated Jan. 22, 2019).



hope in patients that discussions about advance care planning are delayed or not had at all.<sup>43</sup>

## 2. DEMENTIA

Due to a confluence of declining mortality and fertility, older adult population rates are increasing in the United States and the trend is expected to continue.<sup>44</sup> Though most older adults do not have dementia, the incidence of dementia increases dramatically with age.<sup>45</sup> The Centers for Disease Control and Prevention (“CDC”) predict that the number of Americans with Alzheimer’s Dementia will nearly triple by 2060.<sup>46</sup> Persons with dementia are likely to need support from legal surrogates as the disease progresses and decisional capacity is affected.<sup>47</sup> Surrogates, like a healthcare agent or a guardian (when no agent or default surrogate is available), may be called on to make health care decisions for individuals who are no longer able to convey their views on their health care preferences, values, and care goals.<sup>48</sup>

Dementia, like cancer, is not a single disease, but a group of illnesses.<sup>49</sup> Dementing illnesses all share a common bond: progressive loss of brain function in several domains.<sup>50</sup> The most common form of dementia is Alzheimer’s type,<sup>51</sup> but other types include vascular dementia, frontotemporal dementia, Parkinson’s Disease with dementia,

---

43. See generally Christine R. Sanderson & David C. Currow, *Palliative Care Meets Immunotherapy: What Happens As Cancer Paradigms Change?*, 8 *BMJ SUPPORTIVE & PALLIATIVE CARE* 431 (2018); see also Gina Kolata, ‘Desperation Oncology’: When Patients Are Dying, Some Cancer Doctors Turn to Immunotherapy, *N.Y. TIMES*, (Apr. 26, 2018), <https://www.nytimes.com/2018/04/26/health/doctors-cancer-immunotherapy.html>.

44. JENNIFER ORTMAN ET AL., *AN AGING NATION: THE OLDER POPULATION IN THE UNITED STATES* 25-1140 (2014).

45. Anthony F. Jorm & David Jolley, *The Incidence of Dementia: A Meta-Analysis*, 51 *NEUROLOGY* 728 (1998).

46. CTRS. FOR DISEASE CONTROL AND PREVENTION, *New Estimates of Americans with Alzheimer’s Disease and Related Dementias Show Racial and Ethnic Disparities*, CDC NEWSROOM, <https://www.cdc.gov/media/releases/2018/p0920-infographic-alzheimers.html> (last updated Sept. 20, 2018).

47. Betty S. Black et al., *Surrogate Decision-makers’ Understanding of Dementia Patients’ Prior Wishes for End-of-Life Care*, 21 *J. AGING & HEALTH* 627, 628 (2009) [hereinafter Black et al.].

48. *Id.*

49. 2018 *ALZHEIMER’S DISEASE FACTS AND FIGURES*, *ALZHEIMER’S ASS’N* 1, 5 (2018).

50. *Id.* at 5-6.

51. *Id.* at 6.

and dementia with Lewy Bodies.<sup>52</sup> Dementia can also be caused by life-long substance use as well, which is the case with alcohol-related dementia.<sup>53</sup> While the etiologies of these illnesses differ, they have many similarities. Typically emerging later in life with some exceptions, they present insidiously, beginning with small memory errors that are frequently attributed to other causes.<sup>54</sup> The trajectory of dementia is often viewed from a hindsight perspective where people look back from the point of diagnosis and recognize subtle changes that had been occurring for several years.<sup>55</sup>

As opposed to the path of cancer progression, dementia is marked by a slow and steady decline over a period of years.<sup>56</sup> The illness progresses through several hallmarks: being unable to work because of memory loss, loss of autonomy and ability to manage one's personal finances or other complex tasks, then difficulty dressing, bathing, and eventually loss of continence, the ability to ambulate and speak before culminating with progressive appetite decline and increasing difficulties swallowing.<sup>57</sup> In severe dementia, individuals who are completely dependent on others for care experience a loss of language, making conversations about medical goals and values impossible without previous knowledge of what the individual would want.<sup>58</sup> The slow course of dementia does offer the opportunity for early discussions regarding a patient's preferences as the disease progresses, and the ability to devise care plans in advance.<sup>59</sup> For example, an individual may want emergency medical interventions if they still maintained the ability to ambulate independently. However, if an individual is unable to walk, he or she may not want intensive interventions in the event of a medical emergency if the individual knows the trajectory of the underlying illness. These preferences may be known by family and friends. Unfortunately, in the case of isolated older adults, such advance care planning

---

52. *Id.* at 6-7.

53. *Id.* at 5.

54. Alireza Atri, *The Alzheimer's Disease Clinical Spectrum: Diagnosis and Management*, 103 *MED. CLINICS N. AM.* 263, 268 (2019) (explaining memory loss, especially for recently learned information, is an early symptom of dementia).

55. *Id.* at 266 ("In retrospect, some of the earliest symptoms manifest years before receiving a clinical diagnosis of dementia.").

56. *Id.*

57. *Id.*

58. *Id.*

59. Black et al., *supra* note 47, at 628.

with communication of personal values and goals may not happen, and if the individual presents for medical care in later stage dementia it may be too difficult to elucidate these preferences.

The harbinger of end-stage dementia is the emergence of frequent physical complications like difficulty swallowing, aspiration pneumonia, and recurrent urinary tract infections.<sup>60</sup> These complications are often a signal that the illness is progressing and that despite medical interventions, the individual is at the end of his or her life.<sup>61</sup> One of the most difficult decisions for healthcare teams, guardians, and persons with dementia involves what to do when the individual is unable to feed themselves or swallow. Physicians previously recommended inserting a feeding tube in order to prolong life and provide nutrition.<sup>62</sup> Now, extensive research has demonstrated that a feeding tube does not prevent infections or aspirations, and does not alter the life expectancy of individuals with end-stage dementia.<sup>63</sup> In fact, medical interventions were demonstrated to cause more problems, such as pain or infection surrounding the feeding tube insertion site.<sup>64</sup> It is important that guardians are knowledgeable about these palliative care issues in dementia as they navigate their decision-making role.

### 3. ORGAN FAILURE

While dementia and cancer have more predictable illness trajectory curves, the trajectories of individuals with chronic heart, lung, kidney, or liver diseases that lead to organ failure are more difficult to describe. In a similar vein, prognostication—the ability to predict clinical outcomes<sup>65</sup>—is also more difficult and nuanced. Patients with cancer and dementia often demonstrate clear terminal phases prior to death and experience progressive functional deterioration. Unlike cancer,

---

60. Mairead M. Bartley et al., *Dementia Care at End of Life: Current Approaches*, 20 CURRENT PSYCHIATRY REP. no. 7, at 1, 4 (2018).

61. *Id.*

62. AM. GERIATRICS SOC'Y ETHICS COMM. & CLINICAL PRACTICE & MODELS OF CARE COMM., *American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement*, 62 J. AM. GERIATRIC SOC'Y 1590, 1591 (2014).

63. *Id.*

64. Joanne Brooke & Omorogieva Ojo, *Enteral Nutrition in Dementia: A Systematic Review*, 7 NUTRIENTS 2456, 2463–64 (2015).

65. Stephen J. Evans et al., *The Risk of Adverse Outcomes in Hospitalized Older Patients in Relation to a Frailty Index Based on a Comprehensive Geriatric Assessment*, 43 AGE & AGING 127–132 (2014).

where initial treatments are often the most aggressive, in chronic organ failure cases the most invasive and potentially disease-altering interventions are oftentimes applied late in the illness course.<sup>66</sup> These interventions include organ transplant, implantable devices, and constant intravenous therapy (“IV”) infusions of potent medications.<sup>67</sup>

Heart disease and lung disease are the first and third leading causes of death in the U.S. respectively.<sup>68</sup> Because patients commonly suffer from both heart and lung disease,<sup>69</sup> the ability to prognosticate and make decisions for future care is further complicated. Accordingly, guardians may find themselves in the challenging situation of making health care decisions for patients who previously responded to certain aggressive medical interventions, but now possess diminished reserves and impaired ability to recover or respond to treatment. Although patients with multiple illnesses are common, individuals in their last year of life require the largest percentage of Medicare spending.<sup>70</sup> While individuals with cancer and dementia are often best served by avoiding hospitalization late in their disease course, individuals with lung and heart disease often require more frequent hospitalizations, benefitting from advanced therapies and aggressive Intensive Care Unit (“ICU”) interventions.<sup>71</sup> Individuals with heart failure may experience severe symptoms like pain and breathlessness, but studies have demonstrated that they also have better social functioning six months prior to death than those with cancer.<sup>72</sup> For this population, hospitalizations late in the disease course can lead to symptom improvement and the ability to maintain an acceptable quality of life.

---

66. Colleen K. McIlvennan & Larry A. Allen, *Palliative Care in Patients with Heart Failure*, 353 B. M. J., 1, 3–4 (2016).

67. *Id.*

68. Nicole Blair Johnson et al., *CDC National Health Report: Leading Causes of Morbidity and Mortality and Associated Behavioral Risk and Protective Factor – United States, 2005-2013*, CENTERS FOR DISEASE CONTROL & PREVENTION (Oct. 31, 2014), <https://www.cdc.gov/mmwr/preview/mmwrhtml/su6304a2.htm>.

69. Frans H. Rutten et al., *Heart Failure and Chronic Obstructive Pulmonary Disease: An Ignored Combination?*, 8 EURO. J. HEART FAILURE 706, 710 (2006).

70. Gerald F. Riley & James D. Lubitz, *Long-Term Trends in Medicare Payments in the Last Year of Life*, 45 HEALTH SERVICES RES. 565, 570 (2010).

71. Lisa Martinson et al., *Quality of End-of-Life Care in Patients with Dementia Compared to Patients with Cancer: A Population-Based Register Study*, 13 PLOS ONE 1, 2 (2018).

72. James W. Levenson et al., *The Last Six Months of Life for Patients with Congestive Heart Failure*, 48 J. AM. GERIATRICS SOC’Y S101, S101 (Apr. 2015).

Older individuals with heart failure may experience a myriad of paths towards the end of life. For example, one patient may experience steady and predictable decline in health, while another patient may experience a sudden unexpected cardiac death. Other patients may undergo frequent hospitalizations and receive effective treatment, but then return to a state of health slightly worse than before the hospitalization. Because chronic illnesses are difficult to predict, discussing prognosis and conducting advance care planning can be challenging. There are competing concerns for guardians to balance when respecting a patient's wish to not discuss matters immediately after a diagnosis or hospitalization, and when they have difficulty determining if there will be a sudden change in the patient's condition in the near future. Further, when caring for individuals who are seriously ill there are often larger forces at work, including preconceived notions on how care decisions are made, fear of making a mistake, and wrongly interpreting prognostic information. These concerns within the healthcare system may make the guardian's advocate role more challenging.<sup>73</sup>

End-of-life care planning for such individuals is best accomplished by frequent communication with healthcare providers. Early involvement of palliative care may be useful to maximize the person's quality of life while the healthcare providers and guardian consider possible next steps. In situations where the patient is being intensively treated by specialists, it may be the guardian who poses the question about the care trajectory or asks for a palliative care consult. A palliative care consult does not mean that intensive disease directed treatments will be stopped, but rather is a request for a discussion about disease trajectory and care plan.<sup>74</sup>

The three disease processes illustrated above each present unique challenges to meeting patients' needs. Under ideal circumstances, patients benefit from the support of family and friends. A trusted family member or friend would be able to advocate for the person's wishes as a healthcare agent, ideally bringing lifelong knowledge of the person's values and a perspective on past approaches to the individual's health care. However, care planning is further complicated when the person lacks capacity to make health care decisions or lacks advance directives

---

73. See Deborah Cook & Graeme Rocker, *Dying with Dignity in the Intensive Care Unit*, 370 NEW ENG. J. MED. 2506, 2508 (2014) [hereinafter Cook & Rocker].

74. See Temel et al., *supra* note 20, at 734.

and does not have anyone willing or able to serve as a surrogate, and is instead appointed a professional guardian. The following section presents data from four studies about what happens to such individuals when they confront end-of-life care, as well as the perspectives of guardians called upon to make end-of-life care decisions for them.

### III. Findings of Four Studies on End-of-Life Care for Unbefriended Adults

The following data are from four studies focusing on unbefriended adults who may need a public or professional guardian: (1) a survey of Massachusetts clinicians, mostly social workers; (2) a survey of clinicians nationwide, mostly physicians; (3) a survey of guardians in Massachusetts; and (4) interviews with guardians in Massachusetts. Findings specific to end-of-life care are provided below. A complete description of methods is available in the footnote citations listed.<sup>75</sup> As three of our samples are drawn from Massachusetts, they may reflect issues specific to healthcare and guardianship laws within Massachusetts.

#### A. Clinician Findings

The Study 1 sample (N=81) is mostly social workers (69.4%), who work in skilled nursing facilities (44.2%), medical hospitals (29.9%), and other settings (e.g., psychiatric hospitals; 25.9%) recruited through telephone calls made to the “discharge clinician” at each institution. The Study 2 sample (N=49) is mostly composed of physicians (56.5%) and nurse practitioners (26.1%) who worked in medical hospitals across thirty-eight states, and recruited through the American Geriatrics Society website.<sup>76</sup> A survey instrument, developed from previous qualitative interviews focused on the care of unbefriended adults subject to guardianship by professional guardians, was used.

---

75. See Jennifer Moye et al., *Ethical Concerns and Procedural Pathways for Patients Who are Incapacitated and Alone: Implications from a Qualitative Study for Advancing Ethical Practice*, 29 HEALTHCARE ETHICS F. 171 (2017); see also JENNIFER MOYE ET AL., EXAMINING THE NEED FOR A PUBLIC GUARDIAN IN MASSACHUSETTS: PHASE 1 (Guardian Community Trust 2016); see also JENNIFER MOYE ET AL., GUARDIANSHIP FOR ADULTS WITHOUT SURROGATES IN MASSACHUSETTS (Guardian Community Trust 2018).

76. AGS *Geriatrics Healthcare Professionals*, AM. GERIATRICS SOC'Y, <https://www.americangeriatrics.org/> (last visited Mar. 12, 2019).

Finding 1: Unbefriended adults subject to guardianship experience delays in transition to end-of-life care and receive medically non-beneficial care. Two-thirds (65.1%) of the clinicians expressed concern about a delay in transitioning unbefriended individuals to hospice care as shown in Table 1. About half of the clinicians (53.2%) said they had to continue medically non-beneficial care. Each of these consequences was reported more frequently by those in the inpatient medicine sample, as compared to the skilled nursing facility sample, as shown by the *chi-square* values which compare the distribution of responses.

TABLE 1: PROPORTION OF CLINICIANS WHO REPORT NEGATIVE CONSEQUENCES FOR UNBEFRIENDED PATIENTS

Sample	Yes (n)	Yes (%)	No (n)	No (%)	Chi Square	p value
<b>Delay in appropriately transitioning to hospice or end-of-life care</b>						
Study 1 sample	40	51.9%	37	48.1%	15.02	<.001
Study 2 sample	42	85.7%	7	14.3%		
Combined samples	82	65.1%	44	34.9%		
<b>We had to continue with medically non-beneficial care</b>						
Study 1 sample	30	39.0%	47	61.0%	16.07	<.001
Study 2 sample	37	75.5%	12	24.5%		
Combined samples	67	53.2%	59	46.8%		

Finding 2: Delays in transition to hospice care for unbefriended adults are perceived to be most often due to difficulties in getting appointed guardians to act. Clinicians perceived delays in transitioning to appropriate hospice or end-of-life care as related to various aspects of guardianship such as finding an individual willing to serve as guardian (17.6%), getting an already appointed guardian to act (52.9%), or both causes (29.4%). These responses are from Massachusetts Study Sample 1 only; we did not ask this question in Sample 2.

Finding 3: Court oversight of end-of-life care for unbefriended adults is perceived to be burdensome and harmful to patients. Clinicians report frustration with the processes for end-of-life care for unbefriended adults under guardianship, and in particular the appropriateness and delay associated with court oversight as indicated in the following excerpts presented in Table 2.

TABLE 2: EXEMPLAR CLINICIAN COMMENTS ABOUT  
END-OF-LIFE CARE

- *“The real issue is the length of time it takes the court to address end of life care. This is very frustrating when there is a frail elderly dementia or chronically ill patient who is declining and the requirements around obtaining permission for end of life care options. Guardians don’t have the authority to make the decision. I know that this is not in their authority to act. It is the legal system; there is no balance.” (#1.15)*
- *“[The] Guardian stated an inability to decide advance directives without a special court permission. [This] causes unnecessary discomfort, even harm to [a] very ill, elderly patient.” (#1.13)*
- *“[There is ] difficulty changing people’s advanced directives to CMO [comfort measures only] when they are on hospice/ end of life care.” (#1.7)*
- *“Guardian did not have authority to make end of life decisions and had to go back to court to get it. [The] patient had to be treated on a vent until court would hear the case. Took 24 hours.” (#1.69)*
- *“Older adult with end stage heart failure, dementia and cardio-renal syndrome would benefit from comfort focused treatment but receiving aggressive life prolonging measures. Unable to be placed [due to] dialysis, lack of surrogate, unclear goals of care.” (#2.25)*
- *“Palliative care and Ethics were both consulted to help manage an unbefriended patient who ended up in the MICU with sepsis, who progressed to multi-organ failure. Some on his treatment team did not feel that it was appropriate to institute aggressive life sustaining measures, but felt that withholding these might go against policy, especially since there was not evidence of the patient’s preferences. After Palliative Care and Ethics had weighed in about options, the case went to the hospital leadership to help institute a rarely used part of our policy to not institute aggressive measures.” (#2.26)*
- *“Patient with end stage dementia receiving futile treatments but remains full code due to no surrogate, awaiting guardianship.” (#2.29)*

## B. Guardian Findings

The Study 3 sample (N=11) is comprised of individuals serving as guardians, most were attorneys (64%) recruited through the Massachusetts Guardianship Association and other advertisements. The Study 4 sample (N=20) is also comprised of guardians, who were identified through publicly available lists accessed on the websites of the National Guardianship Association and the Massachusetts Guardianship Association. Fifty-seven guardians were approached to participate; one re-



fused, thirty-seven did not respond, and twenty agreed to be interviewed, resulting in a response rate of 35%. Guardians were trained as attorneys (60%), social workers (25%), healthcare workers (10%), and other (5%). Forty-five percent of the sample provided guardianship as part of a larger law practice, 25% worked as part of a guardianship agency, and 10% identified their individual practice as solely guardianship. The remaining guardians were family members or volunteers.

Finding 4: Guardians find end-of-life decisions challenging. Most guardians (87.5%) said end-of-life care decisions were somewhat or very challenging; as shown in Table 3, in contrast to almost all other duties, end-of-life care decisions were more challenging. Guardians also find making decisions about supervised living placements to be a challenge. Guardians said working with courts and completing paperwork for courts was less challenging.

TABLE 3: RATINGS OF CHALLENGE OF TASK BY GUARDIANS

Task	How Challenging			
	Not at all	Somewhat	Very	Sum somewhat or very
Making end-of-life care decisions	12.5%	62.5%	25.0%	87.5%
Making decisions about supervised living placements	12.5%	50.0%	37.5%	87.5%
Completing a Medicaid application	25.0%	25.0%	50.0%	75.0%
Understanding psychiatric medications and their implications	25.0%	62.5%	12.5%	75.0%
Completing required paperwork for the courts	37.5%	62.5%	0.0%	62.5%
Working with the courts	50.0%	50.0%	0.0%	50.0%

*N*=8; Missing data (not answered) = 3

Finding 5: Guardians are unsure of their authority to make end-of-life decisions, while they balance a desire to honor the wishes of the person and to prevent a “bad death.” Based on content coding, guardians most commonly commented on questions of authority in end-of-life care (*n*=26 comments), which revealed differing opinions and a lack of clarity about guardians’ authority to make end-of-life care decisions. Some guardians believe they have (or should have) the authority to

make end-of-life care decisions; while others report having been instructed to petition the court for any end-of-life care decision-making. The next most common theme was related to efforts to honor wishes (n=20 comments) and concerns about bad deaths (n=14 comments). Exemplar comments appear in Table 4.

TABLE 4: EXEMPLAR GUARDIAN COMMENTS ABOUT  
END-OF-LIFE CARE

<p><b>Unclear Authority</b></p> <ul style="list-style-type: none"> <li>• <i>"I think the law says as long as there is no controversy, a guardian can do it. As long as family members don't object. As long as there's a medical consensus." (#4.17)</i></li> <li>• <i>"I think a horrible, horrible situation is that the court's very reluctant to grant changing code status unless the person's on death's door, which I think is horribly disrespectful . . . I say, 'Judge, he doesn't want to be full code, can you help me make this not full code?' The judge says to come back when they're on death's door, and at that point they could get all kinds of treatment, which is horrible." (#4.16)</i></li> <li>• <i>". . . Someone was in the hospital. The doctor was saying to me, 'Are you kidding me?' I said, 'We're in the process of going back to court.' I allowed a code status change while he was in the hospital. Then when he was going back the nursing home wouldn't accept the code change . . . Now we have a court date again." (#4.9)</i></li> <li>• <i>"I do think that if there was a training that talked a little bit more, to clarify when we really do . . . we have to go to court? I would love to be part of something like that because I think the judges are all over the place. I mean, Judge [name redacted] He'd go in to see me and is like, 'I don't want to see you. I appointed you. You make that decision.' That's what he would say to you." (#4.15)</i></li> </ul>
<p><b>Honor Wishes</b></p> <ul style="list-style-type: none"> <li>• <i>"We talked about what do you want? 'I don't want any of that stuff. If it's bad just let it be.' We'll do our best . . ." (#4.1)</i></li> <li>• <i>"We, obviously most of the time you can't, we talk to the person to the extent we can, obviously. In a way in which they'll understand. Then there's family members involved. We talk to them. We want to make sure everybody's on the same page . . ." (#4.9)</i></li> <li>• <i>"Another difficult decision is when you have an elderly person who's said they want to be full code, and the hospital and the nursing home and everyone's like, what are you saying? . . . I had a lady who said once, 'I want everything so long as there's even a twinkle of hope,' and so now they've reached the point where they</i></li> </ul>

<i>can't even talk and they're getting dragged back and forth from the hospital and you feel horrible about that." (#4.13)</i>
<p><b>Avoid Bad Death</b></p> <ul style="list-style-type: none"> <li>• <i>"I got a call from one of my facilities Monday morning, the whole staff was going nuts, 89 pounds, she coded, didn't have the instructions. She bled to death internally and she goes, 'I am losing [staff]. I am losing people because this was so shattering.' She was so sweet and little thing. That's when I started saying, that's when I started helping the facilities." (#4.12)</i></li> <li>• <i>"I had a woman languishing in an emergency room for I don't know how long. Hooked up to everything and she had no chance to recover. I've had that happen a number of times." (#4.17)</i></li> <li>• <i>"I had a woman that was 10 days in ICU that was just . . . I went in and I said, 'Nobody deserves to die this way.'" (#4.11)</i></li> </ul>

### C. Summary and Implications for Guardianship Practice

Across three surveys and one interview study focusing on the care for unbefriended adults subject to guardianship by professional guardians, end-of-life care consistently emerged as a concern and challenge for clinicians and guardians. Clinicians reported frustration in a perceived delay in transitioning patients to appropriate end-of-life care, which they attribute not so much to waiting for a guardian to be appointed, but rather for an appointed guardian to act, although both factors are cited. Clinicians also noted having to deliver medically non-beneficial care presumably while waiting for guardians or the guardianship process. Similarly, guardians pointed to challenges in making end-of-life care decisions. Guardians rated these decisions as among the most difficult situations.

In our interview study, guardians reported variable understanding of their authority to make end-of-life care decisions within Massachusetts. Guardians discussed their desire to honor the wishes of the person whom they are appointed to serve, noting that conversations with the individual under guardianship are sometimes possible and sometimes not possible. Guardians also discussed difficulty in determining whether wishes changed when a person's condition deteriorated to the extent that no conversations are possible. Some guardians described undesirable death experiences for the individuals they served. These findings may not be surprising to the clinicians and guardians who work in the healthcare setting, but taken together the findings set forth the critical problem of providing quality end-of-life

care for unbefriended adults, and the challenge it presents to guardians. The following section responds to this challenge by discussing values assessment and palliative care perspectives on three common end-of-life decisions.

#### IV. Substitute Decision-Making at the End of Life

To better understand the process of assisting individuals facing death in making health care decisions, it is important to remember how far medicine has advanced in caring for patients who are dying. For much of the twentieth century, doctors did not discuss death with patients.<sup>77</sup> This lack of communication had several causes, including limitations to treatment for many diseases like cancer, a strong culture of paternalism, and fear that telling patients bad news would lead to negative emotional outcomes, or at worst, suicide.<sup>78</sup> A 1961 survey of physicians found that 90% preferred not to tell their patients of a life-threatening cancer diagnosis.<sup>79</sup> This position is fortunately no longer the standard.<sup>80</sup> Providers now include patients, and if necessary, their surrogates, in discussions about death and approaches to end-of-life care.<sup>81</sup> Guardians, therefore, may be actively involved in end-of-life care discussions and called to make medical decisions presented to them by healthcare providers.

##### A. The Role of Values and Goals

The contemporary concept of surrogate decision-making is the idea that a surrogate provides substitute judgment based on values and goals.<sup>82</sup> However, it may be hard to articulate one's own "values and goals," and harder still to articulate those values to others. One means of sharing values and goals is through health care advance directives. Unfortunately, confronting end-of-life decisions is a serious task,

---

77. See Jonathan F. Will, *A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making*, 139 CHEST 669, 671 (2011).

78. See *id.*

79. Donald Oken, *What to Tell Cancer Patients: A Study of Medical Attitudes*, 175 J. AM. MED. ASS'N 1120, 1122 (1961).

80. Ranjana Srivastana, *Should a Doctor Always Disclose a Terminal Diagnosis?*, THE GUARDIAN (Apr. 3, 2018, 2:00 PM), <https://www.theguardian.com/commentisfree/2018/apr/04/should-a-doctor-always-disclose-a-terminal-diagnosis>.

81. See Cook & Rocker, *supra* note 73, at 2508.

82. *Id.* at 2507.

avoided by many, with rates of advance care planning completion remaining relatively low.<sup>83</sup> While public relations campaigns like the Conversation Project, Five Wishes, and National Healthcare Decision Day offer helpful information and may help encourage local culture change, making plans regarding health care values and wishes can raise ethical, spiritual, and emotional concerns for individuals and their healthcare agents.<sup>84</sup>

Advance care planning requires an implicit acknowledgement, if not outright confrontation, of one's own mortality. Even when advance directives are completed they tend to focus primarily on naming a healthcare agent and focus less on conveying and documenting values of the patient that may underlie health care decisions.<sup>85</sup> However, research and clinical evidence suggest that completing advance directives—in the absence of communication about an individual's and his or her family's values, fears, and preferences—may not ultimately help facilitate good decisions on behalf of individuals with dementia or other incapacitating illnesses.<sup>86</sup>

---

83. Kuldeep N. Yadav et al., *Approximately One in Three U.S. Adults Completes Any Type of Advance Directive for End-Of-Life Care*, 36 HEALTH AFF. 1244, 1248–50 (2017).

84. Anand D. Naik et al., *Goals of Older, Multimorbid Adults Facing Life-Threatening Illness*, 64 J. AM. GERIATRICS SOC'Y 625, 627 (2016) [hereinafter Naik et al.] (explaining that the majority of participants in a study believed in the importance of spiritual and social relationships among their friends, family, and healthcare providers).

85. Corrina Porteri, *Advance Directives as a Tool to Respect Patients' Values and Preferences: Discussion on the Cease of Alzheimer's Disease*, BMC MED. ETHICS (Feb. 20, 2018), <https://bmcomedethics.biomedcentral.com/articles/10.1186/s12910-018-0249-6> [hereinafter Porteri] (explaining that people cannot ask for clinically unavailable healthcare, thereby indicating that the explicitly named healthcare agent ought not be the only consideration).

86. Marike E. de Boer et al., *Advances Directives in Dementia: Issues of Validity and Effectiveness*, 22 INT'L PSYCHOGERIATRICS 201, 207–08 (2009); Emalee Joyce Weidemann, *The Ethics of Life and Death: Advance Directives and End-of-Life Decision Making in Persons with Dementia*, 12 J. FORENSIC PSYCHOL. PRACT. 81, 84 (2012); see also Porteri, *supra* note 85.

### B. What is the Difference Between Values and Goals?

It is important to distinguish values and goals as we have used them in the course of this Article. Goals refer to the outcome or action like “I want to stay at home,”<sup>87</sup> whereas values are the broader sentiments underlying these choices such as “I value privacy.”<sup>88</sup> It is important to distinguish between values and goals, and to investigate the values which underlie goals—as sometimes it may be useful to find a different goal or outcome—while honoring the underlying value. Table 5 provides examples of ways to follow up on statements to elicit values underlying goals.

TABLE 5<sup>89</sup>

Goals If a person says	Values Ask
“I want you to do everything possible”	What makes life good or meaningful for you? What factors might sway you to undergo a healthcare treatment, even if it harmed your quality of life? What circumstances may lead you to decline a treatment that could possibly extend your life?
“I want to stay at home”	Why is being home important to you? What aspects of being at home are most important? What makes a place feel like home?
“I don’t want to be a burden”	How might your feelings about being independent affect decisions about your healthcare? Are there any abilities that are so important to your life you can’t imagine living without them?

87. Elizabeth H. Bradley et al., *Goal-Setting in Clinical Medicine*, 49 SOC. SCI. & MED. 267, 272 (1999) [hereinafter Bradley et al.].

88. Hilary A. Llewellyn-Thomas & R. Trafford Crump, *Decision Support for Patients: Values Clarification and Preference Elicitation*, 70 MED. CARE RES. & REV. 50S, 535–45 (2013); See Angela Fagerlin et al., *Clarifying Values: An Updated Review*, 13 BMC MED. INFORMATICS DECISION MAKING 1, 2 (2013) (“The relevant chapter in the IPDAS Collaboration’s 2005 Background Document uses the term ‘values clarification exercises,’ and defines these as ‘[exercises to] help patients to clarify and communicate the personal value of options, in order to improve the match between what is personally most desirable and which option is actually selected.’”).

89. Naik et al., *supra* note 84, at 627–28.

### C. What are Health Care Values?

The values that people communicate as they make health care choices are important and appear to fall into several broad themes: self-sufficiency, comfort and enjoyment, connection and legacy, balancing quality and length of life, and preferences for engagement in care (e.g., self, family, physician; others versus alone).<sup>90</sup> It can be useful to have a structured manner to specifically assess health care values, as multiple studies have demonstrated that family member proxies, as well as clinicians, are rarely able to predict patients' treatment preferences beyond chance.<sup>91</sup> There are multiple tools available for assessing values, as recently summarized by the ABA Commission on Law and Aging.<sup>92</sup>

In assessing values related to self-sufficiency, comfort and enjoyment, and connection and legacy, a "valued activities" list may be useful for patients and surrogates alike.<sup>93</sup> Some people may want to rate all the items as very important so guardians can begin by having the patient pick out the most and least important values and then rank all items relative to those anchors. Oftentimes, people are inclined to rate all or most of these values highly, so the task is to emphasize which "matter most."

---

90. *Id.* at 625.

91. Lois Downey et al., *Life-Sustaining-Treatment Preferences: Matches and Mismatches Between Patients' Preferences and Clinicians' Perceptions*, 46 J. PAIN & SYMPTOM MGMT. 9, 14-17 (2013); Angela Fagerlin et al., *Projection in Surrogate Decisions About Life-Sustaining Medical Treatments*, 20 HEALTH PSYCHOL. 166, 167-68 (2001); Michele Karel & Margaret Gatz, *Factors Influencing Life-Sustaining Treatment Decisions in a Community Sample of Families*, 11 PSYCHOL. & AGING 226 (1996); Bettina Schmid et al., *Family Matters: Dyadic Agreement in End-of-Life Medical Decision Making*, 50 THE GERONTOLOGIST 226, 236 (2010).

92. See COMM. ON LAW AND AGING, *Advance Directives: Counseling Guide for Lawyers*, A.B.A. (Nov. 7, 2018), [https://www.americanbar.org/groups/law\\_aging/resources/health\\_care\\_decision\\_making/ad-counseling-guide/](https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/ad-counseling-guide/).

93. Jennifer Moye et al., *Assessment of Capacity to Consent to Treatment: Challenges, the "ACCT" Approach, Future Directions*, 31 CLINICAL GERONTOLOGIST 37, 39 (2008).

TABLE 6: VALUED ACTIVITIES

1-2 -	3-4 -	5-6 -	7-8 -	9-10
Not important to my quality of life; I could live without this.	Somewhat important to my quality of life	Very important to my quality of life	Extremely important to my quality of life	Of utmost importance to my quality of life; I could not live without this.
Life value or goal, i.e., your ability to ...				How important is this to your Quality of Life? 1 - - - - 10
1. Take care of myself (e.g., bathing, dressing), rather than rely on others for help with daily life				
2. Walk or move around by myself				
3. Live at home				
4. Think clearly about things				
5. Avoid being a burden to others				
6. Practice my religion or spiritual life (faith, prayer)				
7. Have relationships with family and friends				
8. Make my own life decisions (e.g., about health, finances, housing)				
9. Have my privacy				
10. Have emotional or sexual intimacy in my life				
11. Consider the needs and interests of my family				
12. Live without significant pain or discomfort				
13. Eat "normally," to enjoy meals				
14. Control my bodily functions (e.g., urination)				
15. Engage in productive work - in a job, at home, or in the community				
16. Do specific activities or hobbies that I enjoy (e.g., reading, TV, gardening)				

Although a person may lack the capacity to make a formal health care decision, the person may be able to convey health care values and express wishes about end-of-life care. These conversations may be especially intimidating for a guardian who has only just met the person they are now representing. Despite the challenges before guardians, advance care planning has demonstrated positive impacts on both the individual and surrogates, mainly by providing care that aligns with the person’s values and lowering rates of psychological distress in surrogates.<sup>94</sup>

94. Deborah Carr & Elizabeth A. Luth, *Advance Care Planning: Contemporary Issues and Future Directions*, 1 INNOVATION AGING 1, 2 (2017).



#### D. Do Values and Goals Change?

Successful advance care planning should not simply be about dying, but instead about how to craft a roadmap to inform future care decisions that will give the individual's guardian and health care team the information needed to make decisions in the individual's absence. Therefore, these conversations should begin early in the disease course and it may be necessary to readdress them at various points along the trajectory. Compared to patient goals, values are relatively stable<sup>95</sup> (although they may change over the lifespan<sup>96</sup>), whereas goals may change as health worsens.<sup>97</sup> For example, a person may express a wish to have cardiopulmonary resuscitation ("CPR")—a goal—but as health declines that goal may change, while values (e.g., to avoid pain) remain stable.

#### E. What if the Person Cannot Convey Values?

While adults may be able to convey values even when they lack decision-making capacity, this Article focuses on the end-of-life care for persons without family or friends to serve as surrogates who are subject to guardianship. In this context, the individual is likely quite ill, and may not be able to convey their current values and goals, and the guardian may have limited historical information. Healthcare ethics frameworks suggest when substituted judgment is not available, a best interest standard may be applied.<sup>98</sup>

When applying a best interest standard, relevant literature on what most adults say they would want at the end of life and how the field of palliative care measures quality end-of-life care is helpful. Though patient preferences for end-of-life care vary from person to person, there are also similarities in patient reports. In general, most people prefer to die at home,<sup>99</sup> and this preference does not appear to

---

95. Michele Karel et al., *Three Methods of Assessing Values for Advance Care Planning: Comparing Persons with and without Dementia*, 19 J. AGING & HEALTH 123, 124 (2007).

96. Valdiney Gouveia et al., *Patterns of Value Change During the Life Span: Some Evidence from a Functional Approach to Values*, 41 PERSONALITY & SOC. PSYCHOL. BULL. 1276, 1277 (2015).

97. See Bradley et al., *supra* note 87, at 274–75.

98. Loretta M. Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J. L. MED. & ETHICS 187 (2007).

99. Barbara Gomes et al., *Heterogeneity and Changes in Preferences for Dying at Home: A Systematic Review*, 12 BMC PALLIATIVE CARE 1, 11 (2013).

change as illness progresses.<sup>100</sup> Dying at home is most likely to occur when individuals are enrolled in hospice and received palliative care services.<sup>101</sup> Relatedly, a number of factors have been identified as indicators of poor end-of-life care including emergency room visits, frequent or lengthy hospitalizations near the end of life (as evidenced by the total number of days in the hospital near the end of life), and ultimately death in the hospital.<sup>102</sup> These factors are particularly significant when the person is receiving highly aggressive interventions of limited value to prolonging life or preserving quality of life.<sup>103</sup> Guardians can support the team in avoiding or minimizing these outcomes as much as possible. In this vein, we close by discussing three common health care decisions guardians may be asked to make for adults at the end of life.

**1. CPR AND DNR: WHAT IF I AM ASKED TO MAKE A CHANGE IN CODE STATUS?**

Cardiopulmonary resuscitation (“CPR”) is commonly shown on medical dramas, often with the individual surviving and making a full recovery. In these fictionalized accounts, 71.9–77% of people who undergo CPR in popular American medical dramas survive.<sup>104</sup> This fictionalized success rate contrasts wildly with the reality of CPR success rate, which is estimated to be no greater than 15% in instances of out of hospital cardiac arrests.<sup>105</sup> CPR is more effective when performed in a hospital, likely due to improved CPR technique, but is still quite low

---

100. *Id.* at 1.

101. Ebnun Abarshi et al., *General Practitioner Awareness of Preferred Place of Death and Correlates of Dying in a Preferred Place: A Nationwide Mortality Follow-Back Study in the Netherlands*, 38 J. PAIN & SYMPTOM MGMT. 568, 575 (2009).

102. See generally Lialoma Salem-White et al., *Predictors of Emergency for Acute Hospital Admissions Prior to Death Among Hospice Palliative Care Clients in Ontario: A Respective Cohort Study*, 13 BMC PALLIATIVE CARE 1, 1–12 (2014).

103. Risha Gidwani-Marszowski et al., *Hospice Care of Veterans in Medicare Advantage and Traditional Medicare: A Risk-Adjusted Analysis*, 66 J. AM. GERIATRICS SOC’Y 1508, 1508–09 (2018).

104. Jaclyn Portanova et al., *It Isn’t Like This on TV: Revisiting CPR Survival Rates Depicted on Popular TV Shows*, 96 RESUSCITATION 148, 149 (2015) [hereinafter Portanova et al.]; Susan J. Diem et al., *Cardiopulmonary Resuscitation on Television: Miracles and Misinformation*, 334 NEW ENG. J. MED. 1578, 1579 (1996).

105. Peter A. Meaney et al., *Cardiopulmonary Resuscitation Quality: Improving Cardiac Resuscitation Outcomes Both Inside and Outside the Hospital: A Consensus Statement from the American Heart Association*, 128 CIRCULATION 417, 417 (2013).

with survival to discharge ranging from 3.4–22%.<sup>106</sup> This range is a consequence of the many variables impacting the effectiveness of CPR, including time of day when the arrest occurs, and specific location within the hospital and county in which the hospital resides.<sup>107</sup> However, survival after hospital discharge does not mean discharge at the same level of functioning—in fact a patient’s functioning is typically significantly impaired.<sup>108</sup> In-hospital CPR survival with functional recovery ranges from 0.8–20.1%, depending on facility.<sup>109</sup> Plainly put, while CPR commonly appears effective, the reality is that it frequently fails to extend life and when it does, CPR frequently leads to significant debility for older individuals.

Guardians may be asked to make decisions about CPR and may be asked to consider changes in “code status” to a do-not-resuscitate (“DNR”) status for patients with advanced illnesses like cancer, dementia, or advanced organ failure. Discussions regarding resuscitation and code status are often fraught with challenges. There is no standardized format in which physicians or guardians are taught to have these discussions.<sup>110</sup> The absence of a standard leads to variability in the effectiveness of communication. CPR is often described in a piecemeal manner and codified on Physician Orders for Life-Sustaining Treatment (“POLST”) forms where intubation, artificial hydration, and cardiac resuscitation are offered as separate entities.<sup>111</sup> During a cardiac arrest, chest compressions, and intubation, gaining IV line access is typically performed together to support the patient’s heart, lungs, and to provide medications and invasive measures in the fastest way possible.<sup>112</sup>

Central to CPR discussions is the assumption that patients have a choice. Patients are presented with an option to undergo a procedure that may extend their life, without the acknowledgement that death is

---

106. Emelia J. Benjamin et al., *Heart Disease and Stroke Statistics – 2018 Update: A Report from the American Heart Association*, 137 *CIRCULATION* e67, e357 (2018).

107. See *id.*; see also Saket Girotra et al., *Regional Variation in Out-of-Hospital Cardiac Arrest Survival in the United States*, 133 *CIRCULATION* 2159, 2161 (2016) [hereinafter Girotra et al.].

108. See generally Mark H. Ebell et al., *Survival After In-Hospital-Cardiopulmonary Resuscitation: A Meta Analysis*, 13 *J. GEN. INTERNAL MED.* 803 (1998).

109. Girotra et al., *supra* note 107, at 2163.

110. Portanova et al., *supra* note 104, at 148.

111. See *id.*

112. Charles N. Pozner et al., *Advanced Cardiac Life Support (ACLS) in Adults*, UPTODATE, <https://www.uptodate.com/contents/advanced-cardiac-life-support-acls-in-adults> (last visited Mar. 12, 2019).

inevitable, and that for some patients a cardiac arrest does not represent a reversible situation. Frequently, decisions to change code status are made after the individual has experienced a complication or is very near the end of life.<sup>113</sup> For example, an individual with widely metastatic lung cancer suffers respiratory failure and is admitted to the ICU and placed on a mechanical ventilator. This is an individual who will die soon regardless of whether CPR is administered, and most physicians and family members would feel that a DNR order would be appropriate.<sup>114</sup> More difficult to discuss is addressing resuscitation status before the respiratory failure, or even before the cancer diagnosis.

How then should guardians approach decisions about resuscitation? Clearly, the discussion needs to be more than the question “do you want CPR if your heart stops?” When approaching a decision about code status and CPR it is helpful for guardians to talk about the patient’s desired outcome.<sup>115</sup> Oftentimes, the conversation hinges on asking the patient—or considering on their behalf if they cannot communicate—if he or she would be willing to undergo invasive treatments for the opportunity to live longer with the same or worsened quality of life.<sup>116</sup> An effective way for physicians and guardians to have this discussion is to frame CPR in the context of the patient’s prognosis and goals, the likelihood that CPR will produce results consistent with the above goals, and finally, considering a treatment recommendation, informed by realistic information about the likely success of CPR.<sup>117</sup> An informed conversation that includes these aspects allows guardians to make decisions that align with the individual’s wishes. Communication with the healthcare team, and ideally a palliative care team, is helpful in these situations.

---

113. Mae Zakhour et al., *Too Much, Too Late: Aggressive Measures and the Timing of End of Life Care Discussions in Women with Gynecologic Malignancies*, 138 *GYNECOLOGIC ONCOLOGY* 383, 383 (2015).

114. See generally Cristina A. Reichner et al., *Outcome and Code Status of Lung Cancer Patients Admitted to the Medical ICU*, 130 *CHEST* 719 (Sept. 2006).

115. See Julie W. Childers et al., *REMAP: A Framework for Goals of Care Conversations*, *J. OF ONCOLOGY PRAC.* 700 (2017).

116. Wendy G. Anderson et al., *Code Status Discussions Between Attending Hospitalist Physicians and Medical Patients at Hospital Admission*, 26 *J. GEN. INTERNAL MED.* 359, 362 (2011).

117. See *id.*

2. **DO NOT HOSPITALIZE: WHAT IF I AM ASKED TO DECIDE WHETHER A PERSON SHOULD BE TRANSFERRED FROM A NURSING HOME TO A HOSPITAL AS NEEDED?**

Another frequently encountered decision for individuals approaching the end of life is whether to return to the hospital.<sup>118</sup> The default position, to transfer all patients to the hospital, implies that a transfer to the hospital is beneficial; in contrast, there are times in which a hospital transfer is not appropriate and leads to prolonged suffering, confusion, use of restraints, and IV lines without benefits in mortality.<sup>119</sup>

When addressing this issue, it is important for guardians to discuss what the goal of a hospital transfer would be. For an individual with end-stage dementia, who is also experiencing terminal complications of his or her illness, like frequent infections, a hospital transfer can result in increased confusion because of the change in setting; and though antibiotic treatment may be started and the individual sent home, the underlying issue is not modifiable—the overall illness course cannot be reversed.

The order to “Do Not Hospitalize” (“DNH”) is reversible.<sup>120</sup> For example, should an individual fall and require imaging, it would be appropriate to send the person to the emergency room. In effect, the DNH order adds a pause—an opportunity for the clinician and health care proxy to speak about what would be in the best interest of the patient.<sup>121</sup> When a DNH order is in place fewer patients are hospitalized, which leads to a reduction in medically unnecessary interventions at the end of life.<sup>122</sup>

---

118. Andrew B. Cohen et al., *Do-Not-Hospitalize Orders in Nursing Homes: Call the Family Instead of Calling the Ambulance*, 65 J. AM. GERIATRICS SOC'Y 1573, 1573 (2017) [hereinafter Cohen et al.].

119. Muriel R. Gillick et al., *Adverse Consequences of Hospitalization in the Elderly*, SOC. SCI. & MED. 1033, 1036–37 (1982); Debra Saliba et al., *Decision to Transfer Nursing Facility Residents to the Hospital*, 48 J. AM. GERIATRICS SOC'Y, 154, 160–61 (2000).

120. Cohen et al., *supra* note 118, at 1575–76.

121. *See id.*

122. Taeko Nakashima et al., *Are Hospital/ED Transfers Less Likely Among Nursing Home Residents with Do-Not-Hospitalize Orders?*, 18 J. AM. MED. DIRECTORS ASS'N 438, 441 (2017).

### 3. ICU DECISIONS: WHAT IF I AM ASKED TO DISCONTINUE LIFE-SUSTAINING TREATMENT IN THE ICU?

Despite a majority of individuals in the United States expressing a desire to die at home, many are not able to make that wish a reality. Nearly one in five deaths occur in the ICU.<sup>123</sup> Frequently, individuals who are in the ICU are unable to communicate effectively due to delirium, being intubated and sedated, or simply being critically ill.<sup>124</sup> For guardians who care for individuals whose wishes are not known, or were not discussed prior to hospitalization, this lack of communication can be a significant cause of distress. Decisions regarding withdrawing life-sustaining treatments or administering life-sustaining treatment are difficult when there appears to be little hope.<sup>125</sup>

The ICU is an environment teeming with technology, and typical herculean efforts are undertaken on a regular basis to extend life. This effort, at times, comes at the cost of patient dignity. Researchers Cook and Rocker describe “dignity conserving care” as a framework for understanding end of life in the ICU.<sup>126</sup> This model, which closely aligns with the goals of palliative care, proposes that death with dignity recognizes the value of preparedness, interpersonal connection, physical comfort, autonomy, and meaningfulness, in addition to the intrinsic quality of life.<sup>127</sup> Using this framework, valuing the dignity of the individual allows acknowledgement of the inevitable outcome that all individuals die.

Existing literature has demonstrated that surrogate decision makers often overestimate survival.<sup>128</sup> For older adults who survive the ICU, particularly those with additional complex medical problems,

---

123. See Derek C. Angus et al., *Use of Intensive Care at the End of Life in the United States: An Epidemiologic Study*, 32 *CRITICAL CARE MED.* 638, 640 (2004).

124. Hoorn S. Ten et al., *Communicating with Conscious and Mechanically Ventilated Critically Ill Patients: A Systematic Review*, *CRITICAL CARE* 333, 333 (2016).

125. Andrew B. Cohen et al., *Guardianship and End-of-Life Decision Making*, 175 *JAMA INTERNAL MED.* 1687, 1689 (2015).

126. Cook & Rocker, *supra* note 73, at 2506.

127. *Id.*

128. See Susan J. Lee Char et al., *A Randomized Trial of Two Methods to Disclose Prognosis to Surrogate Decision Makers in Intensive Care Units*, 182 *AM. J. RESPIRATORY CRITICAL CARE MED.* 905, 907 (2010); see Lucas S. Zier et al., *Surrogate Decision Makers' Interpretation of Prognostic Information: A Mixed-Methods Study*, 156 *ANNUALS INTERNAL MED.* 360 (2012).

many will die within one year following hospitalization, with the majority of deaths occurring within weeks or months.<sup>129</sup> One common concern for individuals who are near death in the ICU is what death will look like.<sup>130</sup> Involving palliative care or asking the ICU physicians what care would look like if the focus was no longer on attempting to preserve life, but instead on comfort, can be helpful for elderly patients. Finally, it is important to acknowledge that both guardians and providers are frequently in a situation where they are making decisions based on the best information they have. Serving as a professional guardian in an end-of-life care context is likely to be one of the most challenging, important, and humbling aspects of a guardian's work.

## V. Conclusion

This Article discussed the challenges of end-of-life care for individuals who lack advance directives, lack family and friends to serve as surrogates, are unable to make a health care decision, and are subject to guardianship. End-of-life care is particularly challenging for professional guardians who may find themselves operating in clinical settings where the default approach is treating with the intent to cure, and a legal context, which may also be skewed towards a focus on the preservation of life.<sup>131</sup> Such situations are particularly challenging in the setting of advanced illness in which treatment is not likely to cure or even improve the quality of life, especially when the values of the individual subject to guardianship are not known, and the individual is unable to communicate them. Guardians must balance their duties to honor the individual's values as the person ages and underlying health conditions evolve, while also upholding their professional duties under the law.

In our studies, clinicians and guardians both reported significant barriers to providing appropriate end-of-life care in situations described above. To improve care for these vulnerable individuals, more interprofessional education and dialogue is needed. For example, it

---

129. Tamas Szakmany et al., *Risk Factors for 1-Year Mortality and Hospital Utilization Patterns in Critical Care Survivors: A Retrospective, Observational, Population Based Data Linkage Study*, 47 *CRITICAL CARE MED.* 15, 18–19 (2019).

130. Cook & Rocker, *supra* note 73, at 2507.

131. See Crister, *supra* note 9, at 76.

may help clinicians to know more about guardianship, and for guardians to know more about end-of-life care, and for both to find strategies for more frequent and successful communication. Further studies should investigate particular risk factors for becoming “unbefriended,” so interventions to locate surrogates and document values can be achieved earlier. Similarly, studies should look for other factors that contribute to medically unnecessary care or delay to palliative care involvement among individuals under guardianship.

While it is difficult to write a “one size fits all” primer on palliative care for guardians, asking for a palliative care consult early in the process may help to develop a roadmap for guardians and clinicians. Asking for palliative care does not imply the guardian is calling for a termination of life-sustaining treatment, but rather for a conversation regarding how to best care for the individual as the illness progresses towards the end of life. Finally, our surveys of clinicians and guardians pointed to distress surrounding certain decision-making for unbefriended individuals. We believe this distress reflects the psychological toll of caring for these individuals at the end of their lives and the desires of all persons involved to improve the process, as they approach this care in a sensitive, compassionate, and ethical manner. Highlighting these dilemmas, and providing ongoing support, education, and dialogue is critical.

While providing care for individuals under guardianship at the end of life can be difficult, it is also rewarding. It provides a final opportunity for guardians and clinicians to honor an individual and offer compassionate care. Many clinicians and guardians come to this work through a sense of duty to those who are most vulnerable, and attending to end-of-life needs is an important part of helping individuals across the entire lifespan.

### **Acknowledgements**

This material is the result of work supported with resources and the use of facilities at VA Boston Healthcare System and the Bedford VA Medical Center. The contents do not represent the views of the U.S. Department of Veterans Affairs or the United States Government. A portion of the data presented in Table 1 is in preparation for submission to the Journal of the American Geriatrics Society. Funding for studies herein was supported by Guardian Community Trust. We thank individuals from the American Geriatrics Society (AGS) and AGS Ethics



Committee for support of data collection for Study 2. We thank the individuals who participated in the research surveys. We thank Erica Wood, J.D., from the American Bar Association Commission on Law and Aging for her helpful comments on earlier drafts of this paper. Finally, we thank the veterans who have allowed us to contribute to their health care, particularly at the end of life.

