

Alzheimer's Disease and Decision-Making:  
Are Mental Health Directives Appropriate for  
Illinois Residents?

*Meghan Funk\**

I. INTRODUCTION

Many Americans fear the prospect of being diagnosed with Alzheimer's disease because it progressively destroys a person's memory and other mental functions.<sup>1</sup> Alzheimer's falls under the umbrella of diseases classified as dementia because it results in the loss of intellectual and social skills.<sup>2</sup> A patient diagnosed with Alzheimer's may eventually lack the ability to complete even the simplest of tasks, to recognize loved ones, and to communicate her needs.<sup>3</sup> Both the causes of this disease and methods of prevention are still not fully understood.<sup>4</sup> Further, Alzheimer's has no cure, and its debilitating progress is irreversible.<sup>5</sup> The average age of diagnosis is sixty years old; however it can appear in patients as young as thirty years old.<sup>6</sup> Sadly, over five million Americans are currently suffering from

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\* Juris Doctor Candidate, Loyola University Chicago School of Law, Class of 2014. Ms. Funk is a staff member of *Annals of Health Law*.

1. See MAYO FOUNDATION FOR MEDICAL EDUCATION AND RESEARCH, *Alzheimer's Disease* (Jan 19, 2013), <http://www.mayoclinic.com/health/alzheimers-disease/DS00161>, [hereinafter MAYO FOUNDATION]; see also Chad S. Dodson, *Alzheimer's disease and memory-monitoring impairment: Alzheimer's patient show a monitoring deficit that is greater than their accuracy deficit*, 49 NEUROPSYCHOLOGIA 2609, 2609 (2011) (remarking upon the memory deficit found in Alzheimer's patients).

2. MAYO FOUNDATION, *supra* note 1.

3. NATIONAL INSTITUTES OF HEALTH, ALZHEIMER'S DISEASE FACT SHEET 1, (July 2011), available at [http://www.nia.nih.gov/sites/default/files/alzheimers\\_disease\\_fact\\_sheet\\_0.pdf](http://www.nia.nih.gov/sites/default/files/alzheimers_disease_fact_sheet_0.pdf) [hereinafter FACT SHEET] (explaining that Alzheimer's is a form of dementia, the loss of cognitive functioning and that dementia interferes with a person's daily life and activities).

4. FAMILY CAREGIVER ALLIANCE, *Alzheimer's Disease & Caregiving*, [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=567](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=567), (last visited Feb. 18, 2013).

5. FACT SHEET, *supra* note 3; MAYO FOUNDATION, *supra* note 1.

6. See FAMILY CAREGIVER ALLIANCE, *supra* note 4.

Alzheimer's.<sup>7</sup> Of the five million Americans affected by the disease, an estimated 211,000 live in Illinois.<sup>8</sup> Researchers in Illinois are active in researching the disease and discovering ways to improve services for residents afflicted with Alzheimer's.<sup>9</sup> Additionally, a need exists to help the caregivers of Alzheimer's patients with decision-making for these patients.

Once a patient is diagnosed with Alzheimer's, planning for the future is especially important.<sup>10</sup> A patient diagnosed with Alzheimer's lives, on average, eight years.<sup>11</sup> Some patients have been known to live over twenty years after diagnosis.<sup>12</sup> This disease affects patients and their caregivers for years, particularly in the area of decision-making. Over time, an Alzheimer's patient's memory fades and decision-making ability diminishes, until eventually he requires the help of others to make nearly all of his decisions.<sup>13</sup> These decisions include where to live, with whom to be romantically involved, and how to manage property and money.<sup>14</sup> Making these decisions presents both ethical and legal dilemmas to patients and their caregivers.<sup>15</sup> Ethical and legal dilemmas exist concerning how a patient's wishes may differ significantly as the disease progresses and

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7. ILLINOIS DEPARTMENT OF PUBLIC HEALTH, *Health Beat*, <http://www.idph.state.il.us/public/hb/hbalzheimer.htm>, (last visited Feb. 18, 2013).

8. *Id.*

9. 410 ILL. COMP. STAT. 405/2 (2013). The Alzheimer's Disease Assistance Act seeks to establish a program for conducting research regarding the cause, cure, and treatment of Alzheimer's. *Id.* It also seeks to establish a comprehensive, statewide system of regional and community-based services to diagnose and treat those with Alzheimer's. *Id.*

10. MAYO FOUNDATION, *supra* note 1.

11. *Health Beat*, *supra* note 7.

12. *Id.*

13. See FAMILY CAREGIVER ALLIANCE, *supra* note 4 (explaining through the use of a chart the progression of Alzheimer's); see also Lisa Brodoff, *Planning for Alzheimer's Disease with Mental Health Advance Directives*, 17 Elder L.J. 239, 240 (2010); FACT SHEET, *supra* note 3.

14. Brodoff, *supra* note 13, at 240.

15. FAMILY CAREGIVER ALLIANCE, *supra* note 4.

affects his or her mental capacities.

This article examines how current Illinois law and policy affects patients with Alzheimer's and their caregivers, specifically guardianship law and Illinois's Physician Orders for Life-Sustaining Treatment (POLST) form.<sup>16</sup> This article focuses on the option of using mental health advanced directives (MHADs), in addition to or as an alternative to guardianship and a POLST form, for Alzheimer's patients in Illinois. Current Illinois law falls short in assisting patients with Alzheimer's and their caregivers with decision-making. In many instances, MHADs are the best option for Alzheimer's patients because it is a planning tool that gives the patient more control over their quality of life in the future.

## II. CAREGIVING FOR ALZHEIMER'S PATIENTS

Alzheimer's is a disease that affects a vast number of Americans, whether through a personal diagnosis, or through playing the role of caregiver for a friend or loved one.<sup>17</sup> In the early stages of the disease, many caregivers are the patient's own family, relatives, or friends.<sup>18</sup> In 2011, nearly fifteen million Americans provided unpaid caregiving to those living with Alzheimer's.<sup>19</sup> The United States Department of Health and Human Services ("HHS") predicts that unpaid family caregivers will become the largest source of long-term care services in the country.<sup>20</sup> Accordingly, it is important that these caregivers understand the legal and

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16. Illinois provides other advanced directives to its residents. See ILL. DEP'T OF PUBLIC HEALTH, *Statement of Illinois Law on Advanced Directives and DNR Orders*, <http://www.idph.state.il.us/public/books/advdir4.htm> (last updated Aug. 2, 2011). Illinois currently regulates the following advanced directives: health care power of attorney, living wills, mental health treatment preference declarations, and do-not-resuscitate (DNR) orders. *Id.* None of these advanced directives completely address the needs of Alzheimer's patients.

17. Brodoff, *supra* note 13, at 240.

18. FAMILY CAREGIVER ALLIANCE, *supra* note 4.

19. *Id.*

20. Debra H. Kroll, *To Care or Not to Care: The Ultimate Decision for Adult Caregivers in a Rapidly Aging Society*, 21 TEMP. POL. & CIV. RTS. L. REV. 403, 404 (2012).

ethical issues surrounding the care of their loved ones.

A large part of caregiving involves helping a patient with decision-making.<sup>21</sup> The decisions a person would make prior to being diagnosed with Alzheimer's diverge from those that he or she makes once the disease advances.<sup>22</sup> A person with Alzheimer's may want to start a new romantic relationship, even if married, sell his or her property without considering the consequences, or protest being placed in a long-term care facility.<sup>23</sup> Caregivers must often make these financial and emotional decisions without the express consent of the person for whom they are caring.<sup>24</sup> As dementia progresses, conflict often arise between what a caregiver believes is in the best interest of his or her loved one and what the patient actually wants.<sup>25</sup> Illinois law gives some guidance to caregivers on what to do in these situations, but leaves caregivers a lot of discretion causing them to face ethical dilemmas.<sup>26</sup>

### III. ILLINOIS GUARDIANSHIP LAW

As a last resort, a caregiver of an Alzheimer's patient may consider petitioning for guardianship over the patient.<sup>27</sup> While it should not be used merely for convenience by the caregiver, this sort of control over a patient's decisions is used in Illinois for a sound and necessary purpose.<sup>28</sup> Every

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21. See FAMILY CAREGIVER ALLIANCE, *supra* note 4.

22. Brodoff, *supra* note 13, at 240-41.

23. *Id.* at 240.

24. *Id.* at 241.

25. See *id.* at 240-41.

26. See generally *Statement of Illinois Law on Advanced Directives and DNR Orders*, *supra* note 16.

27. IL GUARDIANSHIP AND ADVOCACY COMMISSION, *Guardianship Facts*, <http://gac.state.il.us/osg/osgfs.html>, (last visited Feb. 18, 2013); 755 ILL. COMP. STAT. 5/11a-3 (2004).

28. *Id.* The Office of the State Guardian explains that guardianship should be used as a last resort and only for a "sound and necessary purpose" because guardianship fully takes away one's legal rights. *Id.*

state has laws that govern guardianships.<sup>29</sup> Illinois guardianship law is considered unique and progressive.<sup>30</sup> Once a caregiver, or other individual, submits a petition for guardianship, a hearing takes place in Illinois Probate Court.<sup>31</sup> This hearing can involve lawyers, witnesses, and a jury if the patient opposes the guardianship, and the process can be costly.<sup>32</sup> The Illinois Probate Court may determine that a guardianship is not required, or it can appoint a “person guardianship” or “estate guardianship.”<sup>33</sup>

Although appointing a guardian for a patient with Alzheimer's is, at times, a viable option, it often does more harm than good.<sup>34</sup> Usually family members and caregivers only consider guardianship after the patient has entered the advanced stages of the disease.<sup>35</sup> Under Illinois law, the patient must receive a copy of the petition and notice of the hearing, but he or she will likely be unable to understand the documents or comprehend the proceedings.<sup>36</sup> Although Illinois allows the person with Alzheimer's to participate in his guardianship hearing and states the court will take his opinions into consideration, this participation is largely a farce.<sup>37</sup> Some guardians abuse their positions of authority and fail to protect the interests of their wards.<sup>38</sup> At least forty-five states report cases of financial

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29. Vaughn E. James, *No Help for the Helpless: How the Law has Failed to Serve and Protect Persons Suffering from Alzheimer's Disease*, 7 J. HEALTH & BIOMEDICAL L. 407, 414 (2012).

30. IL GUARDIANSHIP AND ADVOCACY COMMISSION, *supra* note 27.

31. *Id.*

32. *Id.*

33. *Id.* The court appoints a “guardianship of the person” to make decisions concerning medical treatment, place of residence, and other needs. *Id.* On the other hand, a “guardianship of the estate” is appointed to make decisions concerning the patient's finances and estate. *Id.*

34. James, *supra* note 29, at 417-20.

35. *Id.* at 420.

36. *Id.*; 755 ILL. COMP. STAT. 5/11a-10(e) (2012).

37. James, *supra* note 29, at 420; *see also* IL THE OFFICE OF STATE GUARDIAN, *supra* note 24; 755 ILL. COMP. STAT. 5/11a-11 (1995).

38. James, *supra* note 29, at 423.

exploitation and physical abuse by guardians.<sup>39</sup> The U.S. Government Accountability Office (“GAO”) found that guardians across the nation stole millions of dollars in assets from their wards between 1990 and 2010.<sup>40</sup> The GAO discovered flaws in Illinois’s guardianship system when it conducted an experiment; it used two fictitious identities, one with bad credit and one with the Social Security number of a deceased person to petition to be guardians in the state.<sup>41</sup> These fictitious identities were accepted as guardians in Illinois<sup>42</sup>, which leads to question of whether Illinois adequately protects its most vulnerable citizens, especially those with Alzheimer’s. MHAD’s, used in conjunction with or as an alternative to guardianships, may be able to better protect Illinois’ residents with Alzheimer’s.<sup>43</sup>

#### IV. ILLINOIS POLST FORM

Illinois recognizes that its laws and policy concerning advanced directives needs updating.<sup>44</sup> Illinois demonstrates this understanding with the implementation of the POLST (Physician Orders for Life-Sustaining Treatment) Paradigm.<sup>45</sup> The POLST Paradigm is a method to facilitate end-of-life planning based on conversations between patients, loved ones, and medical providers.<sup>46</sup> Its goal is to ensure that seriously ill patients can choose the treatments they wish to receive at the end of their life and that

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39. U.S. GOV’T ACCOUNTABILITY OFFICE, CASES OF FINANCIAL EXPLOITATION, NEGLECT, AND ABUSE OF SENIORS 5 (2010) available at <http://www.gao.gov/assets/320/310741.pdf>.

40. *Id.* at 7.

41. *Id.* at 25.

42. *Id.*

43. See discussion *infra* Part VI.

44. 20 ILL. COMP. STAT. 2310/2310-600 (2012).

45. *Id.*

46. For information about the national POLST Paradigm, please refer to <http://www.polst.org/about-the-national-polst-paradigm/>.

their wishes are honored by their medical providers.<sup>47</sup> Using the POLST paradigm, the patient fills out a brightly-colored POLST form, which is to travel with the patient across the continuum of care.<sup>48</sup> All but four states are currently developing or have already implemented a POLST paradigm.<sup>49</sup> In the spring of 2013, the Illinois Department of Public Health (IDPH) published a revised version of the IDPH Uniform DNR Advance Directive, which is now referred to as a POLST form.<sup>50</sup> Medical providers are required by law to honor the treatment choices written on a POLST in order to promote patient autonomy.<sup>51</sup>

The use of a POLST form is an excellent resource for terminally ill patients in Illinois. However, the POLST form is not an appropriate resource for patients with Alzheimer's. A POLST form should only be used for patients for whom death within the next year is expected.<sup>52</sup> Given that Alzheimer's patients live on average eight years after initial diagnosis, a POLST form is inappropriate for Illinois residents with Alzheimer's.<sup>53</sup> It is not advantageous for a patient with Alzheimer's to wait until a year before death to fill out an advanced directive that will enable them to make end-of-life decisions. Alzheimer's patients' memory and decision-making ability erode over a period of years.<sup>54</sup> An Alzheimer's patient should complete an advanced directive, such as an MHAD, while an Alzheimer's

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47. *Id.*

48. CHICAGO END-OF-LIFE CARE COALITION. Physician Orders for Life Sustaining Treatment (POLST) <http://www.cecc.info/resource-links/physicians-order-for-life-sustaining-treatment-polst> (last visited March 25, 2013).

49. See POLST, *Programs in Your State* <http://www.polst.org/programs-in-your-state/> (last visited March 25, 2013). The four states that are not currently developing or implemented a POLST paradigm are Arkansas, Mississippi, South Dakota, and Washington D.C. *Id.*

50. See CHICAGO END-OF-LIFE CARE COALITION, *supra* note 48.

51. *Id.*

52. *Id.*

53. See discussion *supra* Part I.

54. See MAYO FOUNDATION *supra* note 1.

patient still has the cognitive ability to make sound decisions.

#### V. MHADS

Since a mandated guardianship over a patient with Alzheimer's should be used as a last resort, and a POLST form is only appropriate for Illinois residents for whom death is expected within the next year, it is advantageous for a patient and caregiver to instead use a different planning method closer to the patient's diagnosis. It is important to formulate such a strategy together well in advance of the patient's final days to ease the burden of decision-making as the disease progresses. Illinois law and policy fails to facilitate such planning because the advanced directives available to Alzheimer's patients are geared towards end-of-life medical planning,<sup>55</sup> but they fail to address other important social decisions such as where to live and with whom to be romantically involved.<sup>56</sup>

MHADs are the best option to help Alzheimer's patients and their caregivers with long-term decision-making. Typically, MHADs are used by patients with mental disabilities such as bipolar disorder and severe depression in order to make predictions about what kind of care he or she would likely need and want in the future.<sup>57</sup> MHADs are also useful for patients in the early stages of Alzheimer's.<sup>58</sup> Attorneys, patients, and caregivers can work together while the patient is in an early stage of Alzheimer's to discuss predictable future decisions that the patients will face and draft a MHAD.<sup>59</sup> One of the most important aspects of a MHAD is that it should include a section discussing the patient's personal history

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55. *Statement of Illinois Law on Advanced Directives and DNR Orders*, *supra* note 16. (listing the current advanced directives available in Illinois).

56. *See generally Statement of Illinois Law on Advanced Directives and DNR Orders*, *supra* note 16.

57. Brodoff, *supra* note 13 at 241.

58. *Id.* at 242.

59. *Id.*

and core values.<sup>60</sup> With the use of this section, caregivers will better understand the decision that a patient would make in various situations, even those not explicitly stated in the MHAD.<sup>61</sup> MHADs can be used to plan the patient's wishes concerning finances and estate-planning, in-home care, and when out-of-home care would be required.<sup>62</sup> MHADs can facilitate planning for appropriate responses to aggressive behaviors and intimate relationships.<sup>63</sup>

It is important to note that even with a MHAD, care of a patient with Alzheimer's can present ethical dilemmas. One can only imagine the difficulty of telling a patient in advanced stages of Alzheimer's that they are not allowed to do things they would like to do, especially when the patient is a family member. The person with Alzheimer's disease may insist that he changed his mind concerning a decision that has already been made in the MHAD.<sup>64</sup> The caregiver is then torn between making the final days of the person's life peaceful, and following his wishes prior to the advanced stages of dementia. This dilemma shows that even with a MHAD, the care of a patient with Alzheimer's is difficult, but utilizing a MHAD may help alleviate the burden on patients and their caregivers as the disease progresses.

This article does not seek to advocate the use of MHADs with all Alzheimer's patients. MHADs should not be mandated by Illinois law as necessary in all instances when a patient is diagnosed with Alzheimer's. However, Illinois should recognize MHADs as an option for such patients and by doing so regulate the use of this advanced directive to better help the

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60. *Id.* at 260-61.

61. *Id.* at 261.

62. *Id.* at 262-79.

63. *Id.*

64. *See id.* at 240-1.

residents of this state. Until this action is taken by Illinois, Alzheimer's patients and their caregivers will be left largely unaware of this unique planning tool for long-term decision-making.

#### V. CONCLUSION

Caring for a person afflicted with Alzheimer's disease is both physically and emotionally demanding, and this caregiving can even negatively affect the caregiver's health.<sup>65</sup> It is important for caregivers to not only understand the disease, but to have a flexible strategy in place to provide the best care possible as the disease progresses.<sup>66</sup> Illinois law and policy is currently inadequate for providing patients and caregivers this type of flexible strategy.<sup>67</sup> There is not, and likely never will be, one plan that best fits the needs of all Alzheimer's patients in Illinois. However, when a viable option, a MHAD is an excellent strategy that a patient and caregiver can use as guidance as Alzheimer's progresses. It is impossible to predict all decisions that will need to be made a patient's disease progress, but a MHAD can still be an effective planning tool.

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65. MAYO FOUNDATION, *supra* note 1.

66. FACT SHEET, *supra* note 3.

67. See *Statement of Illinois Law on Advanced Directives and DNR Orders*, *supra* note 16.