

# *Advance Directives to Withhold Oral Food and Water in Dementia*

## *A Surrogate's Moral Obligations*

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*Abstract.* Euthanasia advocates have recently begun counseling people to create advance directives calling for oral food and water to be withheld if the person reaches a certain stage of dementia. The author shows that these directives are in fact requests for euthanasia, and they leave vulnerable people subject to poor-quality care. Both surrogate decision makers (health care proxies) and Catholic institutions have a moral obligation not to implement such directives, and surrogates, rather than withdrawing as proxies, have a moral obligation to advocate for the life and proper care of the incompetent person. Finally, the author argues that society is morally culpable if it does not strongly resist euthanasia in all its forms. *National Catholic Bioethics Quarterly* 16.3 (Autumn 2016): 421–434.

There is a new movement in the United States encouraging people to prepare an advance directive for dementia (ADD). This document directs caregivers to withhold food and water by mouth when a person reaches a specified level of dementia, even though the person is not dying and nourishment is not physically burdensome.<sup>1</sup> The goal is for persons with dementia to be able to die instead of living for years with a quality of life that, at the time they sign an ADD, they believe would be

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unacceptable. For proponents, this approach is a critical step toward “controlling the end game of dementia.”<sup>2</sup>

An ADD is actually a request to be euthanized by dehydration and starvation. Although not legally recognized in the United States, ADDs are being promoted as viable options for end-of-life planning.<sup>3</sup> Their interpretation, however, is highly subjective; their implementation presents difficult and fundamental challenges;<sup>4</sup> and they leave vulnerable persons open to neglect and abuse. ADDs illustrate the “then-self” versus “now-self” problem<sup>5</sup>: Should caregivers follow an instruction in an ADD to starve a person with dementia, that was signed while the person was competent, now that the person is incompetent and begging for food?<sup>6</sup>

Clearly, an ADD raises significant moral issues for everyone involved: the competent person who adopts a directive asking to be killed, the designated surrogate decision maker who decides when the killing should commence, caregivers who carry out the killing, the institution where the person resides, and society as a whole.

This paper will focus primarily on the moral obligations of surrogates who are expected to authorize the euthanization of the person. It argues that surrogates have no ethical duty to give consent to withholding food and water by mouth<sup>7</sup> pursuant to an ADD. Nor do surrogates have a duty to withdraw as health care proxies. Rather, surrogates have a moral obligation to prevent euthanasia, by refusing to consent to an ADD.

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1. Paul T. Menzel and M. Colette Chandler-Cramer, “Advance Directives, Dementia, and Withholding Food and Water by Mouth,” *Hastings Center Report* 44.3 (May–June 2014): 23–37.

2. Paul T. Menzel and M. Colette Chandler-Cramer, “Controlling the End Game of Dementia,” *Hastings Bioethics Forum* (blog), February 3, 2015, <http://www.thehastingscenter.org/>. Another recommended option is to kill oneself while still competent by using VSED (voluntarily stopping eating and drinking). Menzel and Chandler-Cramer note that the disadvantage of using VSED while still competent is that it will require “sacrificing . . . still valuable life.” But to some that will seem “a small price to pay for assurance that they will not live long into dementia.”

3. Ibid. The issue of withholding oral food and drink from incompetent patients will become more common given the rapidly increasing number of patients with end-stage dementia. Alzheimer’s disease is creating a growing population of patients who ultimately will be unable to make their own medical decisions. The number of people with dementia worldwide is expected to double by 2030 and more than triple by 2050. Cynthia A. Meier and Thuan D. Ong, “To Feed or Not to Feed? A Case Report and Ethical Analysis of Withholding Food and Drink in a Patient with Advanced Dementia,” *Journal of Pain and Symptom Management* 50.6 (December 2015): 887.

4. Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,” 25.

5. Ibid., 25–34.

6. Wesley J. Smith, “The Ethics of Food and Drink: Starvation Is Not Mercy,” *Weekly Standard*, July 28, 2014, <http://www.weeklystandard.com/>.

7. This statement assumes, of course, that food and water do not excessively burden the person physically.

This paper will summarize the arguments made to justify ADDs and show that such directives are actually requests for euthanasia. Then, using Catholic moral principles, including the *Ethical and Religious Directives for Catholic Health Care Services (ERDs)*, it will analyze the ethical duties of Catholic institutions and surrogates with respect to ADDs. Finally, it will examine the moral obligation of surrogates to refuse consent to withholding oral food and water from persons being cared for in secular institutions. The highly subjective nature of ADDs and the dangers they pose to the proper care of incompetent persons also will be addressed.

### A Request for Euthanasia

An advance directive or durable power of attorney designates an agent, commonly referred to as a proxy or surrogate, to make health care decisions in the event that a person becomes incapacitated.<sup>8</sup> It allows an individual to specify that certain life-sustaining treatments be withheld or withdrawn if the person is in a terminal condition and unable to make health care decisions.<sup>9</sup> Advance directives were conceived as a shield to protect dying persons from having new, intrusive measures forced on them to artificially prolong life.<sup>10</sup>

Recently, euthanasia supporters have begun advocating that individuals create advance directives that instruct caregivers to withhold food and water by mouth when they reach an advanced stage of dementia.<sup>11</sup> The goal is to bring about death when a person thinks her quality of life will be unacceptable, that is, when she thinks her life will no longer be worth living.<sup>12</sup> A critical element of the argument used to justify ADDs is as follows: A competent person has a right to cause her own death at any time by voluntarily choosing to stop eating and drinking (VSED).<sup>13</sup> This person should not lose that right when she becomes incompetent; rather, “someone else just has to exercise those rights for them.”<sup>14</sup> Proponents of ADDs frankly state

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8. William E. May, *Catholic Bioethics and the Gift of Human Life*, 3rd ed. (Huntington, IN: Our Sunday Visitor, 2013), 285. An advance directive and a durable power of attorney may be combined into a single document. There are two main types of advance directives, living wills and directives to physicians. See Albert R. Jonsen, Mark Siegler, and William J. Winslade, *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 8th ed. (New York: McGraw-Hill Education, 2015), 88–89, 93.

9. May, *Catholic Bioethics*, 285.

10. Marion Danis, “Following Advance Directives,” *Hastings Center Report* 24.6 (November–December 1994): s21.

11. Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,” 23–37.

12. Menzel and Chandler-Cramer, “Controlling the End Game.”

13. See Thaddeus Mason Pope and Lindsey E. Anderson, “Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life,” *Widener Law Review* 17.2 (2011): 386–387. As used here, VSED is limited to the competent person who is physically able to take food and liquids by mouth and digest them but deliberately chooses to stop eating and drinking in order to hasten death.

14. Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,” 25. In support of their thesis, they also incorrectly claim that oral food and water are a form

that, instead of VSED, they wish people could use advance euthanasia directives to stipulate that so-called aid in dying be administered once a certain stage of dementia is reached.<sup>15</sup> Proponents note, however, that advance euthanasia directives are far from becoming legal in the United States.<sup>16</sup> They propose using ADDs to withhold food and water by mouth instead, as a more realistic option to accomplish the same end. They assert that ADDs “are arguably already legal.”<sup>17</sup>

Its supporters cannot escape the reality that an ADD, in fact, is a request to be euthanized.<sup>18</sup> Contrary to what they imply, withholding food and water by mouth from an incompetent person is not a form of VSED. In VSED, a competent individual takes self-directed steps to end her own life.<sup>19</sup> Morally speaking, when a competent person voluntarily stops eating and drinking with the intent to kill herself, she is committing suicide.<sup>20</sup> By contrast, when a caregiver, pursuant to an ADD, deliberately withholds oral food and water from an incompetent person in order to cause her death, the caregiver engages in a form of passive euthanasia. Passive euthanasia

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of medical treatment that can be refused. Food and water are not medical treatment. Eating and drinking are not a medical decision but a basic activity of living. See Michael D. Cantor, Jeanie Kayser-Jones, and Thomas E. Finucane, “To Force Feed the Patient with Dementia or Not to Feed: Preferences, Evidence Base, and Regulation,” *Annals of Long-Term Care* 10.8 (August 2002): 45–48. Hand-feeding is not a medical procedure. See Meier and Ong, “To Feed or Not to Feed,” 888.

15. Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,” 24. See also Paul T. Menzel and Bonnie Steinbock, “Advance Directives, Dementia, and Physician-Assisted Death,” *Journal of Law, Medicine and Ethics* 41.2 (Summer 2013): 484–500.

16. Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,” 24. Advance euthanasia directives are legal in the Netherlands (36 note 11).

17. *Ibid.*, 24–25.

18. Menzel and Chandler-Cramer cannot acknowledge that an ADD is a request to be euthanized, however, and at the same time claim that ADDs “are arguably already legal.” (“Advance Directives, Dementia, and Withholding,” 25). Euthanasia is illegal in the United States. Menzel and Steinbock note that “obviously, where euthanasia is illegal, there cannot be operative advance *euthanasia* directives” (“Advance Directives, Dementia, and Physician-Assisted Death,” 484, original emphasis). In an effort to get around the legal prohibition against euthanasia, they suggest that people instead write advance directives that ask for “aid-in-dying” that they hope could be recognized in states where physician-assisted death is legal.

19. Thaddeus Mason Pope and Amanda West, “Legal Briefing: Voluntarily Stopping Eating and Drinking,” *Journal of Clinical Ethics* 25.1 (Spring 2014): 68: “In order to qualify as VSED, a decision to stop eating and drinking must be fully autonomous and self-directed.” See also Timothy Kirk, quoted in AHC Media, “Advance Directives Covering Dementia Care: Patient Preferences Can Change over Time,” *Medical Ethics Advisor*, October 1, 2014, <http://www.ahcmmedia.com/>: “By definition, VSED is a voluntary course of action. If a patient is sufficiently incapacitated such that his advance directive comes into effect regarding eating and drinking, it is not clear to me how withholding food and drink from him—even if this was a prior expressed wish—is voluntary.”

20. Congregation for the Doctrine of the Faith (CDF), *Declaration on Euthanasia* (May 5, 1980), n. 3.

“brings about the death of a person for merciful reasons by an act of omission, i.e., by withholding or withdrawing medical treatments that could preserve that person’s life, precisely in order to bring about death.”<sup>21</sup> Food and water are ordinary care, not medical treatments.<sup>22</sup> Obviously, withholding ordinary care from a person in order to cause death, even for merciful reasons, also is euthanasia.<sup>23</sup>

ADDs and VSED thus call for actions of a very different nature. An ADD does not preserve, for an incompetent person, the same “right” a competent person has to engage in VSED.<sup>24</sup> Rather, an ADD takes away the critical right that is inherent in VSED, personal control of the process—that is, the right to change one’s mind. When a competent person engages in VSED, she can change her mind at any time, for any reason, and thereby continue living.<sup>25</sup>

By contrast, to be effective, an ADD must be structured and implemented so that a change of mind will have no effect.<sup>26</sup> A model ADD specifically provides that

21. May, *Catholic Bioethics*, 254. Passive euthanasia can be voluntary, when the person gives free and informed consent, or nonvoluntary, when the person killed is incompetent and incapable of giving consent. There is a good argument that euthanasia of a demented individual is nonvoluntary even if she gave prior consent in an advance directive. Legal authorities may see the failure to help a debilitated patient eat and drink as more similar to prohibited active euthanasia than to permissible withholding and withdrawing life-sustaining treatments. See Rebecca Dresser, “Toward a Humane Death with Dementia,” *Hastings Center Report* 44.3 (May–June 2014): 39.

22. US Congress of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 5th ed. (Washington, DC: USCCB, 2009). dir. 58. Eating and drinking are not a medical decision but a basic activity of living. See Cantor, et al, “To Force Feed the Patient with Dementia.” Hand-feeding is not a medical procedure. See Meier and Ong, “To Feed or Not to Feed,” 888.

23. Withdrawing nutrition and hydration from a patient thereby causing death by starvation and dehydration constitutes euthanasia by omission. John Paul II, Address to the International Congress on “Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas” (March 20, 2004), n. 4. See also May, *Catholic Bioethics*, 256.

24. Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,” 24–25.

25. See, for example, Ross Fewing, Timothy W. Kirk, and Alan Meisel, “A Fading Decision,” *Hastings Center Report* 44.3 (May–June 2014): 15; and Pope and Anderson, “Voluntarily Stopping Eating and Drinking,” 383, 397 note 257.

26. In an attempt to justify withholding food and water from the now-demented person, Menzel and Steinbock discuss the “then-self, now-self” concept, which acknowledges that people change in dementia. Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,” 25, 27–29. What a competent person thought would be an unacceptable quality of life in dementia turns out to be not so bad when they actually become demented. Should the desires of the then-competent person or the now-incompetent person be followed? What the incompetent person “desires” is based on what others perceive to be her critical and experiential interests, a highly subjective process that results in a judgment about whether the person’s life is still worth living. Of course, these quality-of-life judgments are basically the same as those made to advocate for the approval of advance euthanasia directives for

once it has been determined that starvation should begin, food and water are to be withheld even if the person shows distress.<sup>27</sup> Decision makers may determine that it is not yet time to implement the directive, but only so long as they “remain committed to implementing the directive in the future.”<sup>28</sup> Thus, by design, there is no way for the demented person effectively to change her mind and live.

A leading article concludes that the most ethical and morally justifiable approach is to implement an ADD only when a person suffers from severe dementia.<sup>29</sup> This highlights that the action being taken is euthanasia. In severe dementia, a person is most vulnerable and least able to adequately communicate a change of mind, that is, the desire to eat, drink, and live. Often, there is no reliable way to determine whether a person in this state wants to be fed or would be distressed by not being fed.<sup>30</sup> An ADD mandates starving someone who accepts assistance with eating, occasionally appears to take pleasure in it, and seldom expresses distress or discomfort during the process.<sup>31</sup> As one commentator noted, an ADD seeks to “empower competent persons to impose potential discomfort and distress on a later self who will be unable to understand the reasons for that choice. In this situation, the price for respecting autonomy is paid by a frail incapacitated patient who has no idea why food and water are no longer offered to her.”<sup>32</sup> Rather than providing escape from the “trap” of dementia, an ADD becomes a snare from which there is no escape.<sup>33</sup>

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persons with dementia. Menzel and Chandler-Cramer, “Advance Directives, Dementia and Physician-Assisted Death,” 492–498. There is no consensus in the literature about which “self” should be honored. See also Meier and Ong, “To Feed or Not to Feed,” 889.

27. Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,”

32. Menzel and Chandler-Cramer suggest that arguably there should be a delay in implementing an ADD if the demented person shows unrelievable distress at not being fed (34). However, it seems unlikely that distress would delay the withholding of food and water. Under the model ADD, distress-relieving drugs are to be administered when a person shows distress at not being fed and also as a matter of routine comfort care when the person is agitated or anxious (32). Thus it appears that a person with an ADD who is distressed by not being fed simply would be drugged into a compliant state. They also note that “withholding food and water by mouth will be accomplished by withholding assistance, not by withholding food and water straight out” (30). This is a distinction without a difference, when the only way a person can eat and drink is with assistance. Failing to help a debilitated patient eat and drink may be seen as active euthanasia. See Dresser, “Toward a Humane Death,” 39. Failing to offer food to an incompetent patient could be viewed as neglect. See Meier and Ong, “To Feed or Not to Feed,” 888.

28. Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,” 34.

29. *Ibid.*, 35. However, a person can designate any stage of dementia as the time to be killed. “The most effective directive will . . . refer clearly to the stage of dementia when food and water by mouth is to be withheld” (34).

30. Meier and Ong, “To Feed or Not to Feed,” 889.

31. Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,” 23–37.

32. Dresser, “Toward a Humane Death,” 39.

33. Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,”

24. The trap is described as “One wishes to end one’s life because one is demented, but [when that time comes] one cannot . . . end one’s life because one is demented.” With an ADD, one



### Euthanasia as a Crime against Life

Euthanasia is a “crime against life” and a grave violation of the law of God.<sup>34</sup> It is defined as “an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated. Euthanasia’s terms of reference, therefore, are to be found in the intention of the will and in the methods used.”<sup>35</sup> From this definition it is clear that an advance directive that requires withholding oral food and water when they are not physically burdensome, solely for the purpose of causing death so that suffering may be eliminated, contains both an intention of will and a method that constitute euthanasia.<sup>36</sup>

The primary argument in support of euthanasia is based on a death-focused conception of autonomy in which the “freedom of self-determination includes the freedom to choose to be killed,” and “meaningful human dignity ... consists in the ability to control one’s own life and death and to determine the manner of one’s demise.”<sup>37</sup> This notion of autonomy purports to be expansive and noble, but in reality it is based on elitism and fear, confining and debasing all those involved.

Euthanasia advocates conceal this fact by using euphemisms that blur distinctions between euthanasia and assisted suicide to make the acts seem more palatable. For example, physician-assisted suicide is now called aid-in-dying, and both it and euthanasia may be referred to simply as assisted death or assisted dying.<sup>38</sup> But “no word has the power to change the reality of things.”<sup>39</sup> The need to disguise these acts merely confirms their moral depravity. We must “have the courage to look the truth in the eye and to call things by their proper name, without yielding to convenient compromises or to the temptation of self-deception.”<sup>40</sup>

Euthanasia advocates also would deny others the freedom they claim for themselves. They assert that “death control, like birth control, is a matter of human dignity. Without it persons become puppets.”<sup>41</sup> Yet they have no compunction about turning others into puppets by requiring them to engage in euthanasia against their-

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who wishes to live cannot live because one is demented. Pope argues that an incompetent person in severe dementia is not legally qualified to change her mind. A person who opens her mouth to eat and shows a preference for certain foods cannot overcome the ADD she signed while competent and should be killed. Pope and West, “Legal Briefing,” 77.

34. Vatican Council II, *Gaudium et spes* (December 7, 1965), n. 27; and John Paul II, *Evangelium vitae* (March 25, 1995), n. 65.

35. CDF, *Declaration on Euthanasia*, art. II.

36. John Paul II, “Life-Sustaining Treatments and Vegetative State,” n. 4.

37. May, *Catholic Bioethics*, 257.

38. Menzel and Steinbock, “Advance Directives, Dementia, and Physician-Assisted Death,” 484.

39. John Paul II, *Evangelium vitae*, n. 58.

40. Ibid.

41. Joseph Fletcher, “The Patient’s Right to Die,” quoted in May, *Catholic Bioethics*, 257.

consciences.<sup>42</sup> Autonomy, properly understood, does not justify euthanasia. “The claims of autonomy cannot properly extend to choices which are inconsistent with recognising the basic worth and dignity of every human being.”<sup>43</sup> “When human autonomy is conceived as the creator and arbiter of good and evil, of right and wrong, we are no longer able to guide our choices by the truth but only by subjective and changing human opinions.”<sup>44</sup>

What is the truth by which we are to guide our choices? The truth is that we are made in the image and likeness of God,<sup>45</sup> which endures even into a demented old age. The truth is that we did not create ourselves, so we do not have absolute ownership or dominion over our lives, but only exercise stewardship over them.<sup>46</sup> The truth is that we have a duty to the God who created us to use ordinary and proportionate means to care for our lives and our health.<sup>47</sup> It follows that life and death cannot be just about our wishes and preferences. Morally, we cannot kill ourselves or ask that someone else do so when we believe our quality of life is unacceptable. Finally, the truth is that death is unavoidable. We should accept its reality and prepare for it but not in any way hasten its approach.<sup>48</sup>

### **Catholic Institutions Must Refuse Requests for Euthanasia**

Catholic health care institutions are governed by the *ERDs*, which embody the moral principles on which Catholic health care is based. Most importantly, human dignity must be promoted and defended by respecting the sacredness of every human life from conception until death.<sup>49</sup> What is a Catholic institution to do about patients who have an ADD? The answer is clear: it cannot honor ADDs, because they are requests for euthanasia,<sup>50</sup> which Catholic health care institutions may never condone

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42. For example, if there were increasing social acceptance of ADDs it appears Menzel and Chandler-Cramer would take away the right of conscientious objection and require caregivers to euthanize incompetent patients by withholding oral food and water. Menzel and Chandler-Cramer, “Advance Directives, Dementia, and Withholding,” 34.

43. Luke Gormally et al., in *Euthanasia, Clinical Practice and the Law*, 132, quoted in May, *Catholic Bioethics*, 264.

44. May, *Catholic Bioethics*, 264–265.

45. National Conference of Catholic Bishops (NCCB) Committee for Pro-Life Activities, “Nutrition and Hydration: Moral and Pastoral Reflections,” *Linacre Quarterly* 59.4 (November 1992): 34.

46. Ibid. See also USCCB, *Ethical and Religious Directives*, part 5, introduction.

47. NCCB, “Nutrition and Hydration,” 34–35 (n. 4). One is not obligated to use either extraordinary or disproportionate means to preserve life. Those are means that offer no reasonable hope of benefit or that involve excessive burdens. See also USCCB, *Ethical and Religious Directives*, dirs. 32, 56, 57.

48. NCCB, “Nutrition and Hydration,” 35 (n. 6).

49. USCCB, *Ethical and Religious Directives*, part 1, intro.

50. This assumes food and water are not physically burdensome. Nor can a Catholic institution sanction or facilitate a competent patient’s request for VSED when the purpose is to hasten death. Maureen Cavanagh, “How Should a Catholic Hospice Respond to Patients



or cooperate with in any way.<sup>51</sup> Moreover, food and water constitute ordinary care, which there is a particular obligation to provide.<sup>52</sup> “Oral feeding, when it can be accepted and assimilated by a patient, is a form of care owed to all helpless people.”<sup>53</sup> All patients in a Catholic institution, including those with an ADD, must receive loving care, psychological and spiritual support, and appropriate remedies for pain and other symptoms so they can live with dignity until the time of natural death.<sup>54</sup> Finally, Catholic institutions must take special care of the elderly and patients with dementia. An important part of the mission of Catholic health care is to “distinguish itself by service to and advocacy for those people whose social condition puts them at the margins of society and makes them particularly vulnerable to discrimination.” In particular, a person with a mental disability, such as dementia, regardless of the cause or severity, “must be treated as a unique person of incomparable worth, with the same right to life and to adequate health care as all other persons.”<sup>55</sup>

Euthanasia supporters erroneously contend that Catholic moral teachings have dire implications for people admitted to Catholic institutions.<sup>56</sup> In fact, Catholic institutions may become the only places where defenseless patients, particularly the poor and incompetent elderly, will be safe from being killed under the guise of a right to die.<sup>57</sup>

### **A Surrogate Must Never Consent to Euthanasia**

When a patient is in a Catholic health care institution, her surrogate’s rejection of an ADD is supported by the *ERDs*. In a secular health care institution or long-term

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Who Choose to Voluntarily Stop Eating and Drinking in Order to Hasten Death?” *Linacre Quarterly* 81.3 (2014), 283–284.

51. USCCB, *Ethical and Religious Directives*, dir. 60. See also directives 24 and 28. An institution will not honor an advance directive that is contrary to Catholic teaching. The free and informed health care decision of a person or their surrogate will be followed unless it contradicts Catholic principles.

52. *Ibid.*, dir. 58.

53. NCCB, “Nutrition and Hydration,” 36 (n. 2).

54. USCCB, *Ethical and Religious Directives*, dir. 60.

55. *Ibid.*, dir. 3.

56. Compassion and Choices, “End-of-Life Care and Choice: The Looming Crisis of Suffering in the US,” March 8, 2016, 2, <http://www.compassionsandchoices.org/>: “Religiously affiliated hospitals and nursing homes often impose restrictions that interfere with a person’s ability to direct their end-of-life care based on specific doctrines. For example, . . . the *Ethical and Religious Directives for Catholic Health Care Services* . . . specify that patients’ end-of-life decisions will not be honored if they conflict with Catholic moral teaching. This has dire implications for people admitted to the more than 600 Catholic hospitals in the US each year.”

57. See John Paul II, *Evangelium vitae*, n. 52: “Before the moral norm which prohibits the direct taking of the life of an innocent human being there are no privileges or exceptions for anyone. It makes no difference whether one is the master of the world or the ‘poorest of the poor’ on the face of the earth. Before the demands of morality we are all absolutely equal.”

care facility, however, the *ERDs* do not apply. A surrogate's duties in that situation will be addressed also considering how the surrogate was appointed.

Proponents of ADDs recommend that, in conjunction with the directive, a person use a durable power of attorney to appoint a surrogate and specifically discuss withholding food and water with the surrogate.<sup>58</sup> Most likely, the person will select a surrogate who is a relative or close friend. A would-be surrogate who learns of the existence of an ADD has a moral obligation to refuse to be appointed surrogate under these circumstances and to try to dissuade the person from using an ADD, explaining that it amounts to an immoral request to be euthanized. If the person appoints the refusing individual as a surrogate anyway, she has effectively granted the surrogate enhanced authority to act in a manner the surrogate thinks best, regardless of the patient's expressed wishes.<sup>59</sup> However, an individual also may find themselves designated as surrogate without any prior discussion, after the patient is incapacitated.<sup>60</sup> The surrogate's proper course of action is determined by moral and practical considerations, including the duties owed to God and oneself, and the duties of love, care, and protection owed to the incompetent person.<sup>61</sup>

### **Moral Obligations of Surrogates**

When discussing the moral obligations of a surrogate, we must begin with the truth that "euthanasia is an attack on life which no one has a right to make or request,

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58. Menzel and Chandler-Cramer, "Advance Directives, Dementia and Withholding," 34–35.

59. Joseph J. Fins et al., "Contracts, Covenants and Advance Care Planning: An Empirical Study of the Moral Obligations of Patient and Proxy," *Journal of Pain and Symptom Management* 29.1 (January 2005): 56. A patient's chosen surrogate generally is someone the patient trusts and even loves. The surrogate has a source of moral authority or procedural authority that stems from being chosen by the patient, which is at least as important as the preferences expressed by the patient. "Here the patient empowers a trusted individual with interpretative discretion to access novel and perhaps unforeseen circumstances and to make a moral judgment, conceivably even one that might counter the patient's previously expressed wishes" (56).

60. Surrogates are often appointed by a person's durable power of attorney. However, a surrogate also may be appointed pursuant to a statute that gives family members authority in order of ranked priority, or pursuant to court order. See Jonsen et al., *Clinical Ethics*, 93. See also USCCB, *Ethical and Religious Directives*, dir. 25.

61. There also may be legal considerations. As previously discussed, an ADD is not legal because it requests euthanasia, so a surrogate has no legal obligation to carry out its terms. Neither are caregivers or facilities legally required to implement ADDs. See Menzel and Chandler-Cramer, "Advance Directives, Dementia and Withholding," 27. In fact, there are "medical and ethical mandates" to provide food and drink. A surrogate may face legal charges of neglect if they authorize withholding oral food and water from a patient, or if they carry out the withholding themselves. See Meier and Ong, "To Feed or Not to Feed," 888, 890. Even if ADDs were to become legal, a surrogate morally cannot authorize withholding oral food and water in order to cause a patient's death. "Man can never obey a law which is in itself immoral. . . . Moreover, he may not collaborate in its application." Paul VI, *Declaration on Procured Abortion* (June 28, 1974), n. 22. It is never licit to obey an intrinsically unjust law, such as a law permitting euthanasia. John Paul II, *Evangelium vitae*, n. 73.

and which no government or other human authority can legitimately recommend or permit.”<sup>62</sup> No one in any way can permit an innocent human being to be killed, even if that person is old, suffering from an incurable disease, or dying.<sup>63</sup> Given that an ADD is a request for euthanasia, it is immoral in itself. When the underlying request is immoral, carrying it out is also immoral. “Morally, the proxy may not deliberately cause a patient’s death or refuse what is clearly ordinary means, even if he or she believes the patient would have made such a decision.”<sup>64</sup>

Unfortunately, as a result of the isolated focus on patient autonomy, current debates largely overlook the needs and rights of surrogates and the effects on them of making life and death decisions for another person.<sup>65</sup> Euthanasia harms the surrogate who consents to it and the health care providers who carry it out as well as the person who is killed.<sup>66</sup> A person’s actions define who they are. “It is in and through the actions we freely choose to do that *we determine ourselves* and establish our identity as moral beings.”<sup>67</sup> Regardless of how a surrogate feels, if she gives permission to withhold food and water or directs that they be withheld pursuant to an ADD, she participates in an act of killing and, in a sense, becomes a killer.<sup>68</sup> “Adopting a proposal to bring about a person’s death does not require that one regard that person’s death as desirable in itself, or that one will be pleased when it occurs. . . . One might be very reluctant to kill the person. . . . Nevertheless, if one adopts a proposal to hasten death . . . one

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62. NCCB, “Nutrition and Hydration,” 34. See also John Paul II, *Evangelium vitae*, n. 57: “The direct and voluntary killing of an innocent human being is always gravely immoral. . . . [Before this moral norm,] there are no privileges or exceptions for anyone.”

63. John Paul II, *Evangelium vitae*, n. 57.

64. NCCB, “Nutrition and Hydration,” 44.

65. Making medical decisions for a loved one can take a substantial emotional and physical toll on the surrogate. Recent studies have begun to document that surrogate decisions to withdraw life-sustaining treatments are associated with high levels of stress. Signing a do-not-resuscitate order can raise many negative emotions, including guilt, ambivalence, and conflict. How many more problems would there be for a surrogate who, pursuant to an ADD, directs or consents to killing someone who is not dying? See Elizabeth K. Vig et al., “Responding to Surrogate Requests That Seem Inconsistent with a Patient’s Living Will,” *Journal of Pain and Symptom Management* 42.5 (November 2011): 779–780. See also Catherine M. Handy et al., “The Surrogate’s Experience in Authorizing a Do Not Resuscitate Order,” *Palliative and Supportive Care* 6.1 (2008): 13–19.

66. Vatican Council II, *Gaudium et spes*, n. 27, gives some examples of this moral distress. Clearly ADDs will cause moral distress: “There are enough difficult cases that caregivers’ and care facilities’ conscientious objections to participating should be respected.” Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,” 34. Further, in a case where staff were asked to stop orally feeding a demented patient who was able to eat (that is, engage in euthanasia), staff were “very distressed” by the request and did not want to comply, because it would compromise the “integrity of their professional identity.” Meier and Ong, “To Feed or Not to Feed,” 889. For many, the plea of “professional identity” may represent the judgment of conscience that an act is morally wrong.

67. May, *Catholic Bioethics*, 61, original emphasis.

68. Ibid., 60: Human acts “embody and carry out human choices; because they do, they abide within the person as dispositions to further choices and actions of the same kind.”

does an act of killing in the strict sense.”<sup>69</sup> This choice by the surrogate “cannot be redeemed by the goodness of any intention or of any consequence; [it is] irrevocably opposed to the bond between persons.”<sup>70</sup>

The surrogate should not be misled into thinking the patient’s decision to adopt an ADD exonerates her from the moral responsibility for implementing it. It is wrong to participate in or help others commit morally impermissible acts, and carrying out an ADD constitutes formal cooperation with evil.<sup>71</sup> Formal cooperation occurs when one intends to further the end or goal of a person who engages in an act of wrongdoing.<sup>72</sup> This cooperation can never be justified by asserting the autonomy of the principal actor.<sup>73</sup> “Each of us is specially responsible for what *he* does rather than for what other people do.”<sup>74</sup> A surrogate has moral responsibility for the act she personally performs by directing or consenting to euthanasia. “No one can be exempted from this responsibility, and on the basis of it everyone will be judged by God himself.”<sup>75</sup>

Morally, then, a surrogate cannot consent to withholding food and water pursuant to an ADD. This does not mean that the surrogate should withdraw from acting as the decision maker, however. Instead, it means she has a moral obligation to ensure that the person continues to receive good medical and personal care and the obligation to protect her from being euthanized.<sup>76</sup>

### Advocate for Good Care

ADDs leave incompetent persons at the mercy of arbitrary decisions that will result in their death. They require that judgments be made about whether a demented person wants to be fed, even though there may be no reliable way to determine the answer, and they force surrogates and caregivers to make highly subjective decisions about the person’s quality of life.<sup>77</sup> Moreover, ADDs put incompetent persons at a great risk of receiving poor care by shifting the focus from living to dying and

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69. Germain Grisez and Joseph M. Boyle Jr., *Life and Death with Liberty and Justice: A Contribution to the Euthanasia Debate* (Notre Dame, IN: University of Notre Dame Press, 1979), 415.

70. John Paul II, *Evangelium vitae*, nn. 66, 75.

71. Lynn A. Jansen, “No Safe Harbor: The Principle of Complicity and the Practice of Voluntary Stopping of Eating and Drinking,” *Journal of Medicine and Philosophy* 29.1 (February 2004): 67.

72. Jansen, “No Safe Harbor,” 68.

73. John Paul II, *Evangelium vitae*, n. 74.

74. Bernard Williams, “Critique of Utilitarianism” (1973), quoted in Jansen, “No Safe Harbor,” 65, original emphasis.

75. John Paul II, *Evangelium vitae*, n. 74.

76. See CDF, *Declaration on Procured Abortion*, n. 24, “Following one’s conscience in obedience to the law of God is not always the easy way. One must not fail to recognize the weight of the sacrifices and the burdens which it can impose.”

77. See Menzel and Chandler-Cramer, “Advance Directives, Dementia and Withholding,” 34. For example, a surrogate is supposed to decide whether survival retains enough “significant subjective value” to the incompetent patient to justify keeping the patient alive. See also Meier and Ong, “To Feed or Not to Feed,” 889.

indicating that, at some point, the person should be killed. Thus, an ADD minimizes the incentive to maintain an incompetent person's quality of life.<sup>78</sup> This is particularly dangerous in an environment where poor quality of care is already a serious concern.<sup>79</sup>

Quality of care in nursing homes is a long-standing policy challenge. Almost half of residents have dementia, and the nursing assistants who provide most of their care often have only limited training in working with this population. Poor quality of care leads to weight loss, behavioral and emotional problems, cognitive difficulties, and diminished physical functioning.<sup>80</sup>

Furthermore, nearly two-thirds of all nursing home residents receive psychoactive medications. Overuse of psychoactive drugs, including improper use as chemical restraints, is a pervasive problem for residents with dementia.<sup>81</sup> Its effects include "lethargy, unresponsiveness, increased drooling, and/or lack of expressiveness."<sup>82</sup> In an ADD, these effects are quality-of-life indicators that indicate that oral food and water should be withheld from a patient.<sup>83</sup>

Advocates for ADDs paint a rosy picture of the conscientious care received by dementia patients, where caregivers provide artful encouragement to eat, but this is not the reality for many patients.<sup>84</sup> The idea that patients are forced to eat against their will also lacks support; the opposite is the norm. Inadequate staffing and lack of supervision are the most significant factors that influence how patients eat. They result in patients being fed too quickly and not being given enough time to ingest their food, which leads to coughing and choking, especially for those who have difficulty swallowing. Lack of attention to food preferences and to the provision of ethnic food choices may also lead to decreased food intake and weight loss.<sup>85</sup>

Thus, it is likely that a person with an ADD will meet the criteria to be euthanized as a result of poor care. Moreover, there may be little incentive to provide good care to a person who previously indicated a willingness to be killed. As an

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78. "It is frequently remarked that after a do not resuscitate order (DNR) is written, attention to the patient's needs diminishes." Jonsen et al., *Clinical Ethics*, 160.

79. See Dresser, "Toward a Humane Death," 39. There is a general lack of care and services for people with dementia. "People with dementia and their families struggle mightily, often making do without the support and resources that could vastly improve their quality of life."

80. Kaiser Commission on Medicaid and the Uninsured, "Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2009 through 2014," Kaiser Family Foundation, August 2015, 2, 14, 16, <http://www.kff.org/>.

81. *Ibid.*, 2, 3, 12.

82. Washington State Long-Term Care Ombudsman, "Reduce the Misuse" brochure, September 2013; see also "Misused Antipsychotics," accessed June 28, 2016, <http://www.waombudsman.org/>.

83. See, for example, the addenda to the ADD of M. Colette Chandler-Cramer, in Menzel and Chandler-Cramer, "Advance Directives, Dementia and Withholding," 33.

84. Menzel and Chandler-Cramer, "Advance Directives, Dementia and Withholding," 23, 30.

85. Cantor et al., "To Force Feed People with Dementia," 45–48.

advocate for euthanasia callously pointed out, caring for an elderly patient when she is dying from starvation and dehydration is less demanding than caring for her under normal circumstances, because “the patient’s diapers would need to be changed less frequently.”<sup>86</sup>

One can see that a person with an ADD is particularly vulnerable to receiving inadequate care. Thus, it is especially important for the surrogate not to withdraw but instead to act as a vigilant and strong advocate for life and proper care. “Every man is his ‘brother’s keeper,’”<sup>87</sup> especially when that brother’s life is threatened.

### **Responsibility of Society**

The recommendation that people create ADDs is a continuation of the surreptitious effort to make euthanasia socially acceptable and, ultimately, legal. Pro-euthanasia campaigners “always have a next step.”<sup>88</sup> As a society we must continue to oppose this effort as strongly as possible and remember that “true ‘compassion’ leads to sharing another’s pain; it does not kill the person whose suffering we cannot bear.”<sup>89</sup> We will not be able to distance ourselves from this crime against life by claiming it is the result of an individual’s autonomous choice. Autonomy is a poor excuse to justify our own conclusion that the lives of people with dementia are not worth living. Nor should we think that we are not culpable for what society decides. Its moral conscience already encourages behavior that is contrary to life and creates structures of sin which go against life.<sup>90</sup>

We have seen that, morally, a person is prohibited from adopting an ADD, and neither a Catholic health care institution nor a surrogate may ever give effect to one, because it is a request to be euthanized. Everyone has a duty to strongly resist euthanasia in all its forms because it hurts us all, even if we do not approve of or participate in it. As the poet John Donne so eloquently wrote, “No man is an island entire of itself. . . . Any man’s death diminishes me, because I am involved in mankind, and therefore never send to know for whom the bell tolls; it tolls for thee” (Meditation XVII).

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86. Pope and Anderson, “Voluntarily Stopping Eating and Drinking,” 397 note 254.

87. John Paul II, *Evangelium vitae*, n. 19.

88. Douglas Murray, “Grim Reaper, MD: The Low Countries Slide down the Euthanasia Slippery Slope,” *National Review*, April 25, 2016, <http://nationalreview.com>.

89. John Paul II, *Evangelium vitae*, n. 66.

90. *Ibid.*, n. 24.