

End of Life Care: Why Living Wills are Ineffective
and Why Death with Dignity Acts are a More
Effective Approach

*Ashley Whitefield**

I. INTRODUCTION

End of life choices for terminally ill patients are among the most challenging decisions made by patients and their families.¹ Patients and their families must make complex decisions that balance the needs of the patient, the family, and his or her values about end of life care. These patients will not recover from their illnesses, and while physicians cannot give these patients a cure, they should be able to give them control over how to spend the remainder of their life. Some terminal diseases may leave patients in severe pain or in a vegetative state, which is why many take advantage of existing laws or actively petition courts to expand their laws to give patients a right to die with dignity.²

Due to the severity of these terminal illnesses, many patients feel the need to regain control and make pertinent decisions regarding their end of life care. To avoid suffering or loss of control at the end of their life, some patients request to have ventilation machines or nutritional tubes removed,³ while others prefer to obtain a lethal prescription from their physician to

* Juris Doctor Candidate, Loyola University Chicago School of Law, Class of 2014. Ms. Whitefield is an Associate Editor of *Annals of Health Law*.

1. *End of Life Issues and Care*, AMERICAN PSYCHOLOGICAL ASSOCIATION (Mar. 22, 2013), <http://www.apa.org/topics/death/end-of-life.aspx>.

2. See Kathryn L. Tucker, *Health Law Symposium: When Dying Takes Too Long: Activism For Social Change To Protect And Expand Choice At The End Of Life*, 33 WHITTIER L. REV. 109, 114 (2011).

3. James Estrin & John Schwartz, *Living For Today, Locked In A Paralyzed Body*, N.Y. TIMES (Nov. 7, 2004), available at http://www.nytimes.com/2004/11/07/health/07ALS.html?_r=0.

bring about a peaceful death. Based on evidence that terminally ill patients want the right to make decisions regarding care, most states have adopted statutes addressing patient rights to end of life care.⁴

Many states adopted living will statutes. Living wills state how an individual wants to be treated in end-of-life situations or if declared incompetent.⁵ But, as this article will explore, these documents are often ineffective because they fail to address many of the concerns of terminal patients; and evidence shows that physicians do not always honor these wills.⁶ In an effort to provide patients with more control over their death, some states have adopted right-to-die laws or “death with dignity” legislation.⁷ For example, Washington and Oregon have adopted Death with Dignity Acts (the “Acts”). Under these laws, terminally ill adults may request a prescription for a lethal medication, which is ingested to bring about a peaceful death.⁸ These Acts protect physicians from civil or criminal liability when acting in compliance with the act, and affords patients an additional option. Regardless of the viewpoint that physicians should not assist their patients in dying, terminal patients should at least be afforded the option of dying with dignity, when this option has been proven to be successful and effective. In many cases, simply being provided with an additional option or choice about their end of life care can provide comfort for a terminal patient. Although living wills provide terminal patients with some control about their end of life care, this article will

4. Kimberly Dayton, et al., *Living Will Statutes*, 3 *ADVISING THE ELDERLY CLIENT* §33:40 (2012).

5. *JESSE DUKEMINIER ET AL., WILLS, TRUSTS, AND ESTATES* 457 (Vicki Been et al. eds., 8th ed. 2009).

6. See Jack Schwartz, *Living Wills: Time to Say Goodbye*, 5 *MD. B.J.* 6, 8-9 (2005).

7. Cyndi Bollman, *A Dignified Death? Don't Forget About the Physically Disabled and Those Not Terminally Ill: An Analysis of Physician-Assisted Suicide Laws*, 34 *S. ILL. U. L.J.* 395, 398 (2010).

8. Tucker, *supra* note 2, at 115.

demonstrate that right to die laws are a more effective solution to meeting patients needs giving them more control over their illness and treatment.

II. TERMINAL ILLNESSES AND THE FIGHT FOR CONTROL

Families and patients must prepare for the inevitable end of a terminal illness. Many terminal illnesses can cause unbearable pain and suffering, and often result in financial and emotional hardship.⁹ For example, Amyotrophic Lateral Sclerosis (ALS), a neurodegenerative disease most commonly known as Lou Gehrig's disease, involves the progressive degeneration of motor neurons that allow the brain to control muscle movement.¹⁰ ALS is often described as "living death" because the physical body goes flaccid while the mind remains completely aware.¹¹ As these neurons degenerate, they can no longer control muscle movement, which affects arms, legs, speaking, swallowing and breathing.¹² The average life expectancy of a person with ALS is two to five years.¹³ Patients with this disease are twenty-five times more likely to die with physician-assisted suicide than patients with other diseases.¹⁴ Leaving patients paralyzed and completely reliant on others or machines to eat and breathe, this disease has driven many to commit suicide.¹⁵

These patients face psychological issues such as fear of the unknown. In fact, family members and patients cite fear of cognitive and physical deterioration, pain, and emotional suffering as the basis for requesting

9. Stephen K. Bushong & Thomas A. Balmer, *Breathing Life Into the Right to Die*, 11 ISSUES L. & MED. 269, 269 (1995).

10. THE ALS ASSOC. WHAT IS ALS? <http://www.alsa.org/about-als/what-is-als.html> (last visited Mar. 23, 2013) [hereinafter WHAT IS ALS?].

11. Estrin & Schwartz, *supra* note 6.

12. WHAT IS ALS?, *supra* note 10.

13. THE ALS ASSOCIATION, FACTS YOU SHOULD KNOW, <http://www.alsa.org/about-als/facts-you-should-know.html> (last visited March 23, 2013).

14. Estrin & Schwartz, *supra* note 11.

15. *Id.*

physician assisted suicide.¹⁶ Additionally, the Oregon Public Health Division reported that the three most common end-of-life concerns were loss of dignity, loss of autonomy, and the decreasing ability to participate in activities that made life enjoyable.¹⁷ These fears may cause patients to desire to regain control over their life and choose to die on their own terms rather than being controlled by the disease.

III. THE LIVING WILL AND ITS INEFFICIENCIES

Living wills afford patients the right to make a written statement instructing their physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition.¹⁸ Living wills emerged because “people feared that they would receive undesirable or painful life support at a time that they were unable to make a decision to refuse it.”¹⁹ It is a well-established policy that patients have a right to refuse medical treatment, but a living will expresses the patient’s wishes after they are declared incompetent or after any loss of capacity.²⁰ Therefore, these living wills only become effective when the patient is in a coma or otherwise declared incompetent by at least one physician.

Forty-seven states have enacted living will statutes with various requirements, but for the same underlying purpose.²¹ Washington, which has enacted requirements similar to a majority of states, requires that the individual acknowledge that they are signing the directive willfully and

16. Barry Rosenfeld, *Assisted Suicide, Depression, and the Right to Die*, 6 PSYCHOL. PUB. POL’Y & L. 467, 468 (2000).

17. Oregon Public Health Division, *Oregon’s Death with Dignity Act 2012*, 2 (2013), <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year15.pdf>.

18. Schwartz, *supra* note 6, at 6.

19. Rebecca Dresser, *Symposium: Precommitment Theory in Bioethics and Constitutional Law: Bioethics: Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 TEX. L. REV. 1823, 1844 (2003).

20. Schwartz, *supra* note 6 at 6.

21. Dayton et al., *supra* note 4.

voluntarily.²² In order for the directive to become effective, two physicians must verify in writing that the patient has a terminal condition or is in a permanent unconscious position.²³ To validate the will, the attending physician must certify that the patient's death is imminent except for death delaying procedures, and two witnesses must sign it.²⁴ In the absence of the individual's ability to give directions concerning life-sustaining treatment, the individual must confirm that it is her intention that the physician and family members honor this document.²⁵ Additionally, like many states, if the patient is pregnant and the fetus is viable, the patient's living will declaration will not be honored until the patient is no longer pregnant.²⁶ Although there are minor differences between the requirements of other states, such as the number of physicians that need to verify the patient's condition, or the number of witnesses required to sign the document, the underlying purpose of these wills is to prevent death delaying procedures. Though designed to give patients a right to determine their end of life care, it is unlikely that these instruments are effective in carrying out every patient's true intentions.

There are several recognized problems with these wills, such as vagueness, stability across time, and lack of enforcement.²⁷ Many living will statutes are limited or have been narrowly construed.²⁸ Language that instructs a physician to withhold or withdraw medical interventions can be vague. The physician may be unfamiliar with the patient's views causing

22. WASH. REV. CODE. ANN. §70.122.030 (2012).

23. *Id.*

24. *Id.*

25. *Id.*

26. *Id.*

27. Schwartz, *supra* note 6, at 8-9.

28. Jennifer A. Zima *Assisted Suicide: Society's Response to a Plea for Relief or a Simple Solution to the Cries of the Needy?* 23 RUTGERS L.J. 387, 394 (1992).

the physician to misinterpret the will.²⁹ For example, in a Washington case, a woman who lived in a nursing home drafted a living will stating that she did not want to receive extraordinary measures if she was dying.³⁰ Later, a nurse mistakenly gave her the wrong medication, which caused severe complications.³¹ However, the nursing home staff did not take her to the hospital because the physician misinterpreted her will to mean that she would not want treatment and she died that night.³²

Another drawback to living wills is the inability to determine whether the patient has changed their mind.³³ A living will may have been made long before an incapacitation has occurred, and the patient's feelings and desires may be unknown or may have changed.³⁴ In some states, living wills must be written or notarized by an attorney. Attorney's fees can make it expensive to make changes to living wills.³⁵ As a result, costs may deter or delay a patient from updating their will to truly reflect their intentions.³⁶

One major concern of living wills is that they are not always honored.³⁷ A 1995 study showed that less than half of the critically ill patients who requested do not resuscitate orders on their living wills actually got them.³⁸ Family members are often unaware of a living will, or if they are aware, they often do not want it upheld because they fear losing their loved one.

29. Rita Marker, *Are Living Wills a Good Idea?*, (June 9, 2008) <http://euthanasia.procon.org/view.answers.php?questionID=000178>.

30. *Id.*

31. *Id.*

32. *Id.*

33. Schwartz, *supra* note 6, at 8.

34. Marker, *supra* note 29.

35. Patti Walden, *Living Wills: Not Always the Right Answer*, YAHOO VOICES, <http://voices.yahoo.com/living-wills-not-always-right-answer-6262930.html>.

36. *Id.*

37. Kristie Jernigan, *Pros and Cons of the Living Will*, LIVESTRONG (Dec. 18, 2009), <http://www.livestrong.com/article/60586-pros-cons/>.

38. *Are Living Wills Honored?*, BEFORE I DIE: LIVING WILLS, <http://www.wnet.org/bid/sb-livingwills.html> (last visited Feb. 16, 2013).

When the family does not want to honor the will, physicians often refrain from fighting with those who contest the living will.³⁹ This may result in expensive and time-consuming legal battles. In order to avoid litigation, medical staff often does not honor the living will and will follow the wishes of family members instead.⁴⁰ However, ignoring a patient's living will is a big risk and it may lead to severe consequences. In Michigan, a family was awarded over sixteen million dollars because the hospital ignored a patient's living will.⁴¹ The patient had suffered a series of strokes, which left her with a serious brain disorder.⁴² She expressed that she did not want to be saved if she could not be restored to her former state, yet these wishes were not honored.⁴³ The patient is currently completely disabled, in constant pain, unable to take care of herself, and unable to be returned to her former state.⁴⁴ Even with the medical profession's official endorsement of patient rights in living wills when deciding whether to use life-sustaining machines, some healthcare institutions will not honor a patient's wishes.⁴⁵

Another problem with living wills is that each state has their own statute and requirements, meaning that a will in one state may not be effective in another state. Additionally, certain terms have different definitions. For example, "treatment" is defined under state law, and in some states medically assisted nutrition and hydration are both considered treatment.⁴⁶

39. Jernigan, *supra* note 37.

40. *Id.*

41. Are Living Wills Honored, *supra* note 38.

42. *Id.*

43. *Id.*

44. *Id.*

45. Willard H. Pedrick, *Arizona Tort Law and Dignified Death*, 22 ARIZ. ST. L.J. 63, 68 (1990).

46. Marker, *supra* note 29.

IV. DEATH WITH DIGNITY – A PEAK AT WHAT OREGON AND WASHINGTON HAVE ENACTED

Right to die laws include euthanasia, which is the administration by a physician of a lethal injection, and physician-assisted suicide, a lethal medication for self-administration by the patient.⁴⁷ Right to die laws, or aid in dying, involve terminally ill or elderly loved ones suffering with painful debilitating and life-ending illnesses.⁴⁸ Due to the physical and mental suffering of patients and their families, these deaths are often desired not only to avoid a painful or undesirable death, but also to avoid a meaningless and hopeless life.

Unlike living wills, which only become effective when the patient is incompetent or otherwise incapable of making health care decisions for his or herself, a person requesting aid in dying must retain the capacity and the ability to affirmatively request this treatment.⁴⁹ Therefore, rather than waiting to become incompetent in order for a living will to go into effect, right to die laws allow patients to receive their preferred end of life treatment while they are still coherent. Additionally, living wills only permit the removal of feeding tubes or other life-sustaining treatment, whereas aid in dying allows a patient to request a lethal prescription that the patient can choose to ingest.

Some opponents to right to die laws show concern because the suicide rates among person over sixty are high and steadily increasing.⁵⁰ However, these facts may also show that people would rather submit to illegal activity than suffer or become a victim to their own disease. In fact, some patients

47. Lara L. Manzione, *Is There a Right to Die?: A Comparative Study of Three Societies (Australia, Netherlands, United States)*, 30 GA. J. INT'L & COMP. L. 443, 445 (2002).

48. *Id.* at 444.

49. Bollman, *supra* note 7, at 399.

50. Zima, *supra* note 28, at 398 (citing Erwin Ringel in MARY ROSE BARRINGTON, *APOLOGIA FOR SUICIDE IN SUICIDE: THE PHILOSOPHICAL ISSUES* 90 (M. Pabst Battin & C. Mayo, eds. 1980) at 208).

have killed themselves to avoid a horrifying death or to avoid being a burden to family and loved ones.⁵¹ Additionally, public approval of physician assisted suicide and euthanasia has grown.⁵² In a 1990 study, sixty-four percent of the surveyed adults supported physician-assisted suicide;⁵³ and a 1993 study showed that twenty-six percent of physicians had received at least one request for assisted suicide or euthanasia.⁵⁴ Additionally, in September of 2012, New Jersey proposed a bill to legalize physician-assisted suicide for terminally ill patients.⁵⁵ And in Montana, courts have stated that physician assisted suicide is legal, but with several restrictions. The Montana legislature is still attempting to structure a right to die law.⁵⁶ Currently, Oregon, Washington, and Montana have right-to-die laws that afford patients with terminal diseases the right to determine their own death.⁵⁷

A. *The Oregon Death with Dignity Act*

Oregon was the first state to legalize physician-assisted suicide. Since Oregon passed the Death with Dignity Act (“DWDA”) in 1997, a total of 1,050 people have had DWDA prescriptions written and 673 patients have died from ingesting medications prescribed under the DWDA.⁵⁸ In 2012, 115 people received prescriptions and there were 77 known deaths.⁵⁹ Under the DWDA, “[a]n adult who is capable, is a resident of Oregon, and has

51. *Id.* at 395.

52. Rosenfeld, *supra* note 16, at 471.

53. *Id.* at 470.

54. *Id.* at 477.

55. *NJ Could Become 3rd State to Legalize Right to Die*, FOXNEWS.COM, Sept. 27, 2012, at 1, <http://www.foxnews.com/health/2012/09/27/nj-could-become-3rd-state-to-legalize-right-to-die/>

56. *Id.*

57. *Montana Joins Short List of States Allowing Assisted Suicide*, 3 COMP. & BENEFITS L. BULLETIN No. 2 (2010).

58. Oregon Public Health Division, *supra* note 17, at 2.

59. *Id.* at 1.

been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his or her life in a humane and dignified manner. . . .⁶⁰ Two witnesses must sign the request, and at least one of the witnesses cannot be a relative or someone who could be financially affected by the patient's death.⁶¹ The statute does not require physicians to honor the patient's request, but if they choose to do so, they must fulfill a variety of requirements to protect themselves from civil or criminal liability,⁶² such as: (1) determining that the patient has a terminal disease and has made this end of life request voluntarily, (2) obtaining confirmation by a second physician, (3) offering the patient optional counseling, (4) adhering to a fifteen day waiting period between the oral and written requests and (5) giving the patient the prescription.⁶³ Patients are also asked if they have informed their family of their decision.⁶⁴ Lastly, patients are reminded that they have the right to rescind the request at any time.⁶⁵

Contrary to opinions that DWDAs would target low-income uneducated patients looking to receive this treatment to avoid hefty medical bills, most patients had a high level of education and over ninety percent of the patients had either private insurance, Medicare or Medicaid.⁶⁶ Additionally, the option of aid in dying has brought peace of mind to many healthy and terminally ill individuals in Oregon.⁶⁷ The availability of this option gives terminally ill patients autonomy, control and choice, and it gives healthy

60. OR. REV. STAT. §127.805 (2012).

61. Bushong & Balmer, *supra* note 9, at 272.

62. *Id.*

63. *Id.*

64. *Id.*

65. OR. REV. STAT. §127.897 (2012).

66. Tucker, *supra* note 2, at 117.

67. *Id.* at 120.

individuals peace of mind knowing that if they are diagnosed with a terminal illness, they will have this end of life option.⁶⁸ Ultimately, however, many patients who elect to have the prescription do not follow through with taking it.⁶⁹ In fact, in Oregon, more than one-third of the patients who received a prescription did not consume it.⁷⁰

B. The Washington Death with Dignity Act

In 2008, Washington followed Oregon's lead and became the second state to make physician-assisted suicide legal.⁷¹ The Washington legislature had attempted to pass this legislation since 1991.⁷² Based on studies and the success in Oregon showing that the right to die option would not jeopardize patients, put vulnerable populations at risk, or undermine quality end of life care, this DWDA was passed by the significant margin of fifty-eight percent to forty-two percent.⁷³

In Washington, an adult resident who is competent, determined by two physicians to be suffering from a terminal disease, and who voluntarily expressed his or her wish to die, is legally capable of making a written request for medication to self-administer to end his or her life in a humane and dignified manner.⁷⁴ Two individuals, one of whom is not a relative of the patient, entitled to any portion of the patient's estate, or an owner or employee of a health care facility where the patient is receiving treatment, must witness the request.⁷⁵ Similar to the Oregon DWDA, Washington requires a minimum of fifteen days between the patient's request and the

68. *Id.*

69. *Id.* at 118

70. *Id.*

71. Bollman, *supra* note 7, at 403-4.

72. Tucker, *supra* note 2, at 115, 121-122

73. *Id.*

74. WASH. REV. CODE. ANN. § 70.245.020 (2009).

75. WASH. REV. CODE. ANN. § 70.245.030 (2009).

writing of a prescription.⁷⁶ In 2011, physicians and pharmacies gave lethal medication to 103 individuals, and 70 patients ingested the medication.⁷⁷ Of these patients, seventy-four percent had some college education and ninety percent had either cancer or a neurodegenerative disease, such as ALS.⁷⁸

V. CONCLUSION

Living wills are not appropriate to meet the needs and demands of people with terminal illnesses because of the vagueness, inconsistent enforceability, and because right to die laws do not afford patients more options about their end of life care. As one court has noted, there is no living will that specifically refers to administering any artificial substance.⁷⁹ Evidence in Oregon and Washington demonstrates that patients do desire these DWDAs and they appear to be an effective solution to patients suffering from terminal illnesses. More states should look to the public demands and the success of these right-to-die laws in other states to provide patients with terminal illnesses a right to their own life.

76. WASH. REV. CODE. ANN. § 70.245.110 (2009).

77. WASHINGTON STATE DEPARTMENT OF HEALTH 2011 DEATH WITH DIGNITY ACT REPORT EXECUTIVE SUMMARY 1, 2 (2012), available at <http://www.doh.wa.gov/portals/1/Documents/5300/DWDA2011.pdf>.

78. *Id.* at 5.

79. Schwartz, *supra* note 6, at 6.