

## Bacon, Eggs, and Advance Directives: The Patient Self-Determination Act 20 Years Later

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### Who Talks about Dying at Breakfast?

“Good morning honey, I made your favorite for breakfast, bacon and eggs...oh, and remember we have the kids’ school play tonight.” “I wouldn’t miss it...which reminds me, if you are ever in a terminal or irreversible condition, or at least we think you are, what kind of medical care do you want? Do you consider life worth living if you are in a minimally conscious state, what if you’ll never be able to breath on your own?...You know, how do you want to die?” It’s certainly not typical breakfast conversation, but then again, does there ever seem to be a right time to bring up end-of-life discussions with your family and loved ones? During the 20<sup>th</sup> century, chronic diseases displaced infectious diseases and injury as the leading cause of death at the same time advances in medical science and technology radically changed the practice of Western medicine. In the 1970s and 1980s advance directives,<sup>1</sup> although not creating a significant impact, emerged in response to perceptions that modern techno-medicine<sup>2</sup> was prolonging the process of dying from chronic disease through overzealous, burdensome and futile attempts to keep patients alive.<sup>3</sup> Since the 1990s there has been an increasing awareness of the inadequacy in planning for end-of-life-care and of the poor knowledge of patients’ wishes about their medical treatment at a time when they lose the capacity to make decisions,<sup>4</sup> resulting in patients being cared for in a way they would not have chosen.<sup>5</sup>

### When Did We Start Worrying About End-Of-Life Treatment?

In 1983, at the age of 26 years, Nancy Cruzan was rendered comatose in an automobile accident, never regaining consciousness and leaving her in a persistent vegetative state.<sup>6</sup> In 1986, her parents requested that artificially fed nutrition and hydration be stopped.<sup>7</sup> Before acquiescing to her parents’ request, Missouri State Hospital insisted on a court

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<sup>1</sup> Advance directives are descriptions of one’s preferences for medical treatment, made in advance, either in writing or orally, in anticipation of a future time when the patient may be mentally incompetent or otherwise incapacitated, thereby allowing patients to exercise their fundamental right to self-determination over future events and to ensure they receive care at the end-of-life consistent with their values.

<sup>2</sup> *HE v A Hospital NHS Trust* (2003) 2 FLR 408.

<sup>3</sup> C. Jordens, M. Little, I. Kerridge and J. McPhee, *From advance directives to advance care planning: current legal status, ethical rationales and a new research agenda*, 35 INTERNAL MED J. 563 (2005).

<sup>4</sup> The Support Investigators. *A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments*, 274 JAMA 1591 (1995); G.S. Winzelberg, L.C. Hanson, J.A. Tulskey. *Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families*, 53 J. AM GERIATR SOC’Y 1046 (2005); P.A. Singer, D.K. Martin, M. Kelner, *Quality end-of-life care: patients’ perspectives*, 281 JAMA 163 (1999).

<sup>5</sup> G.S. Winzelberg, L.C. Hanson, J.A. Tulskey. *Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families*, 53 J. AM GERIATR SOC’Y 1046 (2005).

<sup>6</sup> *See Cruzan v. Dir., Missouri Dep’t of Health*, 497 U.S. 261 (1990).

<sup>7</sup> *Id.*

order. The trial court granted permission to discontinue Ms. Cruzan's tube feeding. However, on appeal, the Missouri Supreme Court disagreed and reversed the lower court's decision.<sup>8</sup> In a 1990 review of the decision,<sup>9</sup> the U.S. Supreme Court acknowledged the presumed right of competent patients to refuse unwanted medical treatment, but upheld the Missouri Supreme Court's procedural requirement in cases involving incompetent patients.<sup>10</sup> In its ruling, the U.S. Supreme Court permitted states to set their own evidentiary requirements for allowing surrogate decision-makers to withdrawal life-sustaining therapy from incompetent patients.<sup>11</sup>

### Have We Done Anything About It?

In the wake of *Cruzan*, considered by many as an egregious case of overtreatment,<sup>12</sup> and in a climate of fear that incompetent patients were at risk for prolonged treatment,<sup>13</sup> the U.S. Congress passed the Patient Self-Determination Act (PSDA) in 1990<sup>14</sup> as an amendment to the Omnibus Budget Reconciliation Act of 1990.<sup>15</sup> The PSDA, effective December 1, 1991,<sup>16</sup> requires health care facilities receiving Medicare and Medicaid funding to provide written information that specifically addresses the patient's legal rights concerning medical care, including the right to refuse medical treatment, advance directive options, and any relevant written policies of the institution.<sup>17</sup> Additionally, the health care provider's responsibility includes documenting the existence of advance directives in the patient's medical record, ensuring compliance with state laws, maintaining organizational policies and procedures, and providing community and staff education on advance directives.<sup>18</sup> Most importantly, the regulations also stipulate that health care provided to a patient may not be conditioned on the existence of advance directives.<sup>19</sup> While the PSDA did not create any additional substantive rights for patients, the legislative effort spotlights the importance of preserving end-of-life autonomy.<sup>20</sup> The perceived solution was to facilitate patients' ability to direct their family and physicians through legal documents, completed in advance of their incapacity.<sup>21</sup> At the time, the

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<sup>8</sup> *Id.*

<sup>9</sup> *Id.*

<sup>10</sup> *Id.*

<sup>11</sup> *Cruzan*, *supra* note 6.

<sup>12</sup> *Id.*

<sup>13</sup> Thomas J. Prendergast, *Advance Care Planning: Pitfalls, progress, promise*, 29:2 CRITICAL CARE MED. (2001), N34.

<sup>14</sup> S.K. Madson, *Patient Self-Determination Act: Implications for long term care*, 19:21 J. GERONTOLOGICAL NURSING 15 (1993); S.M. Wolf, *Sources of concern about the Patient Self-Determination Act*, 325 NEW ENG J. MED. 1666 (1991).

<sup>15</sup> Patient Self-Determination Act (PSDA), Ascensionhealth.org 2011, available at [http://www.ascensionhealth.org/index.php?option=com\\_content&view=article&id=188&Itemid=172](http://www.ascensionhealth.org/index.php?option=com_content&view=article&id=188&Itemid=172) (last visited Mar. 30, 2011).

<sup>16</sup> George Annas, *Nancy Cruzan and the right to die*, 323 NEW ENG. J. MED. 670 (1990); K.A. Koch, *Patient Self-Determination Act*, 79 J FLA. MED. ASS'N 240 (1992).

<sup>17</sup> Madson, *supra* note 14; Wolf, *supra* note 14.

<sup>18</sup> Madson, *supra* note 14; Wolf, *supra* note 14; Koch, *supra* note 16.

<sup>19</sup> *Id.*

<sup>20</sup> C.M. Galambos, *Preserving end-of-life autonomy: the Patient Self-Determination Act and the Uniform Health Care Decisions Act*, 23:4 HEALTH & SOCIAL WORK (1998).

<sup>21</sup> Prendergast, *supra* note 13, at N34.

major underlying assumption of the PSDA was that increased awareness and information on advance directives would generate discussion between patients and their health care providers, resulting in an increase in completed advance directives and therefore an increase in respect for a patient's right to choose their own medical treatment, especially when incapacitated.<sup>22</sup> The anticipated effect of implementing the PSDA was to bring discussion of advance directives into the daily routine of acute care hospital admissions<sup>23</sup> and encourage patients of certain healthcare facilities to consider their treatment preferences, decide in advance about the types and extent of medical care they will accept or refuse,<sup>24</sup> and in particular, to determine the circumstances in which life-sustaining therapy will be provided to them.<sup>25</sup>

### That Sounds Good. Did It Work?

Early enthusiasm for the advance directive, as a legal document, was not supported by research into their effectiveness.<sup>26</sup> In fact, varying levels of familiarity with advance directives still persist among both medical personnel and the public.<sup>27</sup> After the passage of the PSDA, although existing advance directives were recorded by medical personnel more often, they were not more frequently completed by patients and the process of recording them did not enhance patient-physician communication.<sup>28</sup> Despite the fact that some research shows that the measures implemented by health care facilities used to meet PSDA requirements increased patient awareness of living wills, they failed to increase the number of patients who act on this awareness. Completion rates for advance directives remain at the rate of 4 to 15 percent despite the PSDA's emphasis on education.<sup>29</sup> (Note: Although the PSDA legislated community education, no funds were appropriated to assist in the implementation of these programs).<sup>30</sup> This finding indicates that simply informing patients about their right of self-determination by handing them a

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<sup>22</sup> H.J. Silverman, P. Tuma, M.H. Schaeffer, and B. Singh, *Implementation of the Patient Self-Determination Act in a hospital setting*, 155 ARCH. OF INT. MED. 502 (1995).

<sup>23</sup> K.D. Grant, *The Patient Self-Determination Act: implications for physicians*, HOSP. PRACT. (Jan. 1992).

<sup>24</sup> The Patient Self-Determination Act, Cancer.org, Jun 15, 2009, available at <http://www.cancer.org/Treatment/FindingandPayingforTreatment/UnderstandingFinancialandLegalMatters/AdvanceDirectives/advance-directives-patient-self-determination-act>.

<sup>25</sup> R. Shapiro, *Unanswered Questions Surrounding the Patient Self-Determination Act*, Spring 1:2 CAMB. Q. HEALTH ETHIC 118 (1992).

<sup>26</sup> Predergast, *supra* note 13, at N36.

<sup>27</sup> G.H. Gordon, S.W. Tolle, *Discussing life-sustaining, treatment. A teaching program for residents*, 151 ARCH. INTERN. MED. 567 (1991); D.J. Dockas, D.W. Gorenflo, S.S. Coughlin, *The living will: a national survey*, 23 FAM. MED. 354 (1991); L.L. Brunetti, S.D. Carperos, R.E. Westlund, *Physicians' attitudes towards living wills and cardiopulmonary resuscitation*, 6 J. GEN. INTERN. MED. 323 (1991); M.K. Goldstein, R.P. Vallone, D.C. Pascoe, C.H. Winograd, *Durable power of attorney for health care. Are we ready for it?*, 155 WEST J. MED. 263 (1991).

<sup>28</sup> E.J. Emanuel, D.S. Weinberg, R. Gonin, *et al.*, *How well is the Patient Self-Determination Act working? An early assessment*, 95 AM. J. MED. 619 (1993).

<sup>29</sup> J.K. Weinberg, M. Brod, *Advance medical directives: Policy perspectives and practical experiences*, 1:1 J. ETHICS, LAW, & AGING 15 (1991).

<sup>30</sup> Galambos, *supra* note 20.

packet upon admission to a health care facility is insufficient to meet one of the main goals of the legislation.<sup>31</sup>

### Good Intentions, But Wrong Approach

In addition to the lackluster performance of the PSDA, there is reluctance on the part of many physicians to discuss end-of-life care with patients. This significantly contributes to the failure of completion of advance directives by overlooking the importance of communication between the physician and patient. A recent Harvard study<sup>32</sup> revealed the number one reason stated as a barrier to completing the advance directive was lack of physician initiative in bringing up the subject, while the least stated barrier was the disturbing nature of the topic.<sup>33</sup> This study identifies the need for personal and detailed discussions between physicians and patients about advance directives. However, if physicians are to have meaningful conversations with patients regarding their medical treatment and advance directives, they must routinely explore patients' values and attitudes toward uncertainty.<sup>34</sup> One reason standard advance care planning has failed is that many interventions to facilitate advance care planning have been focused on specific treatment decisions,<sup>35</sup> while recent research suggests that preferences for care are not fixed but materialize in a clinical context from a process of discussion and feedback through a system of the patient's most significant relationships.<sup>36</sup> The standard advance care planning takes the checklist approach, which assumes that patients have preferences that can be pinpointed and that will remain constant over time. To focus on specific treatment decisions outside of this process is to assert a narrow and possibly unworkable definition of autonomy.<sup>37</sup> Singer's<sup>38</sup> findings suggest that to approach advance care planning with a checklist of consent for specific treatments<sup>39</sup> does not meet patients' needs. Such decisions are essential, but only as part of a broader dialogue of the patient's values and occurrence of illness.<sup>40</sup> Therefore, a physician-centered/lawyer-centered, document solution alone that focuses on specific interventions might not address patients'

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<sup>31</sup> M.K. Robinson, *Effects of the Patient Self-Determination Act on patient knowledge and behavior*, 37:4 J. FAM. PRAC. 363 (1993), available at [http://findarticles.com/p/articles/mi\\_m0689/is\\_n4\\_v37/ai\\_14609183/](http://findarticles.com/p/articles/mi_m0689/is_n4_v37/ai_14609183/) (last visited Mar. 30, 2011).

<sup>32</sup> L.L. Emanuel, M.J. Barry, J.D. Stoeckle, *et al.*, *Advance directives for medical care – a case for greater use*, 324 NEW ENG. J. MED. 889 (1991).

<sup>33</sup> *Id.*

<sup>34</sup> Predergast, *supra* note 13, at N37.

<sup>35</sup> *Id.* at N34.

<sup>36</sup> *Id.* at N34.

<sup>37</sup> *Id.* at N38.

<sup>38</sup> P.A. Singer, D.K. Martin, J.V. Lavery, *et al.*, *Reconceptualizing advance care planning from the patient's perspective*, 158 ARCH. INTERN. MED. 879 (1998).

<sup>39</sup> Emanuel, *supra* note 32; L.L. Emanuel, E.J. Emanuel, *The medical directive: A new comprehensive advance care document*, 261 JAMA 3288 (1989).

<sup>40</sup> C. Laine, F. Davidoff, *Patient-centered medicine. A professional evolution*, 275 JAMA 152 (1996); D.G. Larson, D.R. Tobin, *End-of-life conversations: Evolving theory and practice*, 284 JAMA 1573 (2000).

own concerns.<sup>41</sup> Patients and physicians should focus on goals of care rather than on specific treatment for particular circumstances<sup>42</sup>

### Maybe We Should Start Talking About Death At Breakfast

The biggest drawback of the PSDA legislation is that it “imposes a minimal standard of behavior” and “may become the maximum standard performed.”<sup>43</sup> The requirement in the Patient Self-Determination act that the hospital must provide information about advance health care directives boils down to, do you have one, and if not do you want information about one? And if so, here is a packet. This simply is not sufficient. “As a culture, we need to get more matter-of-fact about talking about death,” says physician Paulanne Balch, whose family practice includes many geriatric patients.<sup>44</sup> “We are in denial, but we need to start thinking about advanced directives in the same category as dieting or quitting smoking, i.e., something that people don’t want to do, but it’s good for us. Advance care planning improves end-of-life care and patient and family satisfaction,” says Balch.<sup>45</sup> The starting point is realizing that merely completing an advance directive form will do patients very little good if they skip the planning process. The process requires patients to talk about their values, preferences and options with their physician, family and whomever they will rely on to speak for them when they no longer can speak for themselves.<sup>46</sup> The process should be a continuing conversation, as patients views change as they age, and may change dramatically if they encounter serious illness. Completing an advance directive form should be the end product of the planning process, repeated at various turning points in patients’ lives.<sup>47</sup> For the physician, communication about end-of- life care has become part of the practice, and researchers have provided clues about making those communications more effective. With the help of their insights, communication with patients and their families can be one of the most rewarding aspects of caring, especially during the final stage of a patient’s life.<sup>48</sup>

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<sup>41</sup> T.S. Drought, B.A. Koenig, T.A. Raffin, *Advance directives: Changing our expectations*, 110 CHEST 589 (2006).

<sup>42</sup> K.M. Detering, A.D. Hancock, M.C. Reade, *The impact of advance care planning on end of life care in elderly patients: randomised controlled trial*, 340 BMJ c1345 (2010), available at <http://www.bmj.com/content/340/bmj.c1345.full.pdf> (last visited Mar. 30, 2011).

<sup>43</sup> J. LaPuma, D. Orentlicher, R. Moss, *Advance directives on admission: clinical implications and analysis of the Patient Self-Determination act of 1990*, 266 JAMA 402, 404 (1991).

<sup>44</sup> Martin C. Dying, *A difficult subject, a vital conversation, Paperwork alone won’t guarantee your end-of-life decisions*, DENVER POST, (Dec. 12, 2010), available at [http://www.denverpost.com/rss/ci\\_16953302?source=rss#ixzz1HSTzVGoN](http://www.denverpost.com/rss/ci_16953302?source=rss#ixzz1HSTzVGoN) (last visited Mar. 30, 2011).

<sup>45</sup> Detering, *supra* note 42.

<sup>46</sup> Health Care Advance Directives – What is the Patient Self-Determination Act?, ABA, available at [http://www.americanbar.org/groups/public\\_education/resources/law\\_issues\\_for\\_consumers/patient\\_self\\_termination\\_act.html](http://www.americanbar.org/groups/public_education/resources/law_issues_for_consumers/patient_self_termination_act.html) (last visited Mar. 30, 2011).

<sup>47</sup> *Id.*

<sup>48</sup> Predergast, *supra* note 13, at N38.

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