

The Campaign for Truth in Advance Care Planning  
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June 26, 2017

The Honorable Thomas E. Price, M.D.  
Secretary  
U.S. Department of Health and Human Services  
Hubert H. Humphrey Building  
200 Independence Ave. S.W.  
Washington, D.C. 20201

The Honorable David Shulkin, M.D.  
Secretary  
U.S. Department of Veterans Affairs  
810 Vermont Avenue, N.W.  
Washington D.C. 20420

Dear Secretaries Price and Shulkin:

The Campaign for Truth in Advance Care Planning is writing to express our concern regarding the letter you received from The Pew Charitable Trusts and fourteen co-signing organizations dated February 17, 2017 and to provide advice regarding advance care planning policy. A copy of the Pew Charitable Trusts letter and other exhibits are included in the accompanying Appendix.

The Campaign for Truth in Advance Care Planning urges both Departments (HHS and VA) to disregard the recommendations provided by the Pew Trusts and will explain our reasons in this letter and in the supporting Appendix.

We believe the controversial Advance Care Planning promoted by Pew Trusts will lead to premature deaths and outrage by surviving families.

There is ... strong reason for concern that, motivated by cost concerns, promotion of advance directives and advance care planning frequently deviates from a neutral effort to elicit and implement patients' genuine wishes in the direction of influencing them, subtly or not too subtly, to reject life-preserving treatment.<sup>1</sup>

The Pew recommendations repeatedly call for the national substitution of hospice and palliative care (pain relief) for the life preserving and curative standard of care (which also includes pain relief). Implementing checkbox medical orders will cause premature deaths when, for whatever reason, people select inappropriate restrictions of measures as simple as food, water, antibiotics and short-term hospitalization (so-called "comfort care"). Persons dying under these restrictions experience pain and suffering – increasing demand for palliative and hospice care interventions so that such deaths appear "humane".

We are alarmed that your Departments have been asked by Pew Trusts to support the

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<sup>1</sup> *The Bias against Life-Preserving Treatment in Advance Care Planning*; National Right to Life Committee (NRLC), March 2015 at Appendix A, page 4 accessed from <http://www.nrlc.org/communications/advancecareplanningbias/>.

controversial Advance Care Planning and federal legislation<sup>2</sup> endorsed by Compassion & Choices. This organization is to euthanasia and assisted suicide what Planned Parenthood is to abortion. Previously known as the Hemlock Society, Compassion & Choices with funding from George Soros and others<sup>3</sup> promotes early quick deaths under the guise of personal choice through a multi-pronged effort, including controversial Advance Care Planning.

The Advance Care Planning promoted by the Pew Trusts created a firestorm of opposition dubbed “death panels” when it was included in the original 2009 Affordable Care Act bill.<sup>4</sup> Despite the “death panels” language being characterized as an extreme overreaction, the concerns were and remain realistic. The bill called for an “Advance Care Planning Consultation” process that would create preplanned medical orders called POLST (physician orders for life sustaining treatment). A sample is attached at Appendix D. These POLST check box orders are intended to override the standard of care by limiting access to life sustaining treatment in the sick, the elderly and the disabled. The bill also contained physician “quality measures” on the creation of and adherence to the POLST orders. Such “quality measures” constitute a method to force physicians to comply with the POLST Paradigm when they might otherwise object.

Proponents finally achieved Medicare payment for Advance Care Planning consultations in 2016 through an obscure regulatory process. Regulations now contain a “care plan” [previously called Advance Care Plan] quality measure.<sup>5</sup> Recently, Rep. Steve King, R-Iowa, introduced H.R. 410 to revoke the Medicare regulation.<sup>6</sup>

[Rep. King called Medicare payments for Advance Care Planning]... yet another life-devaluing policy....Allowing the federal government to marry its need to save dollars with the promotion of end-of-life counseling is not in the interest of millions of Americans who were promised life-sustaining care in their older years.<sup>7</sup>

In late 2010, an explicit Advance Care Planning regulation became so controversial; it was withdrawn a few weeks after it became effective.<sup>8</sup>

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<sup>2</sup> Federal bills endorsed by Compassion & Choices. Appendix B, accessed from <https://www.compassionandchoices.org/federal-programs/legislative-briefs/>.

<sup>3</sup> *The Rise and Rise of America's Suicide Lobby*, Neil Maghami, Capital Research Center Foundation Watch, March 2016 at Appendix C, accessed from <https://capitalresearch.org/app/uploads/FW0316.pdf>.

<sup>4</sup> H.R. 3200 (2009) –Section 1233 which was not enacted, required doctors to promote medical orders called Physician Orders for Life Sustaining Treatment (POLST) to limit life-preserving and curative care.

<sup>5</sup> Care Plan Quality Measure PQRS 47/NQF 0326. Individual Measure Specification for 2016 available at [https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/PQRS/downloads/2016\\_PQRS\\_IndMeasuresSpecs\\_ClaimsRegistry\\_022316.zip?agree=yes&next=Accept?agree=yes&next=Accept](https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/PQRS/downloads/2016_PQRS_IndMeasuresSpecs_ClaimsRegistry_022316.zip?agree=yes&next=Accept?agree=yes&next=Accept)

<sup>6</sup> The Protecting Life Until Natural Death Act (<https://www.congress.gov/bill/115th-congress/house-bill/410/all-info?r=5>)

<sup>7</sup> <http://www.usatoday.com/story/news/2017/02/09/kaiser-docs-bill-medicare-end--life-advice-death-panel-fears-reemerge/97715784/>

<sup>8</sup> Robert Pear, *Obama Returns to End-of-Life Plan That Caused Stir*, 12-26-2010 at <http://www.nytimes.com/2010/12/26/us/politics/26death.html?ref=policy&pagewanted=all>; Robert Pear, *U.S. Alters Rule on Paying for End-of-Life Planning*, 1-4-2011 at [http://www.nytimes.com/2011/01/05/health/policy/05health.html?\\_r=1&hpw](http://www.nytimes.com/2011/01/05/health/policy/05health.html?_r=1&hpw).

A recent review of POLST research<sup>9</sup> says there is a “... dearth of evidence that POLST programs, as currently designed, improve care for the dying.” Much of the so-called rigorous, evidence-based research cited by the Pew Trusts is simply advocacy and marketing research from companies and health care systems selling turnkey Advance Care Planning systems.

We have formed the Campaign for Truth in Advance Care Planning because Advance Care Planning coupled with POLST is fraught with risks and unwanted, unintended consequences for patients and their families. Instead, we advocate that people plan for the future by having a legal surrogate with power of attorney and prepare the patient and their surrogate to make the best possible in-the-moment medical decisions when the time comes.<sup>10</sup> We would ask your Departments to use their offices to promote public understanding of the importance of selecting a surrogate with power of attorney. If a person is unable to designate a surrogate, a living will is an alternative, although we note it does not offer the protections and flexibility of a surrogate. We further ask the Department to support H.R. 410, which would repeal Medicare payment for Advance Care Planning with POLST and to halt any consideration of POLST completion or adherence as a quality metric. We will address the problems with POLST in more detail in future letters.

Thank you for this opportunity to express our views. The Campaign for Truth in Advance Care Planning offers itself as a resource to you on matters of POLST and end of life care policy and looks forward to working with you in the future. You may contact Dr. Frank Smith directly at (262) 951-1783.

Sincerely,

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<sup>9</sup> Appendix E - *The Problems with Physician Orders for Life-Sustaining Treatment*, Kendra BA, Rubin MD, JD and Halpern MD, PhD, JAMA 2016; 315(3): 259-260 Jan 2016; accessed from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4822707/pdf/nihms758093.pdf>

<sup>10</sup> Appendix F - *Redefining the “Planning” in Advance Care Planning: Preparing for End-of-Life Decision Making*, Sudore, Rebecca MD and Fried, Terri MD. Ann Intern Med 2010; 153: 256-261, Aug 2010

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## APPENDICES

- A The Bias against Life-Preserving Treatment in Advance Care Planning; National Right to Life Committee (NRLC), March 2015
- B Federal Bills endorsed by Compassion & Choices
- C *The Rise and Rise of America's Suicide Lobby*, Neil Maghami, Capital Research Center Foundation Watch, March 2016
- D Wisconsin POLST form
- E *The Problems with Physician Orders for Life-Sustaining Treatment*, Kendra BA, Rubin MD, JD and Halpern MD, PhD, JAMA 2016; 315(3): 259-260 Jan 2016
- F *Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making*, Sudore, Rebecca MD and Fried, Terri MD. Ann Intern Med 2010; 153: 256-261