The National Association of Catholic Nurses – USA
Where NURSING, MINISTRY and CATHOLIC MISSION meet

May 30, 2017

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

Dear Secretary Price:

The National Association of Catholic Nurses - U.S.A. (NACN-USA) is the national professional organization for Catholic nurses in the United States. The NACN-USA is approved by the U.S. Conference of Catholic Bishops and a part of the International Catholic Committee of Nurses & Medico-Social Assistants, which collaborates with the Holy See and its Dicastery for Promoting Integral Human Development. Thus the NACN-USA stands in solidarity with Catholic nurses throughout the world, united in charity and the promotion of a Christian, moral approach to health care. It is in regard to an approach to health care and advance care planning proposed to you in a letter dated February 17, 2017 by the Pew Charitable Trusts and fourteen co-signing organizations that we write to express our concern.

The Pew Trusts approach is reckless and unjust. Under this approach health care costs are reduced by incentivizing providers to engage patients in advance care planning discussions that discourage treatment even if it might be beneficial to them and to expand hospice services, which ordinarily are reserved for persons with terminal disease and near the end of life, to include persons who are seriously ill but able to be cured. It requires that patient advance care planning documents, some immediately actionable medical orders, be part of an electronic health care record database that is instantly accessible across the health care system. This sets in stone decisions made in advance of a problem and in the absence of context, which makes it difficult, if not impossible, to alter specific decisions given real time circumstances. It further calls for the development of quality measures of these activities to which providers are held accountable and upon which payment decisions are made. While such an approach may reduce health care costs, it does so by reducing health care treatment to patients who actually may benefit from it by incentivizing what amounts to patient neglect and then financially rewarding providers for it.

The actions recommended in the Pew Trusts approach are expensive, as they call for the expansion of programs and the creation of new ones which will drive up administrative costs. The only way their approach would even hold costs steady is if more people declined treatment than do so currently, opted for less expensive palliative and hospice care, and did so earlier in the course of illness. For that reason, the approach targets not only patients at the end of life or having terminal illness, but also patients at any age who have what they call "serious illness" which they define broadly, vaguely and includes conditions in which a cure may be possible. Thus advance care planning discussions...
would need to steer patients away from treatment, even if treatment might be appropriate and beneficial. Incentivizing providers to sway patients promotes bias and violates the trust essential to the patient-provider relationship.

This dangerous bias already exists, according to the literature, and the Pew Trusts approach further promotes it. A 2015 report documents that, "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" (Robert Powell Center for Medical Ethics 4). Moreover a recent study in the American Journal of Hospice and Palliative Medicine found that nearly half of the clinicians working in palliative care identified themselves as having "a bias against aggressive treatment [defined as] a clinician's assumption that many/most interventions at the end of life are not beneficial" (Callaghan & Fanning 4). In addition, clinicians admitted having "distorted narrative preconceptions [defined as a] clinician's imposition of generalized storylines on patients due to anecdotal evidence or societal norms/expectations" (4). These biases are considered to be professional hazards that clinicians struggle to manage because, "unchecked biases can hinder clinicians' ability to attend to patients' values and preferences"(6). Thus provider bias in favor of withholding treatment is worrisome, especially when decisions are made and set in stone in advance of a problem or its context.

Making decisions through advance care planning absent of context is precisely what the Pew Trusts approach promotes. A clear example is the Pew Trusts support of Physician Orders for Life Sustaining Treatment (POLST), forms that are portable and serve as specific, immediately actionable medical orders for persons with a serious but not necessarily terminal illness, or frailty, and for whom the provider would not be surprised if they died within the next year (The National POLST Paradigm). Besides specifying whether resuscitation should be attempted, care as simple as antibiotics and as basic as food and fluids potentially can be withheld. This opens the door to abuse and even passive euthanasia, particularly given the fact that the informed consent standard that calls for the patient's signature or that of his surrogate is not required in all states. Uploading such dangerous forms into a centralized database for easy and quick access is a goal of supporters of POLST.

The approach proposed by the Pew Trusts is reckless and unjust. A more prudent and just approach would not erode trust critical to the integrity of the patient-provider relationship but would strengthen and preserve it. It would remind us that health care is a moral enterprise, that the patient-provider relationship is fiduciary in nature and that the fact of illness and the lack of medical knowledge make the patient vulnerable, thus placing great moral responsibility on the provider and making the provider morally complicit in what happens to the patient (Pellegrino & Thomasma). Such an approach does not promote a bias of neglect in advance care planning or in any other aspect of health care. Rather, it promotes a fairness and respect grounded in an understanding of each patient as a person of inherent dignity, made in the image of God, someone who is owed the truth about their diagnoses, prognoses and treatment, someone who deserves to be cared for as if he were Christ himself.

Sincerely,

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President, National Association of Catholic Nurses-USA

Pellegrino, Edmund D. & Thomasma, David. C. *The Virtues in Medical Practice*. Oxford. 1993, pp. 42-44.

