



May 21, 2009

The Honorable Max Baucus
Chairman
Senate Finance Committee
United States Senate
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Charles E. Grassley
Ranking Member
Senate Finance Committee
United States Senate
219 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Baucus and Senator Grassley:

On behalf of Compassion & Choices, the nation's largest and oldest non-profit organization dedicated to improving and ensuring access to quality, patient-centered end-of-life care, I am writing to share with you our views as the Senate Finance Committee continues to work on developing consensus legislation on health care reform. We applaud your leadership and commitment to reforming our nation's health care system and stand ready to work with you and your colleagues to accomplish this task.

Compassion & Choices strongly believes health care should focus on the needs and desires of the patient. Creating a patient-centered system is not only fiscally responsible, but it also empowers the patient to control his or her own health care, yielding immediate feedback on the quality of care administered. The proposed Chronic Care Management Innovation Center's (CMIC) initial testing models that would focus on a patient-centered medical process and require patients to submit reports on the quality of their care is a promising approach to meaningful health care reform. While physicians may employ various pain management procedures, it is the patients' right and responsibility to determine the amount of pain he or she can endure. Only by following the patient's lead can a physician make appropriate recommendations for pain and symptom management.

In addition, we agree with you about the importance of transparency, research and information in our health care system. Patients nearing the end of life should be informed of all legal medical options, including aggressive pain management, hospice services, palliative sedation and other treatments. In California, Compassion & Choices championed the California Right to Know End-of-Life Options Act, instructing physicians to provide patients who ask with information about all end-of-life care options legally available in California. This piece of legislation initiates a broader discussion of how to make information more accessible to Americans who need it.

Following the tragic case of Terri Schiavo in 2005, we rediscovered the crucial need for advance directives. To reduce confusion at the end-of-life, these documents explain the wishes of the patient. However, advance directives are not binding and studies reveal medical officials usually do not implement them. Various jurisdictions have adopted the Physician Orders for Life-Sustaining Treatment (POLST) Program

Paradigm, which translate advance directives into clear and specific physician orders. This program creates as an efficient method to effect the desires of the patient and promote dignity and respect at the end-of-life. To this end, we encourage the Committee to support HR 1898, “The Life Sustaining Treatment Preferences Act,” which would extend Medicare coverage to conversations about end-of-life care between patients and physicians and provide funding to states to develop and expand POLST programs.

America’s health care workforce is the backbone of a successful health care system, and it is in our best interest to support these hard-working individuals. Compassion & Choices encourages the Committee to support programs to improve health care education, especially end-of-life care and pain management. In 1998, Oregon passed the Death with Dignity Act that allows a competent, terminally-ill patient to obtain medication to self-administer if suffering in the dying process becomes unbearable and prolonged. After the law passed physicians enrolled in record numbers in seminars and workshops on end-of-life pain and symptom management. Despite the requirement for end-of-life care training in medical schools, many institutions still fail to provide adequate preparation for their students. We encourage you to support efforts to address these issues.

Again, we applaud your leadership and commitment to reforming our nation’s health care system and stand ready to work with you and your colleagues to find ways to expand access to high quality, affordable healthcare, particularly end of life care, and improve the cost effectiveness of the nation’s health care system.

Thank you for considering our comments.

Sincerely,

A handwritten signature in black ink that reads "Barbara Coombs Lee". The signature is written in a cursive style with a long horizontal line extending to the right.

Barbara Coombs Lee
President, Compassion & Choices

Principles for Patient-Centered End-of-Life Care

1. End of life care should focus on the patient's life and experience.
2. Dying patients define and determine their own acceptable level of pain and suffering. They should receive state-of-the-art comfort care accordingly. Only patients can determine whether they are suffering, or have suffered enough.
3. All decisions regarding end-of-life care begin and end with the patient. The answer to the question "who should decide?" is "the patient decides." If patients are no longer capable of decision-making, their known wishes still dictate decisions.
4. Patients must have comprehensive, candid information in order to make valid decisions and give informed consent. Patients should receive encouragement to exercise a "BRAIN" process assessing the **B**enefits, **R**isks, **A**lternatives, what their **I**ntuition says, and consequences of doing **N**othing, before giving consent to procedures and treatment.
5. Patients should be empowered to make health care decisions based on their own deeply held values and beliefs, without fear of moral condemnation or political interference.
6. Patients should be empowered to make health care decisions based on their own assessment of the balance between quantity and quality of life.
7. Patients must have early, forthright and complete notice of institutional or personal policies or beliefs held by health care providers that might interfere with their treatment wishes at the end of life.