Testimony to the Senate Special Committee on Aging
“The Right Care at the Right Time: Ensuring Person-Centered Care for Individuals with Serious Illness.”
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My name is Amy Berman and I am terminally ill. I was diagnosed five and a half years ago with stage IV inflammatory breast cancer, a rare form of cancer that has the worst prognosis. My cancer is not a lump that can be found on a monthly self-exam. By the time a red spot appeared on my breast it had already spread to my lower spine. It is uncurable cancer.

Roughly 90% of people diagnosed with breast cancer survive five or more years, unfortunately the likely course of the disease according to the National Cancer Institute, is an 11-20% chance of survival to five years. This means it is highly unlikely that I would survive five years.

Yet I sit before you five and a half years following the diagnosis. I feel like I look, great. I work full time. I travel and enjoy my family and friends. I haven’t been hospitalized once. I am a walking triple aim of better health, better care, and I have saved more than a million dollars to date. But the care that I receive is the exception.

At the beginning, I went to see two very different oncologists. One oncologist wanted to throw everything at the cancer. He heroically suggested the most intense chemotherapy, followed by a mastectomy, many courses of radiation, then more intense chemotherapy. He admitted that it would not cure the disease but said, “This is what I do for all my patients.” He never asked me a single question about what I was hoping for. He never discussed the futility of his approach or other treatment options. He wanted to do a “Hail Mary” pass on my body. He wasn’t going to live with the consequences of the care. I was.

I went to another oncologist who talked to me about my diagnosis, the likely course of the disease, and treatment options. She shared openly what she knew and asked me what I hoped for. I told her that I wanted the Niagara Falls trajectory. I wanted to feel good and then drop off the cliff. I told her that I wanted to maximize my good days and not aggressively push for more bad days. She said I could opt for treatment (medication) that had the least amount of side effects which could help to hold back the cancer and allow me to continue to feel well. My doctor said I didn’t need to have a mastectomy because the cancer was already floating throughout my body. The mastectomy wouldn’t get rid of the cancer. It would work against my goal of holding onto the life that I have. The surgery would be debilitating, make me miss work, cause pain and possibly swelling of the arm. This is everything I told her I wanted to avoid.

My mother was with me as I went on these visits. She participated in the conversations with me and my care team. She fully understands and supports my choices. She is my health care proxy and I am hers. I completed my proxy with a social worker at my medical center just after diagnosis.

But perhaps the most important aspect of my care, reason that I am doing so well despite being seriously ill, is palliative care. Palliative care is the best friend of the seriously ill. It is an extra layer of support that goes along with the care provided by my oncologist. Studies have shown that when palliative care is added at the beginning of a serious illness that people feel better and live longer (http://www.nejm.org/doi/pdf/10.1056/NEJMoa1000678). My palliative care provider has helped me determine what care to opt for and addressed my pain and symptoms. The team-based care also addresses the needs of the family, care coordination, and even spiritual needs.

I am terminally ill. But I also have a professional role as senior program officer at The John A. Hartford Foundation in NYC (www.jhartfound.org) where I lead efforts to develop, test and spread of evidence-based models of care that improve the care of older adults. The majority of those with serious illness are older adults.

The John A. Hartford Foundation is a national health care foundation focused on improving the care of older adults. The Foundation was founded in 1929 by John A. Hartford. He was the son of the founder, and a former CEO, of the Great Atlantic and Pacific Tea Company, later known as the A&P grocery store chain. We have funded efforts to improve the care of older adults since 1982 and have invested roughly half a billion dollars in the development, testing and spread of models of care and training of the health care workforce.

We are longtime funders of palliative care supporting the Center to Advance Palliative Care, the leading national resource for the field of Palliative Care, for more than a decade. We also fund the leading efforts in care, training and public engagement. These efforts include Atul Gawande and Susan Block's Serious Illness model, Respecting Choices, Home-Based Primary Care (Independence at Home), National POLST (Physician Orders for Life Sustaining Treatment), Vital Talk, The Conversation Project, and the Coalition to Transform Advanced Care also known as C-TAC.

I am here to speak about the importance of care planning, the workforce, models of care including community-based palliative care.

Care planning is key to providing the right care and avoiding the wrong care for the seriously ill person. It is more than just advance care planning and the end of life. Care plans include goals of care conversations over time and specifically before critical choices about treatment need to be made. The seriously ill very often aren't told their prognosis. You can only make reasonable decisions and plan for the future when you know how ill you are and the likely course of the disease. A survey of 2000 physicians published in Health Affairs (http://content.healthaffairs.org/content/31/2/383.full) found that a startling two-thirds of the physicians reported that they either gave a rosier prognosis or were not truthful with their patients. Similarly, less than 50% of people living with Alzheimer's Disease or their family caregivers are informed of the diagnosis (http://www.usnews.com/news/articles/2015/03/24/most-alzheimers-patients-not-told-about-their-diagnosis). Understanding where you are in terms of your overall health is one of the key components to a person's participation in decisions about one's care. It astounds me that we have more protections around full disclosure when buy a home than when we are treated for serious illness.

Our workforce needs experts to support the care of the seriously ill and competence in others that care for this population. We do not have a sufficient number of palliative care physicians and nurse practitioners to care for the seriously ill demographic. Did you know that we pay for graduate medical education slots for cardiologists, neurologists, even plastic surgeons, but not one slot for palliative care? We have a rapidly aging society with an older demographic that is doubling. Yet we have not dedicated a single slot to train our palliative care workforce, a workforce that decreases unnecessary high cost care such as hospitalization and nursing home placement, and improves the quality of life for seriously ill.

There are a number of models that address the complex needs of people battling serious illness and approaching the end of life. The John A. Hartford Foundation investigated these care models for years before determining what efforts showed the greatest efficacy and evidence. I mentioned Dr. Gawande's Serious Illness work, Respecting Choices (advance care planning), Independence at Home (comprehensive primary and palliative care of the homebound) and others. The most important thing you could do is to create a mechanism to cover community-based palliative care. This proactive care is the kind of high value care we all desire. Yet palliative care remains largely only available in the hospital, an essential part of good inpatient care. It is care you need when everything goes wrong. But we need a proactive approach to care that avoids unnecessarily high cost care that people want to avoid.

I am reminded of the charge of the Campaign to End Unwanted Medical Treatment (http://endumt.org/), a coalition of 19 national organizations such as the Gerontological Society of America, the society for people doing research in the field of Aging. They summed it up for me with their mission. "Patients, families and their advocates deserve and demand all the information necessary to make informed choices about their treatment preferences and expect that healthcare professionals and institutions honor their wishes."

My one request is that, should you pass legislation to further these aims and improve the care of the seriously ill, I would like to be there at the signing of that legislation. I ask that you move quickly and make this happen in my lifetime.