

**Testimony of Edo Banach
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House Committee on Ways and Means

**Hearing on Caring for Aging Americans
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Chairman Neal, Ranking Member Brady, and members of the Committee, thank you for the opportunity to testify at this important hearing focusing on caring for aging Americans. I also want to thank Congressman Reed, a hospice volunteer, and Representative Panetta for their leadership on hospice issues. As well as Representatives Kind and Walorski for their advocacy to help support greater access to hospice in both rural and underserved communities. Finally, I want to thank Committee professional staff Rachel Dolin with the majority and Carla DiBlasio with the minority for their work on hospice.

My name is Edo Banach, President and CEO of the National Hospice and Palliative Care Organization (NHPCO). Founded in 1978, NHPCO is the nation's largest membership organization for providers and professionals who care for people affected by serious and life-limiting illness. Its broad community of members includes local hospice and palliative care providers, networks serving large regions of the United States, and individual professionals. NHPCO's members include over 2,200 hospice and palliative care providers, account for over two thirds of the Medicare beneficiaries served by hospice and employ nearly 60,000 professionals and hundreds of thousands of volunteers; it should be noted that under the Medicare hospice benefit, five percent of patient care hours must be provided by trained volunteers.

Hospice is not, and should not be, a partisan issue. We all get sick at some point in our lives, and eventually we will all die. For many people, hospice provides the right level of care at

the right time for the patient and family at the end of life. Today, I am honored to provide a perspective on how we can and should care for our fellow Americans with serious illness as well as those who are terminally ill. We have a moral and fiscal imperative to do better than we are currently doing for our seniors who are seriously ill, sometimes suffering from multiple chronic conditions, and who deserve a choice when it comes to their care.

Hospice Background

Almost 40 years ago, Senator Dole and Congressman Leon Panetta, father of Congressman Jimmy Panetta, your colleague who sits on this committee, were two of the bipartisan, bicameral leaders of the fledgling hospice movement on Capitol Hill. Without their early leadership in advancing hospice, we would have no benefit. Without your leadership, hospice will not achieve its full potential.

The hospice benefit began as a demonstration in 1978, and within five years grew to a permanent part of the Medicare program. In the provision of person-centered and interdisciplinary care, hospice is everything that the rest of the health care system is aspiring to be. Hospice provides medical and non-medical supports and services, caregiving training for family caregivers, bereavement services for the patient and their family and spiritual counseling. Most people assume that hospice is a place. In fact, hospice care is often provided in the patient's home or wherever a patient might consider their home. Hospices care for whole communities that are impacted by public tragedy, such as the shootings in Las Vegas and Orlando, and natural disasters like Hurricanes Katrina and Maria, and the California wildfires, by offering compassionate grief support on an ongoing basis. Many hospices, recognizing the value of the human and pet bond, have programs to provide pet care and then to help find caring homes for furry companions who are left behind once their owners have died.

Hospice providers also care for our nation's veterans through the We Honor Veterans program funded by the Department of Veterans Affairs, a pioneering partnership that recognizes the unique needs of those who have served our nation in the military as they face the end of life. We Honor Veterans focuses on respectful inquiry, compassionate listening and grateful acknowledgment. By recognizing the unique needs of America's veterans and their families, community providers, in partnership with VA staff, learn how to accompany and guide veterans through their life stories toward a more peaceful ending. We encourage everyone on this Committee to participate in a veteran pinning ceremony conducted by your local hospice. We also care for first responders like NYPD Detective Lou Alvarez, a 9-11 first responder who was diagnosed with cancer after serving in the aftermath of the terrorist attacks on the twin towers (a video of Mr. Alvarez's story "My Legacy, My Hospice: Lou's Story" is available on YouTube, (<https://youtu.be/sSuUwZjUXsA>)). We do so much more than most people realize, and we thank all of you for your continued support of this treasured benefit.

Challenges in Hospice Care

Over 50% of those dying in Medicare, approximately 1.5 million beneficiaries, choose to take advantage of the hospice benefit as their life journey comes to an end. Unfortunately, far too many people receive hospice care for a few days (26%) and many for less than 30 days (54%). One of the most common sentiments shared by family members is, "we wish we would have had hospice sooner." Analysis of the length of stay in hospice shows that the median length of stay on hospice is only 18 days and has remained at that number since 2000. More importantly, we focus on lengths of stay instead of appropriate access and what's best for patients, families, and this country. We can do better, and we can do more. This includes reforms that will help to reduce red tape and waste while improving patient care and outcomes.

As the baby boomer generation ages, 10,000 turning 65 every day, addressing shortages in the healthcare workforce is essential as the demand for high quality care will continue to increase rapidly. The number of hospice and palliative care physicians and members of the interdisciplinary team will drop dramatically over the next two decades. This Committee has the ability make changes to the current healthcare delivery system.

But, above all else, we can provide better quality hospice care and better oversight of that care. As you are aware, the July OIG reports outlined issues with CMS oversight of hospice and examples of poor care. OIG and CMS confirmed that the issues are not systemic, which is consistent with the hospice program's very high-quality scores and high patient and satisfaction levels. However, we share OIG and CMS' concerns about persistent poor performers. We have been working with this Committee as well as the Senate on improving oversight over the hospice benefit. We at NHPCO are supportive of the policies that promote smart oversight outlined in Senators Portman and Cardin's bill, *the Hospice Care Improvement Act (S. 2807)*, which focuses on implementing new safeguards, like improving the survey process, education for both providers and surveyors, as well as enhancing information available to consumers in order to protect patients facing serious illness at the end of life. This legislation was introduced last week, and we look forward to supporting the work that Representatives Panetta and Reed are undertaking on this issue. Any provider that is not fully committed to meeting regulatory and quality requirements and providing the best care possible to each and every hospice patient should not be providing hospice care. I want to thank the Committee for your collaboration on this very important issue.

Gaps in Serious Illness Care

Before we get to the ways we can improve hospice, I want to spend a little time on what comes before it. I'll do this by focusing on two of my own family members. Great Aunt Ruby, my wife's great aunt— who lives in Richmond, VA— and my late Great Aunt Grace, who lived in New York City. Both great aunts live and lived amazing lives, but ones that fell apart as they entered old age. It does not need to be this way.

Great Aunt Grace

Great Aunt Grace was a college graduate and physics whiz who taught college into her late 80s. A widow, she lived alone in a 5th floor walkup in New York City. She lived in the same apartment for over 50 years. After her husband died, she became more reclusive, more physically frail, and began to decline. Friends and neighbors came out of the woodwork, not always with the best of intentions. Ultimately, Grace fell down her stairs, was scammed out of money, and was admitted to a nursing home before finally coming back home for a week to die on hospice. The system failed her.

Great Aunt Ruby

Great Aunt Ruby is a fiercely independent former Pentagon staffer who retired to Richmond, VA. She lives on her own and — as a former smoker— suffers from Chronic Obstructive Pulmonary Disease (COPD). Ruby has a pulmonologist and sees him regularly but breathing problems and general anxiety often lead Ruby to visit the emergency room or urgent care. Ruby recently had a post-acute stay in a nursing home and is now back home. She received home care, but no longer does because she does not meet the home health requirement to be home bound. Ruby does not consider herself to be terminally ill— although her pulmonologist does— so Ruby is frightened by the idea of having to “give up” all curative care to go on hospice. As a result, Ruby gets no help with her social, spiritual, personal or medical needs from

the healthcare system. She is depressed and is declining. About once a week, Ruby calls 911 and ends up being taken by ambulance to an emergency room. The system has failed Ruby.

Solution: Person-Centered Interdisciplinary Care

Both Great Aunts have had less-than-great declines. They were hurt by a reactive system that requires you to get broken before you can get fixed. That is an insane way to honor aging Americans. Improving care for aging Americans will require many reforms, but I will focus on a few reforms to hospice, and a few broader reforms that are informed by the hospice experience.

Improving Access to Hospice

We all know folks like my own Great Aunts. Folks who went in and out of the hospital, who declined in a nursing or assisted living facility, and did not get nearly the care or support they needed as they became ill. It doesn't need to be this way. Thankfully, members of this committee have stepped up to introduce and support important reforms that will improve our care system and proactively provide needed care to folks.

Representatives Kind and Walorski have introduced H.R. 2594, the *Rural Access to Hospice Act*. This legislation would allow terminally ill patients who are seen by a trusted doctor at a safety net medical provider such as a Rural Health Clinic (RHC) or Federally Qualified Health Center (FQHC) to stay with that doctor when they transition to hospice. We hear stories in the field that some patients that utilize RHCs or FQHC do not choose hospice because changing doctors is too much to bear after they receive a terminal diagnosis. We know that hospice is the right level of care at the right time and reduces unnecessary medical spending and hospitalizations when a person is at the end of their life. A hospice worker recently told me a story from the field about how this bill would improve care. An elderly woman who received

care in a FQHC was in the hospital and the decision was made that she needed hospice care. She accepted that care but was upset that her doctor could not follow her to hospice and continue to care for her, but instead had to be treated by a doctor she did not know. She liked and trusted her FQHC doctor. The FQHC physician met her in her car in the parking lot of the hospice to say goodbye. Each time I think of this story, I think of what an additional burden at such a stressful time the current law imposes on both the patient, and their family but also the providers that have taken care of them. We also thank Committee members Representatives, Sewell, DelBene, Blumenauer and Adrien Smith for cosponsoring this important legislation.

Finally, I want to thank the leaders of the bipartisan Senate Comprehensive Care Caucus, Senators Rosen, Barrasso, Fischer and Baldwin, for calling attention to these important issues as well as the champions on this Committee including Representatives Kind, Thompson, Sewell, Panetta, Blumenauer, Reed, Walorski, Buchanan and Adrian Smith. We would welcome the opportunity to work with the members of this Committee on such a caucus.

Hospice 2.0 and Community Based Palliative Care: A Moral Imperative

As important as these steps have been, I want to suggest a few additional reforms that should be non-controversial and bipartisan. The time has come for preventing declines rather than waiting for a decline and then treating it.

We have seen the consequences of a reactive approach including:

- Social isolation
- Depression
- Anxiety
- Suicide, especially among veterans

What if we provided person-centered interdisciplinary care for people before they fall down stairs or cried out for help? Intuition tells us that addressing health-related social needs by surrounding the lonely with emotional supports, helping the struggling with mobility issues and tasks of daily living, providing a chaplain for those who cannot make it to their house of worship, and providing both physical and emotional support to those whose disease is progressing will advance health equity and result in better health outcomes. Effectively integrating this compassionate and person-centered care that hospices provide every day directly into the delivery of care for the elderly would be an important step forward in breaking down barriers which regrettably are a part of today's over-medicalized care for the seriously ill.

Beyond the important incremental changes, I discussed above, I want to offer a vision for bigger changes that would improve quality, provide better care at a lower cost, and move beyond the current hospice benefit. These changes would also help our society deal with the scourge of social isolation and the many health and emotional impacts that flow from it.

Hospice today involves arbitrary rules that may have made some sense for a primarily cancer-based benefit in 1983 but make much less sense today when cancer diagnoses have a longer disease trajectory because of advances in medicine and when dementia often comes with a slow and uncertain decline. Today, some of these limitations serve to drive people to hospitals or other inpatient settings, driving up costs and reducing patient and family satisfaction. There are reforms that, if developed and paid for in a bipartisan way much like the hospice benefit was originally created, would bring hospice into the 21st century to address the growing needs of our aging population. These changes include reforming the following:

- Six-month limitation— Due to an outdated and arbitrarily assigned eligibility requirement, hospice is limited to those who have a prognosis of less than six months to live.
- Concurrent care— Hospice requires giving up curative care. This either/or limitation means that folks like my own Great Aunt Ruby or Great Aunt Grace spend months or years “fighting”— that is, declining— because patients and families are frightened by the notion of “giving up” and only receive anything resembling interdisciplinary, person-centered care for the last few days or weeks of their life.
- True Community-Based Palliative Care— Seriously ill patients and their families are in need of support from the community. If we had a community-based palliative care benefit that covered needed health and health-related social services, we could help aging Americans with significant need like Great Aunts Ruby and Grace remain at home and receive personalized care that helps to prevent decline. NHPCO is leading in this work and has developed a framework that can be drafted into legislative text.

Conclusion

Thank you for the opportunity to testify today. NHPCO looks forward to working with you— in Washington, D.C. and in your communities— to better serve aging Americans. We stand ready with ideas and with actions to improve the way that we all care for our parents and grandparents as they near their final chapter. Thank you for your work today, and for the work we are all going to do tomorrow.