

**Testimony Before the
Special Commission on Aging
United States Senate**

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 ***Palliative Care***
at Care New England

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Chairman Collins, Senator Whitehouse, and members of the Senate Special Committee on Aging, my name is Dr. Kate Lally and I am Chief of Palliative Care and Hospice Medical Director for Care New England Health System, Medical Director of the Integra Accountable Care Organization and Assistant Professor of Medicine at Alpert Medical School. I work as a hospice and palliative medicine physician and have the honor of providing care to patients in the last months and years of their lives. I feel blessed to do this work, and to be able to reflect with my patients on the life they have lived, their joys and regrets. I feel I am able to share some of the most sacred moments of their life, and be at their side as they consider what is most important to them in their limited time. It is through this lens that I view the American health care system, and the gaps that our sickest patients often fall through. I would like to share our work at Care New England to provide palliative care both in our hospitals and the community as well as our efforts to educate health care providers in how to provide the highly skilled, complex medical care that our sickest patients need.

Care New England (CNE) Health System is comprised of four hospitals - two community, and two specialty hospitals - a home health and hospice agency, the Visiting Nurses Association of CNE, and a community behavioral health organization in Rhode Island. In 2015, the system partnered with a large independent practice association, Rhode Island Primary Care Physician Corporation, which consists of approximately 150 primary care practices, to create an accountable care organization (ACO), Integra Community Care Network.

Palliative Care at Care New England

Our palliative care program has only been in existence for a few years, but has grown rapidly during that time. In August 2012, Care New England began our palliative care program with a goal of improving the care of patients with advanced illness and helping them manage the symptoms associated with their disease. Like many other programs across the country, palliative care at Care New England started where the need was most acute, inside of one of our community hospitals. We identified that many of our patients were living and dying in ways that were not consistent with their wishes, and that as health care providers, we often had no idea what mattered most to our patients as they approached the end of their life. This often resulted in care that was unwanted, potentially harmful, and expensive.

Care New England is not alone in this - a California study showed that while 70 percent of us say we want to die at home, 70 percent of us will die in a hospital, nursing home or other long-term care facility. Also, while 90 percent of us say it is important to talk about our end-of-life wishes, less than 30 percent of us have talked to our loved ones and less than 10 percent have talked to our doctor.^{1,2}

Care New England looked to the field of palliative care to help provide high quality care that is focused on the patient's goals and encouraged our patients to have a voice in developing a treatment plan that centered on what mattered most to them. Palliative care is defined by the Center to Advance Palliative Care as symptom-focused care for patients with a serious illness. The main goal is to improve the quality of life for both the patient and their family. Palliative care is provided by a team of doctors, nurses, social workers and other specialists and can be

provided at any stage of a serious illness, regardless of prognosis. Palliative care consultations frequently consist of conversations about goals of care and “what matters most” with patients who have a serious illness, as well as helping to manage symptoms of the illness. Our palliative care program was quickly identified by both patients and providers as high value and grew rapidly, prompting us to quickly expand to see inpatient palliative care consults at all four of our hospitals.

Patients seen by palliative care often have multiple concerns that extend beyond their medical problems. One patient we saw early on was Mr. L, a 62-year-old with a new diagnosis of pancreatic cancer. He was aware that his cancer was advanced and decided to try chemotherapy. While his cancer initially responded well to the chemotherapy, further testing showed that the cancer had spread to his bones and spine, creating severe abdominal and back pain. He was admitted to the hospital for pain management, where his oncologist recommended a palliative care consultation. We met with Mr. L and his daughter and talked about what mattered most to him. He said he understood his time was limited, but felt he had a very good quality of life.

Until very recently, he had gone for a walk every day, had large Sunday dinners with his extended family, and helped his wife care for their young grandchildren. The thing that mattered most to him was controlling his pain so he could spend as much time as possible with his family. We discussed that for his quality of life to be acceptable to him, we had to manage his pain more effectively and anticipate and manage other symptoms, such as nausea and anxiety. We worked with his oncologist to start him on pain medications and, after a few days, we had his pain well controlled. In caring for Mr. L, the key to understanding him was understanding what he valued most so we could provide care in alignment with it. That’s what effective palliative care strives to do: understand what matters most to individuals at the end-of-life.

In 2012, about the same time we started our palliative care program, Care New England partnered with the Institute for Healthcare Improvement (IHI) as a Pioneer Sponsor of The Conversation Project and Conversation Ready. The Conversation Project is a nationwide campaign to make sure everyone’s end-of-life wishes are heard and respected.³ It encourages each of us to sit around the dinner table and talk about what matters most to us at the end-of-life. As a health system, if we are going to encourage our patients and families to have these conversations, we needed to be Conversation Ready and able to engage effectively with patients about their wishes when they came to us for care.

As a Pioneer Sponsor, we worked with the IHI and 10 other health systems nationwide to define what it means to be Conversation Ready. Care New England learned that many of our providers were not comfortable talking with patients and families about what matters most to them at the end-of-life, and we needed a way to expand the number of people who had those skills. Given that we had limited availability of palliative care-trained physicians, we developed the role of Conversation Nurse, a nurse who is trained to have end-of-life conversations. Initially, we used these nurses to expand the reach of our inpatient palliative care team and be a resource to physicians seeing their patients in the hospital. We eventually determined that this skill set was needed in both the hospital and the community.

Community-Based Palliative Care

As our palliative care program grew and developed within our hospitals, we were able to help many patients. However, as we cared for patients like Mr. L, we started to identify gaps in the patient-centered care we were hoping to address. Mr. L had his pain managed well in the hospital and had a good conversation about his illness, prognosis and his goals for care. He was discharged to his home with his oncologist and his primary care physician, but unfortunately he did not have access to a palliative care team in the community that was comfortable managing the significant amounts of medications he took, or trained at having conversations about what options were available for when he was at the end-of-life. For patients like Mr. L, there is a gap in community-based palliative care. There are often no providers in the community who are skilled with ongoing conversations around goals of care, or who are comfortable adjusting medications for pain, shortness of breath, or other symptoms associated with the illness.

We realized there was a significant gap in the care of patients with serious illness, not just here in Rhode Island, but on a national level. Hospice, while a wonderful service, is limited to patients with a prognosis of six months or less who choose to forgo aggressive treatments like chemotherapy or radiation. What about patients who have a serious illness, but are not quite at the end of their lives, or who have a significant symptom burden? How can we ensure that these patients can get ongoing palliative care that is consistent with what matters most to them?

To bridge this gap, Care New England expanded palliative care outside the walls of the hospital and developed a community-based program. Our initial goal was to bring the experience of highly skilled palliative care specialists to an outpatient setting. We did this in a number of ways, the first being the introduction of a nurse practitioner home visit program. When a patient like Mr. L was discharged from the hospital, he could have a nurse practitioner come to his home, assess him for symptoms, and work with his oncologist to adjust pain medications and treat other symptoms as they arose. The nurse practitioner was also skilled in talking about disease progression and prognosis and could help a patient like Mr. L and his oncologist determine when he was approaching end-of-life and when hospice might be a reasonable option. Many of our physicians were already convinced of the benefits of palliative care, so they quickly referred to the home-based program and it rapidly expanded. We quickly realized that we still needed more support, as the community need was significant.

As a way to further expand specialist palliative care, in 2015 we integrated palliative care into our newly-formed ACO, Integra Community Care Network. A major focus of an ACO is to achieve the IHI Triple Aim for health care, the simultaneous goal of improving the health of populations, improving the patient experience of care, and reducing the per-capita cost of health care. ACOs are an alternative payment model that focuses on high quality care and allows for interventions to improve care that might not be reimbursed under traditional fee-for-service models. We identified that many of our highest need Integra patients would benefit from palliative care and conversations about what matters most to them. We developed a Complex Care Management program of nurse care managers, nurse practitioners, and social workers who operate under physician oversight and collaborate with the primary care providers to provide in-home care for our highest need patients. In addition to this basic team, we brought in specialist expertise in geriatrics, palliative care, and behavioral health.

Our Complex Care Management team would provide home visits to see where the patient lived, meet their family, and assess support structures. Seeing patients at home often allows them to open up about their hopes and fears as their disease progresses. During one home visit, a woman with advanced lung disease told her nurse, “I feel like I am dying but everyone is afraid to tell me.” The nurse felt at a loss for how to respond to the patient. To improve the skill of our Complex Care Management team, palliative care providers and geriatricians offer a series of training sessions on conversation skills and the unique management skills required to take care of patients with an advanced illness. In addition, geriatricians and palliative care specialists meet with health care providers on the Complex Care Management team weekly to review patients and provide opinions on care management.

Finally, this past January, as a way to continue to expand specialist palliative care into our community and particularly into our area skilled nursing facilities and Visiting Nurse Association, a member of the Care New England palliative care team obtained a Practice Change Leader grant from the John A. Hartford Foundation to improve transitions of care for palliative care patients and continue end-of-life conversations into the community.

We realized that while we were starting conversations inside the hospital, they were often not being transmitted when our patients were cared for at a skilled nursing facility or by a visiting nurse. A preliminary review of the readmission rates of patients seen by a palliative care team in one of our community hospitals showed that for our sickest patients, there was a reduction in readmissions compared to similar patients not seen by palliative care. Our initial data was not sophisticated enough to identify what intervention caused the reduction in readmissions; however, we speculated that linking our sickest patients more effectively to community-based resources, particularly hospice and our community-based palliative care programs, made a difference.

The goal of the Hartford Foundation grant was to follow each patient seen by inpatient palliative care for 30 days after discharge to identify what level of care they transitioned to and if they were readmitted to the hospital. We quickly identified that very few of our patients that were sent to hospice were being readmitted to a hospital. This was due in part to the high mortality of patients sent to hospice, but on a larger level, we felt it was due to the intense support patients get on hospice. A patient on hospice knows their prognosis is terminal and they often have a clearly stated goal of being at home. They have access to specialized nurses, who are focused on meeting that goal of staying at home and who can come to their home 24 hours a day to help. We felt this clear goal of care and specialized nursing helped prevent hospital readmissions.

However, when we looked at other discharge dispositions for our palliative care patients, such as a skilled nursing facility or home with therapeutic VNA, they were frequently readmitted. We speculated the reason for the hospital readmission was that goals of care were not clear, nursing staff was not trained in managing palliative care patients, and adequate supports were not in place. These were often patients with a serious illness who were being discharged to a facility of skilled nursing with a goal of “getting stronger.” As could be predicted based on their advanced illness, they did not get stronger, but in fact got weaker. As their illness advanced, instead of having a conversation about their goals and the fact that their illness was progressing, they were often sent back to the hospital.

To improve the care of our palliative care patients who are transitioning out of the hospital, we started a pilot project in local skilled nursing facilities and our health system VNA to continue highly skilled conversations about goals of care and what matters most in the community. When we identify a patient who has been seen in the hospital by our palliative care team, and who is being transitioned to one of the pilot skilled nursing facilities or VNA for therapeutic nursing services, we send one of our Conversation Nurses to continue the palliative care relationship with the patient and their care team in the community. We are using Conversation Nurses to have ongoing conversations and identify when a palliative care nurse practitioner from our home-based palliative care program is needed to assist in symptom management. We hope that by using Conversation Nurses in this manner, we will reduce readmissions, improve communication from the acute to the post-acute setting, and help design ongoing treatment plans that accommodate the patient's serious illness.

Health Care Provider Education

As we have done this work, we realized that there is a need, and desire, on the part of health care providers to understand how to more effectively manage complex patients with serious illness. As we work in the community, we are frequently approached by health care providers asking for resources to better manage patients who could benefit from palliative care. To meet this need, the University of Rhode Island, in collaboration with Care New England, was awarded a Geriatric Workforce Enhancement Program (GWEP) grant from the Health Resources and Services Administration. The objective of this grant is to increase the skills, on a statewide level, of health care providers who care for older adults and to develop training materials for managing older adults with serious illness. As a result of this grant, we are developing a series of didactics for health care providers from such disciplines as physicians, nursing, and social work. We are also sending palliative care and geriatric specialists into primary care offices to discuss difficult cases, evaluate the training needed to improve the care of these patients, and provide targeted education on advance directives, billing for advance care planning conversations, and managing patients with serious illness.

Beyond our work with the GWEP grant, Care New England is an academic institution. We believe the best way to ensure that future patients can get the type of care they need is by training the doctors of tomorrow. As a result, all internal medicine and family practice residents at Care New England spend a month in a geriatrics and palliative care rotation. We also provide a series of didactics, shadowing opportunities, and exercises in our simulation center. In this experience, residents experience difficult conversations around end-of-life and prognostication with actors playing the patient and family. The residents describe this as very realistic and, at times, very stressful. However, it allows them to have difficult conversations in a safe space and debrief after about what went well and what didn't. The residents describe this as an excellent way to prepare them for having these conversations on their own.

Looking to the Future

Our health care system is rapidly changing and there are amazing opportunities to change how we care for our patients while acknowledging the complexities of caring for people with serious illness. Excellent care involves listening to our patients' voices as they review what they understand about their illness and what they hope for the future. It is by listening that we can help understand what they value and help orchestrate medical care consistent with those values. Excellent care involves using a team of providers from different professions and understanding how the strengths of each team member can help provide a better understanding of our patients and what matters most to them.

While we are working to overcome many of the challenges patients face as they struggle with a life-limiting illness, there are some barriers, such as regulatory requirements, that we cannot overcome. I mentioned previously that many of our patients who go to a skilled nursing facility after the hospital are readmitted. One such patient was Mr. S, an 82 year-old patient I recently met with bladder cancer. After beginning chemotherapy, he developed multiple complications from both his cancer and its treatment, including pneumonia and a urinary tract infection, as well as significant pain and nausea. He asked his oncologist for an honest assessment of prognosis, and his oncologist felt he had a couple of months to live at most. Given how weak he was, he needed to go to a skilled nursing facility for 24-hour care and wanted to start hospice there. Unfortunately, Mr. S discovered that Medicare will only pay for his room and board at the skilled nursing facility if he went for rehabilitation; it would not if he went for hospice care.

Mr. S and his physicians knew that by going for rehabilitation, he was likely to be readmitted to the hospital, since he was unlikely to meet his goals and would likely get sicker and weaker. However, it was important to him that he not put a financial burden on his wife, so he made the choice to go for rehabilitation to avoid the room and board fee, and as a result was readmitted to the hospital. He is one of many patients we care for who make similar choices. This choice between financial incentives and the best level of care is a barrier to providing the patient-centered care that we strive for.

To address this and other barriers that patients face at the end of their lives, Senator Whitehouse is introducing a bill called "Removing Barriers to Person-Centered Care Act of 2016". This work was begun as a result of multiple meetings with various stakeholders in the state of Rhode Island, to help improve the care our patients receive.

The population of Americans who are living with advanced illness continues to grow and healthcare needs to adapt. We need ways to both train healthcare providers in the management of these complex patients and identify better ways to pay for this highly complex care.

One current legislative effort to improve palliative care in the community is S.2748/H.R. 3119, named The Palliative Care Hospice Education and Training Act. This legislation would establish education centers and career incentive awards to improve the training of health care professionals in palliative care. In addition to this training, the act would expand research funding for palliative care and pain and symptom management, and require a national education and awareness campaign. These programs would allow doctors to be prepared for difficult conversations and operate more effectively when they arise in the work place.

A second legislative opportunity to expand the idea of community-coordinated care is the Care Planning Act of 2015. The proposed legislation, S.1549, would provide Medicare coverage for advanced illness care coordination services, develop quality metrics for the services, and require education about the availability of these services. Educating patients about these services and providing them on a more common basis would allow patients like Mr. L to receive the care they need, in a high quality manner that satisfies both the patient as well as the care provider.

As we look at a national level toward what can benefit our patients with advanced illness, we need to focus on expanding the number of trained palliative care specialists, improving the skills of all providers in caring for patients with serious illness and finding ways to pay for that care than doesn't force patients to choose between aggressive rehabilitation focused care and comfort care. As our population ages, this will only become more critical.

Thank you for your time and support.

References:

1. National Survey by The Conversation Project 2013
2. Survey of Californians by the California Health Care Foundation 2012
3. TheConversationProject.org.