

Opening Statement
Senator Susan M. Collins
Special Committee on Aging

“The Right Care at the Right Time: Ensuring Person-Centered Care for Individuals with Serious Illness”

June 23, 2016

Good Morning. Not long ago, one of my dear friends was a patient at the Gosnell Memorial Hospice House in Scarborough, Maine. Despite her serious illness, her days were filled with visits from friends and families and many joyful moments, and she was surrounded by her family when she died peacefully.

In many cases, hospice care enables dying patients to remain in the comfort of their own homes, free from unnecessary pain, and surrounded by family and friends. The Gosnell Memorial Hospice House provides an alternative when care in the home is no longer possible or is no longer sufficient. It provides a comfortable and attractive home-like setting for hospice patients and their families where they can receive patient-centered care.

From pain and symptom management to psychological and spiritual support, and even to delivering longed-for scones to go with my friend’s tea, the care at the Gosnell Memorial Hospice House is first-rate. Such compassionate, high-quality, and seamlessly coordinated care can make a tremendous difference for seriously ill patients, such as my friend, and their families.

Advances in medicine, public health, and technology are helping more and more of us live longer and healthier lives. But when medical treatment can no longer promise a continuation of life, patients and their families should not have to fear preventable pain, avoidable distress, or care that is not consistent with their values or needs.

A majority of Americans say that they would prefer to die at home, yet -- most people die in the hospital. Fewer than 45 percent of Americans receive hospice care at home during their last stages of life, and nearly half of those receive hospice care in the final weeks – or even days – of their lives.

Federal policies must support efforts to relieve suffering, respect personal choice, provide opportunities for people to find meaning and comfort during serious illness, and – most important – remain in control of their own care.

We know that hospice care can benefit both the patient and family. So why aren’t people accessing this service sooner? I am concerned that this may be the result of a restriction in Medicare that requires beneficiaries to stop conventional curative care for their terminal diagnosis in order to elect hospice care. It is encouraging that CMS and organizations such as

Blue Cross Blue Shield of Massachusetts are beginning to evaluate the benefits of allowing beneficiaries to receive curative and palliative care concurrently.

As the Senate Co-Chair of the Congressional Task Force on Alzheimer's disease, I am also particularly aware of the needs of Alzheimer's patients and their families.

Although it is the fifth leading cause of death for seniors, Alzheimer's is not always viewed as a terminal illness, and too little attention has been paid to the special end-of-life needs of Alzheimer's patients and their families. While strides are being made in improving care, people with dementia often die without the benefit of hospice care.

Medicare's eligibility requirements for hospice can prevent some individuals with dementia from accessing quality care. Current regulations require a physician to certify that a patient entering hospice is likely to die within six months. It is difficult for physicians to determine with precision how long anyone with a terminal disease will live, and it is particularly challenging with a disease like dementia, which has an unpredictable trajectory. As a consequence, Alzheimer's patients – who could benefit from the better pain control, fewer hospitalizations, and greater family satisfaction that hospice provides – are under-enrolled in hospice.

Additionally, since hospice has been traditionally used for the care of patients with cancer, hospice staff aren't always sufficiently trained or prepared to meet the special needs of Alzheimer's patients and their caregivers.

Today, we will explore ways to improve the quality and availability of care, and discuss models of care that are helping people with serious illness and their families.

We are fortunate to have an outstanding panel of witnesses, including a personal hero of mine, Dr. Atul Gawande, whose book Being Mortal has been a bestseller. This book, by the way, and my ownership of it has an interesting journey. It first was read by Jay Rockefeller who passed it on to Angus King, who passed it on to me. I had my husband read it first and then I got to read it. Now Dr. Gawande is probably not happy about what that means for book sales, that there were so many readers. I passed it on to my staff whom I asked to bring it today.

We also have other truly outstanding witnesses, one of whom Senator Whitehouse will introduce and I will introduce the other. But, I want to thank all of them for being here today. Regrettably one witness who was supposed to be here today is Dr. Katherine Pope, she was the medical director of that wonderful hospice house in Southern Maine. But, the thunderstorms caused her early morning plane to be cancelled.

I know that this issue is a personal passion for my colleague from Rhode Island, Senator Whitehouse, and I so appreciate his serving as Ranking Member at today's hearing. I now turn to Senator Whitehouse for his opening statement.