Good afternoon. I am Kristen Santiago and I am here today on behalf of C-Change. We are a national cancer collaborative made up of the leaders from major private, not-for-profit, and public organizations devoted to reducing the burden of cancer on our Nation’s people.

We would like to thank the Institute of Medicine and this Committee on Transforming End-of-Life Care for your important contributions. In particular we want to note your important, high quality and thoughtful 1997 report. Its themes and recommendations provided an excellent roadmap for the changes we needed to make in this important area. While important progress on some fronts has been made in the intervening 15 years, sadly there is all too much of what you recommended that remains to be done. We must update and reiterate these recommendations, and we should devote considerable attention to defining how best we can move change faster than we have in the past.

As part of our collaborative efforts to improve the quality of care and life for individuals with cancer, we have incorporated some of your recommendations into our work to increase the use of palliative care throughout cancer treatment; to increase the number of individuals accessing hospice care, and to increase the length of hospice care.

You noted in the 1997 report that: “people suffer needlessly at the end of life …when caregivers fail to provide palliative and supportive care.”\(^i\) We have known for a long time that pain control is an important part of caring for cancer patients. Yet, currently nearly 40% of cancer survivors, and 60-85% of people with advanced cancer are still living in pain.\(^ii\)

We would argue that people with cancer are harmed when they are not active partners in their treatment decisions and when their treatment options and realistic treatment benefits are not
discussed openly as those decisions are being made. We must radically improve the quality of
the conversations that occur when patients, families and providers talk about these critical life
decisions. This needs to include: realistic discussions of goals of care and treatment options, the
role of palliative care from the time of diagnosis to the end-of-life, and timely referrals to
hospice so that patients and their families can receive the full benefit of those services.

Yet, we note that fewer than 40% of patients with advanced cancer have realistic conversations
with their providers about treatment options and alternatives.iii 65% of medical oncologists wait
until there are no more non-palliative options before they bring up hospice as an option.iv Some
important strides currently are being made by a number of professional groups, including
significant leadership from the American Society of Clinical Oncology.

The 1997 report notes that “medical culture still tolerates and even rewards the
misapplication of life-sustaining technologies while slighting the prevention and relief of
suffering.”v This “rescue” mentality and our inability to have more timely, direct and honest
conversations results in 16-20% of individuals with cancer receiving chemotherapy within 14
days of death, when the impact on quality of life likely outweigh any potential benefit.vi We need
to change how care is delivered as well as the understanding and expectations that individuals
receiving care and their families have.

The 1997 report addresses the struggles that our nation has in “speaking realistically [and]
comfortably about the end of life.”vii Clearly this involves better quality conversations between
patients and health professionals as I noted moments ago. But your report also recognized that
“in addition to dedicated professionals, many volunteers contribute their time and energy
to provide emotional and practical support to dying patients and those close to them.”viii
C-Change has recently conducted focus groups with hospice volunteers. Some of the comments that were made by these remarkable individuals who are an important extension of the cancer workforce, were illuminating, and framed things in a beautiful and telling way. One older volunteer, a retired nurse working at an in-patient hospice, stated that “there is a myth that hospice is where you go to die… but in fact, you go there to celebrate life!” This statement was made by a woman who has seen many loved ones pass away from cancer, and who has decided to “pay it forward” and volunteer in a hospice. A younger hospice volunteer who began volunteering to give back as a way of saying thank you after her mother had benefited from hospice care stated that “the most intimate thing you can do with someone is help them as they are dying.”

If we can keep these types of sentiments in our minds, we can begin to tell a different story, one about the quality of how one lives and less about unrealistic expectations of immortality and a health care system that is expected to save everyone no matter the cost or what their wishes may be. We should have the capability and the courage to change the national conversation around end-of-life issues. We should be able to counter what your report noted as the “unhelpful combination of public fear, misinformation, and oversimplification that view misery as inescapable, pain as unavoidable, and public spending as misdirected for people who are approaching death.” And we must continue to counter misrepresentations of what we know to be true, and what has been proven to be high quality care.

To do all this well, we must, as your report noted, recognize that “people approach death along many different paths” and that people take different care paths for different reasons. We need to make changes that recognize the great diversity that exists in our society today – and respect
the right of people to choose their own path. But we believe those choices can only be made properly if people have the information they need and a health system environment where their needs and wishes will be respected and followed.

To progress, and improve the care for persons with serious illness we must accomplish four key goals. First, we must develop a robust research agenda to build our body of evidence for high quality care, and we must ensure that this research agenda addresses and reflects the views of populations with health disparities. The success of future policy changes in palliative and end-of-life care will be reliant on the products of a strong research agenda. Second, we need to define and implement supportive payment structures. Third, we must address the workforce challenge. There are far too few palliative care specialists now, and in the foreseeable future to meet the needs of persons with serious illness and their families. We need to focus not only on training palliative care specialists but also ensuring that basic palliative care knowledge and skills as well as training to have difficult conversations and address psychosocial issues are integrated within the curricula of all medical, nursing, and social work schools at a bare minimum. We also need to ensure that every health care institution in the country can provide high quality palliative care to all their patients and their families. Finally, we need to engage in an extensive, population wide, sustainable campaign to ensure that all Americans know what palliative care is and that they know to request it at the time of diagnosis of a serious illness and not in the days before death. Similarly, the role and benefits of hospice in end-of-life care needs to be better understood by the public and practicing clinicians.

In closing, I would like to once again thank the IOM for taking up this issue yet again. The work you did in 1997 was not only well done, it was prescient about many of the issues we face yet
today. What has been very rewarding of late is to see the increasing amount of public discourse that is taking place on these important issues – much more than we have ever seen before. Much of this is being fueled by real people telling their stories or the stories of loved ones in very public and open terms. It is also very encouraging to see the self-reflection among providers and health systems looking at what we do well, but more importantly what we do poorly – and then to thoroughly discuss what needs to change and how. And it is deeply gratifying for us at C-Change to see our patient, advocate, provider, health system, payer, industry, and so many other partners working on these things together. No one group, or sector, or organization will solve this on their own. This is a foundational, societal and cultural change process. So this is a sentinel time for you to reflect on your past work and remake the path going forward.

We very much agree with the final statement in your 1997 report that we can “…‘approach’ death constructively and create humane care systems that people can trust to serve them well as they die.”\(^{1}\) Increasing the use of palliative care throughout treatment; increasing the number of patients and families accessing hospice care, and increasing the length of hospice care will ultimately improve the quality of care for those who need it, when they need it most. Thank you.

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