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TRANSCRIPT OF THE MINUTES

of the

COMMITTEES ON AGING AND HEALTH

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HELD AT: 250 Broadway
Hearing Room – 14th Floor

BEFORE:
JOEL RIVERA,
MARIA DEL CARMEN ARROYO
Chairpersons

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CHAIRPERSON RIVERA: Good afternoon ladies and gentlemen. My name is Joel Rivera; I'm the Chair of the City Council's Health Committee. Today the Committees on Health and Aging are conducting a joint hearing on end of life care. I would like to thank my co-chair, Council Member Maria del Carmen Arroyo for joining me in holding this important hearing and for all her leadership and advocacy for New York City's older adults.

End of life care can be broadly defined as the medical treatment and decisions made as an individual is becoming increasingly ill. For obvious reasons this is a very sensitive topic to discuss with one's family and even with medical professionals. As the individual approaches the end of life it is important to ensure that they are adequately prepared. End of life care is more than the medical treatment that one receives. It pertains to ensuring that an individual is able to make personal medical decisions, that they are able to have their affairs in order and make arrangements with their family and loved ones.

A cornerstone of end of life care

is honoring the wishes of the individual and ensuring that they decide on their treatment options. This may take place after lengthy conversations with family, friends and medical professionals. It is important that medical professionals understand the unique needs of individuals in this very trying situation. For this reason it is necessary that medical professionals receive proper training in helping patients make these individuals.

From the perspective of a doctor this type of care is counter to what they learned in medical school. For the most part in medical school doctors are taught about exhausting every option to retain life, while this type of care focuses on the comfort of the dying patient.

The New York City Health and Hospital Corporation provides palliative care services, which strive to relieve the pain of individuals who are suffering. This care takes into account the patient’s medical, psychological and spiritual needs. HHC also offers bereavement and caregiver support services to family members during these difficult times.

In 2006, HHC launched their palliative care initiative, expanding these services to all of HHC’s hospitals. Part of the car that is included involves patients being treated by teams consisting of doctors of various specialties such as psychiatry and internal medicine, nurses, psychologists, social workers and chaplains. Today the committees would like an update on this initiative.

I would like to thank the staff of both committees for their hard work, and before we hear from our first panel I want to introduce the members who we have here today and then obviously my co-chair of today’s hearing. We have, to my left, Council Member Ken Mitchell; we have my two Legal Counsels, Joe and Adira. We have to the right Melissa Mark-Viverito; City Council Member and Comptroller Elect John Liu; Council Member Gale Brewer, and of course my Co-Chair, Maria del Carmen Arroyo, who will introduce her legal staff and make an opening statement.

CHAIRPERSON ARROYO: Thank you, Mr. Co-Chair, and thank you for agreeing to hold this joint hearing with the Committee on Aging. And

I’m going to say thank you to the Committee Staff first, because if I don’t I usually forget and they’re the ones that do all of the work. You guys have heard me say it many, many times over. They’re the ones who make us look so, so incredibly smart. Kris Sartori, who is the Counsel to the Aging Committee. To my right we have Shauneequa Owusu, who I have not seen; she’s probably working on something else. And Pakhi Sengupta, who is our Fiscal Analyst for the Committee. Good afternoon and welcome. I am Maria del Carmen Arroyo and I Chair the Committee on Aging, and again, I want to thank my colleague Council Member Rivera, Chair of the Committee on Health, for agreeing to hold this joint hearing with the Committee to have this important conversation, where we hope to examine issues of end of life care.

And as we all know, the older adult population is growing rapidly. For example, every seven seconds—well, that’s a lot of people—a baby boomer turns 60. By the year 2030, 7.5 million Americans will be age 65 or older, making up about 20% of the nation’s population. In our City the numbers are a little bit higher. Existing services geared towards older adults will help to keep pace with this rapidly growing population, especially as the cost of the entire healthcare system in the country continues to rise dramatically.

Services related to end of life care are no exception to the reality of service need. It is important that not only seniors, but everyone, be aware of and plan for end of life care, since we all hope to grow old someday. However, many people are unaware of the most basic type of end of life planning tools, namely healthcare proxies and living wills, and many are very uncomfortable even discussing the topic anyway. And we need to talk about how we can break down those barriers to get people to indeed engage in those processes so that we can help them in their end of life decision-making, so no one else is making decisions that they otherwise would not have done for themselves. That’s why it’s important for local government to do what it can to educate the public on end of life care as well as provide assistance to those who need help understanding their options and how to plan for their own care or for the care of a loved one.

And those of us who have parents who are aging often come up and take on the responsibility of caring for that individual, and always hope that we would make the right decision on their behalf. But there should never be a doubt. As an example of what local government is currently doing, our Department for the Aging in the City manages the Center for Organization and Development, or it’s Center of Organization and Development runs a online training program that helps older adults and their caregivers understand how to plan for various end of life issues. The program includes information on how to make arrangements for dealing with medical issues that arise at the end of life, as well as help regarding funeral, burial arrangements and legal and financial issues.

A part of the program is also dedicated to helping individuals understand the various stages of Alzheimer’s Disease and how to care for someone with that disease. For those already at the stage where care is needed, DFTA’s community support demonstration program provides free non-medical services for those who are terminally ill, regardless of their life expectancy or what their treatment options are, through the use of a case manager who assists clients and their families in managing and understanding end of life care issues. And I’m sure that our Commissioner will share a lot more details about those programs. And these are just two examples of the services and resources available in our City.

At the hearing we hope to get an understanding of what these and other programs, what programs are available and what these programs need in order to be viable and help with end of life issues. I look forward to hearing from the Administration and the advocates who have come here to testify. We always have an incredible conversation that opens up some thinking that helps us plan better for the future and I know that today’s hearing will be no exception.

I think at my colleague introduced all of the members of the Committee. Council

Member Brewer, Council Member Helen Sears just joined us, Ken Mitchell at the end is a member of the Health Committee, and Council Member Melissa Mark-Viverito who is not only a member of the Committee on Aging but also Chairs the Subcommittee on Senior Centers. Thank you all for being here and I guess you can introduce the first panel. Okay. We have—oh no. You’re going to do that.

CHAIRPERSON RIVERA: We’re going to see who butchers whose name. Okay. Dr. Eric Manheiner [phonetic]. How close am I?

DR. ERIC MANHEIMER: 80%.

CHAIRPERSON RIVERA: 80%. It’s okay to correct us. Lilliam—

MS. LILLIAM BARRIOS-PAOLI: [Interposing] Barrios Paoli.

CHAIRPERSON RIVERA: Barrios-Paoli. And Sean Morrison, an MD from Mt. Sinai. And if you could just state your name for the record. If you have testimony, please provide it to the Sergeant-At-Arms and you may proceed with your statements.

ERIC MANHEIMER: Good afternoon,

Chairpersons Arroyo and Rivera and Members of the Aging and Health Committees. My name is Dr. Eric Manheimer and I am the Medical Director at Bellevue Hospital Center. Thank you very much for the opportunity to describe the palliative care programs on behalf of the New York City Health and Hospitals Corporation.

I’d like to begin with a brief overview of palliative care. Palliative care is the medical specialty focused on relief of the pain and other symptoms of serious and chronic illnesses. The goal is to prevent any suffering and also to offer patients and their families the best possible quality of life. It is provided simultaneously with appropriate medical treatments. It differs from hospice care, which is a subset of palliative care, by intervening on the patient’s behalf early in the course of the illness and providing continuity of care as the illness progresses and the patient seeks out various specialist. As the illness advances and stress increases, the role of palliative care increases.

This is what the World Health

Organization has to say: Palliative care improves the quality of life of patients and their families through the prevention and relief of suffering and treatment of pain and other problems, physical, emotional, social and spiritual. It uses a team approach. It offers a support system to help patients live as actively as possible and a support system to help families cope. It affirms life and regards dying as a normal process. It intends to neither hasten nor postpone death.

Palliative care options stress dignity and comfort and take into account a dying patient’s medical, psychological and spiritual needs. The needs of the patient’s family are also carefully considered and caregiver support and bereavement services are often available. Palliative care helps to empower and support patients and their families if they choose to diminish some of the anguish and suffering associated with the use of invasive end of life technology.

Recognizing the need to provide specialized care to patients who face life-threatening or terminal disease, HHC initiated a corporate-wide clinical initiative in 2006 to expand or create palliative care programs of all of our acute care hospitals in order to make this service available to more New Yorkers. Prior to the corporate-wide initiative in 2006, several HHC facilities were offering palliative care services, most notably at Bellevue, Coney Island, Elmhurst, Lincoln and Metropolitan and at our long-term care facility on Staten Island, the Sea View Nursing Home and Rehab Center.

These facilities had incorporated various aspects of the palliative care philosophy and specialized knowledge base into their patient care. This service is not something that all hospitals offer in New York or nationwide. It is estimated that only 30% of public hospitals and 70% of voluntary hospitals provide this service. Our palliative care team consists primarily of doctors with various specialties, like geriatrics, psychiatry and internal medicine, nurses, psychologists, social workers and chaplains.

To foster and coordinate our efforts across facilities, HHC established a Palliative Care Council with representation from each hospital and HHC Health and Homecare to act as an ongoing advisory body, focus group and arena for learning and providing solutions. A palliative care website was created for all HHC facilities, a means of further promoting the sharing of clinical skills and information. More than 1,000 staff have been trained in the palliative care specialty so far. We have also trained an additional 120 nurse educators, who will each in turn create four training sessions in their facilities as a means of spreading both the philosophy and clinical skills of palliative care.

HHC has distinguished itself in its commitment to multi-disciplinary approaches by taking national curricula and adapting them to provide knowledge and competencies for several different disciplines. This broad training fosters a common body of professional knowledge among our staff to assist them in their day-to-day interactions with patients and families. As you can well understand, training and education efforts are an ongoing process. Just this past Tuesday Lincoln Medical Center hosted a grand rounds session on pain management and its cultural implications. We also take advantage of technology to hold webinar grand rounds to train our clinicians. I recently was on a webinar between several of our facilities, just parenthetically, where a NICU patient, a premie, was presented who had been transferred from another HHC facility to Bellevue. And this young child had an unfortunate birth and complications during the pregnancy and it was a year old at that time and there were a lot of difficulties culturally and in managing the child and discussing issues with the family, so I just wanted to let you know, this became one of the webinars.

Utilization has grown since we embarked on this initiative. In fiscal year 2008, more than 3,200 patients and their families benefited from the specialized services of palliative care teams on an inpatient basis at HHC's facilities. We had nearly 1,000 outpatient visits as well in '08. This grew remarkably to more than 4,300 patients receiving services on an inpatient basis and more than 1,850 outpatient visits in fiscal year '09.

In order to assist with the identification of patients who may benefit from palliative care, a decision tool was created to assist admitting doctors and nurses in identifying which patients could benefit from a palliative care consultation. The program serves end of life patients as well as individuals suffering from chronic pain and stress of a serious illness, including cancer, sickle cell anemia, multiple sclerosis, AIDS, congestive heart failure and advanced dementia. As I've stated, the goal is to improve quality of life for patients and their families and can be given at any point in an illness for patients who are hospitalized as well as on an outpatient basis.

Increasing palliative care awareness amongst patients, families and their communities is also considered a goal of the initiative. Ensuring access to services has always been a firm commitment of HHC. The initiative has produced media to further these goals, including brochures translated into several languages, and a short video to be shown at community group meetings, in clinic waiting rooms as well as at the bedside. HHC’s facilities use these materials at health fairs and when speaking to community groups in order to ensure heighten awareness.

One of the reasons that hospitals may not choose to offer this service could be financial. There is very little dedicated funding from government payers, Medicaid or Medicare, to support the expansion of palliative care. In fiscal year ’08, HHC spent more than $2.75 million to expand or further develop our palliative care programs. To bolster our programs we have sought and have been successfully awarded financial support from the private sector. HHC has received $100,000 grant for two years from the United Hospital Fund to advance the palliative care’s initiative strategic goals. The Fan Fox Leslie Samuels Foundation has provided $100,000 to Elmhurst provided for additional physician time, expand bereavement services and create the availability of a hospice bed for the uninsured. They have also provided $200,000 to Metropolitan Hospital to enhance their program to include outpatient palliative care services and establish better linkages between the emergency department and palliative care service.

Many people confuse palliative care with hospice care, or believe it is only applicable at the end of life. Indeed, a major subset of palliative care involves end of life care, but in order to reach optimal effectiveness and provide greatest patient and family relief. It should be considered whenever an illness that is serious or chronic or advanced is diagnosed. By introducing palliative care early in the course of illness, discomforts can be minimized, plans and wishes elucidated, social and financial situations considered and anxiety and emotional and spiritual aspects addressed. Palliative care begins at the beginning of such a diagnosis even though the focus at that point, based on patient’s wishes, may include the most aggressive curative treatments and tests to support them.

Patients and doctors might rightfully anticipate that such a patient with a new diagnosis has many, many years to live. But as symptoms become more difficult to manage, whether they are symptoms from the disease and the treatments, patients need more and more specialized treatments, so palliative gets involved early in order to help the patient and to provide continuity of care during the natural course of an illness. This role typically increases as curative treatments begin to fail. However, palliation of discomfort does not necessarily mean the end of aggressive treatment. For example a patient might choose to have chemotherapy or radiation to shrink a tumor as a means of alleviating pain, despite the fact that there is no expectation the treatment will be curative, or even provide significant prologation of life.

In view of the goals of palliative care to intervene early and other factors, it will no longer be surprising that over 60% of the palliative care patients are under the age of 65 and 25% of patients are over 80. To ensure continuity of care, we have created liaisons with both hospices at nursing facilities, those that are standalone facilities and with nursing services which provide home hospice. Some HHC facilities also have hospice beds on site.

Our work on palliative care initiative is an ongoing process. Just this morning we held a palliative care conference in conjunction with the Department for the Aging at Metropolitan Hospital to review our achievements and discuss our future challenges. In addition to holding ongoing training and education sessions, we are working to create a patient-centered needs assessment, further evaluate the clinician decision-making tool, and we will continue to provide overall support for the growth and improvement of palliative care. We also look forward to continuing our collaborative efforts with our partners at the Department for the Aging and other stakeholders to expand public awareness of palliative care.

The importance of palliative care and HHC’s dedication to it arises from many facts and a response to documented patient needs. It brings with it a specialized body of professional knowledge. It enhances efforts for patient safety and dignity. And lastly, for some patients and their families, it is the right thing to do. Thank you very much for the opportunity to testify. I’d now be happy to answer any questions.

CHAIRPERSON ARROYO: Before we continue with the panel, I’d like to acknowledge we’ve been joined by Council Member Al Vann, that I know is here, and Council Member Helen Foster, a member of the Aging Committee.

LILLIAM BARRIOS-PAOLI: Good afternoon, Chairs Arroyo and Rivera and Subcommittee Chair Mark-Viverito and members of the Committee on Aging and Health. My name is Lilliam Barrios Paoli. I’m the Commissioner of the Department for the Aging, DFTA. Thank you for holding this hearing on the important topic of end of life for older adults.

As you know, Mayor Bloomberg and Speaker Quinn, in collaboration with New York Academy of Medicine, my department and numerous other City agencies recently launched the Age Friendly New York City, a project comprised of 59 initiatives designed to enhance the livability of the City of New York for older New Yorkers. Key among the initiatives were advancing palliative care and promoting the use of advanced directives, which will be the focus of my testimony this afternoon. Specifically I will talk about the importance of palliative care and advanced directives as resources for older adults, their caregivers and families, as well as discuss the work we have already done in this area by engaging in conversations with City agencies and leading experts in the field. I will also touch briefly on possible new steps.

I won’t proceed to describe palliative care, since my colleague so aptly did that, but I would like to say why it is an important topic among seniors. I think, as you know, the majority of our seniors attending our centers, 90% of our seniors attending our centers are old, they are over 75; they’re also poor. About 90% of them of them are very poor. So the combination of being elderly and poor are two very disempowering combinations. In the healthcare system, when we participate in it by and large we do so as uninformed consumers and we don’t know what options we have and it’s a profoundly disempowering experience that we have. For poor people, that is even worse. And we feel that as adults age and have to live with chronic diseases, some of which are very painful, understanding their options in the healthcare system and understanding how things don’t have to be just one way or the one way it’s being described to you becomes increasingly important.

Research has shown that patients who receive palliative care have better outcomes than those who merely receive the usual course of treatment with out the addition of palliative care. Patients receiving palliative care report their care as superior in areas such as the attention paid to their dignity and autonomy, their receipt of emotional and spiritual support and their access to information and communication, the management of their pain, the connection to services in their community and their overall well being.

Palliative care represents a new way of thinking about medical care, with great promise for improving care of New Yorkers with serious illness. Studies have shown that in treating such patients, traditional medical care has not been completely effective in regard to the management of pain, the provision of emotional support and the coordination of care services. Palliative care responds to these unmet needs. Contrary to misinformation generated in the ongoing healthcare debate, that physicians may curtain sustaining care, palliative care empowers individuals and families to receive the appropriate care that is consistent with their personal wishes and preferences while living life to the fullest. The Department for the Aging particularly is interested in the involvement of caregivers and family members as critical stakeholders in the delivery of palliative care.

As you know, DFTA is committed to promoting home and community-based services that allow older adults to remain in their homes as long as possible while reserving institutional care only for those with the most advanced illness. Too often hospitals, home care agencies and other healthcare institutions do not communicate as much as they should with patients and their families. Discharges to the community can be premature, without regard for the patients wishes or considerations of the family’s ability or capacity to provide the necessary follow up care. We see palliative care as a bridge to create better connectivity among healthcare settings and provide greater comfort and support for older adult patients and their families by including them in their rightful place as part of the care team working together on the decision-making process. Just as palliative care seeks to empower patients and actively involve them in their own treatment, advance directives can empower patients to express their wishes in the event that they’re no longer able to communicate them.

More specifically advance directives are documents that capture an individual’s choices regarding medical treatment. While these are highly personal and important decisions, many individuals do not make them known to other. In fact, only 15 to 25% of adults complete advance directives, and often only after hospitalization for serious illness. By completing advance directives well before reaching advanced stage or encountering serious illness, New Yorkers can ensure that their wishes regarding care are known and followed.

In New York State there are three types of advance directives, healthcare proxies, living wills and Do Not Resuscitate Orders. A healthcare proxy allows individuals the ability to appoint another person to make medical decisions on their behalf, if they should become unable to make decisions on their own. A living will allows individuals to explain their healthcare wishes, including wishes regarding life-sustaining treatments or procedures administered in the midst of a terminal condition or permanent unconscious state.

While many state legislatures have passed laws that specifically give their residents the ability to complete living wills, New York's unfortunately has not. However, the validity of living wills has been recognized by the New York Courts. In contrast, a Do Not Resuscitate order, DNR, is more narrow in scope, allowing individuals to specify that they do not want CPR or other extraordinary measures should their hearts or breathing stop.

A more recent innovation, begun in

New York State in 2005, is the MOLST, or Medical Orders for Life-Sustaining Treatment program. Under MOLST program, a form is completed by a physician after consultation with is or her patient that includes medical orders and patient preferences regarding CPR, intubation and mechanical ventilation, artificial hydration and nutrition, future hospitalization and transfer and antibiotics.

The MOLST program is based on the believe that individuals have a right to make their own healthcare decisions, including decisions about life-sustaining treatments, to describe these wishes to a healthcare provider and to receive comfort care where wishes are being honored. In contrast to a healthcare proxy, the MOLST applies at any time, crosses care settings and is not conditional on losing decision-making capacity. The MOLST form can aid medical professionals in honoring treatment goals from those patients who wish to receive all appropriate life-sustaining treatments to patients who would place limits on life-sustaining treatments.

It is important to know that the

Department of Health and Mental Hygiene has also been active in promoting public awareness with respect to advance care planning. In February 2009, DOHMH launched a new webpage focused on advance directives, palliative care and related issues. The new webpage provides a variety of information and resources including a City health information publication for healthcare providers entitled, Improving Palliative Care in End of Life; a healthcare bulletin publication for individual entitled, Advance Directives: Who Will Make Your Medical Decisions If You Can’t; and New York State healthcare proxy forms. In, healthcare proxy forms are available both online and through 311 in several languages, English, Spanish, Chinese and Russian.

Next steps. The City is in the initial states of formulating its thinking on how to promote and support palliative care and advance directives as resources for the public. These are highly personal and sensitive topics that require an approach fully respectful of cultural differences among the City’s diverse cultural constituencies. This effort will require partners including policy makers, aging services and other social services providers and medical and legal communities as well as religious institutions, older adults, caregivers and their families, to name a few.

We are fortunate to have some of the most highly regarded experts in the fields of palliative care in New York City. Under the guidance of Deputy Mayor Linda Gibbs, we are currently dialoguing to gain more knowledge and insight. As HHC has testified today, we hosted a palliative care conference in conjunction with DFTA. The conference is serving as a springboard for larger City efforts as part of the age-friendly New York and will engage multiple City agencies and a variety of external stakeholders. We are thankful that members of both Council’s Aging and Health Committees could attend the conference today and I look forward to working together.

I now would like to introduce Sean Morrison to the Committee. Dr. Morrison is the Director National Palliative Care Research Center and the Hertzberg Professor of Palliative Care and

Professor of Geriatrics at Mt. Sinai Hospital. We have worked actively with Dr. Morrison. He’s guided us in some of the preliminary plans that we’ve had. He’s probably one of the authorities on the topic in this city and in the nation. And I would like you, if possible, to hear his testimony.

CHAIRPERSON ARROYO: First we want to know old he is? I’m sorry, I couldn’t resist that.

DR. SEAN MORRISON: No, it’s absolutely fine and believe me, I’ve heard it before. I’m 45 and my 16-year-old gets tired of this question too, so no worries. Thank you very much. Good afternoon Chairs Arroyo and Rivera, Subcommittee Chair Mark-Viverito and members of the Committees on Aging and Health and thank you very much for the opportunity to speak with you today.

As the Chairman said, my name is Dr. Sean Morrison. I’m a geriatrician and palliative medicine physician at the Mt. Sinai School of Medicine in New York City, and I also direct the National Palliative Care Research

Center, which is a national organization which is headquartered here in the City and it’s purpose is to improve care for persons living with serious illness and their families, through the fostering and promotion of high quality research and palliative care. And I’m also the President Elect of the American Academy of Hospice and Palliative Medicine.

I am really honored to be here today and in my remarks to you, I’d like to accomplish three key objectives. First I’d like to outline for you the current experience of New Yorkers living with serious and life-threatening illness and the need for change. Second I’d like to introduce the modern specialty of palliative care and discuss how palliative care not only can improve care for New Yorkers with serious illness in their families, but also help our healthcare system more generally. And finally I’d like to offer a few suggested steps the City can take to serve as a model for other major cities in the United States and indeed internationally in promoting high quality care for seriously ill Americans and their families.

As Chairman Arroyo already noted, our society is facing one of the largest public health challenges in its history, the growth of the population of older adults. Improvements in public health, the discovery of antibiotics, advances in modern medicine have all resulted in unprecedented gains in human life expectancy. For most New Yorkers, the years after age 65 are a time of good health, independence and integration of life’s works and experience. Eventually, however, most of us will develop one or more chronic illnesses with which we will live for many years before we die.

Unfortunately these years are characterized by physical and psychological challenge, progressive functional dependence and frailty and increased need for family and external support. And studies over the past 10 to 20 years suggest that medical care for patients with serious and advanced illness is characterized by the under treatment of symptoms, including pain, questions about who should make decisions about the patient’s care and immense pressures placed on caregivers and their resources.

Traditionally medical care in the United States has been articulated as having two mutually exclusive goals, either to cure the disease and prolong life or to provide comfort care. In this dichotomy, decisions to focus on reducing suffering are made only after life-prolonging treatment has been ineffectual and death is imminent. The division of services results both in the provision of burdensome life-prolonging treatments when they're no longer beneficial and in a tremendous amount of preventable suffering during all stages of advanced illness. By contrast, my patients would benefit most from care that included a combination of life-prolonging treatment when possible and appropriate, palliation of symptoms, rehabilitation, and support for caregivers.

As was already noted, palliative care is a new healthcare specialty in this country that focuses on the relief of suffering and achievement of the best quality of life for patients and their loved ones. It involves formal symptom assessment and treatment; addressing the distressing symptoms that people live with in the setting of chronic illness, pain, shortness of breath, nausea, fatigue, appetite disturbances; aid with decision-making in establishing goals of care, identifying what is the most appropriate goals of care for an individual patient; mobilization of community supported resources to assure secure and safe living environments; and collaborative and seamless models of care across all of our care settings, the hospital, home, nursing homes, homes and hospice. And most importantly, it is not end of life care restricted to those who are dying. It is offered simultaneously with all other appropriate life-prolonging curative therapies for persons living with serious, complex and eventual terminal illness.

Studies that we and others have performed clearly demonstrate that palliative care improves patient comfort, is associated with extremely high patient and family satisfaction and indeed is associated with similar or increased survival when compared to patients receiving usual care alone. Because if you’re comfortable and you’re not in pain, you’re not in distress, it’s a lot easier to get to your doctors appointments, it’s a lot easier to get to your chemotherapy appointments than if you’re suffering.

Furthermore, specifically by sitting down with patients and families in a setting of serious illness, asking about their goals for medical care, their wishes for treatment, empowering the patient and then matching treatments to those goals, palliative care teams ensure that patients are treated in care settings of their choice, while reducing unplanned and unwanted emergency department visits and hospitalizations.

In my practice, nobody should be forced to go to an emergency department in the middle of the night because they have untreated pain or a pain crisis. They would much rather be cared for at home, and that’s what the palliative care teams can do.

It’s perhaps no wonder that given the benefits of palliative care we’ve seen a number of palliative care programs in hospitals grow from less than 5% of hospitals in 1999 to over 55% of all hospitals in 2008. And here in

New York City more than 70% of New York City Hospitals, both public and private, have a palliative care program—one of the highest, if not the highest, prevalence rate of any major US city. This is the good news. The bad news is that 45% of hospitals nationwide don't have a palliative care program and one-third of our City hospitals lack a palliative care program and most Americans who've lived with multiple distressing symptoms for years before they access palliative care, if indeed the access it at all. Our national estimates are that about 1.5% of hospital discharges actually had access to palliative care.

So in order to enhance palliative care's availability and ensure access to the highest quality healthcare, I would respectfully recommend a few key initiatives. First, workforce initiatives can ensure sufficient number of specialists to effectively provide high quality palliative care. Second, research initiatives can augment the currently inadequate knowledge or evidence base in order to ensure that we can treat symptoms such as pain and breathlessness as rigorously and scientifically as we treat diseases such as diabetes. Finally, there needs to be educational initiatives to increase awareness both in the public and healthcare professions of the benefits of palliative care in the setting of a serious illness and the difference between palliative care and end of life care. Palliative care should be a right for all of our citizens. It should be something that they don’t have to ask for, that it’s just as accessible as every other part of healthcare.

It’s specifically to this latter goal that I would address the Council’s attention. A major barrier to the continued growth of palliative care is the perception that palliative care is synonymous with end of life care, care of the dying or most distressingly, an alternative to curative or life-prolonging treatments. This inhibition inhibits access to palliative care early in the course of the illness, when patients and families can benefit greatly from services that palliative care programs provide. Consequently, we need to increase public and professional awareness about the important role that palliative care can play in our healthcare system. Such education would have a major impact on improving care for New York’s most vulnerable citizens.

In closing, let me thank you once again for the privilege of addressing this Council. Too often my patients and families ask me why they didn’t know about palliative care earlier and why they suffered so much before they met our palliative care team. With your help, we can ensure that no patient asks such a question again and that no family feels alone in their struggle with a serious and life threatening illness. Thank you very much.

CHAIRPERSON ARROYO: Thank you, Dr. Morrison. I have two questions and then we’ll turn it over to my co-chair and colleagues, but first I want to acknowledge we’ve been joined by Council Member Eugene, a member of the Committee on Aging; Council Member Vacca, also a member of the Committee on Aging; and Council Member Dickens, who is a member of the Committee on Health.

I may not have listened to the definitions of palliative care and end of life care. And obviously at the end of your testimony, Doctor, you make a very clear distinction. What are they?

SEAN MORRISON: Let me start with what palliative care is. Palliative care is team-based care focused on improving quality of life for patients living with serious illness, and their families. It's directed at addressing distressing symptoms such as pain, nausea, shortness of breath; facilitating communication between patients and families and their healthcare professionals; and improving transitions and coordinating care across a fragmented healthcare system in the setting of a serious illness. And it is provided to all patients with serious illness, regardless of their prognosis. So in fact many of the patients that I take care of have months, years, and in some cases many years to live.

End of life care makes the erroneous assumption that we can identify when people are at the end of their life and when they are dying. And as a physician, I'm really good at that, but I'm really good at that somewhere between 48 hours and three weeks prior to death. Most of my patients who are living with a serious illness have an unpredictable prognosis. Somebody I’m taking care of right now, a year ago with my best scientific judgment, I thought she had four to six moths to live and we’re still talking right now. And so if I thought about her as end of life care or dying, you know, a lot of people don’t get access to care.

The other thing and the other major barrier is it requires that we target a group of people and ask them to self-identify them as dying. That’s wrong. Because then what we’re doing is we’re saying to a group of people, you are very, very special, we have a separate system of care for you and you might have to give something up. In reality what palliative care does is says you can have the best, most accessible care. You will be comfortable. You will get treatment that is based upon your goals and your wishes, and you know what? You don’t have to say that you’re dying. That is a critical distinction, but it’s based upon patient and family need, not an arbitrary prognosis or an arbitrary time left to live. You shouldn't have to say, I only have six months to live to be comfortable.

CHAIRPERSON ARROYO: Thank you for that, Doctor. It certainly helps me understand it better. When we talk about either or and we look at insurance coverage, what does or doesn't insurance cover for either point or either category of patient. Does anyone here know?

SEAN MORRISON: In the United States there is one formalized system for coverage, and that is the Medicare Hospice Benefit. That is a fabulous benefit. It's unique actually in western healthcare systems. But in order to access the hospice benefit, two things have to happen. One is a physician needs to certify that you have six months or less to live, and we've already talked about how difficult that is. And as a patient and a family you need to state that you are willing to relinquish your traditional Medicare Part A or the right to be in a hospital, or to have expensive curative treatment. Now that's appropriate for people right at the end of their lives, and in fact we have in New York City some of the best hospice programs in the nation, but it is for a very select group of people. It is a benefit and people should elect that benefit when hospice meets their needs and goals.

How is non-hospice palliative care reimbursed? Right now I can bill as a physician for my services, so when I go to make a house call or a home visit and see somebody, I can bill Medicare or traditional third party payers and get my physician fee. My team, however, doesn’t get reimbursed for it. So how are palliative care teams developed in this country? They are primarily hospital-based, and so the hospital pays or funds the development of a team—for several reasons. One is it improves hospital quality, that palliative care teams in hospitals improve the care that they deliver. Number two is that they are associated with tremendously high patient and family satisfaction. For example, family members of people cared for from my palliative care team at Mt. Sinai are more satisfied than new moms who leave our obstetrics unit. So think about that. Families of people with the worse possible diseases are more satisfied than our new moms. So it improves family satisfaction. And the third piece is it improves hospital efficiency, because it identifies patients goals and matches treatment to those goals. And so what it does is it helps eliminate the mismatch between what patients want and oftentimes what we just do because it’s routine. And in any system which truly becomes patient-centered and matches treatments to goals, that improves efficiency. So that’s why hospitals are supporting the development of palliative care teams, but nationally we don’t have a separate reimbursement system for palliative care.

CHAIRPERSON ARROYO: It relies on the judgment and the planning of a hospital to determine whether or not that institution will offer those services to patients who would have better outcomes. And in your testimony you indicate that a third of our city hospitals, both public and private, are not in that universe right now.

SEAN MORRISON: That is correct. I could rephrase that, however and say that 70% are in that universe, but you are correct, one in three don't. I think what we've seen is we've seen a growth nationally of 5% eight years ago to over 50% now and a similar tremendous growth in New York City. But you're right; we still have 30% to go.

I think one of the things as a non-HHC employee that gives me a tremendous amount of satisfaction is that when we look at the major hospital systems throughout the United States, the prevalence of palliative care programs in municipal hospitals is around 10% to 20%. And the fact that HHC has led this as a major initiative is really sort of a beacon to other, and a model for other cities in the United States.

CHAIRPERSON ARROYO: I can go on the rest of the afternoon, but I know that my colleagues and my Co-Chair have a lot of questions. I'm going to stop.

CHAIRPERSON RIVERA: Thank you very much, Maria. I just have a couple of questions for HHC. What is the total HHC budget that is set aside for palliative care?

ERIC MANHEIMER: It's almost a $7

billion budget and the current—I think I mentioned that they spend approximately $3 million allocated towards developing programs. Actually we have programs in all the 11 hospitals and in many of the nursing homes at this point. We have about 3,000 nursing home beds.

CHAIRPERSON RIVERA: Yeah, but for palliative care.

ERIC MANHEIMER: Palliative care, several million dollars.

CHAIRPERSON RIVERA: Several million dollars.

ERIC MANHEIMER: Several million, yes. So HHC is allocated from Central Office and then each institution is allocated additional funds separately to keep the programs going or to add to them. As is mentioned, it’s a multi-disciplinary team. So when you add in that there is physician involvement and social work involvement and there’s case management involvement, you know, chaplain involvement, etcetera, it starts to mount up.

CHAIRPERSON RIVERA: Now if you had to identify a cost per patient, what would the cost per patient—

ERIC MANHEIMER: [Interposing] Really hard to say. Because it depends. Bellevue for example, we have 30,000 discharges. We have 450,000 outpatient visits. I think what's relative is we have a palliative care team, off the top of my head, which probably costs us about $400,000 a year, or $500,000 a year, and then they see approximately 400 patients a year. So if you do that kind of arithmetic, but they see them multiple times. So it would give you some sense. But some of it—yeah, I think that would be the most appropriate way to think about it.

CHAIRPERSON RIVERA: Okay. In terms of you stated in your testimony that there's not dedicated funding from Medicaid or Medicare for this, there's no—

ERIC MANHEIMER: [Interposing] Exactly. I think other—

CHAIRPERSON RIVERA: [Interposing] Is there a reimbursement rate?

ERIC MANHEIMER: No, there really isn't. And I think what this—there is no specific reimbursement rate for this except through the hospice option, and physicians seeing the patient and then billing it. But really, it’s really an add-on cost to a facility and the facility has to decide that it’s in the best interest of the patient population and the facility to provide the service.

I just want to make one comment. Given the healthcare costs in the country and given the issues, there’s never going to be enough palliative care people on these teams to treat all of the patients, particularly if we extend it from end of life care and say it’s everybody with chronic disease. It simply is not going to happen. And I’m a physician; I’ve been a physician for 30 years. The challenge for palliative care is to disseminate the message so that every provider—you don’t need necessarily a palliative care consult. Medicine is already overspecialized; it’s one of the major reasons why it’s too fragmented. The last thing we need is, I can’t take care of palliative care. Imagine you’re a general internist. I need a gynecologist to take care of the women’s health; I need a gerontologist to take of anybody over 65; I need an emergency room specialist; I need a hospitalist for inpatient care—I mean now everybody will need eight physicians. So the key issue for palliative care is to normalize the palliative care throughout the healthcare industry.

So at Bellevue and at HHC we're working to make palliative care routine care, whoever is providing the care. We don't want it to just be end of life or chronic disease, you need a specialist. Because already then what you're doing to patients, you will then ultimately divide up their care. What's happened with palliative care is because it's so powerful it's changing the culture of care in hospitals, and that's why it's so powerful. That's why hospitals are investing. Now you're having a complete patient and family focused environment. There will never be enough specialists and there shouldn't be.

CHAIRPERSON RIVERA: That was actually going to be my subsequent question, what type of training does an individual go through? Who does the training? Is it done in the medical school itself?

ERIC MANHEIMER: These are great questions. You know, the way it works formally is that New York City has been at the forefront of palliative care and Mt. Sinai has been the forefront of palliative care in the United States. Diane Meyer, who is the head of palliative care there is a world-renowned authority on palliative care in the country, and she has trained some of the key individuals who have gone on and trained other people. And she’s an absolutely extraordinary individual. She’s won the McArthur Genius Award; she’s phenomenal. So out of her energy and enthusiasm and I think mission-driven idea, as well as other people—but I’m just saying we have her here in New York and Dr. Morrison is in that hospital, which is phenomenal. I mean that’s widely recognized as the best. There have been developed models that are very well written and developed of how to develop these programs. And they’ve gone on to develop training programs which are now propagating around the country. So most medical schools have developed palliative care and have some rudiments of palliative care articulated parts of their curriculum, although most of them I’d say are fairly rudimentary and not sufficient to train this generation of palliative care-trained, educated, physicians. I’m a professor at the NYU School of Medicine and I have to say our curriculum—we’re developing it, we’re infiltrating it, we’re trying to make it more meaningful. And we have lots of students rotating through our palliative care rotations. So that is an ongoing challenge.

Yes, so there are formal fellowships that train individuals to be specialized and get their Boards in palliative care medicine, so to speak, and then go on to train other individuals. But the key fact, what I’m trying to say is, this is a vast interdisciplinary process and it’s disseminating it through nursing and social work and case management and the chaplains, so it becomes completely routine care.

CHAIRPERSON RIVERA: That makes sense. I can also, like my colleague go on and on on this, but I want to give an opportunity to my colleagues because we have a couple of them that want to ask questions. Council Member Gale Brewer first, then Council Member Sears, then Council Member Vacca.

COUNCIL MEMBER BREWER: Thank you. I have laryngitis. It’s okay. I’ve been talking all day and all night. Sick paid leave. Anyway, my question is on the education front, because Dr. Morrison mentioned that as a challenge. So, I understand that it should be routine in the hospitals, but how would you tell the community-based organizations, how would you make it available as a normative that people understand this is something that really is mainstream and part of healthcare? So how would you, because this City is so big, so wonderfully culturally diverse, it’s hard to get education out. So I’m just wondering as health professional how you can do that and how we can work with you? This morning and—this morning with all the providers of seniors services in my district--because we were talking about bed bugs, my favorite topic--but the fact of the matter is, they are very concerned, how would they for instance get all this information? Go ahead.

SEAN MORRISON: I think that’s a

very important question. I think the way that I think about this; this is a public health issue. This is a public health issue that not only affects patients, as we look at the number of people who are developing serious and chronic illness, but it is a public health issue that addresses caregivers, people like me who have young children and older parents, or an older parent, who are faced with the challenge of taking care of both of those populations. And it is an issue that affects not only our healthcare institutions but also our fundamental aspect of employment, that if you have to take a day off work to care for a seriously ill relative—

COUNCIL MEMBER BREWER: [Interposing] Don’t bring that up in this topic right now, please.

SEAN MORRISON: That’s not—

COUNCIL MEMBER BREWER: [Interposing] You just made my day. Keep talking.

SEAN MORRISON: I look at this as a public health issue.

COUNCIL MEMBER BREWER: You made my day.

SEAN MORRISON: And so the question—

COUNCIL MEMBER BREWER: [Interposing] Everybody’s listening. Go ahead.

SEAN MORRISON: So the question that I think about is what have been the successful public health initiatives that both the City and the nation have embarked on to address issues that go beyond simply hospitals and physicians? Smoking. Think about what we have done as a city in terms of addressing the issue of smoking. Obesity; transfats, exercise. And I think that is the type of message that I would see related to this particular topic. We don’t necessarily have to call it palliative care, but the idea that you should have accessible, affordable care in the setting of a serious illness that maximizes your quality of life, enhances your function, preserves your independence and takes care of your family. That to me is a public health issue and I think that is the message that could be put out, the same way that we’ve done with smoking cessation and the same way we’ve done with obesity.

COUNCIL MEMBER BREWER: And my other question is on the national level—I have not read the 1,000-page—but is there anything in there that would help with the funding in terms of insurance?

SEAN MORRISON: There are a number of initiatives, not quite as many as—you know, putting my national hat on—that I would hope to see. But there are a number of initiatives both in the Blumenauer House Bill and in both the Senate Finance and the Senate Health Bills that address both training of palliative care professionals, that address some aspects of education, and also that address some issues of access.

I think one of the dangers that we saw this summer is when we equate palliative care with end of life care, then people automatically worry about rationing, and I think we all lived through the death panel issues, and I think that's a mistake. It's not about end of life care, it's about providing appropriate care to all citizens. And so the issue about advance care planning got dropped, but there are also some important issues that are still in those bills.

COUNCIL MEMBER BREWER: And my last question, Lilliam, is when you talked about those three aspects that, you know, we are supposed to have in terms of Do Not Resuscitate, proxies and so on, you mentioned that the State of New York does not have Living Will. Is that something that we should be legislating? If we’re one of the few states that does not.

LILLIAM BARRIOS-PAOLI: I think so. I mean I think that part of what we have to do in the legislative agenda is sort of be in to validate any instrument that allows people to plan for the kind of healthcare that they want, and the kind of things that they envision for themselves towards the end of life. I think probably the MOLST is the most efficient tool, the tool that enables you to tell a doctor what it is that you want. When that doctor then makes it into a medical order, that’s binding another physician. What happens right now with living wills and advance directives and DNRs is that many a time they get lost in the shuffle. And, you know, you’re taken to an emergency in an emergency situation, the provider there doesn’t know it, it doesn’t necessarily take effect. So I think that we have to find ways where whatever it is that people want for their own care, you know, it’s legally binding on the practitioners.

COUNCIL MEMBER BREWER: We should work on that. Thank you very much.

CHAIRPERSON ARROYO: Thank you, Council Member Brewer. I have a follow up question on the—your testimony, Commissioner Paoli. You spoke about the medical orders for life sustaining treatment program, an initiative that started in the state in 2005. Is that intended to take the place of the living will and where does that get initiated, if a patient is in a position where they need to have this conversation?

LILLIAM BARRIOS-PAOLI: Yes. It does not take the place of a living will, and maybe you can talk to the MOLST more efficiently than I.

SEAN MORRISON: So, the physician’s orders for life-sustaining treatment or medical orders of life-sustaining treatment are a means by which conversations between doctors and patients about their goals are actually operationalized into physician’s orders. So for example, if I’m living in a nursing home and I would not want to be transferred to the hospital, this is my home, I’d like to be treated in the nursing home. What happens in the middle of the night all too often is there’s somebody there who doesn’t know me. They don’t know my wishes, they don’t know what I would want, and I get very sick. And so the routine is to call 911, put this patient on an ambulance and transfer them over to the nursing home. If somebody has a MOLST order that says in the setting of an acute infection, please do not transfer me to the hospital, that’s a physician’s order that has to legally be followed, and it’s very different from an expressed preference. So what the MOLST orders do is to allow people to state their values and goals and agree to treatments that they want, and many people elect to have life-prolonging curative treatments, but also to allow people to select treatments that they don’t want. And unlike a living will, that is actually translated into a physician order and are followed by both the emergency medical services, the nursing homes and the hospitals. So what could really help prevent, for example, unwanted admissions, unwanted emergency department visits, is for every person who leaves the hospital to have a MOLST order before they to a long-term care institution. Every person who comes in to a long-term care institution should have the opportunity to discuss their wishes and to select and help with their physician, you know, on a one-on-one basis to help select the treatments that meet their goals, rather than having them arbitrarily decided by somebody else. And that's all too often what happens to my patients, is that what they get is decided by who's at the end of the phone in the middle of the night rather than what they want or what their families have said that they want.

CHAIRPERSON ARROYO: Well we certainly need to follow up conversation about how we make this information available to the public. It's the first I've heard of it. I'm not the smartest or the sharpest knife in the drawer, but, given my background I should have heard about this.

LILLIAM BARRIOS-PAOLI: And that’s why I think it’s so important, especially with the elderly. For them to, they and their caregivers, to understand all of the availability of things that are out there and what options they have. Because I think that that—my experience in the healthcare system, no matter how knowledgeable you should be or you may be, is that at the point of the emergency, it’s a very disempowering experience.

CHAIRPERSON ARROYO: Absolutely. Council Member Sears?

COUNCIL MEMBER SEARS: Thank you very much. You know, every day the face of quality healthcare changes where you keep up with technology and everything else. One time, and not too long ago, there was such a thing as clinics for pain management, and that was chronic pain, which is very debilitating and ultimately leads to the demise of the patient. And you stated that the—for your teams, it’s only the hospital where they train and get paid for that. Has pain management been reimbursed by the insurance carriers? Do they? Anyone can answer that.

Because the reason for that question, and I may not be phrasing it quite properly, is that pain management, there's been a very heavy concentration on that so that people can have, manage their own healthcare. That's what it's all about. And for the lack of a living will, which I do have and a healthcare proxy and so on, it's to control your own healthcare, for the patient to be more knowledgeable about what their situation is. And that is a focus--it seems that palliative care is encompassing very strong pain management; patient care, attention, managing their own healthcare; and encompassing the family. So it seems it's broken down into many areas where we've had pockets of this concentration over a period of time with the changing of healthcare. I think that's what I'm really trying to ask you. So where does this all fit in?

ERIC MANHEIMER: I think your set of questions gets to the heart of our healthcare system and its fragmentation. It's an excellent question. A couple of things. Pain—let me just address your initial point. Pain management is part and parcel of every sophisticated healthcare system and hospital. New York has some of the best healthcare in the United States and all the hospitals have pain management programs and they're reimbursed through the usual payers. Most pain management programs are run by anesthesiologists and they have fairly formal training, and they're excellent.

I have to say that my experience, and I think this is true of most palliative care people, they cannot address well enough a lot of the problems that palliative care people deal with, so end of life pain kinds of issues, pain that people have with cancer and other kinds of issues. And palliative care folks have better ways of dealing with this and, let me tell you, they complement formal pain management programs. They're not competing for them, but they're complementary.

And I think what we see is a lot of our patients who end up in traditional pain management program run by anesthesiologists and--this is not to impugn them at all--don't get satisfied and don't good treatment. But they'll do very well—because what happens is a lot of these patients need fairly unconventional kinds of treatments, fairly—treatments that can be adapted better to them, and people are going to follow them closely. So that in fact so what we've seen, interestingly enough, we get called from the cancer center—so NYU, just to give you an example, a very sophisticated, excellent, formal pain management program. The NYU Cancer Center, which is extraordinary, on 34th Street and 3rd, we get called from Bellevue to do consults on them, our palliative care team, all the time, in preference to the traditional program, because it's simply another area of knowledge in dealing with these patients that isn't formally part of a traditional pain service.

So you end up providing a lot of care which falls in between these, what's become, I think I alluded to in my initial point, we've become so over specialized in medicine, the gray areas become where patients just fall through the cracks. And then with primary care essentially withering away—primary care is withering away. So who is ultimately responsible for the patient?

You end up with a ten-doctor thing. If you're in New York and you need a doctor after 5:00, you've got a serious problem. And to find a primary care doctor who can stay with you and manage these series of specialized—and if you look at the data that comes out of Dartmouth, we are so over specialized and so over consulted in the City compared to other places it's frightening.

One of the things palliative care does is it takes a thread through all of these things and pulls them together. And I have to say one thing. You know, we talk about getting advance directives and everything else. You know, people in these situations are vulnerable and they're not always able to make those decisions; they need their families. The people we see at Bellevue, they don't have families. The woman I saw this morning was a Guatemalan woman who made it out of the civil war and the Mara Salvatrucha from Guatemala through Tapachula, to the states. She doesn't have a family. And she and her husband are waiting for a heart transplant. We're seeing them on our palliative care service. But how is she going to make a decision? She's got two kids and she is vulnerable on every social vulnerability scale. She needs assistance and support that we can provide her.

So, you know, we have 1.2 million separate patients that we saw at the public hospital system, 600,000 of which are in this extraordinarily vulnerable group. So they don’t have the levels of support remotely that what could constitute, you know, your kids and your family and multi-generational taking care of each other. It doesn’t exist.

COUNCIL MEMBER SEARS: It’s interesting what you say about primary care, because in 2006 this Council issued a report, and its findings, the major one, was that we needed to develop more primary care facilities and to identify those areas that were so under served and that these primary care facilities—as a matter of fact I think we do have money in the Council—to really look at establishing three of them; and that will be a while to do that. Because it seems that with primary care facilities we would be able to take this fragmentation and really somehow make it a more cohesive unit for education, for identifying and then the treatment as well. Thank you for answering my question. Thank you very much.

ERIC MANHEIMER: You're welcome. Thank you very much.

CHAIRPERSON ARROYO: Council Member Vacca and then Council Member Dickens.

COUNCIL MEMBER VACCA: I thank you Madam Chair and Chairman Joel Rivera. I'm a little familiar with—we have a Madam Chair and a Mr. Chair, so I don't know what to say--from the Bronx, my colleagues from the Bronx.

I'm a little familiar with palliative care and I have to raise some questions. First of all my understanding always with palliative care is for people who are living long term with pain issues, sometimes mental health issues but mostly pain issues. Am I correct that palliative care means people who are not terminally ill but who have long term chronic issues and it revolves around pain?

SEAN MORRISON: No. Let me rephrase that—you're partially correct. It's focused on people living with serious and life-limiting illness, and their families, who have distressing symptoms, and that goes well beyond pain. So it could be pain. It could be shortness of breath. It could be fatigue. It could be difficulty with eating and drinking. Also it also takes care of people in families who also have needs, so people who are having trouble with care giving. And indeed it does extend into some mental health issues. So it’s much more than pain. In fact often times pain is a high symptom but we see people with many, many other distressing symptoms, often three, four or five.

COUNCIL MEMBER VACCA: Well that’s was a point I wanted to make, is that many people with pain have other issues that are contributing their coping with the pain or their level of pain. And many seniors are concerned when it comes to palliative care and their pain management, many seniors do not want to take large amounts of medicine. They’re already on large amounts of medicine for other things and when it comes to pain reduction, they’re worried about side effects. Many seniors want to continue to drive a car and with the pain medicine they feel they cannot. Many seniors also have medicine that they take that does not allow them to take the Advil or the anti-inflammatories if they’re on certain blood thinners or they’re on other things. So my question is, what are we doing about alternatives? Do you espouse alternatives to medication? Do you espouse the non-traditional? Or is that something that you may not because you’re in a position where…? Tell me about that.

SEAN MORRISON: I think your question really has three answers to it. The first is that I espouse the best scientifically available evidence to treat somebody’s symptoms. And oftentimes older adults have very important misconceptions about the effectiveness of pain management and our ability to treat the side effects associated with medications. Your example about somebody driving a car, what I see much too frequently is somebody coming in to my office who, because of bad pain in their joints or their heart disease, doesn’t do anything. It just hurts too much to go somewhere. So first of all, optimizing available scientifically valid treatments, like we would for any other disease, diabetes, heart disease, lung disease.

Number two is that there are very effective complementary therapies that work, and we should be using them when they work and we should be using them in conjunction with pharmacological therapies.

And the third piece that I advocate very, very strongly is that we need more research dollars at the national level so that we have more than two choices for the treatment of somebody’s pain, so that we don’t just have medications that have bad side effects with them, we don’t have medications that you can’t take because you’re on blood thinner. If this was diabetes, if this was high blood pressure, imagine the uproar if you said, well we can’t treat your high blood pressure because all the medicines we have have bad side effects and they all interfere with something else; we can’t use insulin because it has bad side effects and it’s going to interact with your blood thinners. I just think that it’s unacceptable that we think about people having to live in pain on a daily basis and we don’t put research money into it. So that’s the third part, the third answer to your question.

COUNCIL MEMBER VACCA: I could not agree more. And I have to tell you, the more you walk around or even drive, but really walking and you see people in the streets, so many people of different ages are with walkers, with canes. I see more and more of this. I remember as a kid being told, my mother is 80 years old and she only has arthritis. Well you live with only arthritis. Arthritis is not an only type thing; it's often crippling to people. So I'm concerned that we do something, if research is the answer.

But like I say, many of our older people do not know about what is available, the alternatives to the medication that will knock you out and give you only a temporary type of relief. I have an 84-year-old man I know. And he's finally going to physical therapy. He thought it wouldn't work for him, but the physical therapy is giving him some relief and he's happy with the relief he's getting, it's much better than it was before; it did not ease everything. But people are always asking about supplements, MSM and the glucosamine. People are desperate for answers.

So I appreciate what you’re doing and I see that the City is doing something, but I think we have to do more, because people are living this way into their 80s and 90s with these types of debilitating problems.

ERIC MANHEIMER: Can I just mention a little—I’m a firm believer in different kinds of medicine to add to what physicians have—scientific medicine, allopathic medicine unfortunately does not train most of the physician workforce in non-traditional things. And if medicines fail, doctors usually don’t know what to do at that point. And there are a huge range of different types of alternative providers that can provide a huge amount of relief to people’s suffering. Deconditioning is a gigantic problem; having somebody come to the home and do different kinds of exercises with patients, a whole variety of things, can relieve a gigantic amount of distress. A lot of the distress people have is anxiety, mild depression, that actually don’t need to just prescribe another medication for. So I would say that this is a complete other area that is very, very undeveloped in traditional medical education and remains so. It may get worse, actually, because there's a focus on other things.

COUNCIL MEMBER VACCA: Part of it, if I may conclude, is that many seniors don't know when to identify to depression. They do not know that they are depressed and they don't know the symptoms and they don't believe; and they may not be depressed as you and I know depressed, so they don't know to identify it. And you know, that concerns me about seniors, but I think the pain management does also, so. Commissioner?

LILLIAM BARRIOS-PAOLI: I think that that's an area that we definitely need to address and are trying to address, and that's the issue of mental health and helping seniors with mental health issues in mental health centers, in NORCs, and even the homebound seniors. I think depression and being older very many times go hand in hand and goes tremendously under recognized. And I think we need to find a better way of dealing with it. A lot of the time it's loss, you know, a lot of people around you are dying and you don't know how to cope with that loss. You know, not having a lot of family connections, many people worked for 50 years, retired, are now 75 and don’t know what to do with themselves. So there are a lot of different components to it. Group work, which happens in many senior centers, is not the best way sometimes. You know, people don’t necessarily want to bear their soul in front of 17 other people. So we have to find a better way of doing this.

Some programs that we have like Lincoln Square, and I know that Councilwoman Brewer knows this, has an agreement with St. Luke’s Roosevelt in which they have a rotation of psychiatry residents that go to the NORC, I think it’s two or three times a week, and meet with individual patients and see them and work with them. And it’s been incredibly successful. So we have to find better ways of connecting with the mental health community to provide mental health services in senior centers and for the seniors.

COUNCIL MEMBER VACCA: I agree. And Commissioner, part of this has to be a sensitivity of physicians.

LILLIAM BARRIOS-PAOLI: Yes.

COUNCIL MEMBER VACCA: Too many

times I hear about physicians who see elderly people in their 80s and they elderly person will let them know about their conditions and the doctor says, oh, for your age you’re doing great and you shouldn’t—what do you mean, for you’re age you’re doing great?

LILLIAM BARRIOS-PAOLI: You don’t have to be 80. I had that happen to me last week. It’s your age.

COUNCIL MEMBER VACCA: Yes, it’s your age. When doctors see an older person and the older persons says certain things, many times they are dismissed. They’re told to go home and take Tylenol or something. I hear this very often. I send people who told me that to a different—I said go see someone different and get a second opinion because—

COUNCIL MEMBER BREWER: [Interposing] Jimmy, go to these two doctors. Send them to these two doctors.

COUNCIL MEMBER VACCA: I will. Because I think many of our elderly people are being dismissed out of hand. And they should not have to live that way or be treated that way.

They should have every expectation of living through their 80s and 90s and they should have a quality of life. And so I do think there's an aspect of our education concerning palliative care that has to relate to physician education and physician inclusion in our strategy. Thank you.

CHAIRPERSON ARROYO: Thank you, Council Member. We've been joined by Council Members Mendez and Ferreras. Mendes from Manhattan, Ferreras from Queens. And we have Council Member Dickens who has a question or some questions.

COUNCIL MEMBER DICKENS: Thank you. Thank you, Chairs. Pardon me for my lateness, because I had another hearing. But this is so important. Basic question, palliative care, is it research? Is it advocacy? Who pays for it? Where is it available? How can a person access it? I mean these are basic questions I have. What is it? Maybe I don't understand.

ERIC MANHEIMER: I'll give a short answer and I think Dr. Morrison is really an expert in this area. But, you know, palliative care is a field that in US medicine now is really has about a, you know, 15 year, 20 year history. But it’s really coming into its maturity now. It’s evolving into a very mature discipline that is becoming increasingly widespread in all the major cities, all the major academic centers and disseminating itself. So it was sort of in embryonic form say 20 years ago and its really coming into its full adolescent immaturity at this point and it probably within the next 15 to 20 years will become standardized and infiltrate all of the hospitals and be required. It’s usually sort of these phases.

What you’re seeing now is the field is incredibly creative. It’s attracting very talented young physicians into it because it’s so interesting and exciting. Part of it is the demographics are changing. Part of it is doctors are seeing that their parents are aging. You know, that’s how people make decisions. Unfortunately, the payment system in the country— we know that the way it is, it’s very difficult and complex. It doesn’t reward these kinds of fields like it doesn’t reward primary care medicine, like Ms. Sears and I were chatting about. So unfortunately at the same time we’re seeing palliative sort of coming into its own—it has a research agenda—it needs more funding but it has a research agenda, it’s attracting wonderful people in to it—we’re seeing other forces which are really concerning. We’re losing; we’re becoming more fragmented, not less. There are not more people going into primary care, there are less and less. You know, every year—I’m a general internist. Ever year you’re seeing less and less people attracted into it. You graduate with a debt of $150,000, $200,000 you’re not going into general internal medicine; you’ve got two kids, etcetera, etcetera.

So what we’re seeing is, you know, some force moving in one direction, other forces moving into another. But palliative care is going to change, have significant impact on the way medicine is delivered in hospitals. It’s generally a hospital-based discipline, although it certainly extends into ambulatory care and into homes, but generally speaking now it’s where these nurturing training institutes are happening, both at Mt. Sinai—which has really been the fountain for the United States in starting the movement. SO really New York is really the leader because primarily because of that.

COUNCIL MEMBER DICKENS: I appreciate that, but pardon my ignorance, does that mean that at least at this stage it’s more advocacy and research? The reason that I ask is that I want to know how is it accessed for a patient, say that is getting ready to come out of a high impact rehab center such as say Burke [phonetic] or something, and now has to go into the secondary? Is that where palliative care kicks in where they can get some help and understanding? Or when they go into the secondary rehab, where at that skilled nursing setting it’s two parts, it’s the long term and it’s the short term? Where does it come in to play for the patient? That’s what I’m trying to ask.

ERIC MANHEIMER: There’s no one answer. I think in general—I’ll make a broad generalization and ask Dr. Morrison to comment. I mean in general when a patient is in an acute care setting and they have something bad happening or if they’re referred to an outpatient palliative care program, that’s where they access the program in general. So if you entered one of the hospitals here and you were diagnosed with—say you had, just say emphysema, you know, you got hospitalized; then they might call in a palliative care team to assist with your management, the pain the dyspnea, some of the issues, and then you might stay with that program. So that’s the usual entry point. One other might be you see a primary care doctor and he’s - - at Mt. Sinai or our place and he says, gee, you know you might benefit from a consult with palliative care. But it’s going to vary. The Burke may not have—I don’t know, it’s a wonderful institution—

COUNCIL MEMBER DICKENS: [Interposing] I just used that as an example.

ERIC MANHEIMER: But they may not, I’m just saying let’s say they don’t have a palliative care program that they developed yet, so it simply wouldn’t exist. Now if they have it, yes, then you could enter in to it.

COUNCIL MEMBER DICKENS: For instance you come out of an acute, you’re at an acute care facility then, you had a stroke, not cancer, a stroke where the type of stroke is so severe that you will not regain mobility say on one total left side or right side. Now would palliative care give you assistance at the acute care facility prior to being transferred to a rehab, high-impact rehab?

ERIC MANHEIMER: Yes.

COUNCIL MEMBER DICKENS: That's where it comes in?

ERIC MANHEIMER: Correct.

COUNCIL MEMBER DICKENS: I just needed to understand. And insurance pays for this? And when I say insurance, private, Medicare or Medicaid or all three?

ERIC MANHEIMER: For the physician seeing you, but not for the rest of the team.

COUNCIL MEMBER DICKENS: But not for the rest of the team.

ERIC MANHEIMER: Correct.

COUNCIL MEMBER DICKENS: Just for the physician. All right. You've answered my question. Thank you so much.

CHAIRPERSON ARROYO: Thank you, Council Member Dickens. And you know, where you see all this conversation back and forth here, we’re not being disrespectful, we’re just strategizing on how we’re doing to do whatever.

The next question is, what can we do? The insurance doesn’t reimburse for it. Hospitals are obviously doing it and the money’s just not there for them to do more. And my co-Chair will talk a little bit about next steps for us to have, you know, more conversations we need to have. So I just wanted to explain the activity that’s going on here. Okay.

CHAIRPERSON RIVERA: Actually I just wanted to also state the same thing. Whenever you see us chatting it’s because we have, you know, great ideas and we’re looking at what are the next steps in terms of initiatives, looking back at other things we’ve done in the past like infant mortality, to see how we can possibly push something forward for you.

I just had a follow up question in terms of, you know, the national health debate now in terms of healthcare in the United States of America, is this a part of that debate? Is there lobbying taking place in congress to see if there can be dedicated dollars for this type of service or is there no action on this issue in congress?

SEAN MORRISON: There is some. And I think this comes back to the question of advocacy. And I’m going to put my physician hat on just for a moment; there are millions of Americans out there who could benefit from palliative care, but what I hear over and over again from my families is, the system can’t be this bad, what am I doing wrong. And I must admit, if I hear that one more time from a family member who feels like they’re doing something wrong because the system’s not working for them, I’m going to explode.

So what can be done? I think there’s a couple of things. One is patients and families need to recognize that it is not their fault that they can’t make the system work in the setting of serious illness. Number two is they need to start demanding palliative care when they need it. And it really is, I think, behooves us as healthcare professionals to start letting our patients and families know that there is a better way and that we can provide it. We also need to educate our healthcare professionals about that so that in my institution, which you know has been described as a leader in palliative care, there are people who come into my institution and don’t get it because their doctor doesn’t refer. So we need to begin to address that with physicians.

If we do that, I’m enough of an optimist to believe we really can change the reimbursement system at the federal level, because there is a constituency that is going to ask for appropriate healthcare. When you think about the fact that 67% of Medicare dollars go to the 10% of people with the most serious illness, the palliative care population, if we were to provide better care to these people, we could do a huge amount in terms of reducing the enormous expenditures in Medicare. And what would that do? That would allow us to have more dollars in the system for the preventive care that we’ve been asking for. It’s more dollars in the system for the homecare needs; it’s a much better and efficient system.

So what can we do? We can target patients and families so that they don’t feel that they're alone. We can target healthcare professionals and we can begin to speak about the need for reimbursement.

CHAIRPERSON ARROYO: I just want to acknowledge that Council Member Stewart, a member of the Committee on Aging has checked in. He's upstairs chairing another hearing on the 16th Floor, so could not sit with us.

Commissioner Paoli, we had a whole big brouhaha about the Age Friendly New York and all this blueprint stuff for this city being a better place to live for older New Yorkers. And there are 59 initiatives that are included in that. Any of those target this palliative care—

LILLIAM BARRIOS-PAOLI: [Interposing] Yes.

CHAIRPERSON ARROYO: --and are there any discussions in the administration to see how we can put funding into our healthcare system to do all of the things that need to be done; train the medical staff to—because as a healthcare administrator I remember that the issues that really got addressed very quickly were the ones that the medical staff got behind, especially when they had the Doctors Council at the table having that conversation.

LILLIAM BARRIOS-PAOLI: I think today, you know, in the conference that we had, HHC made a very clear commitment to palliative care and I think Dr. Alan Aviles [phonetic] was the one that was articulating that. He’s a profound believer in it and I think he will increase the number of hospitals—I mean they all participate now—but the intensity of the participation. What we want to do, from the seniors point of view, is increase awareness about palliative care, what it is, and begin to have education and conversations with seniors on how to do that. And we’re talking with two different groups to do that. We’re talking to—we’re definitely talking to Dr. Morrison and Dr. Meyer at Mt. Sinai about how to go about it. And they have a Speakers Bureau and we’ll work with that.

We’re also working with a group that is called the Health Chaplaincies. One of the things that I really profoundly believe is that many of our seniors articulate the need for spirituality in their life, not religion, spirituality. And I think—I understand that. I mean I said this morning that, you know, when you get to be a certain age that you realize that there are a lot of things that you will not do, you start questioning, well, the things that I have done, do they have any meaning? And what does it all mean, right? And spirituality becomes increasingly more important. I think that the people that can really have the conversation with seniors about palliative care and end of life are people who are seen as spiritual people and people who understand that other dimension. Yes, healthcare providers, yes people that are in the Speaker - - but people who bring that other dimension. So part of the conversation with the Chaplaincy, who embraces 30 different religions, is can we use their providers as a medium to explain and work with seniors around having these more difficult conversations.

You know one of the things I think is clear, and it was said this morning, is that we live in a culture of denial about death and even about illness. They quoted Woody Allen saying that he feels comfortable with death it’s just that he doesn’t want to be there when it happens. You know, it’s a difficult conversation and I think we have to sort of bring it to a different level with different actors to make it possible to happen.

So, yes, and I think we’re very committed. To me it’s an issue of empowering seniors. I think that I’ve learned that we have to be our own health advocates. And families and seniors have to be empowered to be that for themselves. So the more knowledge they have, the more they know that there are things they can ask for and things that they can say no to, the better it will be. And I think, you know, what Dr. Morrison was saying about, you know, people asking for this; saying, you know wait a second, before I do that can I have a palliative care consult—and know what it is and what’s entitled.

CHAIRPERSON ARROYO: Just to follow up on the definitions and clarification because I think we all just need to have a more in-depth conversation in understanding what palliative care is not. And it does provide for a patient, regardless of age, in a circumstance where they’re managing a very difficult health diagnosis and may transition out of that, because they recover fully and move on to have a healthy, productive life. Is that—am I misunderstanding?

ERIC MANHEIMER: Perfect.

CHAIRPERSON ARROYO: Okay, cool. So it’s about a patient in need of a very comprehensive care management in a very difficult situation.

ERIC MANHEIMER: Perfect.

CHAIRPERSON ARROYO: That doesn’t have to remain, and doesn’t have to end up end of life conversation. Okay.

SEAN MORRISON: Absolutely.

CHAIRPERSON ARROYO: Council Member Sears?

COUNCIL MEMBER SEARS: Just a quick question. Since the HHC has so many tertiary care facilities and I know how the residents and the interns have so much to do, but would it be considered proper if there was to be a mandated session for each one that comes in to the facilities from the medical schools in enlightening them as to what palliative care is?

Nurses have this whole development of sensitivity training, advanced session; I ran a hospital, I always had to have these sensitivity trainings.

So the HHC, which I love dearly, seems to be such fertile ground to do the very thing the Commissioner is talking about, is having to educate, and also have this linkage with senior centers. You have so many around the City that you have a captive audience. And if you do it before lunch they’re - - so in order to enlighten them as to just what this is that we are having this hearing on today and what everybody needs to do in understanding it. Because I still think it comes right down to managing the patients themselves and having that supportive group around them that can actually take them and lead them.

ERIC MANHEIMER: Councilwoman Sears, it’s happening. I mean, I’m not a fan of mandating stuff because everybody—I used to argue with Tom Freidman [phonetic]—

COUNCIL MEMBER SEARS: [Interposing] It may be the wrong word.

ERIC MANHEIMER: No, well tom Freidman, every time I met with him he used to think of two more things that he should mandate the doctors in New York to do. And it turns out there was a nice article published in the public health literature that if the doctors did everything that the public health people told them to do they’d see one patient a day and spend eight hours doing the mandates.

So there are a lot of good things that should be mandated, however think of it the other way; if you have good, successful palliative care programs, here’s how people learn—and your mentor is a Dr. Morrison or a Dr. Meyer or Dr. X or Y or Z who is practicing good palliative care, they will learn it. It’s the mentoring that does it, and that’s what they’ll see. In fact I think what HHC has done, think about it, we have 11 city hospitals where there are 300,000 discharges, 5 million visits, a huge different variety of people, and now we are really moving palliative care to be normative throughout the institutions. We train an enormous amount of residents who go on to practice throughout the country—and medical students. They’ll have the principles through seeing patients managed in an appropriate way.

The big challenge for us, the elephant in the room as far as the City hospital system is going, is we’re facing an $800 million deficit, a billion dollars next year. This is an unfunded mandate. So you tell me there are 55 fabulous unfunded mandates; which ones do I keep? That would help us.

COUNCIL MEMBER SEARS: Actually that’s a challenge for everybody and it’s always been a challenge to this Council, particularly those on the budget negotiating committee because we look at, well they’re cutting healthcare so much and what do we advocate to eliminate—

ERIC MANHEIMER: [Interposing] It’s Sophie’s choice, right?

COUNCIL MEMBER SEARS: --and what do we keep? I agree. But that’s going to be an ongoing challenge. I mean I don’t think that the governor’s proposals at this moment in healthcare are going to boost New York City to any degree, because they’re pretty damaging, actually. That’s something we have to concentrate on because that’s imminent. But thank you.

CHAIRPERSON ARROYO: I don’t know.

The light is on, it’s off? I keep forgetting how these things work.

Doctor, you mentioned a video that was the product of some work or the initiative around palliative care. In your testimony you indicate that media was produced, a short video to be shown to community groups. Is that video available—

ERIC MANHEIMER: [Interposing] Yeah.

CHAIRPERSON ARROYO: --to the public? Is that something—

ERIC MANHEIMER: [Interposing] We could get you a copy.

CHAIRPERSON ARROYO: --we can have for the offices so that in our waiting areas whenever—we often have a captive audience of individuals, a lot who are seniors, a lot of them.

ERIC MANHEIMER: Sure. I think it’s part of the discussion of how do we get the message out. So we would be more than willing to provide speakers, you know, physicians and other folks. We have great nurse practitioners and social workers, psychologists who are super knowledgeable about this. We'd be glad to that— and the video for sure.

CHAIRPERSON ARROYO: If you could share that with the Committee staff—

ERIC MANHEIMER: [Interposing] I'd be glad to do that.

CHAIRPERSON ARROYO: Then we can figure out how to distribute it—

ERIC MANHEIMER: [Interposing] Sure.

CHAIRPERSON ARROYO: --to our colleagues. It would be helpful so that we could have it in the office for demonstrations. Okay, I'm done.

COUNCIL MEMBER BREWER: Can I just say, this is the coolest, best panel I've heard in years.

CHAIRPERSON RIVERA: You know how they say, you got me at hello? You got me with the paid sick leave.

[Laughter]

COUNCIL MEMBER RIVERA: I want to thank you all for joining us here today on the panel. You know we're going to come up with two resolutions, one for the State, one for the Federal government, you know, to support dedicated funding and reimbursement for this type of initiative. Maria del Carmen is going to spearhead one of the Resos and I'm going to spearhead the other one as well. So thank you very much.

ERIC MANHEIMER: Thank you very much.

CHAIRPERSON ARROYO: And just be prepared to answer the call for the discussion around how we can shape an initiative from the council that can help support the work that the system is already taking care of, in that I'll put in my pitch for don't cut this program.

ERIC MANHEIMER: Sounds good.

CHAIRPERSON ARROYO: Okay. Cool.

CHAIRPERSON RIVERA: So the next and last panel that we have for today is Cyril Brosnan from the New York Academy of Medicine. Hopefully I got the name correct. Nathan Goldstein, MD. Yisroel Schulman and Brenda Manber [phonetic].

[Pause]

COUNCIL MEMBER RIVERA: Brenda Manber; we have Yisroel Schulman, Nathan Goldstein and Cyril Brosan. Here we go, four, all right, perfect. You can flip a coin on who goes first and you may begin. Just state your name for the record and proceed with your testimony.

CYRIL BROSNAN: I’m Cyril Brosnan, a staff person working for the New York Academy of Medicine in the health policy arena. I am 81 years old and I also have COPD and emphysema. And since we were asking about the age and condition of people earlier I thought I’d tell you where I’m at for starters.

Thank you for inviting the New York Academy of Medicine to this important hearing on the end of life care. The New York Academy of Medicine has been advancing the health of people in cities since 1847. An independent organization, the Academy addresses the health challenges facing the world’s urban populations through interdisciplinary approaches to research, education, community engagement, and policy leadership. Our current priorities include creating environments that support healthy aging, strengthening systems that prevent disease and promote the public’s heath and working to eliminate health disparities.

The Academy has a particular interest in end of life care. The Academy currently hosts the Conliff Dickson Foundation’s New York City Symposium on the art of medicine at the end of life. These symposia provide doctors in all specialties with an overview of the current issues, ethical dilemmas and the best practices surrounding the end of life care. The Academy also hosts the Urban Bioethics Network, which brings together faculty and hospital-based ethicists from around the Tri-State area to explore bioethical issues including end of life.

We have conducted research in palliative care, in medical education and worked to improve palliative care education in medical school curriculum. We are delighted that the City Council has taken up this important topic. There are many facets to this complex set of issues, and we want to focus our remarks on just one, the issue of racial and ethnic differences in preference for receipt of end of life care.

A number of studies have suggested that racial and ethnic groups vary in the kind of end of life care they want and receive. For example, in a recent review of the literature, scholars found that people of color used hospice services disproportionately less than white patients in 12 out of 13 studies. This is consistent with other studies that suggest people of color are more likely to be hospitalized frequently and for prolonged periods at the end of life compared to white patients.

These studies point to the need to make certain that all individuals have access to high-quality end of care. While hospice care is a benefit covered by Medicare, it is not covered by Medicaid. Unfortunately—look out, sir. Be careful. Research suggests that as much as 16 to 20% of New York City 65 and older are not covered by Medicare and therefore likely do not have access to high quality end of care. However, not all differences between racial and ethnic groups in the use of end of life care are attributable to financial access to services. Research also suggests there may be racial and ethnic differences in the kind of end of life treatment people prefer. A large study of community-dwelling Medicare beneficiaries found that African American elders had a stronger preference for intensive life-prolonging treatment compared to white elders, while another study found that African Americans are less likely than whites to want hospice services.

The New York Academy of Medicine believes that we must ensure that all individuals regardless of race or ethnicity understand their full range of options prior to becoming terminally ill so that their preferences are known and respected at the end of life. The Academy has supported the work of the New York State Task Force on Life and the Law since 1985, and their efforts to change state laws to expand the authority of family members and others close to a patient to make decisions about treatment. However, too often in the absence of clear direction family members struggle and anguish over what to do, often opting for aggressive intervention, even though it might not have been their loved one’s preference.

One way to ensure that an individual has considered the options and clearly communicated his or her preferences is through the use of Advance Directives, legal documents that allow individuals to convey decisions about end of life care ahead of time to family, friends and healthcare professionals. While advance directives can be effective in guiding family members and safeguarding the wishes of the person at the end of life, research strongly suggests that communities of color are less likely to know about and to have the advance directives. However, research also indicates that given equal access to advance directives such as in the Veterans’ Administration System, African Americans were just as likely as whites to have made and documented end of life plans.

We urge the City Council to support community-based programs which promote the use of advance directives, particularly in communities of color. Effective programs will need to take into consideration and need to be sensitive to the religious and cultural differences among people as well as their different relationships to family and to healthcare institutions. One way to help ensure that programs to educate the public about advance directives are culturally competent is to involve community members in their development and implementation.

The City Council has the opportunity to provide real leadership on this issue and to model for their communities how to talk clearly and openly about the ways in which advance directives can help guarantee that each individual’s wishes are respected. We encourage the City Council to support the use of advance directives and to involve trusted community leaders like clergy, social workers, business leaders, healthcare providers and advocates and elected officials in beginning these important conversations about respecting everyone’s wishes at the end of life. Each of us will reach the end of life, and each of us will also have the opportunity and the information we need to make informed choices about the care we receive. Thank you for this opportunity.

BRENDA MANBER: Good afternoon and thank you to the joint Committees on Aging and

Health and all the Council Members present for providing this opportunity to testify, and to the Honorable Joel Rivera and the Honorable Maria del Carmen Arroyo for chairing this meeting. My name is Brenda Manber and I’m the Director of the Shira Ruskay Center, a program of the Jewish Board of Family and Children’s Services. The Shira Ruskay Center was established six years ago as a component of UJA Federation of New York’s Jewish Healing and Hospice Alliance. Our mission is to support those members of New York City’s Jewish Communities facing the impact of life-threatening illness and to provide community education and professional training focused on end of life issues. Our social work and rabbinic staff has served over 2,000 individuals and made over 1,700 community visits in all five boroughs, in clients’ homes, hospitals and nursing homes. We also provided some 1,200 office counseling sessions. Additionally we provided caregiver and bereavement support groups, community education workshops and professional training and education programs. Our services to individuals and families are provided without charge or insurance reimbursement.

In 2008 we were selected as a community service provider partner by the New York City Department for the Aging in the End of Life Care Community Support Demonstration Project in Brooklyn. This collaboration presented the opportunity to broaden the scope of our original focus on the Jewish Community to now encompass all seniors facing life-threatening illness. The partnership with DFTA has enabled us to reach diverse populations and extend access of our program. We're eager, with possibly City Council support and funding, to continue to provide that service for every individual we can possibly reach. Our City deserves no less.

Belle, a current client of ours, is just one story that demonstrates the need and the value of our program, and this is a case that I've come to refer to as, 100 is the new 80. We received a call from the son of a 99-year-old woman, who he described as virtually blind, almost deaf, non-ambulatory and living alone in her apartment, which is not so far from here. He was overwhelmed with concern upon learning that his mother's current care at home was to be discontinued within a week. His mother was being decertified by a hospice program, because as she described it, she was just not dying fast enough. He also shared that his mother consistently refused to share her financial information with any of her children, making it impossible for Medicaid eligibility to be determined; could we talk her into applying for Medicaid, could we recommend a nursing home, was his questions.

Belle had been emphatic with her family that she would die at home and not go to a nursing home. Our initial intervention included information gathering, outreach to the existing service providers, education, support, communication to all three of her adult children, living in California, Massachusetts and Israel. Our staff developed an extensive summary of Belle’s existing services and recommendations for her continued home care. Our staff also provided direction and support to the family when they had to disclose to Belle that they were going to be paying for her private live-in care.

Belle was welcoming to my visits, clearly expressing the hope that our program might assume the cost of the aides. In her typical, straight to the point, no-nonsense New York manner, Belle let me know, no offense, but if you can’t give me anything you’re pretty worthless. As a child of poverty, she knew what it was to work hard and to make sacrifices. She began to speak about how she was forced by life’s circumstances to sacrifice her own childhood to go to work to survive and that she wasn’t able to provide for herself now and was dependent on her children was extremely painful for her.

The decertification of the hospice services was triggering an unresolved sense of fear, insecurity and lifelong abandonment issues. In an effort to remain in control, Belle was refusing to take pain medication, even though the current stress was exacerbating her pain and anxiety. My ability to be present with her, hear her concerns, offer a continuity of support during this very stressful time began to have a positive impact on Belle. Just as I was about to leave after scheduling another visit, Belle looked me in the eye and said, I would like you to be with me when I die.

It’s now two months later. Belle’s pain is better. Her anxiety is diminished and her family is out of crisis. She always ends our visits with, call me before you come. I am 99, that’s really old, you know. I know they don’t believe it, but I really could die at any time. And then she squeezes my hand and gives a big smile.

We will continue to visit with Belle at home, overseeing her care and helping her to explore her life experiences and find meaning and quality in her 99th year. As DFTA’s end of life grant will be ending this May, we would like to ask the Health and Aging Committees to allocate funding for our program through the City Council Health and Aging Committees. Our program’s mission is not to help people die with dignity; our mission is to help people live with dignity during the end of their lives, and for some people that may just be into their 100th year, the new 80.

The immediacy of the needs for support and direction of individuals and families facing life-threatening illness are counted in hours, days and weeks. The need for funding to be able to respond is immediately. At Jewish Board of Family and Children’s Services, the City Council funding has been essential to our mission to educate, advocate, counsel direct individuals and families at the end of life throughout the City. We all understand the challenges our national financial crisis is creating for budgeting on all levels, however while downturns may come and go, and this one hopefully will go soon, the needs of families and individuals cannot be put on hold. End of life care and all human services require continuity. Thank you very much.

CHAIRPERSON ARROYO: Brenda, based on your philosophy, Joel and I have just recalculated our age, and I’m now 32 and he’s 10.

[Laughter]

BRENDA MANBER: I’m right with you.

CHAIRPERSON ARROYO: We’ve been joined by Council Member Vincent Gentile. Thank you.

YISROEL SCHULMAN: That’s okay. It was good. It’s a hard act to follow. Good afternoon. My name is Yisroel Schulman and I’m President of the New York Legal Assistance Group, commonly referred to as NYLAG. NYLAG, for those that don’t know, is a not-for-profit free, civil legal services provider with multiple offices in all five boroughs of New York City. And I thank you for the opportunity to testify today to encourage the City of New York to provide greater resources to help its residents document their preferences for care at the end of life in a timely and legally binding way.

NYLAG provides free, on-site legal services to patients at 16 hospitals in New York City, including six HHC facilities. Through our work with hospice programs, palliative care programs, cancer centers and geriatric departments, we are often called to bedside of someone very ill only to find out that the individual no longer has the capacity, the ability to execute an advance directive or any type of preplanning, leaving the person’s loved ones and often their healthcare providers at a lost about what to do regarding end of life care. As lawyers, we feel helpless in this situation.

The facts are clear, in New York anyone 18 years or older has the right to make their own healthcare decisions and if you become unable to communicate your medical wishes, your family and friends may not be allowed to make healthcare decisions for you. Instead you need to legally empower someone else to make these decisions. Remember, New York is one of the states that does not have a surrogate healthcare law.

As this Committee knows, this can be easily done through living wills and healthcare proxies as noted earlier. Without these legal documents an individual’s personal choices may not be considered or honored. Although the Federal Patients’ Self-Determination Act requires that all Medicare participating healthcare facilities provide information to patients about advance directives, the US Agency for Healthcare Research and Quality has found that less that 50% of the severely or terminally ill patients studied had an advance directive in their medical record. Only 12% of patients with an advance directive had received input from their physicians in its development, and between 65 and 76% of all physicians whose patients had an advance directive were not aware that the advance directive existed.

These statistics prove that the current measures are not enough and more steps need to be taken to ensure that people are informed about the choices that they have the legal right to make. This Council can play an important role in addressing this issue prior to medical crises evolving.

One successful community example is the work of the New York Legal Assistance Group, which provided free legal services to over 46,000 people in 24 languages this past year. In addition to addressing senior issues such as Medicare, Medicaid, access to other government benefits, housing issues, solving insurance disputes and a myriad of other civil legal issues, NYLAG assisted over 1,000 individuals with vital legal information and services in completing advance healthcare directives through our Total Life Choices Program. And you should have received this little flyer here, which is available I believe now in 14 languages. This is a pilot project of the New York Legal Assistance Group. NYLAG’s Total Life Choices services include educational workshops and staff trainings at senior centers, NORCs—naturally occurring retirement communities—hospitals and community-based organizations throughout the City. Last year we conducted over 250 such seminars and trained over 2,000 doctors and social workers on issues involving advance directives, including issues which were discussed earlier, such as how to engage in a conversation.

I’ll just note we’re also working very closely now on a pilot project with the New York City Chaplaincy on religiously sensitive curricula for that.

Basically, we train the trainers and educate the public. In addition, we provide free electronic storage of advance directives to prevent situations in which healthcare professionals are without clear instructions on patients’ preferences for medical care in families and therefore the suffer undue stress because the whereabouts of advance directives are unknown.

I’ll just show you something. Actually this portion of the program evolved out of a personal situation. My mother was visiting me from Florida. As a healthcare lawyer and as an elder law professor in law schools, etcetera, I always knew about the importance of having healthcare proxies. My mother developed blood poisoning, was rushed to a City hospital in a semi-comatose situation, unable to communicate. And they said in the emergency room, do you have a healthcare proxy? My father was with me and said, of course. My father said, I'm the healthcare proxy. Well where is the document? Well, it's in Florida in our house there. My father had to leave the hospital, fly down to Florida to obtain the documents, and I said never again.

And that's when we launched this program and as part of this program we digitalize anyone's healthcare proxies. It's a program which is free to anyone, irrespective of income, who take the healthcare proxies, either our healthcare proxies which we've designed and developed, which are now utilized throughout the state and are actually on many of the state websites. But we digitalize it and you receive in the mail a little credit card. What's the first thing that happens when you're taken to a hospital? They look through your wallet and they find through this credit card that you have a healthcare proxy, registered online. They enter the information and out spits your emergency contact information as well as your healthcare proxy and your living will. And I encourage each of you, if you don't have a healthcare proxy, you should have one. And as well as a living will, but certainly a healthcare proxy. And if you do have one and it's not digitalized, please, you can use the registration form that's in these packets. You can distribute these to your districts.

I know that Council Member Mealy is not here, but we've done a number of seminars in her district and in other Council Members' districts about this wonderful program and we're happy to register and to do more of these types of educational seminars.

It is critical that these types of educational advocacy programs be supported by the City of New York to ensure that its residents have decision-making capacity in times of crises and at the end of life. Again, I thank you and I'm happy to answer any questions.

NATHAN GOLDSTEIN: Good afternoon, Chairs Arroyo and Rivera and Members of the Committee on Aging and Health. Thank you for this opportunity to speak with the Committees. My name is Nathan Goldstein; I'm a physician and Geriatrician and a Palliative Care physician at the Mt. Sinai School of Medicine in New York City. And I know what you're thinking already, sort of another one from Mt. Sinai. But I think I might actually be an example of one of the Councilperson's earlier questions, which is how do we enter as physicians in this field.

So, Dr. Morrison is a mentor of mine, Dr. Meyer has been a mentor of mine. I'm going to tell you about a personal case that I went through when I was a resident at Elmhurst. And so I think in some ways it's nice that there's a couple folks from Mt. Sinai, because it actually answers some of the questions that you asked earlier about how do we get younger physicians interested in these fields.

So I'd like to start today by telling you this story about Mr. C., a patient I took care of at Elmhurst Hospital when I was a medicine resident in 1999. Like many cases relating to palliative care, the story of Mr. C. does start in the emergency room. He was a man in his late 70s with a history of advanced Parkinson’s Disease who came into the Elmhurst Emergency Room with severe shortness of breath. Both an x-ray and lab tests confirmed that Mr. C. had a serious case of pneumonia. And after finding a quiet space to talk with his family, I sat down with his adult son and daughter really to determine what they understood about his illness and what they wanted from his healthcare at that point.

They were clear that in accordance with their Chinese tradition they were most interested in both preserving his dignity and keeping him comfortable. And while they did want treatment for his pneumonia, under no circumstances would they want him put on a breathing machine, that is, on a ventilator. They previously had even had conversations with their father and knew that these were indeed his wishes. I was a trainee, so this conversation was witnessed by the attending physician in the emergency department, and we completed the appropriate paperwork—or so we thought.

A few hours later I was paged by the patient’s nurse on the floor because not only was his breathing worsening, but we had apparently not completed the appropriate paperwork in the emergency department. The in-house medicine attending at that time was called and agreed with the nurse that because the paperwork was wrong, the patient would have to be placed on a ventilator against his wishes and those of his family. Although I tried to explain why the decision was made and even had the medicine attending speak to that emergency room physician, this was all to no avail, the paperwork was the paperwork.

The story, however, luckily does not end in tragedy. We were able to stabilize him overnight. And although he did remain somewhat uncomfortable and short of breath—at that point I did not have the education and knowledge that I have now about how we treat patients’ symptoms, a skill that I’m now pretty well versed in—he was actually never placed on that ventilator. The next morning we were able to have that appropriate paperwork completed and he was discharged about a week later to his home, with hospice in place.

At that time what was missing from the system was palliative care. The problem with medical care in our country, and New York City is really no different, is that the default is to give patients all measures of life-sustaining treatments regardless of the potential benefits. Our system is so overwhelmingly broken that often the standard of practice can actually trump patients’ and families’ wishes.

Now I want to be clear that this was more than a decade ago and I imagine that the story would be very different today at Elmhurst. The palliative care team would have been called directly to the emergency room and not only would they have completed the appropriate forms, but they would have also provided appropriate medical treatments to assure that Mr. C was calm and comfortable overnight. Indeed, he may not have even been admitted to the hospital, but enrolled directly in a homecare program and discharged from the emergency room, both improving the care for the patient and his family as well as reducing costs.

As you’ve heard already today, palliative care is not the same as end of life care, instead it is patient and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering. Palliative care throughout a continuing illness involves addressing physical, intellectual, emotional, social and spiritual needs and facilitates patient autonomy and access to information and choice. In other words palliative care puts the control of the medical system back into the hands of patients and their families. We don’t make decisions for our patients but instead give them back the power to make their own informed choices to determine what it is they want for themselves. Along with this, palliative care improves the quality of care delivered to patients and their families while at the same time improving outcomes.

How do we do this? Again, as you’ve heard, palliative care programs address pain and other symptoms that cause untold human misery and are the number one concern of patients living with chronic illness. Uncontrolled symptoms like the shortness of breath that I described in Mr. C. have been shown to increase hospital complications and length of stay, and many studies have demonstrated poor to nonexistent communication between patients, families and physicians about disease. Palliative care teams provide expert control of pain and other symptoms, they meet with patients, families and physicians to establish clear and feasible goals of care, address care alternatives including withdrawing or not initiating treatments that don’t meet those goals, and develop safe and effective discharge plans for these medically complex patients.

Now in the interest of time I’m going to actually skip to the next page and talk a little bit, because I think you’ve heard a lot about what palliative care does for patients in the healthcare system, but move directly to page 6, where I’m going to talk about Mr. C’s family.

Studies of the families like Mr. C show that when patients receive palliative care, the family is more satisfied with the care their loved one receives and the amount of information they receive from their healthcare providers and the overall control of pain and other symptoms. In addition, research has shown that if Mr. C had received palliative care his some and daughter might have been better able to cope emotionally with the impending loss of their father and also be less likely to suffer consequences to their own health as a result of caring for him.

Since I was a resident there has been tremendous change in the healthcare system. First, you’ve already heard about the standardized medical order for life-sustaining treatment that we have in New York State. This is a document that’s used statewide to ensure that patients’ wishes are known when they make transitions in care from home to the hospital or from the hospital to a long term care facility. In terms of care provided in the hospital, there’s been a tremendous growth of palliative care programs across the country, and this City has made a concerted effort to improve palliative care in its public hospitals. This really has brought New York City in line with other cities across the country. But I think what we're arguing for today is that New York City not just be in line with other cities but really take on a role as a leader in the palliative care movement. New York City is already home to many of the major organizations leading the field, such as the Center to Advance Palliative Care and the National Palliative Care Research Center, both housed at Mt. Sinai.

New York State and many private sector foundations based in New York City, such as the Samuels Foundation, United Hospital Fund, the Kornfeld Foundation and the New York State Health Foundation are currently investing millions of dollars in improving access to high quality palliative care for New York City's most vulnerable patients. So the City is already poised to take on real leadership position I this field.

But with respect, here are the things we think we still need. First, as has already been discussed, we need a major publicity and social marketing campaign, highlighting the importance of palliative medicine in the care of New Yorkers, emphasizing how it's different than hospice or end of life care. This would have allowed Mr. C’s family to know about palliative care and they would have asked for it as soon as he came into the emergency room. Second, we need the City to continue and increase its support of palliative care programs in our public hospitals to assure they can continue to provide high-quality expert care to the sickest and most vulnerable citizens and their families. Thus, the next time that a patient like Mr. C comes to the hospital there will be highly trained clinicians across a wide variety of disciplines to take care of his family. Finally, we need to assure seamless and well-documented transitions for patients across settings of care. By the Council requiring the New York State already approved medical order for life-sustaining treatments be implementing in all healthcare settings across the City, but particularly in nursing homes, can we ensure that patients like Mr. C continue to receive top-quality care at our City’s premiere hospitals. Thank you for the opportunity to speak to you today, and I welcome your questions.

CHAIRPERSON ARROYO: I have one,

and I know I see that my colleague has a list. I’m going to be brief. Mr. Schulman?

YISROEL SCHULMAN: Yes.

CHAIRPERSON ARROYO: This document, I’m going to take it to my office to make copies of it—

YISROEL SCHULMAN: [Interposing] Yes.

CHAIRPERSON ARROYO: --to have it in the waiting room.

YISROEL SCHULMAN: Also, let is know what languages you want.

CHAIRPERSON ARROYO: Oh.

YISROEL SCHULMAN: I mentioned that we have this in multiple languages.

CHAIRPERSON ARROYO: So we should reach out to your office.

YISROEL SCHULMAN: Yes.

CHAIRPERSON ARROYO: Okay.

COUNCIL MEMBER RIVERA: Yeah, just a short list, not too much, about 15 different questions. How does the Medical Order Life-Sustaining Treatment differ from other advance directives?

NATHAN GOLDSTEIN: So the difference between the Medical Order for Life-Sustaining Treatment and something like either a healthcare proxy or living will is really the fact that it’s a physician order. So we’ve talked some about the idea that sometimes these documents, healthcare proxies or living wills can be lost across settings. First of all, it’s unfortunate that I didn’t bring a copy of the MOLST. The MOLST is bright pink and printed on this very heavy stock paper. You cannot miss it when you see it. In addition it not only involves a conversation between physicians and patients and their families about what they would want, but then actually puts the orders out there. So instead of having a living will saying I would not want this, the MOLST, the Medical Order for Life-Sustaining Treatment is actually a physician order saying do not do this to the patient, this is not what they want. So in some ways it actually actualizes these other documents into something that can actually create medical care or change medical care.

CHAIRPERSON RIVERA: Okay. And so

the benefits of the MOLST is pretty much it’s a doctor-oriented document that stipulates the terms of what medical treatment a patient should get.

NATHAN GOLDSTEIN: Right. Exactly. It is a physician’s orders and then it can be transferred across settings of care with patients. So there are some nursing homes that actually will fill out MOLST forms and it will be signed by a physician in the long term care facility, you can do it in the hospital. Doctors can do it in their offices with patients, and then that document is transferred across settings.

CHAIRPERSON RIVERA: Okay. So it travels with the individual themselves or it becomes part of their permanent medical record or do they get an identification card similar to the other one?

YISROEL SCHULMAN: The MOLST can be registered online also.

CHAIRPERSON RIVERA: Okay.

YISROEL SCHULMAN: So in other words some people, a very, very small percentage because the MOLST in our experience is generally only utilized if someone is in a hospital. So if you're in a hospital and you're fortunate enough to find, you know, an excellent palliative care doctor, they'll go through and do the MOLST with you, and that document generally stays in the hospital file. Of course the patient has the right to ask for a copy and they can give it to other doctors, or if they so choose if they're one of our clients or someone who contacts us, we register that online also so that together with your healthcare proxy the MOLST will also spit out.

But it's important to note that for the average senior or average New York City resident completing an advance directive, unless they're sitting with their doctor in a hospital setting, in a palliative setting or end of life type setting, they're not going to be doing a MOLST. They'll have either a living will or a healthcare proxy.

CHAIRPERSON ARROYO: Now I'm sorry, Council Member, but is this—I heard in the testimony that was provided earlier, this is a State initiative, it's not a mandated service that patients ought to be looking for or that a hospital is saying to a patient as they come in the door, by the way you can do this, we can do this for you or work with you on getting this done, the MOLST?

NATHAN GOLDSTEIN: I think that’s an absolutely correct assessment. It is a state form. It has been approved by the state for use. The problem is, I think we’re actually in agreement, the problem is that it’s not used enough and it is not transferred with patients.

YISROEL SCHULMAN: May I just add? Federal law requires that any hospital receiving Medicare funding must upon admission, you know, offer advance directive types of documentation. The problem obviously is compliance. You know, certain hospitals are better than other hospitals. It wasn’t in my testimony but obviously one thing the City Council can do is to—you don’t need to pass a law or anything—but to certainly encourage those hospitals under the purview of the City to certainly comply with those aspects of the federal law.

CHAIRPERSON RIVERA: And my last question. If a patient gets picked up by EMS how would they know, the EMS or the doctors from the receiving hospital, how would they know that the MOLST is there? They wouldn’t know?

NATHAN GOLDSTEIN: Right. So it depends on where the patient is. So if the patient is, for example, in a long-term care facility and is transferred by EMS to the local emergency room, the hope is that the folks at the long-term care facility would give then that document to EMS and that document would be transferred to the hospital. The truth is that is not what always happens in practice. The person taking care of the patient in the long-term care facility may not know they have it. They may not remember to transfer it; they may not be able to find it at that moment. That is also the case I think with healthcare proxies, living wills. It’s the same issue. They don’t know the patient has it, it’s hard to transfer it; it’s following that paperwork trail from place to place.

And I think one of the great things about the MOLST is that it can create practice change. The problem is that the system doesn’t necessarily allow for it to be used as well as it should be or transferred from one place to another.

YISROEL SCHULMAN: I would just like to add that the online registry, which is available for any type of these advance—all the advance directives which were discussed. You don’t need the credit card. If you’re doing it through a hospital domain you can simply do it through the individual’s Medicare number or social security number even without the ID number. It’s a special system which is set up. And indeed this is done thousands of times each year through hospitals, even without the little credit card. So if you have the credit card all you do is type in the information on the credit card into the appropriate secure website. If you don’t have that and you’re from a hospital and you wan to see if anybody has these documents registered all you need is the patient’s name and social security number, which every hospital has.

CHAIRPERSON RIVERA: Now it’s your organization that does all the credit card things? They can do the MOLST online with NYLAG?

YISROEL SCHULMAN: Yes.

CHAIRPERSON RIVERA: Is there anywhere else it can be registered online?

YISROEL SCHULMAN: In New York. It’s the New York Legal Assistance Group.

CHAIRPERSON RIVERA: Okay. Thank you.

CHAIRPERSON ARROYO: Council Member Dickens and Council Member Gentile also has a question.

COUNCIL MEMBER DICKENS: Thank you. Question, palliative healthcare, part of that is the assistance and the understanding and the completion of DNRs as well as healthcare proxies—is that part of palliative care?

NATHAN GOLDSTEIN: So I mean I guess the answer is yes. We don’t always—the question is not should the patient be DNR, is that what we want; the question is what does the patient want, what does the family want. If writing a Do Not Resuscitate Order is in line with that, then we help that, make sure that happens. For all of our patients in the hospital, if they don’t have a healthcare proxy, one of the first things we do in palliative care is explain to them the importance of having a proxy and help them complete that form.

COUNCIL MEMBER DICKENS: So that’s what I’m saying. Part of the palliative care is the assistance and understanding of what is available to a patient, which could be DNR, could be healthcare proxy and what you would like done or not done.

NATHAN GOLDSTEIN: Absolutely. In fact, I often explain to families, what we kind of do is translate medicalese back into English so they really understand what’s going on with their healthcare and what the options are, and then we help them work with the system to make sure those options and those goals are met.

COUNCIL MEMBER DICKENS: Is palliative care also does that include say for a patient that’s in a skilled nursing facility that has the option of either going into long term— they’re in rehab and they’re now exhausted, there’s no further they can go with the rehab; the choice is either they can go to a long term facility or to back home. Does palliative care assist with the decision for the families in that or that’s out of the realm?

NATHAN GOLDSTEIN: Absolutely. One of the things we do for patients and families is help ease the transition from one setting of care to the other to make sure both patients and families are being sent to the appropriate level of care but also they understand that and are making informed choices. We will often communicate with, rather the patient is going to rehab facility or a long term care facility or a nursing home, or home, we will actually directly communicate with whoever the providers are that will be taking care of that patient in the next setting to ensure seamless transition.

COUNCIL MEMBER DICKENS: Last question. A patient that’s in a skilled nursing facility in the rehab portion, which is short term and now has the option of either going into long term or returning home, how would they access that, if the nursing home claims that they have palliative care but the family has not been able to get it?

BRENDA MANBER: As a service provider that’s outside of all of these medical systems, one thing to understand about palliative care is that I think you’ve been presented the medical model in hospital. In nursing homes across the City there are palliative care programs, however it’s not necessarily the same model that we’re hearing today and that’s important to understand that. It’s also important to understand that in nursing homes many palliative care programs are tied to end of life care, not necessarily the broader scope, and many palliative care programs are not comprehensive.

So one of the things that’s important to understand when you’re making those kinds of decisions in families is to understand what is available within the nursing home that you’re in, in terms of rehab, what their palliative care program is, if they say they have one then you can ask for a consult, which is interdisciplinary. And the best person might not necessarily be the medical physician to help guide the family through that process; it may very well be social work staff. And if those answers don’t feel right, call our agency. And, you know, we can guide you because there are many alternatives for care at different nursing homes that are very, very different across the City.

COUNCIL MEMBER DICKENS: Thank you. Before you leave, would you leave a card please?

BRENDA MANBER: Certainly.

COUNCIL MEMBER GENTILE: Thank you, Madam Chair. Dr. Goldstein, I see that at Mt. Sinai you have a whole department of geriatrics and palliative medicine. But are we to understand that that is not the case in many or most hospitals, particularly in the private hospitals, that there’s no dedicated department or area of palliative medicine?

NATHAN GOLDSTEIN: I think you’re right. Mt. Sinai has been a leader in the field of palliative medicine for, depending on when you start counting, about a decade at least. Not every hospital in the country has palliative care. The data show that about 75% of all hospitals in the country have palliative care. That’s about 50% of medium to large-sized hospitals that do have palliative care. Not every program is as advanced as ours. Not every program does the same level of transition that we do. But it is more about it being a new field that’s growing. And as advanced as we are in hospitals, we’re much less—as a field—much less advanced than long term care facilities, outpatient palliative care, rehab facilities.

So what you’re seeing is a movement that has been growing over the last decade. You’re hearing from some of us at one of the programs that we like to think has led that. But you’re right; there are many places that don’t have it and many places that don’t have it as advanced and mature as at Mt. Sinai.

COUNCIL MEMBER GENTILE: And for those hospitals, I guess you wouldn’t know offhand whether a hospital has it or not unless you’re there and you ask for it. Is that correct?

NATHAN GOLDSTEIN: Well we always encourage families to ask for it. There are online resources. For example, there’s a resource called goodpalliativecare.org, which lists every palliative care program in the country and you can figure out if your particular hospital has that program. There’s also a website called palliativedoctors.org, that does a very similar thing that tells you the number of, where you can find palliative care physicians in your local area.

COUNCIL MEMBER GENTILE: And if that care is available, how does it work practically? Is it a separate set of doctors and nursing care that care for the patient in lieu of the physician that admitted the patient?

NATHAN GOLDSTEIN: I’d say 99.9% of the time we are a consulting service that works right next to every other service. So we do not take over the primary care, we do not become their primary service. We work in concerns with the patient’s attending physician and all other physicians working with that patient. So when I am called in to see a patient I don’t just talk to his internal medicine doctor or his primary care doctor, I talk to his primary care doc, I talk to his oncology doctor, I talk to his heart failure doctor, I talk to his infectious disease doctor; I get the story from all of these folks and then sit down with the patient and the family and really work with all of these other folks to make sure the patients and families are kind of getting what they need. And then I go back and report to all of these other teams what the plan is for the patient.

COUNCIL MEMBER GENTILE: But what ability would you have to call the shots, so to speak, as to what type of care is being given?

NATHAN GOLDSTEIN: I think the issue is it’s not about who should be calling the shots; it’s about who really had the time to sit down with the patient and the family and figure out what they want. Everybody wants to do what’s best for the patient and what the patient and the family want; I just have the skill set to be able to communicate in more effective ways than some of those other docs and to figure out what the patient and family wants. I never go to a physician and say, this is what the family said and they say, oh no, no, that’s not what we’re going to do. They say, oh, I had no idea that’s what they wanted; let’s work together to make sure that that’s what they want. So we really work together with those other physicians to make sure that the patient and the family are getting the best care that they possibly can.

COUNCIL MEMBER GENTILE: It's impressive, I must say. Just a quick question for NYLAG, Mr. Schulman. You said that there are times where people are not aware of having an advance directive. I'm just curious, how would that be if there's a sign off on it.

YISROEL SCHULMAN: No, I'm sorry. The individuals themselves know that they have an advance directive.

COUNCIL MEMBER GENTILE: Oh, okay.

YISROEL SCHULMAN: The issue is, is that—

COUNCIL MEMBER GENTILE: [Interposing] Oh, I see. I see. Okay. I misunderstood you. Okay. I misunderstood. Thank you.

CHAIRPERSON ARROYO: Thank you, Council Member Gentile. I am sitting here listening to this conversation, I'm going to make a statement and then I think we need—we have one more person that is signed up to testify.

I'm not sure, and this is I guess food for thought and discussion so that we can advance something else around legislation or lobbying at the state level. We certainly have had advance directives and healthcare proxies in our system for a very long time now, over ten years. And the mandates are that healthcare institutions provide information about the patient’s right to have one. And that’s it. So I think we’ve had this in our life long enough now that we can examine how we can improve what’s not working well with that system or that patient right, so that we can move legislation or change how we handle this component of our healthcare system. Knowing that I have the right and doing it are two different things. And if I do have one, if I go from one level of care to another, it doesn’t necessarily transfer with me. How can we correct for some of those gaps that exist with the current legislation or system. And I don’t know the answer. And given the complexity of the healthcare system and different levels of care that patients often find themselves in, it certainly is a responsibility we have to improve what patients’ experiences are, no matter where they’re at or what spectrum of the care continuum, at what point of the care continuum they find themselves in. So that ideally you have one patient with one proxy that everyone knows and there is no need for someone to say, oh, I didn’t know. So that’s just a general comment and something that I guess would force us to work in the short and long term about how we can help massage the process or the system a little bit to make it better so that there is information about a patient no matter where they find themselves. So thank you all—

NATHAN GOLDSTEIN: [Interposing] Thank you.

CHAIRPERSON ARROYO: --for being here. It’s been a very enlightening conversation, although some of my colleagues thought it was a little depressing at the beginning of the hearing. Thank you very much. Jeanne Dennis, Hospice and Palliative Care Association of New York State. Last but certainly not least.

JEANNE DENNIS: Thank you. I would like to thank Chairwoman Arroyo and Chairman Rivera and the other members of the City Council’s Committees on Health and Aging for the opportunity to comment here today. My name is Jeanne Dennis.

I’m here with basically two hats on. One is that I’m the current Chairman of the Hospice and Palliative Care Association of New York State’s Board of Trustees and I’m also the Vice President of Visiting Nurse Service New York Hospice Care. November is Hospice and Palliative Care month, so this hearing is quite timely.

I’ve been here all afternoon and I’ve been listening to this very interesting discussion and I thought it might be helpful to clarify a couple of things that have come up repeatedly regarding the distinction between hospice and palliative care.

All hospice is palliative care, not all palliative care is hospice care. So there’s a continuum of care based upon the same model of care and the same kinds of patients that are being cared for. Palliative care can begin at the time someone is diagnosed with a serious, progressive illness. Hospice care begins when that patient’s prognosis is assessed to be six months or less. The model is the same; the principles of care are the same for both palliative care and hospice care. It is designed to care for people with an advanced progressive illness where there is not an expected cure. And the delivery of care fits three different domains. One, it is what I call whole person care. And you've heard that, it's the care of the physical self, the symptoms that this illness is causing, the distressing suffering; it is at the emotional level of care for people who have this kind of illness, there's a tremendous emotional impact, and then there's the spiritual piece. So it's designed to be whole person care. It's designed to be whole family care, so that family members are included in the unit of care. When someone is this sick it is a family event. So, all the people that are involved and connected to that person are impacted by this person's illness. And it is delivered by a whole team. So you have a physician, as Brenda was saying, nurse, social worker, chaplain and in hospice we have volunteers, the same way in palliative care, massage therapists, complementary people. So when someone is this ill, and particularly as the illness progresses, we understand in the field that not one clinician can handle this alone.

Those are some of the similarities and differences. The prognostication is a big difference. So hospice care comes in more towards the end of someone's illness. The other difference is palliative care is delivered right now in our country mostly in hospitals. Hospice care is delivered mostly at home. So many of my colleagues were here today from Mt. Sinai and Health and Hospitals. We work with those palliative care hospital-based teams to bring the patient home and continue providing the care in the home setting.

Now to my prepared testimony. The Hospice and Palliative Care Association of New York represents the state's certified hospice providers and some palliative care providers as well as other individuals who are interested. I mention the persons that we serve with advanced life-limiting illness where there is no expected cure and the prognosis is deemed to be six months or less.

Hospice care embraces all diagnoses. Many people think it's only for cancer patients; it's for any person who has one illness or a combination of illness that would put them in the category of a life expectancy of less than six months. The focus is on comfort, not cure. Curative care is over, typically. The patients that come to hospice care are not eligible for curative care. The emphasis is on quality of life and patient choice, you’ve heard a lot about that this afternoon, and respect for the traditions and belief systems of the patient and family, which is very important in New York City for all the reasons we know, because of the diversity of ethnic backgrounds and religious backgrounds.

We utilize state of the art medications and treatments and provide care beyond the death of the patients. So there is a year of bereavement support to those who survive the patient’s death.

Another big difference between hospice and palliative care is right now there is a revenue stream for hospice care. Dr. Morrison mentioned that. Medicare covers hospice care, Medicaid covers hospice care as well as almost all managed care organizations and insurance providers. So if you have a hospice care benefit, you get the team and you have your durable medical equipment, your supplies and your medications covered through the Medicare benefit, with a team of people being available 24/7.

In 2007 New York State’s hospices served a total of 42,549 persons. In New York City in ’07 Hospice served 10,277 patients. The majority of New York State hospices have a median length of stay of 20 days and that’s typical here in New York City. So that’s three weeks, not six months, and that’s our median. The average length of stay in New York State hospices is about three months. So even though the benefit would allow eligibility for six months, typically patients are referred to us much later in the course of their illness, for a lot of reasons that you could think of. I would also like to note that New York City shamefully underutilizes hospice care. Nationally about 35% of all deaths are under hospice care, 35%. In New York City it’s 13%. We as a state are at the bottom of the list, almost. The states that use less hospice care are states like Wyoming and Alaska. So we have a lot of opportunity in New York City to really increase access and utilization of hospice care. We’re a real outlier.

If I could dispel a couple of myths about hospice it would be, one, that it’s not a place. Many people think of hospice as a place. It is not. It is delivered in the home setting. There are hospice inpatient units and hospice residences, but those are really supplementary to the primary setting of care is home. And secondly, that somehow hospice care is less care and you’ve thrown in the towel and you’ve given up hope and there’s nothing left to do. And that’s the opposite of the truth. Hope is always there for our patients, we couldn’t take it away if we wanted to. People’s hopes may change from the time of diagnosis, hoping for a cure then hope I go into an extended remission, then hope I live to see my kid graduate, hope I have my family around me when I die. So hopes change and the literature and the research show that actually people often improve and their life expectancy is extended with good hospice and palliative care because their symptoms are well managed and their family is supported and there’s a stabilization and a reduction of the stress and crises. And finally, hospice is not meant to be brink of death care. It’s meant to be delivered with an opportunity for the hospice program to do some good work and have a couple of months to work with families and patients rather thank a couple of days.

What the Hospice and Palliative Care Organization would ask from the City Council is to do a lot of the kinds of things you were just talking about with the previous group, is to really endorse and promote advance care planning. And advance care planning includes healthcare proxies, living wills, the MOLST, the POLST, all of those documents are really advance care planning. And as has been noted before we happen to live in a state that does not have family surrogate decision-making. So if I lose capacity to make a decision, no one in my family is legally authorized to make a decision for me, therefore I need to have a healthcare proxy. I need to name someone, particularly in our state, that can make decisions on my behalf based upon what I would want if I could speak for myself. Brenda and I are former colleagues. We worked with a nurse who at the time was probably my age, at the time she seemed really old, but she carried her advance care plan, her living will, in her pocket. She wore a white uniform and she felt like if she dropped dead it was right there with her. That’s not how most people handle this, as you’ve heard. These documents get filed away, they’re on a shelf. A crisis happens, nobody can find it and therefore it’s really a very difficult—difficult to enforce now until we have, in my opinion, some kind of shared electronic medical record where this kind of information would be readily available in a hospital emergency room, it’s going to be tricky. But it’s very important, particularly in New York State.

We would also ask for your support to participate with the State Hospice Association in efforts to revive the New York State Hospice Licensure to expand the definition of a terminal prognosis to 12 months. A couple of other states have done this. It would not effect the Medicaid benefit in New York, but it could create access for people who have commercial payers. Aetna just did some very interesting studies and found that opening up access to hospice improved not only their financial outcomes but their clinical outcomes.

And last but not least, and this is big, I think you’ve heard today that hospice and palliative care needs to be acknowledged as a solution in the efforts to reform healthcare. This model is a fabulous model of care for all the things you’ve heard, where you really sit down with patients and families, understand what they want and facilitate that happening across settings, and that is a model of care that could be applied beyond this population of people that we’ve talked about today.

I haven’t said too much, or there hasn’t been too much said about cost-effectiveness. We’ve talked a lot about the important, in my mind the most important outcomes, which are the clinical outcomes. But this is a win-win, because hospice care and palliative care saves Medicare and Medicaid dollars. Hospice is one of Medicare’s most cost-effective programs, and according to an independent study conducted at Duke University, hospice saves Medicare an average of $2,300 per patient. And if you pull out the cancer patients, it saves $7,000 per patient. That’s billions of dollars a year. And the data from another study at Dartmouth proved what we’ve also talked about today, is that more resources, more care, more treatments, more tests do not necessarily get you better outcomes.

So in conclusion, I’d like to thank you for your support, ongoing, of hospice and palliative care. And we would look forward, the Hospice Association of New York would look forward to working with you in the future to ensure that all New Yorkers and particularly New York City residents have access to good hospice and palliative care. And I would be very happy to entertain any questions you may have.

CHAIRPERSON RIVERA: My colleague and I, we were looking over your statements and one of them obviously is the change from six months to 12 months. We agree with that. It makes sense. And we’re going to put forward a resolution asking the appropriate authorities to make that change in the licensing. So that is a pretty good piece of information, especially since other states have already implemented it, based on your information. So no questions, just wanted to give you that heads up.

JEANNE DENNIS: Thank you very much. That’s great news.

CHAIRPERSON ARROYO: And if we keep track, I think we are now up to resolution number three, out of this conversation. So, Council Member Dickens, did you have a question?

[Off Mic]

CHAIRPERSON ARROYO: Yes, we might learn something.

COUNCIL MEMBER DICKENS: You had indicated that Medicare and Medicaid covers hospice if you have that coverage.

JEANNE DENNIS: That’s right.

COUNCIL MEMBER DICKENS: All right. Now what about palliative care? Is that covered by Medicare and Medicaid?

JEANNE DENNIS: No, it is not. It is not at this point, as a couple of the physicians have said, if you’re licensed to practice medicine and you are called upon to do a palliative care consultation you can bill that.

But the whole model of care, which is the team, and where you could—we can bill for a day of hospice care, you cannot bill for a day of palliative care.

COUNCIL MEMBER DICKENS: Thank you.

CHAIRPERSON ARROYO: And I think part of the back and forth that we were having while the testimony was going on was trying to figure out how we can move some kind of initiative to try to support the work that's already going on in our City. So with that, I thank you for coming and sharing your thoughts with us. It certainly has opened up the possibility for yet another action the Council can take to try to move the agenda forward to aid in providing for families in the City that find themselves in situations such as the one where hospice care and end of life planning is required. Thank you for your testimony.

JEANNE DENNIS: Thank you.

CHAIRPERSON ARROYO: Thank my colleagues for hanging out so long this afternoon. And with that, my Co-Chair, do we adjourn?

COUNCIL MEMBER RIVERA: Yes.

CHAIRPERSON ARROYO: Okay.

COUNCIL MEMBER RIVERA: Meeting is adjourned.

CERTIFICATE

I, Erika Swyler certify that the foregoing transcript is a true and accurate record of the proceedings. I further certify that I am not related to any of the parties to this action by blood or marriage, and that I am in no way interested in the outcome of this matter.

Signature_______________________________

Date ___November 28, 2009_______________