HHC NEW YORK CITY HEALTH AND HOSPITALS CORPORATION

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TESTIMONY OF

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NEW YORK CITY HEALTH & HOSPITALS CORPORATION

BEFORE THE NEW YORK CITY COUNCIL

COMMITTEE ON AGING AND COMMITTEE ON HEALTH

OVERSIGHT HEARING: "END OF LIFE CARE"

NOVEMBER 19, 2009

Good afternoon, Chairpersons Arroyo, Rivera and members of the Aging and Health Committees, my name is Dr. Eric Manheimer and I am the Medical Director of Bellevue Hospital Center. Thank you for the opportunity to describe the palliative care programs on behalf of the New York City Health and Hospitals Corporation (HHC).

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 and ease 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 specialists. 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 at 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 Hospital, Coney Island Hospital Elmhurst Hospital, Lincoln Medical and Mental Health Center, Metropolitan Hospital and at our long term care facility on Staten Island, the Sea View Nursing Home and Rehabilitation 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 teams consist 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 Home Care 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 as a means of further promoting the sharing of clinical skills and information. More than 1,000 HHC 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 4 trainings at their facilities as a means of spreading both the philosophy and clinical skills of palliative care. HHC has distinguished itself in its commitment to multidisciplinary 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 their families. As you can well understand, training and education efforts are an ongoing process. Just this past Tuesday, Lincoln Medical and Mental Health 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.

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 FY 08. This grew remarkably to more than 4,300 patients receiving services on an inpatient basis and more than 1,850 outpatient visits in FY 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 among 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 groups, 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 heightened awareness.

One of the reasons that some 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 FY 2008, 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 a $100,000/year grant for two years from the United Hospital Fund to advance the palliative care initiative's strategic goals. The Fan Fox Leslie Samuels Foundation has provided $100,000 to Elmhurst Hospital to provide 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 the 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 and chronic or advanced is diagnosed. By introducing palliative care early in the course of disease, discomforts can be minimized, plans and wishes elucidated, social and financial situations considered, and anxieties 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 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 or the treatments, patients need more and more specialized treatments. So palliative care gets involved early in order to help the patient and to provide continuity of care during the natural course of the illness. Its role typically increases as curative treatments begin to fail. However, palliation of discomforts doesn't 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 prolongation of life. In view of the goals of palliative care to intervene early (and other factors) it will no longer be surprising that almost 60 % of the palliative care patients are *under* the age of 65 and only 25% of patients are over 80 years old. To ensure continuity of care, we have created liaisons with both hospices at nursing facilities, those that are stand alone facilities and with nursing services which provide home hospices. Some HHC facilities also have hospice beds on site.

Our work on our 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 regarding palliative care. The importance of palliative care, and HHC's dedication to it, arises from many facts and it responds 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 for the opportunity to testify. I'd now be happy to answer any of your questions.

NYC

Department for
the Aging

TESTIMONY

presented by

Lilliam Barrios-Paoli

Commissioner

at an oversight hearing on

End of Life Care: What Everyone Should Know

before the

New York City Council Committees on Aging and Health

on

Thursday, November 19, 2009

1:00 P.M.

at

250 Broadway, 14th Floor

New York, NY

Introduction

Good afternoon, Chairs Arroyo and Rivera, Subcommittee Chair Mark-Viverito and members of the Committees on Aging and Health. I am Lilliam Barrios-Paoli, Commissioner of the Department for the Aging (DFTA). Thank you for holding this hearing on the important topic of end of life care for older adults. As you know, Mayor Bloomberg and Speaker Quinn—in collaboration with the New York Academy of Medicine, DFTA, and numerous other city agencies—recently launched *Age-Friendly NYC*, a trailblazing project comprised of 59 initiatives designed to enhance the livability of our City for older New Yorkers. Key among the initiatives are advancing palliative care and promoting the use of advance directives, which will be the focus of my testimony this afternoon. Specifically, I will talk about the importance of palliative care and advance 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 next steps.

What is Palliative Care?

Palliative care is a rapidly growing medical specialty focused on optimizing the quality of life of patients, and their families, in the face of chronic illness. Palliative care involves addressing physical, intellectual, emotional, social and spiritual needs throughout the continuum of illness to facilitate patient autonomy, access to information and choice. Palliative care is provided simultaneously with all other appropriate medical treatment for patients with advanced illness. It is critical to note that palliative care is not limited to the end of life. Rather, palliative care is appropriate at any stage during a serious illness and often is provided in tandem with life-prolonging treatments. Palliative care helps to address the holistic needs of patients and their families by fostering coordination of care across settings that include the hospital, rehabilitation centers, skilled nursing facilities, or the individual's home.

Successes in Palliative Care

Research has shown that patients who receive palliative care have better outcomes than those who merely receive the usual course of treatment without 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, their access to information and communication, the management of their pain, their connection to services in the 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 and services. Palliative care responds to these unmet needs.

Contrary to misinformation generated in the ongoing health care debate—that physicians might curtail life 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 its fullest.

Importance from an Aging Services Perspective

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 health care 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 patient's wishes or consideration 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 health care 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.

Advance Directives

Just as palliative care seeks to empower patients and actively involve them in their own treatment, advance directives empower patients to express their wishes in the event that they are 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 others. In fact, only 15 to 25% of adults complete advance directives, and often only after hospitalization or serious illness. By completing advance directives well before reaching advanced age 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: Health Care Proxies, Living Wills, and Do Not Resuscitate Orders. A Health Care 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 health care 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 New York's courts. In contrast, a Do Not Resuscitate (DNR) Order is more narrow in scope, allowing individuals to specify that they 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 the MOLST program, a form is completed by a physician after consultation with his 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 belief that individuals have the right to make their own health care decisions, including decisions about life-sustaining treatments, to describe these wishes to health care providers and to receive comfort care while wishes are being honored. In contrast to a Health Care 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 of patients who wish to receive *all* appropriate life-sustaining treatments to patients who would place limits on life sustaining treatments.

It is important to note that the Department of Health and Mental Hygiene (DOHMH) also has been active in promoting public awareness with respect to advance care planning. In February 2009, the 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 (CHI)* publication for health care providers entitled *Improving Palliative Care at the End of Life*; a *Health Bulletin* publication for individuals entitled *Advanced Directives – Who will make your medical decisions if you can't?*; and New York State Health Care Proxy forms. In fact, Health Care 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 stages 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 constituencies. This effort will require partners including policy makers, aging services and other social service providers, the medical and legal communities, 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 field of palliative care in New York City. Under the guidance of Deputy Mayor Gibbs, we currently are dialoguing with them to gain more knowledge and insight. As HHC will testify, today they hosted a palliative care conference in conjunction with DFTA. The conference is serving as a springboard for larger City efforts as part of Age-Friendly NYC that will engage multiple city agencies and a variety of external stakeholders. We are thankful that members of both the Council's Aging and Health committees could attend today's conference

I look forward to working with you as we move forward.

TESTIMONY OF

R. Sean Morrison, MD.

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Given before the New York City Council
Committees on Aging and Health

Oversight Hearing: "End of Life Care"
November 19, 2009

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Good afternoon, Chairs Arroyo and Rivera, Subcommittee Chair Mark-Viverito and members of the Committees on Aging and Health. Thank you for this opportunity to speak with the Committees. My name is Dr. Sean Morrison and I am a Geriatrician and a Palliative Medicine physician at the Mount Sinai School of Medicine in New York City. I also direct the National Palliative Care Research Center – a national organization headquartered in New York City whose purpose is to improve care for persons with serious illness and their families by promoting research in palliative care. I am also the incoming President of the American Academy of Hospice and Palliative Medicine. I'm honored to be here and in my remarks today would 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 and their families but help our health care system more generally. 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.

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, and advances in modern medicine have resulted in unprecedented gains in human longevity. For most New Yorkers, the years after age 65 are a time of good health, independence, and integration of a life's work 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. These years are often characterized by physical and psychological challenges, progressive functional dependence and frailty, and increased needs for family and external support. Studies suggest that medical care for patients with serious and advanced illnesses is characterized by the under-treatment of symptoms, questions about who should make decisions about the patient's care, and 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 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 are no longer beneficial, and in preventable suffering during all stages of advanced illness. By contrast, 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.

Palliative care is a new healthcare specialty that focuses on the relief of suffering and achievement of the best possible quality of life for patients and their loved ones. It involves formal symptom assessment and treatment; aid with decision making and establishing goals of care; practical support for patients and their caregivers; mobilization of community support and resources to assure secure and safe living environments; and collaborative and seamless models of care (hospital, home, nursing homes, and hospice). It is offered simultaneously with life prolonging and curative therapies for persons living with serious, complex, and eventually 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 is associated with similar or indeed increased survival when compared to patients receiving usual care alone. Specifically, by sitting down with patients and families in the setting of serious illness, asking about their goals for medical care and their wishes for treatment, and then matching treatments to those goals, palliative care teams ensure that patients are treated in the care settings of their choice while reducing unplanned and unwanted emergency department visits and hospitalizations.

It is perhaps no wonder that given the benefits of palliative care, we've seen the number of palliative care programs in hospitals grow from less than 5% of hospitals in 1999 to over 55% of all hospitals in 2008. 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 U.S. city. This is the good news. The bad news is that 45% of hospitals nationwide and one third of city hospitals lack a palliative care program and most Americans live with multiple distressing symptoms for years before they access palliative care, if indeed they access it at all.

In order to enhance palliative care's availability and ensure access to the highest quality health care, I recommend a few key initiatives. First, workforce initiatives can ensure sufficient numbers of specialists to effectively provide high-quality palliative care. Second, research initiatives can augment the currently inadequate evidence base in order to ensure that we can treat symptoms such as pain and breathlessness as rigorously and scientifically as we treat diabetes. Finally, there need to be educational initiatives to increase awareness both in the public and health care 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.

It is specifically to this latter goal that I would direct 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 the alternative to curative or life-prolonging treatments. This misperception inhibits access to non-hospice palliative care early in the course of illness when patients and families can benefit greatly from the services palliative care provides. Consequently, we need to increase public and professional awareness about the important role palliative care can play. Such education would have a major impact on improving care for New York's most vulnerable citizens.

In closing, let me again thank you for the privilege of addressing this Council. Too often, my patients and their 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.

FOR THE RECORD

Testimony of:

Paul Kronish

Boardmember, UJA-Federation
- Caring Commission Health Healing and Hospice Task Force
- Caring Commission Steering Committee
- Jewish Association for Services for the Aged

Boardmember, Jewish Board of Family & Children's Services
- Co – Chair, JBFCS / UJA Liaison Committee
- Budget & Finance Committee
- Quality Management Committee
- Community Connections Divisional Board

To

Committee on Aging jointly with the Committee on Health

Oversight: End-of-Life Care: What Everyone Needs to Know

The Honorable ~~Robert Jackson~~ Joel Rivera, Chair
The Honorable Maria Del Carmen Arroyo
Members: Maria Del Carmen Arroyo, Bill de Blasio, Simca Felder, Lewis A. Fidler, Helen D. Foster, Daniel R. Garodnick, Vincent M. Ignizio, Melinda R, Katz, G. Oliver Koppell, Jessica S. Lappin, John C. Liu, Domenic M. Recchia, Jr., James Vacca, Peter F. Vallone, Jr., Albert Vann and David Yassky

November 19, 2009

Good afternoon and thank you to the Joint Committees on Aging and Health and all the New York City Council Members present and to the Chair of this Meeting, the Honorable ~~Robert~~ Joel Rivera ~~Jackson,~~ chair, for providing us with this opportunity to testify.

My name is Paul Kronish and I am an active member of the Boards of both UJA-Federation of New York and the Jewish Board of Family and Children's Services. I am here today representing my work on end-of-life care issues, specifically UJA-Federation of New York's Jewish healing & Hospice Alliance.

A diagnosis of an advanced illness can be devastating. For the patient, anxiety and pain can make it difficult to focus on the many choices you need to make. For family members or close friends, stress or sorrow can impede the search for the caring services that their loved one may need.

Because no single organization provides all necessary services, UJA-Federation of New York has facilitated the formation of the Jewish Healing and Hospice Alliance. The Alliance provides simple, streamlined access to quality care — and to peace of mind — with an integrated network of knowledgeable and compassionate resources, including:

- Information and referral services
- Practical assistance and advocacy
- Jewish spiritual and pastoral guidance
- Individual, family, and group counseling and support
- Connections to hospice care
- Bereavement counseling

The Alliance's regional care centers include

- The Shira Ruskay Center of the Jewish Board of Family and Children's Services in New York City

  (who is represented today by Director, Brenda Mamber)

- Partners in Dignity of F.E.G.S. Health and Human Services System in Syosset on Long Island

  and

- Pathways to Care of Westchester Jewish Community Services, located in Hartsdale in Westchester

Families in crisis call the Alliance and are connected to a professional care partner who will be their advocate and guide — helping them learn about care options, giving them the information they need in order to make decisions that are right for them.

We help families navigate the bureaucracy of the healthcare system, locate practical resources and find spiritual counseling and support.

I am pleased to be here in support of Shira Ruskay Center, the Hospice Alliance's New York City provider from the Jewish Board of Family & Children's Services. The Director of the program, Brenda Mamber can speak best to the tremendous service the program provides to New Yorkers in need.

Thank you.

Hospice
& Palliative
Care Association of New York State

Testimony
Oversight – End of Life Care: What Everyone Should Know
Held by the
New York City Council
Committee on Health and Committee on Aging

November 19, 2009

Thank you for the opportunity to comment on end-of-life care. I am Jeanne Dennis, Chairman of the Hospice and Palliative Care Association of New York State (HPCANYS) Board of Trustees. I'm also Vice President of VNSNY Hospice Care. November is National Hospice and Palliative Care Month, so this hearing comes at a very opportune time.

Background

The Hospice and Palliative Care Association of New York State (HPCANYS) represents the state's certified hospice providers and palliative care providers, as well as individuals and organizations concerned with care for patients at the end of life. Hospice serves patients at the end of life and provides pain and symptom management, addresses social, emotional and spiritual needs and provides care and support to the bereaved. Hospice services are provided in the home, nursing home, and inpatient facilities. Hospice:

- Embraces all patients coping with advanced illnesses
- Focuses on comfort rather than cure
- Emphasizes quality of life
- Promotes personal choice and individual dignity
- Respects the traditions and wishes of the patient and the patient's family
- Most often provides care in the patient's home, but when necessary, also provides care in the nursing home and inpatient setting
- Utilizes current treatments and medications
- Addresses physical, social, emotional, and spiritual needs, and
- Provides care and support to the bereaved.

Palliative Care, as defined by the World Health Organization, seeks to address not only physical pain, but also emotional, social and spiritual pain to achieve the best possible quality of life for patients and their families. Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process. Many hospice programs have added palliative care to their names to reflect the range of care and services they provide, as hospice care and palliative care share the same core values and philosophies.

In 2007 New York State's hospices served a total of 42,549 patients. Here in New York City, patients served totaled 10,277. Of those patients, 1,274 were residents of nursing homes. The majority of New York State hospices have a median length of stay of 20 days or less. Median LOS in NYC ranges between 14 and 47 days. Medicaid reimbursement represented 21.9% of all hospice reimbursement in 2007; in NYC Medicaid represented 28% of hospice reimbursement.

If I could dispel just one myth about Hospice, it would be that choosing Hospice means giving up hope. Hospice actually fosters hope—it helps patients reclaim the control they have over the time they have left. It helps them understand that even though death can lead to sadness, anger, and pain, it can also lead to opportunities for reunion, reminiscence, laughter, and HOPE—hope that Hospice will enable a patient to live his or her life to its fullest. It is not uncommon for patients entering hospice to experience an improved sense of well-being and comfort. This sometimes happens because pain management and symptom control issues are openly discussed and effectively resolved. Sometimes, this sense of well-being is a reflection of the patient's sense of control gained from defining his/her goals and from active participation in developing the plan of care.

And finally, Hospice is not meant to be "brink of death" care. If you or your loved one has a life limiting illness, seek an evaluation from Hospice as early as possible. The care and comfort hospice will bring to you and your loved ones are invaluable.

Your support is needed:

1. To promote advance care planning
2. As we seek passage to revise hospice licensure law to expand the definition of terminal prognosis from 6 months to 12 months. (This would not affect Medicaid or Medicare).

3. To get the word out that pediatric palliative care services will soon be available to medically fragile children enrolled in the Care at Home I & II Medicaid Waiver Program.
4. As health care reform is considered in Washington and Albany, please recognize hospice and palliative care as *part of the solution*.

Issues

1) **Advance Care Planning —** HPCANYS has long supported the use of advance care planning to ensure a patient's choices are respected and honored. We partner with United Hospice of Rockland to promote "Assuring Your Wishes," (www.assuringyourwishes.org), a website providing information and instruction on the completion of advance directives as well as secure on-line storage of documents.

- ➢ Advance care planning discussions before the patient finds him or herself in a medical crisis will help ensure that the patient gets the care he or she wants.
- ➢ One of the most frequent comments that hospice providers all across New York and all across the nation hear from family members is: "Why didn't we know about hospice sooner?" Hospice and palliative care are just two options that would be discussed in an advance care planning consultation.
- ➢ Research published just last year by Stephen Connor, Ph.D., and colleagues, presented convincing proof that patients who elect hospice care actually tend to live longer than patients with the same diagnosis and the same acuity who don't elect hospice care.
- ➢ Advance care planning involves:
  - Understanding your healthcare choices;
  - Thinking about your choices in light of what is important to you, your family and the values you share;
  - Talking about your decisions with your loved ones and your doctors;
  - Writing down your plans in Advance Directives so they will be ready if needed.

2) **Expand terminal prognosis to 12 months**—Currently New York State Hospice Licensure Law defines terminal prognosis as six months or less if the disease runs its normal course. We are exploring the possibility of expanding the definition of terminal prognosis from 6 months to 12 months. Both Florida and California have the 12 month terminal prognosis for hospice. We believe this change would

encourage earlier referral to hospice for patients with private insurance; the change would not affect Medicaid or Medicare reimbursement, which would remain at 6 months. A recent report from Aetna, published in the Journal of Palliative Medicine (Volume 12, Number 9, 2009), stated: "The requirement that a physician certify that a patient is expected to die within 6 months may no longer be appropriate as many conditions may entail longer survivals. In summary, case management appears to represent a compelling opportunity to improve the quality of care for those with advanced illness, and hospice benefits might be liberalized within the context of such case management without adverse impact on total costs."

3) **Care at Home I & II Medicaid Waiver**—Pediatric palliative care services—family palliative care education & training, pain & symptom management, massage therapy, expressive therapies (art, music & play) and bereavement services—will soon be included in the Care at Home (CAH) I & II Medicaid Waiver program. Help us get the word out that pediatric palliative care services will soon be available to these medically fragile children.

4) **Health Care Reform**—As health care reform is considered in Washington and Albany, please recognize hospice and palliative care as part of the solution! Hospice and palliative care provides the quality, compassionate care that patients want and need, while being cost effective. Hospice is one of Medicare's most cost-effective programs. According to an independent study conducted at Duke University, hospice saves Medicare an average of $2,300 per patient, or nearly $2 billion a year. Data from the 2008 Dartmouth-Atlas study, "Tracking the Care of Patients with Severe Chronic Illness" demonstrates "...more resources and more care (and more spending) are not necessarily better."

Conclusion

I want to thank the members of the Council for your ongoing support of Hospice and palliative care. I look forward to working with you in the coming year to ensure all New Yorkers with life-limiting illness have access to quality hospice and palliative care.

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TESTIMONY OF

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Given before the New York City Council
Committee on Aging and Committee on Health

Oversight Hearing: "End of Life Care"
November 19, 2009

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Good afternoon, Chairs Arroyo and Rivera and members of the Committees on Aging and Health. Thank you for this opportunity to speak with the Committees. My name is Dr. Nathan Goldstein and I am a Geriatrician and a Palliative Care physician at the Mount Sinai School of Medicine in New York City.

I'd like to start today by telling you the story of Mr. C, a patient I took care of at Elmhurst Hospital when I was a resident in the Internal Medicine training program at Mount Sinai in 1999. Like many cases relating to palliative care, the story starts in the emergency room. Mr. C 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. An x-ray and lab tests confirmed that Mr. C had a serious case of pneumonia. After finding a quiet spot to talk, I sat down with his adult son and daughter to determine what they understood about his illness and what types of care they wanted for their father at this point in his life. They were clear that in accordance with their Chinese tradition, what they were most interested in was preserving his dignity and comfort, and while they wanted him to receive treatment for his pneumonia, under no circumstance would they want him to be placed on a breathing machine, also known as a ventilator. They had previously had conversations with their father and knew that these were indeed his wishes. This conversation was witnessed by an 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 because not only was his breathing worsening, apparently we had not completed the appropriate paperwork in the emergency department. The "in house" medicine attending who was called 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 physician speak to the ER attending physician, this was all to no avail. The paperwork was the paperwork.

This story does not end in tragedy. We were able to stabilize that patient, and though he did remain somewhat uncomfortable and short of breath (at that point I had not been appropriately educated about symptom control in patients with advanced disease, a skill I am now well versed in), the patient was never placed on a ventilator. The next morning we were able to have the appropriate paperwork completed. The patient was discharged within about a week to his home, with hospice in place. At that time, what was missing was palliative care.

The problem with medical care in our country – and New York City is 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 standard practices can actually trump patient and family wishes.

To be clear – this case was from a decade ago, and I imagine that today this story would end very differently. The palliative care team would be called directly to the Emergency Department, and not only would they have completed the necessary paperwork, but they would have also provided appropriate medical treatments to assure that Mr. C was calm and comfortable overnight. Indeed, this patient may not have even been admitted to the hospital, but enrolled directly in a home care program – thus improving the quality of care for the patient and his family while at the same time reducing costs.

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 the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitates patient autonomy, 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 do not make decisions for our patients, but instead give them back the power to make their own informed choices to determine what 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 does it do this? Palliative care programs address pain and 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 my patient – have been shown to increase hospital complications and lengths of stay, and many studies have demonstrated poor to non-existent communication between patients, families, and physicians about the disease, the treatment options, and what to expect. Palliative care teams provide expert control of pain and other symptoms; 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. Through these methods palliative care programs improve the quality of medical care received by our sickest patients while reducing hospital costs, readmissions, and emergency department visits. Typically delivered by an interdisciplinary consultation team working in concert with the patient's primary physician, hospital palliative care programs provide highly specialized and expert care to patients with the most serious and complex symptoms.

Research demonstrates that palliative care programs improve physical and psychological symptoms, caregiver well-being, and consulting physician satisfaction. Employing interdisciplinary teams of physicians, nurses, social workers and additional personnel when needed (for example, chaplains, therapists, psychologists), palliative care teams identify and rapidly treat distressing symptoms which have been shown to impede recovery, increase confusion, and lengthen hospitalizations. Palliative care team members meet and talk extensively with patients and their families to make sure they understand their illness and what it means, support families in crisis, and plan for safe transitions out of hospitals to lower intensity community settings that are preferred by patients and families in the overwhelming majority of cases.

Studies of the families of patients like Mr. C show that when patients receive palliative care the family is more satisfied with the care their loved one receives, the amount of information they receive from their health care providers, and the overall control of pain and other symptoms. In addition, research demonstrates that if they had received palliative care, Mr. C's son and daughter might have been able to better 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 and growth in the field of palliative care. First, we now have a standardized form for documenting patients' wishes for care. This form, the Medical Orders for Life Sustaining Treatment, is a document used state wide to assure 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 has been a tremendous growth of palliative care programs across the country, and the City has made a concerted effort to improve palliative care in its public hospitals. This brings New York City in line with the other major cities across the country. What we are arguing for today, however, is that New York City not just be in line with other cities, but instead take on a role as a leader in the palliative care movement. New York City is already the 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 Mount Sinai. Both New York State and many private sector foundations based in New York City, such as the Samuels Foundation, the 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 NYC's most vulnerable patients. So the city is already poised to take on a leadership position with regards to palliative care. Here is what we still need:

First, we need a major publicity and social marketing campaign highlighting the importance of palliative medicine in the care of New Yorkers, emphasizing how it is 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 entered the Emergency Department.

Second, we need for 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 of our city and their families. Thus the next time when a patient like Mr. C comes to the hospital, there will be highly trained clinicians across a wide range of disciplines to take care of him and his family.

Finally, we need to assure seamless and well-documented transition for patients across settings of care. By the council requiring that the New York State approved Medical Orders for Life Sustaining Treatments be implemented in all healthcare settings across the city – and especially in nursing homes – can we assure 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.

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Testimony of New York Legal Assistance Group

on

The Need for Greater Community Education on Advance Directives

Topic: End of Life Care

Presented before:

A Joint Hearing of the
Committee on Health
and
Committee on Aging

New York City Council

Presented by:

Yisroel Schulman
President
New York Legal Assistance Group

November 19, 2009

Good Afternoon. My name is Yisroel Schulman and I am the President of the New York Legal Assistance Group, commonly known as NYLAG. NYLAG is a not-for-profit organization that provides free civil legal services with multiple sites in all five boroughs of New York City.

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 onsite legal services to patients at 16 hospitals in New York City including six HHC facilities. Through our work with hospice programs, palliative care, cancer centers and geriatric departments, we are often called to the bedside of someone very ill only to find out that the individual no longer has the capacity to execute an advance directive or any type of pre-planning, leaving the person's loved ones and often their health care provider at a loss 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 health care decisions. And, if you become unable to communicate your medical wishes, your family and friends may not be allowed to make heath care decisions for you. Instead, you need to legally empower someone else to make these decisions. As this Committee knows, this can easily be done through living wills and health care proxies. Without these legal documents, an individual's personal choices may not be considered or honored.

Although the Federal Patient Self-Determination Act requires that all Medicare-participating healthcare facilities provide information to patients about advance directives, the U.S. Agency for Healthcare Research and Quality found that:

- Less than 50 percent of the severely or terminally ill patients studied had an advance directive in their medical record.
- Only 12 percent of patients with an advance directive had received input from their physician in its development.
- Between 65 and 76 percent of physicians whose patients had an advance directive were not aware that it existed.

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

One successful community example is the work of the New York Legal Assistance Group (NYLAG) which provided free legal services to over 46,000 people in 2008. In addition to addressing issues related to Medicare, Medicaid, securing other government benefits, addressing housing issues, solving insurance disputes and myriad other civil law matters, NYLAG assisted over 1,000 individuals with vital legal information and services in completing advance health care directives through our Total Life Choices Program (TLC).

NYLAG's services in the area of advance directives includes educational workshops and staff trainings at senior centers, naturally occurring retirement communities, hospitals and social service organizations throughout New York City. We even staff table in hospital waiting rooms with the assistance of law students. In addition, we provide free electronic storage of advance directives to prevent situations in which health care professionals are without clear instructions on patients' preferences for medical care, and families suffer undue stress because the whereabouts of advance directive are unknown. Through a partnership with the U.S. Living Will Registry, advance directives are stored in a secure online database. With this easy and effective system, advance directives will be available to the dying person's family and doctors whenever and wherever they are need.

It is critical that these types of educational and advocacy programs be supported by the City of New York to ensure that its residents have decision-making capacity in times of crisis and at the end of life.

Once again, I thank you for your time and attention.

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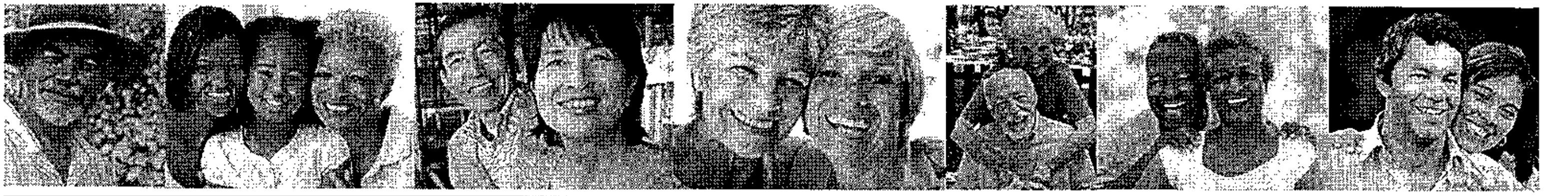
Total Life Choices

The Advance Planning Program of the New York Legal Assistance Group



Advance Directives

Health Care Proxy * Living Will * U.S. Living Will Registry®

Did you know?

- If you are 18 years or older, you have the right to make your own health care decisions.
- If you become unable to communicate your medical wishes, your family and friends will not be allowed to make health care decisions for you. You need to empower someone to make these decisions for you — and TLC can help.

Total Life Choices (TLC) is a program of the New York Legal Assistance Group. TLC staff can help you complete forms and register them on a secure online registry, allowing healthcare providers everywhere to respect and have immediate, 24-hour access to your health care wishes.

Fill out the attached forms and return them to us:

Fax to:	212.750.0820
Mail to:	Total Life Choices New York Legal Assistance Group 450 West 33rd Street, 11th Floor New York, NY 10001

To schedule a Total Life Choices presentation through the Linda Rodgers Emory Lecture Series call Tina Janssen-Spinosa, Esq. at 212.613.5062.

a beneficiary of
UJA Federation
of New York

For more information visit us at www.totallifechoices.org or contact us by e-mail at tlc@nylag.org or phone at 212.371.6873.

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Health Care Proxy: Instructions

Appointing Your Health Care Agent

Item (1)
Write the name, home address and telephone number of the person you are selecting as your agent. You may not choose your attending doctor to serve as your health care proxy unless he/she is related to you by blood, marriage or adoption. You may also not choose an employee of a hospital if you are a patient or resident of such hospital.

Item (2)
If you want to appoint an alternate agent, write the name, home address and telephone number of the person you are selecting as your alternate agent.

Item (3)
Your Health Care Proxy will remain valid indefinitely unless you set an expiration date or condition for its expiration. This section is optional and should be filled in only if you want your Health Care Proxy to expire.

Item (4)
If you have special instructions for your agent, write them here. Also, if you wish to limit your agent's authority in any way, you may say so here or discuss this with your health care agent. If you do not state any limitations, your agent will be allowed to make all health care decisions that you could have made, including the decision to consent to or refuse life-sustaining treatment. However, an alternative to listing specific instructions as exemplified below would be to complete a Living Will, which would guide your health care agent in making decisions.

If you wish to give your agent authority over artificial nutrition and hydration, you must tell this to him/her, and preferably state it in writing on this form. Simply write:

> ***I have discussed my wishes with my health care agent and alternate and they know my wishes including those about artificial nutrition and hydration.***

If you wish to make more specific instructions, you could say:

> *If I become terminally ill, I do/don't want to receive the following types of treatments....*
> *If I am in a coma or have little conscious understanding, with no hope of recovery, then I do/don't want the following types of treatments:....*
> *If I have brain damage or a brain disease that makes me unable to recognize people or speak and there is no hope that my condition will improve, I do/don't want the following types of treatments:....*
> *I have discussed with my agent my wishes about____________ and I want my agent to make all decisions about these measures.*

Examples of medical treatments about which you may wish to give your agent special instructions are listed below. This is not a complete list:

- artificial respiration
- artificial nutrition and hydration (nourishment and water provided by feeding tube)
- cardiopulmonary resuscitation (CPR)
- antipsychotic medication
- electric shock therapy
- antibiotics
- surgical procedures
- dialysis
- transplantation
- blood transfusions
- abortion
- sterilization

Item (5)
This paragraph authorizes your health care agent to act as your representative in respect to the Health Insurance Portability and Accountability Act (HIPAA), authorizing your agent to obtain all medical records and information about you.

Item (6)
You must date and sign this Health Care Proxy form. If you are unable to sign yourself, you may direct someone else to sign in your presence. Be sure your address is included.

Item (7)
Two witnesses 18 years of age or older must sign this Living Will form. The witnesses are only required to witness the registrant's signing of the document and do not have to read/review the document itself. Be sure both witnesses write the date, print and sign their names and include their addresses. If you have appointed a person to be your health care agent or alternate agent, s/he cannot sign as a witness.

Health Care Proxy

(1) I, ____

hereby appoint ____
(*name, home address and telephone number*)

____

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) Optional: Alternate Agent
If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby appoint

____
(name, home address and telephone number)

____

____

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. *(Optional: If you want this proxy to expire, state the date or conditions here.)* This proxy shall expire (*specify date or conditions)*: ______________________

____

____

(4) I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. (*If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.*) I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions (*attach additional pages as necessary*):

____

____

____

____

Please note that in order for your agent to make health care decisions for you about artificial nutrition and hydration (*nourishment and water provided by feeding tube and intravenous line*), your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in the above section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.

(5) I also grant authority and power to my agent(s) to serve as my personal representative for purposes of the Health Insurance Portability and Accountability Act (HIPAA). My agent is authorized to execute any and all releases and other documents necessary in order to obtain disclosure of my patient records and other medical information subject to and protected by HIPAA.

(6) Your Identification ***(please print)***

Name ____

Signature ______________________________ Date __________________________

Address____

(7) Witnesses: Two witnesses must be 18 years of age or older and cannot be the health care agent or alternate.

I declare that the person who signed this document appeared to execute the Health Care Proxy willingly and free from duress. He or she signed (or asked another to sign for him or her) this document in my presence.

Witness 1:	***Witness 2:***
Name *(please print)*: ____________________	Name *(please print)*: ____________________
Signature: __________________________	Signature: __________________________
Address: __________________________	Address: __________________________
Date: ______________________________	Date: ______________________________

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Living Will: Instructions

(NYLAG Short Version)

Item (1)
Print your full name on the line.

Item (2)
This section provides instructions on your medical treatment in the case of any incurable or irreversible mental or physical condition with no reasonable expectation of recovery. Initial any statement with which you agree in the corresponding box.

Item (3)
If you have any special instructions for your physician and/or your health care agent, specify them here. Examples of medical treatments about which you may wish to give special instructions are listed below. This is not a complete list:

- artificial respiration
- artificial nutrition and hydration (nourishment and water provided by feeding tube)
- cardiopulmonary resuscitation (CPR)
- antipsychotic medication
- electric shock therapy
- antibiotics
- surgical procedures
- dialysis
- transplantation
- blood transfusions
- abortion
- sterilization

Item (4)
Initial any statement with which you agree in the corresponding box. You may state specific wishes or instructions about organ and/or tissue donation on this form. A health care agent cannot make a decision about organ and/or tissue donation because the agent's authority ends upon your death. The law does provide for certain individuals in order of priority to consent to an organ and/or tissue donation on your behalf:

(continued)

your spouse, a son or daughter 18 years of age or older, either of your parents, a brother or sister 18 years of age or older, a guardian appointed by the court prior to the donor's death, or any other legally authorized person. You must sign and date this Living Will form. If you are unable to sign yourself, you may direct someone else to sign in your presence. Be sure your address is included.

Item (5)
Two witnesses 18 years of age or older must sign this Living Will form. The witnesses are only required to witness the registrant's signing of the document and do not have to read/review the document itself. Be sure both witnesses write the date, print and sign their names and include their addresses. If you have appointed a person to be your health care agent or alternate agent, s/he cannot sign as a witness.

Living Will

(Specific Form)

This is an important legal document. Read it carefully and talk about it with your doctor and family. It directs the medical treatment you are to receive in the event you are unable to participate in your own medical decisions and are terminally ill, in a permanently unconscious condition, or in a minimally conscious condition in which you are permanently unable to make decisions or express your wishes.

I, ________________________________, being of sound mind, make this statement as a directive to be followed if I become unable to make my own health care decisions, as determined by the physician who has primary responsibility for my care. These instructions reflect my firm and settled commitment to decline medical treatment under the circumstances indicated below.

Health Care:
If I should be in an incurable or irreversible mental or physical condition with no reasonable expectation of recovery, including but not limited to: (a) a terminal condition; (b) a permanently unconscious condition; or (c) a minimally conscious condition in which I am permanently unable to make decisions or express my wishes, it is my wish that the following directions be followed by my health care provider.

While I understand that I am not legally required to be specific about future treatments **if I am in the condition(s) described above I feel especially strongly about the following forms of treatment:**

WRITE YOUR INITIALS NEXT TO ANY STATEMENT WITH WHICH YOU AGREE:

☐ I do not want Cardiopulmonary Resuscitation (CPR), and I want my health care provider to issue a Do Not Resuscitate (DNR) order (an order written in my medical records that CPR is not to be administered to me).

☐ I do not want mechanical respiration.

☐ I do not want artificial nutrition and/or hydration (provision of foods and fluids through tubes).

☐ I do not want antibiotics.

☐ I do not want any other painful or invasive treatment that will result in prolonging my life.

☐ I want maximum pain relief, even if it may hasten my demise.

Other Instructions or Comments about My Care:

____

____

____

____

____

These directions express my legal right to refuse treatment. I intend my instructions to be carried out unless I have rescinded them in a new writing or by clearly indicating that I have changed my mind.

Signed ____ Date _____________________

Address ____

Witnesses: Two witnesses must be 18 years of age or older and cannot be the health care agent or alternate.

I declare that the person who signed this document appeared to execute the Living Will willingly and free from duress. He or she signed (or asked another to sign for him or her) this document in my presence.

Witness 1:	***Witness 2:***
Name *(please print)* ________________________	Name (*please print)* ________________________
Signature ________________________	Signature ________________________
Address ________________________	Address ________________________
Date ________________________	Date ________________________

Optional: Organ and/or Tissue Donation

You may state wishes or instructions about organ and/or tissue donation on this form. A health care agent cannot make a decision about organ and/or tissue donation because the agent's authority ends upon your death. The law does provide for certain individuals in order of priority to consent to an organ and/or tissue donation on your behalf: your spouse, a son or daughter 18 years of age or older, either of your parents, a brother or sister 18 years of age or older, a guardian appointed by a court prior to the donor's death, or any other legally authorized person.

I hereby make an anatomical gift, to be effective upon my death, of (*write your* *<u>initials</u>* *next to the statement of your choice*):

☐ Any organs and/or tissues

☐ The following organs and/or tissues:

____

____

☐ Limitations:

____

____

If you do not state your wishes or instructions regarding organ and/or tissue donation on this form, it will not mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.

Signed ______________________________ Date: ______________________________

Address: ____

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U.S. Living Will Registry®: Description and Instructions

What is the U.S. Living Will Registry®?

Established in 1996, the U.S. Living Will Registry® electronically stores advance directives, organ donor information and emergency contact information, and makes them available 24-hours a day to hospitals and health care providers. All health care providers have access to the documents and information, and privacy and confidentiality are always maintained. In a written agreement with each registrant, the Registry agrees not to release your documents or information to any party other than health care providers.

Why should I register with the U.S. Living Will Registry®?

- Enables medical professionals across the country to have immediate, 24-hour access to your advance directives in time sensitive situations.
- Peace of mind in knowing that your wishes will be known even if you become ill or injured while traveling or if you are admitted to a facility that you do not normally visit.
- Easy modification of your documents if you wish to change your directives.
- Receive annual update letters to confirm that your information is current and up-to-date.
- Completely free, lifetime registration of your advance directives in secure online registry.

How to Register:

Once you have completed your advance directives and a U.S. Living Will Registration Agreement form, please return them to TLC staff. A NYLAG attorney will then review your completed advance directives and have them stored in the online registry.

To submit advance directives for registration, you may send the documents along with the U.S. Living Will Registration Agreement form by either of the following methods:

FAX to 212.750.0820

Mail to:

Total Life Choices
New York Legal Assistance Group
450 W. 33rd Street, 11th Floor
New York, New York 10001

U.S. Living Will Registry®
Registration Agreement

Source Code
37125901

Registrant's Identifying Information (Please type or print clearly)

Name: First____________________ Middle____________________ Last ______________________________ Suffix ______

Social Security Number:__________ ______ __________Date of Birth: Month ____Day____Year________(4 digits, please)

Address - Primary Residence: Street Address ____ Apt #______________

City ____ State ______ Zip Code ______________

Secondary Residence (if any): Street Address____Apt #______________

City ____ State______Zip Code ______________

Phone- Home: ( )______________Work: ( )______________Secondary Res: ( )______________

Emergency Contact #1: Name:____ Relationship:__________________________

Address:____

Telephone Number: Home: ( )____________________Work/Other: ( )____________________________

Emergency Contact #2: Name:____ Relationship:__________________________

Telephone Number: Home: ( )____________________Work/Other: ( )____________________________

I,____ ("Registrant" or "I"), request that the *U.S. Living Will Registry®*, with offices at 523 Westfield Ave., PO Box 2789 Westfield, New Jersey 07091-2789 ("Registry"), electronically store a copy of my attached advance directive (collectively, including but not limited to my: living will, health care proxy, or similar document[s], including organ donor information, provided to the Registry), and provide a copy of the stored advance directive image to any health care provider who requests it in conjunction with my care. A "health care provider" is any hospital, doctor, skilled nursing facility, nursing facility, home health care agency/provider, ambulatory surgery facility, hospice, or any authorized employee, contractor or agent of any of the foregoing, or other person believed charged with giving effect to my advance directive or assisting in same. I voluntarily execute this registration on the date set forth below, without coercion, duress or undue influence from any party, and I warrant and represent that I have the legal capacity to offer my consent to such registration. My registration is not effective until I receive written confirmation from the Registry, at the above address. I can only register through a Registry member Health Care Provider or a Registry Community Partner. The Registry's member Health Care Providers and Community Partners are not owned or operated by the Registry, and they cannot change any terms of this Registration Agreement; any oral changes are not effective. Only the Registry can change the terms of the Registration Agreement, and only in writing (except in emergencies, in the Registry's sole discretion). I have provided my Social Security number to facilitate the identification, retrieval and provision of my stored advance directive images to health care providers, and for the Registry's recordkeeping purposes only.

I. Registration and Certification: I submit the information contained herein to confirm my identity, in the event that a health care provider requests a copy of my advance directive. I certify that this information is correct and that the attached advance directive is my currently effective advance directive, which was properly executed in accordance with the laws of the state where it was executed. If the attached advance directive is a copy, I certify that it is a true and correct copy of the original document. I agree to immediately notify the Registry, in writing, at the Registry's address listed above, in the event of my revocation of the attached advance directive or of this registration, or if the attached advance directive or the identifying information herein are changed in any way. I agree immediately to provide the Registry with a copy of the new/changed documents. I will indemnify and hold the Registry harmless for any damages resulting from the Registry's reliance on these certifications, or on any inaccurate information I supplied. If I don't notify the Registry in writing and in a timely manner of any changes, or of the revocation of my advance directive or this registration, or if I don't provide a true copy of the changed documents to the Registry, the Registry will not be liable for any damages resulting from the production of the documents on file to any health care provider. If my information is accessed over the Internet utilizing my unique registration number, my social security number ("SSN") will not be revealed, and it will not be visible or disclosed on the Registry's web page. If the card containing my unique registration number is lost or otherwise unavailable, health care providers will be able to access my documents using my SSN. Since most health care providers have access to their patients' SSN, providing your SSN to the Registry ensures the widest availability of your advance directive images to health care providers in time of need, even when your card is not available. The Registry will take appropriate steps to safeguard the privacy and confidentiality of each Registrant's SSN, and the Registry will not use SSNs for any purposes not specifically permitted by this Registration agreement. If you do not provide your SSN, your documents will be identified only by the unique registration number assigned by the Registry, which will significantly limit the accessibility of your documents.

II. Authorization: I authorize the Registry to send a copy of my advance directive to any health care provider (as defined herein) that requests a copy of it, provided the request conforms to the Registry's policies and procedures (or as deemed advisable by the Registry in an emergency situation, or as required by law). The Registry is not otherwise authorized to share my personal information with parties other than health care providers (as defined herein). A copy of this Agreement may be used in place of the original document.

III. Limitations on Liability: I understand that I will not be charged a fee to register or to maintain my registration. Registry shall not be liable to me or any person or entity for any liability arising from the improper transmission/disclosure of my advance directive, from the transmission of inaccurate or incomplete materials, or from the loss/misplacement/destruction/unavailability of all or part of my advance directive. If I don't agree to these terms, I am free not to use the Registry's service.

IV. Term: This Agreement shall remain in effect until Registry receives reliable information that the Registrant is deceased, the Registrant requests, in writing, that the Agreement be terminated, or until registration is cancelled pursuant to the Registry's policies and procedures. When the Agreement is terminated, Registry will use best efforts to remove Registrant's advance directive from its files.

I hereby agree to the terms herein, and certify the accuracy of the information provided. I agree to safeguard my Registration ID card from unauthorized access. I understand that anyone who gains access to my card can use it to gain access to my documents and personal information (but not to my SSN), and I will not hold the Registry liable for such unauthorized access.

X____ **DATED:** ____/____/____

Signature of Registrant

WITNESS STATEMENT

I declare that the Registrant who signed this document is personally known to me, that he/she signed or acknowledged this document in my presence, and that he/she appears to be of sound mind, and under no duress or undue influence.

Signature: ____________________________ Print Name: ____________________________

(Witness #1) DATED: ____/____/____

Signature: ____________________________ Print Name: ____________________________

(Witness #2) DATED: ____/____/____

jbfcs

In New York, we all belong.

Testimony of:

The Jewish Board of Family & Children's Services

Brenda Mamber,
Director of Shiray Ruskay Center

To

Committee on Aging jointly with the Committee on Health

Oversight: End-of-Life Care: What Everyone Needs to Know

Joel Rivera
The Honorable ~~Robert Jackson~~, Chair
The Honorable Maria Del Carmen Arroyo
Members: Maria Del Carmen Arroyo, Bill de Blasio, Simca Felder, Lewis A. Fidler, Helen D. Foster, Daniel R. Garodnick, Vincent M. Ignizio, Melinda R, Katz, G. Oliver Koppell, Jessica S. Lappin, John C. Liu, Domenic M. Recchia, Jr., James Vacca, Peter F. Vallone, Jr., Albert Vann and David Yassky

November 19, 2009

UJA Federation of New York

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 ~~Robert Jackson~~ Joel River. for chairing this meeting.

My name is Brenda Mamber and I am Director of The Shira Ruskay Center, a program of the Jewish Board of Family and Children's Services. The Shira Ruskay Center was established 6 years ago as a component of UJA-Federation of New York's Jewish Healing & Hospice Alliance. Our mission is to assist and support those members of NYC'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 5 boroughs) in client's homes, hospitals and nursing homes. We also provided some 1,200 client office counseling sessions. Additionally we provided caregiver and bereavement support groups, community educational workshops, and professional training and educational programs.

In 2008, we were selected as the community service provider partner by the NYC Department for the Aging on their 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 encompass all seniors facing life-threatening illness. The partnership with DFTA has enabled us to reach diverse populations and extend access to our program.

We are eager, with 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. This is a case that I have 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. He was overwhelmed with concern after learning that his mother's care at home was to be discontinued within a week. His mother was being de-certified by a Hospice program because she was not "dying fast enough". He also shared that his mother had consistently refused to share her financial information with any of her childree and that she had been emphatic with the family that she would die at home and not go to a Nursing Home.

Our initial intervention included information gathering, outreach to existing service providers, education, and support and communication to all three adult children (living in California, Mass. and Israel). Our staff understood the issues of shame and privacy surrounding aging and were able to work with the family to gather the information necessary to apply for the assistance available from federal, state and city programs. We 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 live-in care.

Belle was welcoming of 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 NYC manner, Belle let me know: "*No offense, but if you can't give me anything, you are 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 circumstances to sacrifice her childhood to go to work to survive. That she was unable to provide for herself now, and was dependent on her children, was extremely painful for her. The decertification of the hospice program 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 eye and said, "*I would like you to be with me when I die.*"

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

We will continue to visit with Belle at home overseeing her care and helping <u>her</u> to explore her life experiences and find meaning and quality in her 99th year. As DFTA's EOL grant will be ending May 2010, we would like to ask the Health and Aging Committee to allocate funding for our program thru 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 just as immediate. And by providing assistance proactively, we reduce the use of more costly emergency care.

At JBFCS City council funding has been essential to our mission to educate, advocate, counsel, and direct individuals and families at the end of life throughout this 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 can not be put on hold. End-of-life care and all human services require continuity.

Thank you.

The New York Academy of Medicine

At the heart of urban health since 1847

Testimony by Cyril Brosnan
On Behalf of
The New York Academy of Medicine

Hearing before the Council of the City of New York
Health & Aging Committees

Oversight – End of Life Care

November 19, 2009

Thank you for inviting The New York Academy of Medicine to this important hearing on end of life care. The New York Academy of Medicine (NYAM) has been advancing the health of people in cities since 1847. An independent organization, NYAM 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 health; and working to eliminate health disparities.

The New York Academy of Medicine has a particular interest in end of life care. NYAM currently hosts the Cunniff Dixon Foundation's New York City Symposia on the Art of Medicine at the End of Life. These symposia provide physicians in all specialties with an overview of the current issues, ethical dilemmas, and best practices surrounding the end of life care. NYAM also host 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 on palliative care in medical education and worked to improve palliative care education in medical school curricula.

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 preferences for and 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 twelve out of thirteen studies (Cohen 2008). 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 (Smith, Earle and McCarthy, 2009; Baicker et al, 2004).

These studies point to the need to make certain that all individuals have access to high quality end of life care. While hospice care is a benefit covered Medicare, it is not covered by Medicaid. Unfortunately, research suggests that as much as 16-20% of New York city residents 65 and older are not covered by Medicare, and therefore, likely do not have access to high quality end of life care (Gray et al., 2006).

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 that 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 (Barnato et al, 2009); while another study found that African Americans are less likely than whites to want hospice services (Ludke and Smucker, 2007). 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.

NYAM has supported the work of the New York State Task Force on Life and the Law and their efforts to change state law to expand the authority of family members and others close to a patient to make decision 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 health care professionals. While advance directives can be effective in guiding family members and safeguarding the wishes of a person at the end of life, research strongly suggests that communities of color are less likely to know about and to have advance directives (Kwak and Haley, 2005). However, research also indicates that, given equal access to advance directives (such as in the Veteran's Administration system), African Americans were just as likely as whites to have made and documented end of life plans (Fischer et al, 2007).

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 be sensitive to the religious and cultural differences among individuals as well as their different relationships to family and to health care institutions (Dupree, 2000; Waters, 2000). 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 ought to have the opportunity and the information we need to make informed choices about the care we receive at the end of life.

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I represent: NYC HHC

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