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The Bomba Letter

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If you wish to highlight your work in elder abuse or palliative care or have items of interest to include in the next newsletter, please contact me at

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Welcome

As the summer comes to a close, I admit I have missed the opportunity for a slower pace and the opportunity to relax. The daily media coverage on national health care reform clouded by the "Death Panels", Google alerts on the MOLST Program and endless blogs with misrepresentation of the intent of HR 3200 Section 1233 Advance Care Planning Consultation have added a dimension to my life I could not have imagined.

These past few weeks offered a time for reflection on what has been accomplished by the efforts of the Community-wide End-of-life/Palliative Care Initiative and how much more is needed to overcome the death-denying culture in our society. Further, I have focused my energy on working in collaboration with a group of seasoned clinicians on developing a train-the-trainers program and an all-day conference to help providers "get it right and get paid for providing advance care planning for patients with serious illness."

To those of you who think I have missed an opportunity by not publishing a newsletter in the midst of this media frenzy, this issue is devoted to national health care reform. While I could broadly address the need for access to high quality affordable health care for all Americans, I plan to look at the truth about HR 3200 Section 1233 Advance Care Planning Consultation, address the misrepresentation of pages 424-434 of the 1017 page document and share stories that focus on the need for inclusion of this important issue in health care reform.

As a primary care internal medicine and geriatric specialist, I have focused my life's work on caring for frail elders and providing support for their families. I realize there is no easy answer. However, I believe access to affordable health care will not occur without addressing the need for:

- more primary care physicians and geriatricians in our country
- fairness in the reimbursement methodologies for those who provide primary care for those with multiple medical problems and frailty
- new models of care to address the care coordination and counseling needs of individuals with advanced chronic illness
- appropriate tort reform.

I extend a sincere and heartfelt thank you to the many readers who have written to provide support and encouragement for the work being done on advance care planning, palliative care and end-of-life care regionally, statewide and nationally. The Community-wide End-of-life/Palliative Care Initiative has engaged countless professionals and consumers who are working on implementation of the Community Conversations on Compassionate Care (CCCC) and Medical Orders of Life-Sustaining Treatment (MOLST) Programs. Last, but certainly not least, I thank those who have shared their personal stories in this edition of the newsletter and those who have contributed in the past. It is in the stories of fellow Americans we can best find the true need for HR 3200 Section 1233.

Pat

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Facts: Quality Improvement in End-of-life Care Needed

The need for quality improvement in care provided at the end of life and advance care planning consultation is not a new issue with HR 3200.

Discussions about the cost of care at the end of life are not easy and evoke emotion. Nonetheless, if we ever hope to achieve high quality, accessible and affordable health care, sooner or later we will have to confront the hard questions about access to expensive treatments. We must address these tough issues with the facts and look for ethical solutions that balance patient autonomy and social justice, remembering to "First, Do No Harm".

FACTS:

- Advance care planning is person-centered and based on an individual's goals for care. Conversations are best had at a time when a person can express what is important to them and understand the options.
- The wishes shared by the person must be available at transitions of care and honored by health care professionals.
- Surveys reveal 80-90% of individuals would prefer to die peacefully at home.
- The Dartmouth Atlas reveals large unwarranted regional variations in the percentage of deaths occurring in hospitals and unwarranted regional variations in Medicare spending at the end of life.
- High-spending regions provide more inpatient-based and specialist-oriented care; however, there is no improvement in health outcomes, including mortality rates, quality of care, access to care or patient/family satisfaction.
- Dollars are wasted on unwanted, unnecessary and futile treatments. Reducing the amount spent on ineffective treatments will help reduce the total cost of end-of-life care.
- More expensive care is not always better care. Recent research shows thoughtful advance care planning discussions result in less aggressive treatment, lower stress, earlier hospice referral and a better quality of life for the person who is dying as well as comfort and support for those who are grieving the loss of their loved ones. Higher costs were associated with worse quality of death and worse bereavement adjustment.
- Functional Health literacy, the ability to read, understand, and act on health information, is critical to making informed decisions regarding end-of-life care. There is a significant need for reliable information for all!
- Healthcare professional communication skills need improvement.

Fact: Advance Care Planning Consultations Needed

What would happen if you experienced a sudden illness that prevented you from making your own medical decisions? How would you assure that you receive the kind of care that you wanted? Would your family or loved ones know enough about what you value and believe to feel comfortable about making decisions about your care?

According to the End-of-Life Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions, Summary Report, 2008, nearly nine of ten local adults said it is important to have someone close to them making medical decisions for them if they were to have an irreversible terminal condition and were unable to make decisions. Yet, fewer than half had designated a "health care agent" to ensure their wishes are carried out.

Advance Care Planning is a process of planning for future medical care in case you are unable to make your own decisions. Each state has its own laws governing Advance Care Planning and the use of Health Care Proxy forms and Living Wills. Advance Care Directives from each state can be found at your state's Department of Health Web site or caringinfo.org. While advance directive documents differ in each state, the Advance Care Planning process remains the same.

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Healthcare and Community Collaboration Addresses Need to Improve Quality in End-of-life Care

On January 1, 1997, the Institute of Medicine released Approaching Death: Improving Care at the End-of-Life and issued a call to action to improve the quality of care Americans receive at the end of life. The report considers the dying experience in hospitals, nursing homes, and other settings and the role of interdisciplinary teams and managed care. It offers perspectives on quality measurement and improvement, the role of practice guidelines, cost concerns, and legal issues such as assisted suicide.

Gaps in care and quality issues identified include site of death, pain management, treatment preferences and hospice admissions. Palliative care professionals and advocates across the country have worked to bridge these gaps.

In response to the IOM Report, a joint Rochester Independent Practice Association (RIPA)/ BlueCross BlueShield of the Rochester Area (BCBSRA) Professional Advisory Committee was formed to collaborate and identify means of improving the quality of care at the end of life. A community-wide survey was designed and distributed to local hospitals, home care agencies, hospices, disease management programs and nursing homes. The Rochester community had significant quality gaps. However, with the input of more than 150 community volunteers, the Community-wide End-of-life/Palliative Care Initiative was launched to address these gaps.

Starting in 2001, the Community-wide End-of-life/Palliative Care Initiative developed a successful two-step approach to advance care planning with two award-winning programs to help individuals "Know Your Choices and Share Your Wishes."

- Community Conversations on Compassionate Care (CCCC) Program
- Medical Orders for Life-Sustaining Treatment (MOLST) Program

These programs recognize individuals facing serious life-threatening illness and approaching death deserve to be treated with dignity, respect and compassion and to receive care that is focused on the individual's goals for care. Families need and deserve to receive support. Yet too many dying people suffer unnecessarily. While an "overtreated" dying is feared by many, untreated pain and/or emotional abandonment are equally frightening.

To achieve their goals, individuals need to plan ahead, know their choices, make sound decisions and share their wishes with their loved ones and health care professionals.

This approach, adapted for New York, aligns with the National Quality Forum's Framework and Preferred Practices for Quality Palliative Care & Hospice Care:

- Document the designated agent in a Health Care Proxy for every patient in primary, acute and long-term care and in palliative and hospice care.
- Document the patient/surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as condition changes.
- Convert the patient treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital, i.e., the Medical Orders for Life-Sustaining Treatment—MOLST, a POLST Paradigm Program.
- Make advance directives and surrogacy designations available across care settings
- Develop and promote healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals (e.g. Respecting Choices and Community Conversations on Compassionate Care.)

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National Health Care Reform

It is imperative that national health care reform initiatives recognize, and be based upon, the value of informed discussions between patients and their health provider that focus on the patient's goals for care and guide the patient's treatment preferences for their last months and years of life. Further, once these tough conversations occur, it is essential that health care professionals follow these medical orders in an emergency. This is the essence of the "Orders for Life-Sustaining Treatment" Program. It is about honoring patient preferences for care and not about "Death Panels" or euthanasia. The Community-wide End-of-life/Palliative Care Initiative has made significant strides in addressing advance care planning consultations through:

1. Community Conversations on Compassionate Care (CCCC) Program

The CCCC Program is an award-winning program that combines storytelling with "Five Easy Steps" to promote conversations that help you complete your Health Care Proxy and Living Will. Healthy individuals learn why they should complete their advance directive through using a collection of Advance Care Planning resources on-line, reading the Advance Care Planning booklet, or viewing an array of Community Conversations on Compassionate Care videos that illustrates stories from real patients and families and explains the Advance Care Planning process using the Five Easy Steps:

1. Learn about Advance Directives
2. Remove Barriers
3. Motivate Yourself
4. Complete Your Health Care Proxy and Living Will
    - Have Conversations with Your Family and Health Care Provider
    - Choose the Right Health Care Agent
    - Discuss Your Values, Beliefs and What is Important to You
    - Understand Life-Sustaining Treatment
    - Share Copies of Your Completed Advance Directives
5. Review and Update

2. Medical Orders for Life-Sustaining Treatment (MOLST) Program

The Community-wide End-of-life/Palliative Care Initiative developed the Medical Orders for Life-Sustaining Treatment (MOLST) Program, New York State's Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program. Collaborators across New York are working on statewide implementation.
On July 9, 2008, Governor David A. Paterson signed into law a bill that helps to ensure a person's end-of-life wishes are followed whether the person is at home, in a nursing home or in any other non-hospital setting. The new law amends NYS public health law and permanently permits use of the MOLST form in the community throughout New York State. In signing the legislation, Governor Paterson said, "People should be allowed as much say in their end-of-life care as they would have at any other time. This bill will allow many people who are critically ill to make enduring decisions on the care they will receive. These will be difficult decisions for every person to make, but they should have the freedom to make them."

3. Physician Reimbursement for Advance Care Counseling

Currently, physicians do not receive adequate reimbursement for having thoughtful conversations on advance care planning. CMS, the major agency that oversees Medicare and Medicaid, only pays for face-to-face conversation with a patient and does not compensate for non-face-to-face time with family, surrogate decision-makers or patients who lack capacity, in the absence of face-to-face discussion. Key physician leaders are attending the "Beyond the Health Care Proxy: Advance Care Planning for Patients with Serious Illness" conference in November to learn how to get it right and get paid for having thoughtful advance care planning conversations with their patients with serious illness. This conference is presented and developed by the Unwarranted Clinical Variations in End-of-life Care Workgroup jointly led by the University of Rochester Medical Center and Excellus BlueCross BlueShield.

4. Overcoming Functional Health Illiteracy

Nationally there is a lack of consumer education, tools and resources provided or made available to patients and families on advance care planning. The Community-wide End-of-life/Palliative Care Initiative developed the CompassionAndSupport.org Web site in 2002 to educate the community on advance care planning, MOLST, palliative care, pain management and hospice care and related topics. Through the generous funding of the Medical Society of the State of New York and Excellus BlueCross BlueShield, the Web site was enhanced in 2007. A new section for Professionals was added and the section for Patients and Families was improved. Since the launch of the upgraded Web site, we have received 95,946 visits or hits with over 332,046 pages. Half of the visits are from New York State, with the remaining from the other states and 132 other countries.

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Personal Stories Highlight the Need to Retain Advance Care Planning Consultations in Health Care Reform

Afternoon Tea with Lady Fern

"You will never be the best physician you are meant to be, unless you become comfortable talking to your patients about death. It is our death…not your death."

Pat Bomba, M.D.

After four years in academic medicine, I launched a private practice in Internal Medicine and Geriatrics in 1983. I worked as a medical director in a local nursing home where I also served as the primary physician for approximately 90% of the nearly 250 patients. It was there that I met Lady Fern, a woman who changed the course of my professional life.

Shortly after I started at the long term care facility, Lady Fern invited me to have tea and conversation. She spoke on behalf of the ladies in the health related facility and told me, "You will never be the best physician you are meant to be, unless you become comfortable talking to your patients about death. It is our death…not your death." While initially shocked, I also realized I had not fully dealt with my own father's death three weeks before my medical school graduation. Further, in my eyes "death was failure" and my job was to cure and save lives.

She indicated that she never wanted to go to the hospital…another foreign concept. She wanted to die at her "home", meaning the health care facility where she resided. Through our lengthy conversation, she taught me that a patient's goals for care guide the choice of interventions as well the skill of negotiating her own goals for care.

A few weeks later, she sustained a heart attack. In the midst of our conversation, I recommended hospitalization. She chided me, "Did we not have this conversation? Did I not teach you anything?" I contacted her family who came in promptly. After briefing them, their first question was, "What does mom want?" They taught me the value of having an antecedent conversation. After informed, patient-centered, goal-based, shared decision-making, Lady Fern was transferred to the skilled nursing floor. She did well and returned to her regular room after she stabilized.

Based on this encounter, we developed the first set of Treatment Guideline forms in Rochester, a pre-MOLST form in 1983, and developed a process of regular discussions with patients and families, ahead of time before the crisis when people can think more clearly about what is important to them.

Follow My Mother's Advice: Conversations Change Lives

"Death is difficult for all of us. Conversations helped me and my family during my mother's final days."

Pat Bomba, M.D.

My mother was a devout Catholic. When Patient Self-Determination Act was passed, she spoke to me about doing her PA Durable Power of Attorney for Health Care. We began our Thanksgiving tradition of having candid discussions about what our wishes are for end-of-life care. We knew exactly how our loved ones want to be treated if they can't speak for themselves. It's yet another reason to give thanks.

My mother lived with us during the last 15 months of her life. She was forgetful and not able to safely live in her home. She still had the ability to make health care decisions and completed a MOLST form. Her goal was to still visit her children and grandchildren who lived outside Rochester; she also wanted to have a natural death and not die "hooked up to machines." Her MOLST form reflected orders for Do Not Resuscitate, Do Not Intubate, No tube feedings, Accept Limited Interventions and Hospitalization. She became ill during a visit to Pennsylvania and required hospitalization. She received treatment for a kidney infection including fluids and antibiotics by vein. She was also found to have extensive abdominal lymphoma, a type of cancer.

She returned to Rochester. Her goals for care shifted to focus on ensuring the best quality of life. She chose Hospice care and her MOLST form was changed to reflect Comfort Care. Her desire for food diminished as time progressed. The aroma of her favorite foods cooking brought comfort, even if she ate little. She thanked me for not forcing her. Five days before her death, she supervised the aide baking her favorite bread while I traveled to Albany to present the results of the MOLST Community Pilot to state EMS leaders. She died peacefully in our home five days later, after 3 months of hospice care. Death is difficult for all of us, even for an end-of-life expert. Conversations over the years at our Thanksgiving dinner table helped me and my family during my mother's final days.

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Personal Stories Highlight the Need to Retain Advance Care Planning Consultations in Health Care Reform

She Made Her Own Decisions for Her End of Life

"It is important to know that only you are in control of your life's destiny and through Advance Care Planning, your end of life destiny will also be fulfilled."

Julie Perry

This November will be three years since my mom died; it is truly hard to believe that I have not spoken with her since. Our relationship was open, loving and frank. We talked everyday, and talked about just about everything. As her health diminished, and she was in and out of the hospital more often, I felt it was not only VITALLY important to discuss what she wanted after she died, but how she wanted to go.

With the green light from Mom she agreed to complete her advanced care directives / MOLST, which gave her the peace of mind that her wishes would be carried out.

Little did I know that just a few months later Mom would be hospitalized for her final time.

Because my mom had made her end of life wishes known, her family as well as her health care providers knew what she wanted when the time came. There was no confusion, decisions, conflict or guilt on what to do. My mom… who always had control in her life decisions, made her own decisions for her end of life.

With media attention on health care reform today more than ever, regardless of your position on the subject, it is important to know that only you are in control of your life's destiny and through Advance Care Planning, your end of life destiny will also be fulfilled.

View Julie's full story in the MOLST video, "Writing Your Final Chapter: Know Your Choices. Share Your Wishes."

Completing the MOLST Forms to Ensure that My Father's Wishes Were Followed

"As difficult as it was to lose my hero, I take comfort in the fact that he died peacefully and lovingly. We should all be so lucky."

Flora Allen

In the early 80's, my father announced that he had been diagnosed with Parkinson's disease. Not knowing much about it, I researched Parkinson's on the internet and found that this disease not only takes a toll physically, but it takes a toll in terms of Dementia. My father did well until the late 1990's when he was placed in a nursing home. As his health deteriorated, it became obvious that he would be unable to make his own healthcare decisions. I began discussions with my family about completing the MOLST forms to ensure that my father's wishes were followed. Although it was a difficult process for my mother, she soon understood the importance of having the MOLST form.

My father passed away in 2005 as we held him in our arms. His room was filled with other family members including his nurses and nurses' aides. As difficult as it was to lose my hero, I take comfort in the fact that he died peacefully and lovingly. We should all be so lucky.

View Flora's full story in the MOLST video, "Writing Your Final Chapter: Know Your Choices. Share Your Wishes."

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Personal Stories Highlight the Need to Retain Advance Care Planning Consultations in Health Care Reform

She was at peace with her choices

"My mother chose the way she wanted to end her days."

Ellen Sorce

A year has come and gone, since my mom passed away. Before we met with the doctor and received her diagnosis of esophageal cancer, our family sat down with her, to go over advance directives paperwork. In a conversation with six family members, she told us exactly how she wanted to spend her last days. She entrusted her wishes to me and to my youngest daughter, to ensure her passing was what she wanted, if she could no longer speak for herself. She filled out her Health Care Proxy and Living Will forms, and they were signed and witnessed.

When we received the diagnosis, we reviewed her paperwork, and completed a MOLST form, which was signed by her physician. Her decision was to refuse surgery, chemotherapy and radiation. She wanted to be comfortable and pain free, in her own home. She knew she had the option of changing her course of treatment at any time.

I thank God so many of us heard her words and we had this in writing. Well-meaning family members did not agree with her decisions and wanted her to use every means available to survive. She had already discussed survival rates with her doctor, and was at peace with her choices. I was charged with making sure that those wishes were met.

When people told me they were sorry she was gone, I thanked them, but told them it really was okay. The hospice nurse and aids were wonderful, helping her and our family. Her passage was beautiful. My mother left comfortably, at home, with her cat on her bed. If I had never done anything for her, at least I made sure she ended her days in peace.

At the End, Offering Not a Cure but Comfort

The New York Times, published by Anemona Hartocollis, August 19, 2009

Dr. Sean O'Mahony, a palliative care doctor caring for patient, Deborah Migliore, in the Bronx tells their story of working together to ensure her medical wishes are honored. Dr. O'Mahony discusses how he supports and informs Deborah of all her treatment options, in Deborah's time frame making certain she understands these are solely her decisions knowing she can alter them. Read Full Article.

Sisters Face Death With Dignity and Reverence

The New York Times, published by Jane Gross, July 9, 2009

Read the stories of The Sisters of St. Joseph, who resides in the Mother House in a suburb of Rochester NY. The elderly and infirm Roman Catholic sisters live life fully and die peacefully. As Sr. Mary Lou Mitchell points out, "We approach our living and our dying in the same way, with discernment." Read the full article.

Healthy Individuals Need Advance Care Planning Too!

Community Conversations on Compassionate Care (CCCC) Program is an award-winning program that combines storytelling with "Five Easy Steps" to promote conversations that help you complete your Health Care Proxy and Living Will. Learn why healthy individuals should complete their advance directive by viewing an array of Community Conversations on Compassionate Care videos that illustrates stories from real patients and families and explains the Advance Care Planning process using the Five Easy Steps or through using a collection of Advance Care Planning resources on-line or reading the Advance Care Planning booklet.

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2009 Calendar of Events

For detailed information on events, view our Events page.

Sept. 16-17	**Adult Abuse Training Institute: Applying the Bucket List: End-of-Life Care Best Practices,** Albany, NY
Sept. 18-19	**Hospice and Palliative Care in Developing Countries,** Fresno, CA Brochure & Registration
Sept. 30	**MOLST Conference – Capital District,** Latham, NY Save the Date & Brochure & Registration
Oct. 4-6	**Distinctively Blue Conference**, Atlanta, GA
Oct. 9	**National Association of Catholic Chaplains Education Day**, "A Two-Step Approach to Advance Care Planning: The Community Conversations on Compassionate Care (CCCC) and the Medical Orders for Life-Sustaining Treatment (MOLST) Programs", Buffalo, NY
Oct. 13	**In-service for Lifespan Ombudsmen Volunteers** "Honoring Preferences for Care at the End-of-Life: Recognizing the Value of the MOLST Program", Rochester, NY
Oct. 14	"**Advance Care Planning and the Role of MOLST"** Presentation to Rochester Rehab Stroke Support Group, Rochester, NY
Oct. 15-17	**37th Annual Conference for the State Society on Aging of New York: Caregiving and an Aging Population,** Rochester, NY Save the Date
Oct. 15-18	**Vital Signs Conference, New York State EMS Conference,** Rochester, NY
Oct. 16	**Campaign for Quality Conference,** Faxton-St. Luke's, Utica, NY
Oct. 22	**Aaron and Sarah Franzblau Institute for Continuing Education "**Translating Patients' Wishes into Medical Orders: The POLST Paradigm", Daughters of Israel Plafsky Family Campus, West Orange, NJ
Nov 1	**Best Care Practices in the Geriatrics Continuum 2009**; "Translating Patients' Wishes into Medical Orders: The POLST Paradigm," Lake Buena Vista, FL
Nov. 7	**"Beyond the Health Care Proxy: Advance Care Planning for Patients with Serious Illness" Conference,** Rochester, NY
Nov. 8-11	**AAHSA Annual Meeting & Exposition,** Chicago, IL "Honoring Preferences for Care at the End-of-Life"
Nov. 13	**Westchester End-of-Life Consortium Conference,** Westchester, NY
Nov. 19	**Palliative Care Conference,** New Hartford, NY "Honoring Preferences for Care at the End-of-Life: Recognizing the Value of the MOLST Program"
Dec. 7	**Roswell Pastoral Care Series,** "A Two-Step Approach to Advance Care Planning: The Community Conversations on Compassionate Care (CCCC) and the Medical Orders for Life-Sustaining Treatment (MOLST) Programs", Roswell Park, Buffalo, NY

If you know of other events related to Elder Abuse or Care at the End-of-Life, please forward them to me, and I will add them to our calendar of events for the next edition of this newsletter. Thank you.

Access archives of prior publications of "The Bomba Letter."

For further information on Elder Abuse and Long Term Care, visit MedAmerica's website.
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