

# THE IMPORTANCE OF HOSPICE



## IN END OF LIFE CARE

*The experience of Barbara Mallon Lombard and her family during her last illness with Acute Myeloid Leukemia*

John J. Lombard, Jr., Esquire

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*The experience of Barbara Mallon Lombard and her family during her last  
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by  
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Blue Bell, Pennsylvania



This is a tribute to the memory of my wife, Barbara Mallon Lombard. Barbara died this year on July 26<sup>th</sup> at age 67. She was diagnosed with anemia in early March, and acute myeloid leukemia (AML) in mid May. Based on the weekly meetings with her doctors after the hospitalization when she was diagnosed with anemia, that final diagnosis was not unexpected. She was hospitalized in mid June for two weeks. When the blood and platelet transfusions were not working by the end of June, the decision regarding Hospice had already been made. The treating physicians at Pennsylvania Hospital and its affiliate at the University of Pennsylvania Hospital (HUP) were very supportive of the earlier decision regarding Hospice, which had been made in early June. One of our best friends, Edward D. Viner, MD, a hematologist, spent 2 hours with us then reviewing the options before Barbara indicated her decision and remained available for further discussion as the consequences of her illness became more evident.

Barbara was a mother of five (5) and grandmother of ten (10). She was her children's best friend and she was an active part of their life. She was "Meme" to her grandchildren who ranged in age from 2-1/2 to 18 and played an important role in each of their lives. She hardly ever missed a dance recital, a baseball, basketball, soccer or football game, or an event at one of their schools. When three of her grandsons lived in Connecticut, she was a "Hockey Grandmom". Play days with Meme were a major and frequent event for the younger grandchildren. She had a wide circle of friends and loved to travel and had a long list of places still unseen. She enjoyed fishing and held the family record for many years with a shark caught in Bermuda. She had taken up needlepoint 20 or more years ago and was an expert at her craft making dozens of Christmas ornaments, art in needlework and handcrafted rugs. Her production could have supported a commercial enterprise, but instead grace the homes of her family and friends. She also wrote poetry and had become addicted to the new craze - Sudoku. Barbara had an intense love of life. She had traveled the World. We had and have a wonderful family and were looking forward to those golden years and expected many years to come. Unfortunately, that was not to be as God had other plans which did not take long to unfold.

Barbara's sister Peggy died 4 years ago at the age of 59 from ovarian cancer. She'd battled ovarian cancer for 5 years before it took over. She was treated at the same hospital and elected to have every life sustaining treatment possible, including TPN[2] in the two weeks before she died. (That lasted about two days and never should have been started). She elected every clinical trial that was offered in the 5 years of her illness. Barbara, Peggy's one daughter, Megan, who is an RN, and our youngest daughter Barbara were the primary caregivers for Peggy during her long illness and many hospitalizations. They all endured an awful lot in those years. Barbara made it clear to Ed Viner, our doctor friend, that was not a road she wanted to take. A mini bone marrow transplant was discussed and recognized as a possible life extending treatment with obviously some severe morbidity risks to get to the point where the transplant could occur. Barbara made it clear, she knew what lied ahead.[3] The entire care team, knew what she wanted and was supportive to the end with the most compassionate care.

Fortunately, we had time to evaluate the available Hospice programs in the Philadelphia area and selected Holy Redeemer Hospice. They were ready when Barbara was discharged from Pennsylvania Hospital in late June and she was set up at home with oxygen and the care she needed. With the support of the Holy Redeemer team and the moral support of the physicians and other care givers, she set about seeing her close friends and family, particularly the grandchildren, and these visits were much of the daily routine. With her priest she planned her funeral to the last detail. She gave Fr. Dave a copy of the book *When God Winks* which he made a central part of her funeral service and his homily. She planned her Mass to the last hymn, including *An Irish Blessing*. (We had spent a month in Ireland in October 2007 and some of our close Irish relatives came over for the funeral service). She left instructions to "keep it simple". Not sure we exactly followed that instruction, but for the most part we followed her instructions as closely as she suggested. She faced death as a part of life. (I know everyone doesn't necessary look at death quite that way, but she was a realist).

She died at home in the early morning of July 26<sup>th</sup>, in her own bedroom, surrounded by me and our five children. None of this would have been possible without the early recognition and evaluation of her diagnosis and the compassionate care of the physicians who were involved in her treatment. We all have seen situations where Hospice is not offered, or when offered is offered too late in the illness when the patient is less likely to receive the compassionate end of life care that Hospice is designed to provide. The recent Dartmouth Study[4] makes that all to evi-

dent with its conclusion that there is too much “aggressive” treatment at the end of life and the transfer to compassionate, hospice care is either delayed too long or not offered at all.

This past Saturday, I had my first contact again with our Hospice Team at a Memorial Service that Holy Redeemer provided for those who had recently died in the care of its team of RNs and other support personnel. It was a moving service, but even more so was my surprise to see the several hundred names of patients who had benefited from their Hospice care over the last seven or eight months in the Philadelphia area. Even though I have been involved in health care at the end of life issues as the Chairman of an ethic network and a member of the Advisory Board at the BioEthics Center at the Hospital of the University of Pennsylvania, I had no idea that so many end of life patients were receiving Hospice care in our immediate area. There were at least 40 families who came to the service from all walks of life. It was moving to see the gratitude of those families for the care which their loved ones had witnessed through the efforts of Holy Redeemer Hospice. While often not realized to its full impact is the fact that Hospice is a benefit to the patient and the patient’s family which continues after the death of their loved one and that family support is recognized by events for the family members such as the memorial service.

Clearly there is much to do in encouraging greater use of and access to hospice care. Realistically there always will be, but the further recognition and promotion of the benefits of hospice care will make available to all end of life patients the dignity and respect as each of them pass through the inevitable final stages of their life on this Earth. The Hospice personnel also need the support and recognition of their important contribution to this effort without which these patients may very well remain in the hands of technology which has lost its benefits when it is compassionate care they need. While implicit obviously in this discussion is the cost of health care, the appropriate use of compassionate care, when it is recognized that continuing use of technology is no longer appropriate, should have an appropriate impact on health care costs and in my judgment appropriately so. I have deliberately restrained from using the word “futile” but that is nothing more than saying, we have arrived at a point where the continued use of this treatment can and will not have any continuing therapeutic benefit. If it won't why should it be offered, or if accepted, continued like the TPN in my sister-in-law's case?

All adults should have an Advance Directive which appoints a person or series of persons they trust to act on their behalf in making medical decisions of all types when they can no longer provide informed consent for their own medical care. The most important part of that process is the selection of the Agent you trust to make those decisions when the patient no longer can. While some persons may have a condition or moral view requiring specific directions, i.e., no blood products for a person of the Jehovah's Witness faith, except in such cases, consider allowing your Agent to make your decisions without tying their hands with detailed instructions about care you may or may not want. In reality, it is highly probably that you will not know long in advance the kind of illness you may have or the treatment you will need. Advance Directive forms often will ask you whether you want this or that, asking for a yes or no answer. Despite the question posed and the inferred assumption that it can be answered yes or no, in most cases the answer is likely to be “You don't know”. In difficult cases consulting with the individual's regular physician is desirable. Barbara had an Advance Directive of this non specific type. It was never needed as she remained competent and conscious until a few hours before her death in her final sleep. If it would have been needed, as her appointed Agent, I knew clearly what she wanted and those wishes would have been honored as they should have been.

Patients faced with impending death deserve the choice of realistic care. Patients need education of what that realistic care may be. Patient families need to be part of this educational process. Advance Directives should be reviewed or prepared at any serious diagnosis. Often times there is a disconnect between the form of Advance Directive language, whether prepared by a lawyer or not, and the reality of the patient situation and likely care needs. Those who prepared these documents, whether forms or advance directives for individual patients and clients, need to have an understanding of the care and treatment that the patient might need to undergo in a specific illness situation. This is particularly so when the patient has an unusual condition or is likely to consider treatment like TPN which will only involve a small percentage of patients. I have often suggested that the lawyer who prepares Advance Directives, Powers of Attorney for Health Care, or whatever you want to call them, should have a doctor friend to consult about their general forms and particularly specific situations that can arise in chronic illness situations.

In closing with my random thoughts arising from my own experience during my wife's illness, the advancement of the Hospice concept and compassionate care of the terminally ill persons, must be an intense and collaborative effort of the medical profession, the health care community as a whole and the legal community as well. The concerns of the Dartmouth Study that there is more technology in end of life care than there should be deserves attention and correction.

End of life care is not a time, for example, for myths about legal liability making the deferral of compassionate care necessary. It is a time when end of life care includes hospice care as a standard option and a clear advancement of its advantages. The health care community should and must make the benefits of hospice care available as standard practice for their terminal patients and not defer its consideration until there is little of the patient's life left to derive any real benefit. While some states have considered mandating the discussion of hospice as an option, it is far better if hospice is like any patient care option to be discussed with the patient (or the patient's agent) by the health care professionals. Mandates from a legislature in medical care generally and particularly in end of life care should be unnecessary and inappropriate. A race to the state legislature is inappropriate. This is a consistent and firm strong position I have expressed over a long period of time. There are other options to legislation. Good practice guidelines, protocols, and in some instances, regulations and similar efforts within the health care community represent a more appropriate means of addressing medical practice before seeking the help in the State House and putting a new law on the books.

My wife, Barbara, was the beneficiary of that kind of advice and support and received the compassionate care that only Hospice could provide. There is no reason why all patients who face similar terminal diagnoses should not have the same advice and receive the same opportunity for Hospice care. The benefits to the patient's family should not be overlooked as well. Our best efforts must be directed at making it so.

[1] John J. Lombard Jr., is Senior Counsel to the Firm of McCarter & English LLP, in its Philadelphia office. He has been involved in the consideration of patient rights and decision making at the end of life since shortly after the decision by the Supreme Court of New Jersey in *In re Quinlan* in 1975. He is a former Chair of the Real Property Probate & Trust Law Section of the American Bar Association (1990) and President of the American College of Trust & Estate Counsel Foundation (2005-2007).

Mr. Lombard has written and lectured extensively on rights of patients and particularly on issues related to end of life decision-making. He is a Co Founder with Edward D. Viner, MD and Sally Nunn, RN of the Southern Jersey Ethics Alliance, a consortium of hospitals and health care facilities in Southern New Jersey concerned about end of life issues; he is a consultant to KEOL Kidney Coalition, Midlothian VA which is a group which promotes the advancement of end of life care to kidney dialysis

patients; he serves as a consultant to the Medical Society of New Jersey; and served for over 10 years as a member of the Advisory Council to the BioEthics Center at the Hospital of the University of Pennsylvania. (HUP) He wrote and argued the Amicus Brief in *In re Fiori*, 673 A.2d 905 (Pa. 1996) for HUP in which the Pennsylvania Supreme Court sustained the right of a mother to terminate tube provided nutrition and hydration to her son, who had no advance directive, after being maintained in this manner for over 22 years. Mr. Lombard's articles on end of life care appear in many legal and medical publications.

[2] Total parenteral nutrition (TPN) nutrition maintained entirely by central intravenous injection or other nongastrointestinal route. It is administered by providing TPN directly into the blood stream as there is no ability of the intestines to absorb the benefits of the artificial nutrition provided by tube, etc. By a surgical procedure, a line is put into the artery near the clavicle so that the nutrition supplement goes directly into the blood stream.

[3] *The New York Times* on November 6, 2008 had a lead article about the recent DNA identification which resulted from a donation of cancer cells from a now deceased patient. That patient was suffering from the same type of leukemia that Barbara had and the article indicated that 13,000 persons in the U.S. receive this diagnosis each year and 8,800 die. The older the patient the higher the probability of dying as the options like transplantation diminish with older patients.

[4] The Dartmouth Atlas of Health Care, entitled *Tracking the Care of Patients with Severe Chronic Illness*, was published in April, 2008. The Atlas is an extensive study of the treatment of chronically ill and end of life patients throughout the country and reaches the conclusion that geography plays a large part in the care provided but more importantly there appears to be an overabundance of care to these patients when the care provided has little or no therapeutic value. Clearly, a greater use of hospice and earlier decisions as to its use, should assist in reversing some of the concerns set forth in the Dartmouth Study.