

## A Lasting Gift: Organ Donation

Lucille Marchand, MD BSN

*Editor's note. This essay is a collaborative piece coauthored by Dr. Marchand and a patient, who will be referred to as Dr. B for the purposes of this article. Dr. B and his wife reviewed, edited, and approved this essay. Dr. B wished to remain anonymous but considered this narrative of his life and struggle through amyotrophic lateral sclerosis (ALS) as a gift to AAHPM Quarterly readers.*

*This case explores organ donation issues specific to this patient's situation. Organ donation is a valuable gift and this article does not intend to imply that organ donation causes suffering or leads to frustration. Every situation is unique.*

Dr. B is a 55-year-old male with end-stage ALS who wishes to donate his organs at the end of his life. He is a physician and athlete and was in excellent health before his ALS diagnosis. He is currently receiving hospice care, including nursing care and social and bereavement services. He lives with his wife and daughter, and his wife is his primary caregiver. They have a supportive network.

Dr. B worked until 2 months ago when he became more disabled. His symptoms include generalized profound muscle weakness, and he is unable to care for himself. Morphine is his main intervention, primarily for breathing difficulties. His spirituality is important to him, and he relies on meditation for comfort and strength.

When the patient originally expressed an interest in organ donation, his hospice team contacted the university organ procurement team. They felt that organ donation might be possible, and his hospice team was very supportive. Their plan provided that the patient would be admitted to the hospital during his terminal respiratory event; then, he would be a full code and intubated in the emergency room, moved to the intensive care unit, and extubated when the organ procurement team was ready in the operating room.

If Dr. B had a cardiac death within 2 hours, his organs would be harvested at time of death. If not, he would die in the usual manner. There was a case report that this approach had worked with another man who had ALS. That man had accidentally been put on a ventilator against his wishes during his terminal respiratory event, and when he was extubated, he died within the critical 2-hour window and some of his organs were successfully harvested. The hospice team felt the plan was achievable and that the patient would find additional meaning in his life through this generous act.

*Dr. B: I'm a physician, but I don't do direct clinical care. I work as a medical consultant for the Social Security Administration. My colleagues at work have been very supportive in accommodating my disabilities so that I*

*could continue my meaningful work. I've taken good care of myself; I enjoy backpacking, biking, and skiing. I love almost any activity outdoors. It's ironic that my muscles would be the problem here—now I can't even scratch my nose. When I was in medical school, ALS was a disease that scared me. Being locked inside your body with a fully alert and normal mind seemed unimaginable. I still can't believe this has happened to me.*

*People are very kind. My wife in particular cares for me so well, and I wanted to make a significant contribution with my life. My organs are healthy. Organ donation would give life to others and make all this suffering worthwhile. My body has been such a "marvelous toy"—a gift.*

*What keeps me strong is my spiritual path. The mantra (meditative prayer) of my spiritual path plays in my head constantly, giving me enormous comfort. Otherwise, I think I would go crazy.*

I'm a planner. I see planning as good. Usually, there is no down side to planning. Until now.

Dr. B wanted to be admitted to the hospital for his terminal event. Planning for the terminal event for ALS can be tricky. If we didn't get it right the organs might be damaged prior to our intervention of ventilator support. Dr. B's wife might feel enormous pressure in her role of calling the ambulance at exactly the right time during a "terminal event." And if she didn't, would she feel negative feelings about not being able to fulfill her husband's dying wish? And if she did get it right, would she rob him of a peaceful death? And if he did get to the hospital, would the ensuing chaos, despite a plan, cause him and his family suffering? Would a pulmonologist feel comfortable intubating him for the intention of organ procurement, rather than as a therapeutic intervention for the patient? How would the hospital staff respond to this plan? Would many of them question our interventions? Would some refuse to participate?

Although supportive, the patient's pulmonologist had already excused himself from the case because he was uncomfortable with the plan. There was no identified doctor to take his place. How would his family feel in the midst of this plan? Would he die a peaceful death or one full of suffering? How long after cardiac death would we wait if he did die in less than 2 hours? Would he get to the operating room (OR) and possibly have organs damaged by his terminal event that would not be viable? Would his family be able to be present with him in the

OR? What memories would they be left with of his final hours? If this all failed, would they feel that they failed their loved one? Would he be medicated properly for his breathlessness? If he was, would someone question whether we hastened his death? Would his family wonder about this if he died within the 2-hour window?

I feared a miserable death for him, with a slim chance of success. We convened three ethics committee meetings and the unanimous recommendation was to not recommend this plan due to the logistical challenges of ensuring a successful dying process and organ donation. We learned a lot in the process. Conversations were rich with discussion of therapeutic intention and peaceful and meaningful dying. We wanted to support the family with whatever course they chose but felt full disclosure of the risks and benefits of the plan to the family was ethically important.

*Dr. B: I had no idea my plan was complicated. We had a family meeting with the hospice chaplain, hospice physician, and Dr. Marchand. They talked about the ethical and*

*clinical issues involved with our plan. They also thought about my comfort and my family's well-being through this time. We talked about all the ways this dying process could be a gift for me, my family, and friends. My organs weren't the only gift; I had given so much in my lifetime. I hadn't thought about that. I feel more at peace now, having made the decision. I'd like to donate but don't want to put myself or my family through a difficult dying. I want the best death possible. I love life, and I love living. I want the mantra to guide me through this process of dying.*

Our patients' wishes are so important to us. The gift can be the conscious living of each moment in love, connection, and appreciation. "Om namah shivaya. Sad gurunath maharaj ki jah." To life, to the guru, to god, who lives within. 🍷

*Lucille Marchand, MD BSN, is medical director of the St. Mary's Hospital Inpatient Palliative Care Service in Madison, WI, professor of family medicine at the University of Wisconsin School of Medicine and Public Health, and clinical director of integrative oncology services at the University of Wisconsin Carbone Cancer Center, Madison. Contact her at [Lucille.Marchand@fammed.wisc.edu](mailto:Lucille.Marchand@fammed.wisc.edu).*



Continue the conversation at [aahpmblog.org](http://aahpmblog.org).

## Palliative Care Physicians



# Finding Balance

live | work | relax

*HealthCare Partners Medical Group is a multi-specialty medical group that is recognized for its quality of care and high rates of patient satisfaction. HealthCare Partners has over 4,000 employees, including 700+ primary care and specialty physicians, caring for more than 750,000 patients throughout Los Angeles County and Northern Orange County. HealthCare Partners operates 50 medical clinics, five urgent care centers, two medical spas, and an ambulatory surgery center. If you're looking to make a difference with a large, financially stable, well recognized, privately-owned Medical Group, HealthCare Partners is the employer for you!*

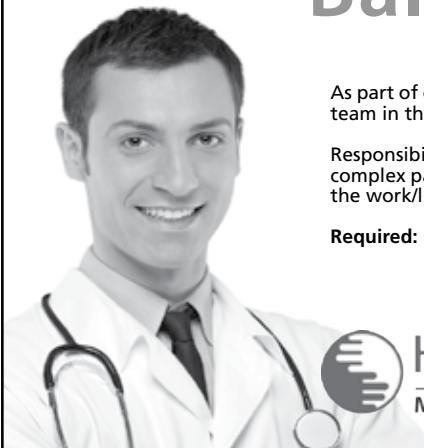
As part of our continued growth, we are currently seeking outgoing **Palliative Care Physicians** to join our team in the Pasadena and Los Angeles areas.

**Responsibilities:** In this team environment, you will have the opportunity to provide care and support to complex patients with chronic co-morbidities, work in a multi-disciplinary medical group while achieving the work/life balance you've been looking for!!

**Required:** Candidates should be Board Certified in Palliative Care or Internal Medicine.

For immediate consideration or to learn more about our company, please email your CV to George Eckhardt at [geckhardt@healthcarepartners.com](mailto:geckhardt@healthcarepartners.com)

You can also visit us at:  
[www.healthcarepartners.com](http://www.healthcarepartners.com)



**HealthCare Partners.**  
Medical Group and Affiliated Physicians