

IS THERE A RIGHT TO *USELESS* MEDICAL TREATMENT?

by Leah Curtin RN PhD

On March 11, 2005, the *Boston Globe* ran an article bylined by Liz Kowalczyk entitled, "Hospital, family spar over end-of-life care." The gist of this article, which is well worth your time looking up, has to do with a 79 year old woman who is now completely paralyzed from Lou Gehrig's disease. "Knowing that Lou Gehrig's disease would slowly cripple her before killing her, Barbara Howe repeatedly told her daughters and doctors and nurses to do whatever it took to keep her alive as long as she could appreciate her family. Like many patients, Howe had numerous conversations with her family and doctors about end-of-life care. Even so, she became stuck in a limbo no one foresaw: unable to make the slightest gesture while her doctors and daughters argue in court about whether she still

wants to live given the advanced stage of her disease since she last communicated more than two years ago.

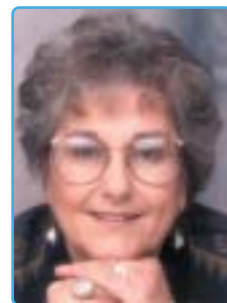
She has not left Mass. General since she was admitted on Nov. 15, 1999, but Blue Cross and Blue Shield of Massachusetts stopped covering her hospital stay nearly two years ago. Moreover, the patient's longtime doctors and nurses believe she is in pain and that keeping her alive is tantamount to torture. The patient's oldest daughter, who is her mother's healthcare proxy, disagrees, saying her mother still recognizes family members when they enter the room and would not want to die at this point. When she senses that her mother no longer appreciates her family, she would be willing to have the ventilator turned off.

"Doctors and lawyers who specialize in end-of-life treatment say Howe's case represents a shift in American medicine, the result of patients and families who are more educated and opinionated about healthcare, and more suspicious that doctors may deny care because of costs." the article notes.

In August 2000, the patient told her doctor that being alert was more important than eradicating pain even though she had constant headaches, stomach aches, jaw pain, and other discomfort. She also said that she wanted doctors to continue her aggressive care, even though her ability to interact was fading fast. At the beginning of 2001, she could follow people with her eyes and move one finger. By the end of the year, these gestures disappeared.

In July 2001, the hospital's end-of-life committee reviewed this case. During the meeting, the patient's daughter was adamant that her mother wanted aggressive treatment until she became semi-comatose, and was unable to enjoy and respond to her family. The committee agreed to honor the request, but then something happened, and committee members began to change their minds. Because Howe could not blink to lubricate her eyes, the dry tissue of her right cornea tore on June 5, 2003 - a complication rarely experienced by a patient with Lou Gehrig's disease. The end-of-life committee met that same day, and the chairman, a psychiatrist and Jesuit priest, wrote: "There is now 100 percent unanimous agreement that this inhumane travesty has gone far enough. This is the Massachusetts General Hospital, not Auschwitz".

The next day, doctors removed Howe's right eye while she lay in bed. Later that month, the hospital's lawyers asked the Probate and Family Court to intervene, but Judge John M. Smoot ruled that there was not sufficient cause to remove the



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patient's daughter as her health care proxy. However, the judge urged the daughter to refocus her assessment from the patient's wishes to the patient's best interests.

On Jan. 13, 2006, doctors and nurses again asked Mass. General's end-of-life committee to order withdrawal of life support, saying the patient is now in danger of losing her left eye, which is taped shut except when her daughters visit. The daughter returned to court, saying her mother's left eye had improved, but said that when she was in danger of losing it, she would allow the hospital to turn off the ventilator. On Feb. 22, the parties met with the probate judge for hours but failed to agree on a course of action.

While this horrific case is playing out in the courts, patient, family and hospital personnel are living it every day. Twenty years ago, I wrote an editorial called "The Prostitution of CPR" which, among other things, expressed concern about physicians who simply would not allow dying patients to die while, at the same time, lauding Massachusetts General for its humane and effective CPR policies. While the author of this particular article in the Boston Globe thought that it is pretty rare for a patient with Lou Gehrig's disease to demand aggressive treatment (and it may be), it is not rare for dying patients and/or their families to insist that everything MUST be done.

Not surprisingly, this case raises a number of legal, ethical, and yes, even financial questions. While numerous court cases have irrefutably established a patient's right to refuse medical treatment, I know of none that have dealt with a patient's right (if there is one) to medical treatment, when all medical authorities agree that the treatment is useless, and, as in this case, even inhumane! While a case can be made that a

right to refuse treatment isn't worth much if there is no right to treatment, one must ask is there a right "to treatment that can in no way benefit the one?" Surely not even the most zealous advocates for universal access (and I consider myself one of them) would demand that patients have a right to medical treatments that DO NOT benefit them and that may, indeed, harm them. Admittedly, we have a much more savvy and sophisticated public, but as of this writing, most do not have a license to practice medicine.

In recent years, most of the world's people have celebrated their diversity: different races and languages, religions and cultures, and, most assuredly, different social mores. Indeed, these differences distinguish one group from another, and lead to a vast range of social norms. These differences are what make life infinitely interesting. Nonetheless, all differences aside, what people value most in life is remarkably similar. People, all the world's people, love their children, seek good friends, need enough food and shelter to live in at least frugal comfort, rejoice in work well done, and expect to be healthy enough to live fully until they die.

When their values are threatened, people become vulnerable, all the more so if they are unable to reduce the threat. Disease, or its threat, wounds what is rarely articulated as a human value, perhaps because it is the substratum upon which all else is built, the human dasein - quite literally one's relationship to self, others and the world. When one is ill, one cannot command one's body to do what one wants it to do, and most certainly, the woman in this case study cannot command her body to do anything. Nor can one determine what is wrong or what to do about it. Thus one is forced to go to another person, to place oneself before this person and to ask for help. Those who are perceived as having the ability to help are invested with enormous powers. So it was, and so it still is.

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Recruitment maneuvers are of unproved safety and do not always enhance oxygenation. Although a variety of RMs have been described, the best technique with which to perform a recruitment maneuver is currently unknown and may well vary with specific circumstances. The risk of hemodynamic compromise occurring during and for a short while after the maneuver is considerable, especially with the high sustained inflation pressure technique is used in the setting of a "non-recruitable" lung. When sustained pressure is applied without relief, mean and peak airway pressures are equivalent. This imposes extraordinary backpressure to impede venous return and poses a high afterload to the right ventricle for the period of its application. In experimental models, pneumonia appears to be the condition with greatest risk for hypotension during the RM. Under these circumstances, redirection of blood flow in conjunction with altered hemodynamics may produce serious hypoxemia in the peri-recruitment period.

Mean airway pressure can be reduced substantially while maintaining the same peak airway pressure value - the actual recruiting pressure by using tidal ventilation with pressure control. Thus, recruiting maneuvers using pressure control may hold an advantage if pressures beyond those tolerated during the sustained high pressure method are required to completely open the lung. Because pressures exceeding 60 cmH₂O may be required for opening, it is clear that for some patients, PCV is more likely to be successful and well tolerated. It should be noted that although sustaining high pressure is believed to be an important component of the recruiting process, the length of time required remains unsettled. Moreover, it is possible that for the same maximum pressure, briefer applications more frequently may be as effective as fewer cycles with a longer inspiratory time.

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Codes of Ethics came into being, as did almost all early laws, to protect the vulnerable from the powerful; the unwary from the unscrupulous. In ancient Summaria, Hammarabi incorporated a canon on medical ethics into his Coda, in China the emperor addressed appropriate medical conduct in the Nei Ching, and in Greece the Pythagoreans are credited with writing the Hippocratic Corpus. The Greek, Galen, and the Jew, Maimonides, expected, actually demanded, high moral character of healers, but only India's Charaka Samhita (1 st Century AD) attributed moral as well as scientific authority to the healer.

Then as now, the total situation for patients includes not only the diagnosis and treatment, but also whether or not someone will stand by them through the course of their illness or death. However, then more than now, practitioners could do little to alter this course; thus the early codes stressed fidelity of the practitioner to the promises of the profession. As knowledge grew and skills proliferated, particularly in the latter half of the 20th century, the practitioner's ability to alter the course of disease shifted the ethical emphasis from fidelity to a more modest sharing of information and decision-making: does the patient want his life altered? If so, to what extent, and who decides? The ancient moral dictum was to choose life. The modern moral dilemma is, as is clearly demonstrated in this case, 'under all circumstances?' The emerging compromise has been to cede moral authority, and with it, responsibility to patients and families (what *ought* to be done), while scientific authority (what *can* be done) remains with the professional. The ancient authoritarian ethos gave all power to determine and decide to the professional: the patient's only protection being the altruism of the professional.

However, the moral hegemony ceded to patients today could lead to an ethos of moral detachment in which the professional is seen as an instrument of the patient/family's, or of society's, will. In this case situation, the family's moral hegemony is now spilling over into that of scientific authority. Thus, the professionals, no longer moral agents, are not even seen as clinical experts. The professional, and the power of the profession, becomes a mere tool used to the ends of others.

No longer an altruistic itinerant, the professional is educated, supported, protected and paid by the community. No longer morally autonomous, the professional's choices are limited and even determined by those whose values he may not share, and whose motives he may not know. No longer a compassionate caregiver, the knowledge he/she possesses could make him/her a powerful instrument of personal control. But be assured, if the physician and other members of the healthcare team are merely the tools of others, could they not become tools of social control?

Today's professionals seek to balance moral authority and responsibility as both the lay and professional publics come to grips with the separation of what ought to be done from what can be done. It is unfair to feed suspicions that doctors may deny care because of soaring costs. In fact, if the woman was still well-covered, there might be a chance that treatment would be continued to this extremis because it was lucrative. However, there is no evidence that the hospital administration or the hospital's financial officer is pushing medical decision-making in this matter. Physicians, nurses and ethics committee all seem to be saying that what is being done to this patient is immoral. I must also add that what is being done to the physicians and hospital personnel is also immoral: it is dehumanizing them because they are being forced to engage in behaviors they believe to be immoral.