

Confusion Reigns in the So-Called “End of Life” Arena

On July 10, 2013, a nighmarish story was reported by ABC news.

Sydney Lupkin wrote, “It was exactly midnight when Colleen Burns eerily opened her eyes and looked at the operating lights above her, shocking doctors who believed she was dead and were about to remove her organs.”

Lupkin tells how officials at St. Joseph's Hospital Health center in Syracuse, New York were in the embarrassing position of having to explain to the U.S. Department of Health and Human Services how it happened that even after nurses had observed Colleen Burns curling her toes and flaring her nostrils and moving her tongue and mouth, that she nevertheless still ended up being treated as a potential organ donor. The impression given by the news story was that in general there are safeguards to keep this kind of thing from happening and that the near-harvesting of organs from this woman who was alive and even capable of recovery was a matter that requires more investigation.

At the beginning of the story, it says that the doctors “believed she was dead” and later on, it says that they had “inaccurately diagnosed Burns with irreversible brain damage.” Was she “dead” or was she “brain-damaged”? There used to be a difference in meaning between these two expressions! When “brain dead” is referred to as “dead,” it becomes confusing.

But no matter. There is something even more profoundly confusing about this story. It gives the impression that if everything is done correctly at our hospitals, patients who can curl their toes and flare their nostrils, and move their mouths and tongues will be safe from becoming organ donors, but this is not the case.

Although Colleen Burns’ escape from organ donation was just reported this month, it actually took place in 2009. But here we are in 2013, when the organ procurement guidelines

currently in place at many U.S. hospitals would allow plenty of foot-curling, nostril-flaring, tongue and mouth movements, and eye-opening! The policy of the Organ Procurement and Transplantation Network allows patients with neurological injuries who are ventilator dependent but not brain dead to be organ donors in a procedure called Donation after Cardiac Death (DCD). Patients with “end stage musculoskeletal disease, pulmonary disease, and high spinal cord injury” are also eligible. The patient’s life supports are withdrawn, and then the medical team waits for the heart to stop and declares death. Then the transplant team can remove the organs. By the time they get to the organ removal, there is no more foot-curling and nostril-flaring, but at the beginning, when the decision is made to remove the life supports, there certainly can be! In fact, the patient can even be conscious! There are patients who are fully conscious but who reach a point where they cannot live without a ventilator. These patients may be prime candidates for organ donation because their heart, lungs, kidneys and other organs may be unaffected. These patients can often communicate either by speaking or with the aid of computer devices.

Many Americans are unaware of this. Although they surf the internet, going to all sorts of fun websites, they don’t keep up with what is happening on optn.transplant.hrsa.gov. And if they should happen to read this website, they might easily misunderstand it if they read just a little of it. For example, in section 2.8 of Policy 2, Minimum Procurement Standards for an Organ Procurement Organization (OPO), it says, “The decision to withdraw life sustaining measures must be made by the hospital’s patient care team and legal next of kin, and documented in the patient chart.”

The reliance on the “legal next of kin” might give the impression that the patient is unconscious. However, a little further down, this is clarified. Down in B.

Authorization/Approval, 4, it says, “For purposes of these model elements, ‘legal next of kin’ shall also include the patient, a designated health care representative, legal next of kin, or appropriate surrogate.”

That means that a conscious person just in the process of undergoing a terrible crisis of being unable to breathe independently could be approached and asked to donate his organs before he has had a chance to adjust to his situation.

A few years ago, I traveled to upstate New York and New Jersey and met a few patients who had survived for long periods of time on noninvasive ventilation, treated by Dr. John Bach, an expert in pulmonary rehabilitation working at the University of Medicine and Dentistry of New Jersey. I met a 17 year old boy whose parents who had been told that because of his Spinal Muscular Atrophy, Type 1, he would die at the age of two, and I met a 47 year old man with Duchenne Muscular Dystrophy whose mother had been told that he would die as a teenager. Both of these patients had been able to maintain a very high quality of life (see their stories on www.roomtoimprovehealthcare.com). But it is exactly patients like these who are targets for organ donor recruitment. Here, too, we see confusion, because patients and families are convinced that being on mechanical ventilation would be an awful existence, but the actual research shows that patients who choose to live on mechanical ventilation have a satisfactory quality of life.

We should not be shocked by the newspaper story about Colleen Burns. Nor should we be shocked by how the situation has actually worsened since 2009 by the increase in the number of organ transplants using Donation after Cardiac Death instead of brain death criteria.

We should not be shocked because we should understand that when a society is not guided by Torah principles, it will surely stumble. In Darash Moshe, on the posuk in Parshas

Masei, “Ki hadam hu yachanof es haaretz . . .,” Rav Moshe Feinstein wrote, “All governments have laws against murder. There is, however, a vast distinction between the prohibition of bloodshed issued by the secular governments and the prohibition of bloodshed issued by the Torah. . . .An outgrowth of the common view of the prohibition of bloodshed is that most countries do not legislate the duty to preserve a person’s life if he can live only a short time; neither do they insist on the preservation of the life of elderly people. The prohibition of the Torah, however is a function of the importance of human life. Therefore, even if a person is considered to be of no value to society - e.g. an imbecile, or a terminally ill person - the prohibition to slay him bears the same gravity as the prohibition to slay anyone else.”

Our technical progress, which has enabled us to keep people alive longer, has revealed to us the truth of what Rav Moshe Feinstein understood earlier. Before we could accomplish the preservation of life, we might not have realized that our society would shrink from doing it, that they would have all sorts of considerations that they would put above human life.

When Colleen Burns opened her eyes, it was immediately obvious to all that they had vastly underestimated her potential for recovery. But there are many other patients who perish without their potential for recovery being discovered. Dr. Allen Lempel, speaking at a panel discussion of end of life issues at the Conference of Synagogue Rabbonim at the Agudah Convention in 2010, spoke of his concern that the standard of care for elderly patients was slipping downward. He presented four cases of elderly patients who, when they presented with symptoms of decline, were sent to hospice, but who actually had fixable medical problems such as dehydration, overdoses of medication, and electrolyte imbalances, but confusion reigned - these conditions weren’t picked up. It didn’t make the ABC news when Dr. Lempel

successfully treated these patients, and there are many more like them who are not being treated and who have attracted no attention.

Fortunately, many Jewish families are alert enough to realize when their loved one should be getting more medical evaluation and treatment, and these families can turn to an organization called Chayim Aruchim, a project of Agudas Israel of America. It has been started with the goal of providing culturally sensitive health care counseling to Jewish families, helping them find health care settings where they can obtain the treatments that they are halachically required to pursue but which may not be offered to them by their local hospital or hospice.

But, as standards for the sanctity of life slip in American health care facilities, we may find that our health care options are shrinking.

In Israel, they have a hospital, Mayanei HaYeshua, which is run according to Torah principles. There is a special Kollel at the hospital that researches questions of medicine and halacha, and the decisions are made according to the rulings of the Kollel.

Surely there would be financial, legal, and political obstacles to creating such a health care setting here in the United States, but encountering and overcoming these obstacles would be worthy even for its own sake. By trying, we could dispel the confusion about what is possible and what is not possible. We would attain tremendous insights into the limitations of our society and what we can accomplish when we set goals that merit Hashem's help.

