I WILL NEVER SUBMIT TO DEATH!: THE CASE OF LEONARD STEPKOWSKI

Susan Stepkowski sits across the table from you, staring at her hands. her head down. Finally, she looks up at you and at the treatment team gathered for the family conference.

"I hear what you are saying." she says tearfully, but in a firm voice, "And I can see that my dad has deteriorated over these last three months. But I know what he would have wanted--he was perfectly clear with me when we went over and signed the advance directive. He wanted absolutely everything to be done for him."

Leonard Stepkowski has been on and off of your unit for years. He has had multiple physical problems, but never lost his fighting spirit--until now. After his last stroke, he was unable to speak, and finally unable to maintain respirations independently, needing first oxygen, and finally a trach and intermittent ventilatory support. At each juncture, his daughter, a lawyer, was clear that her father wanted the most aggressive care possible. You knew this to be true: when he was awake, even when he was ill, he would remind you that he had survived Auschwitz. "You don't survive by giving up," he would tell you in his whispery voice."I will never submit to death!"

But this admission was different. You are convinced that he can respond to neither you and the staff, nor even to his daughter and her friends, who visit regularly. And his bedsores are now intractable. Finally, he will now need surgery to amputate part of his foot. And that is just the beginning. You know that his daughter agrees that this aggressive care is problematic. What the whole treatment team is recommending is withholding of all but comfort measures, and allowing Mr. Stepkowski to die peacefully.

"Look, I did not agree with him when he was younger, either," she said. "I made him a promise, though, that I would fight for him when he could no longer could fight for himself. He wanted everything even if he was in a coma. And I am going to make sure that he gets what he wanted from you people."

" THIS IS A HOSPITAL, NOT A PRISON!": THE CASE OF MR. "BUFF" MORGAN

Maddy Peirson, MSW slams into the staff lounge and throws herself into a chair. You have never seen her normally placid face full of such anger.

"I never have heard so much abuse come out of one person's mouth," she mutters to the nurses and physicians assembled for break. "And I am supposed to be the type who can therapeutically listen. Boy have I reached my limit with Buff Morgan."

You can barely suppress a bitter laugh. Everyone else has long ago reached their limits with Buff Morgan. You can hardly keep his care staffed: nurses and attendings take turns that are as short as possible in caring for him.

"No one can convince him to comply with even the simplest of orders. He fights every single intervention, until he is too sick to resist. Then we treat him until he is well enough to start to sabotage his care, and the whole cycle starts over again," sighed Maddy. You know she is right.

Buff, 16 years old, was a gang member and proud of it, boasting that he had "killed 5 guys and got away clean." You do not know how much is bravado and how much is real, but whenever Buff is in your unit, he gets a stream of visitors, young men who look and act ready for a fight. And Buff has relatively little to boast of these days. He was shot in the spinal cord in a drive-by shooting two years ago and became a complete quadrapelegic. He can move only his shoulders, head and neck. He lives alone, like he has since he ran away from his last foster care placement when he was 11. He has frustrated several rounds of home health nurses, had two skin flaps for pressure sores, and this last admission presented with multi-drug resistant staph sepsis and multiple decubiti. He has been here now for seven months.

Last week he managed to "escape" from the floor for a day and a half before he was found by the police and brought back, nearly o.d.'ed from crack cocaine and alcohol. When he woke up, he demanded his motorized wheelchair and access to the cafeteria, and when he was told that he had to stay on the floor, he protested.

"This is a hospital, man, not a prison, I didn't do anything wrong, I am sick and you have to take care of me!" You wonder how much further you have an obligation to go with his care. The suggestion has been made by the UR office that you simply discharge him to a local hotel, since he is now refusing to take his meds. You wonder if it is fair to keep treating him--or if it is right to stop.

"EVERY DAY IS PRECIOUS TO ME!": THE CASE OF MS. ELLEN MARTERS-SCHEFFIELD

You have known Ellen since the first days after her first cancer surgery 3 years ago. She had the best sense of humor of all your patients, responding to your teaching about the ostomy care with quiet attention. And she has done well since, living a full and active life, handling her work, and her disease process well.

But now her cancer has spread, and she has added a series of non-traditional remedies to her regime--one that you are not supportive of, shark enemas, and megavitamens. Last week, she was hospitalized for a transient infection, and while in the hospital, she was placed on hyperal. Immediately, she felt much better.

Today, she confronts you.

"You have this therapy that I know will not save my life, this hyperal," she says. "But it will buy me time, and make me feel a lot better. Why on earth didn't you tell me about this before? Every day is precious to me! If I can get more time, maybe the alternative therapies will work--you cannot tell me that they won't! Look at me, don't I look better?"

You think she is retaining fluid, and you know of studies that say that terminal patients do not derive any medical benefit from hyperal. You think that it is immoral to give it, and besides, it is not on the formulary for the hospice. But you can see that it makes this dying woman feel better--and it is the first thing that has in weeks. Should you support her demand for this therapy? The resident has ordered the treatment--should you point this out to the attending and have the treatment stopped?

BETTER OFF ANGRY

Mrs. Cippio was the hit of every party. Long after the younger guests would quit, she was up and dancing, pulling the cousins on to the dance floor. "Come on, come on," she'd laugh, "What is this younger generation coming to?" But in September, after she had picked and harvested thirty bushels of green beans, she was tired. "She can't feel her feet so good, Doc." her daughter said. Mrs. Cippio interrupted. "You made me come in here, you don't have to speak for me." she said. "Doc, I need to feel my toes to dance for the parties coming up. Me and my Tony, we have a lot to celebrate. She patted her daughter on the stomach proudly. Her daughter blushed. "MA!" she protested.

Dr. Arrowsmith had good reason to be optimistic. A skilled and dedicated cardiovascular surgeon, he had known the family for years, treating Mr. Cippio's brother, and enjoying the best fruitcake in San Francisco, made by Mrs Cippio. "I'll get those toes nice and pink," he promised, as he described the risks and benefits of surgery. The family listened carefully, proud that he took so much time to talk to them.

But while the surgery did go well, and while the toes of your patient in the ICU are in fact nice and pink, that is probably the only organ system now functioning independently. Mrs. Cippio has been your patient for 4 months. She is your first patient in this unit; you are a new grad. She has had numerous intractable infections, and now is colonized with candida. Her kidneys have failed, and she is on dialysis. She cannot tolerate feedings and is on hyperal and lipids. Her bowel has become necrotic and she has a colostomy. She is on and off the ventilator, and now it seems that she will never be weaned. She remained fully conscious, but too angry to speak. She crumpled up the consent form for the latest surgery that Dr. Arrowsmith has proposed: a gastronomy. She shakes her head and grabs your hand. "No more!" she mouths.

You return to the nurses station with the crumbled paper. "She won't sign, Doctor" you sigh. He is astonished. "Well, why not," he demands. He takes the form and goes into the room, returning shortly, clearly frustrated. "You nurses have scared this woman to death, and that is not a figure of speech." he says. "I don't need her consent at this point anyway, she is not competent, probably is in an ICU psychosis, and besides her electrolytes are out of control. She needs this surgery to live. I can't get her well if I can't get her well-nourished. I'll talk to her husband."

A few minutes later, Dr. Arrowsmith returns and writes pre-op orders for tomorrow at 6:00 a.m.