

On Second Thought

By Joel Rebibo

Education for Life

A few months ago, in a column on Mrs. Risa Rotman's memoir on the aftermath of the Har Nof massacre, I mentioned that her husband Chaim, *Hy"d*, who was fatally wounded in that attack, had spent time in Herzog Hospital in Yerushalayim, which I described as "a place where people pretty much go to die."

A day after the article appeared I received a call from the hospital's spokeswoman, Eilat Mishor, politely setting me straight. True, the hospital gets the most difficult cases, the patients who are on respirators or elderly or in need of long-term psychiatric care — not the ones who go home after surgery good as new — but it's grossly inaccurate and unfair to describe it as a place where people go to die.

She didn't demand an apology, but in describing all the things the hospital does, including brain research that has led to patented drugs for the treatment of Parkinson's disease, depression and schizophrenia, she said something that piqued my curiosity: The hospital has a school for children who are chronically on respirators and brain-damaged.

How can that be? I know that the Education Ministry sends teachers to pediatric oncology wards to help children keep up with their classes, but how's it possible to teach youngsters who, in many cases, are in long-lasting comas?

This was something I had to see for myself. And with the help of Professor Rena Gale, director of the Children's Chronic Care Respiratory Department, Michal Yaer, one of the teachers at the Herzog School of Special Education, and a dedicated mother who allowed me to interview her at her comatose son's bedside, I got an education in appreciating the value of life.

The children in this department fall into two categories: Those with congenital disorders whose brains did not fully develop or who suffer from genetic problems, and those who were born normal, but experienced some kind of accident — like a drowning — or, as in the case of 4-year-old Motti*, a medical event like cardiac arrest that denied his brain oxygen for too long.

Motti looks like he's napping. His face is angelic, with large, red cheeks framed by curled *peyos*. His mother stands at his bedside,



The prize pupil is Tzvi. He's hooked up to a respirator and uses a computer with a touch screen that helps him communicate.

as she does every morning. She talks to him and *davens* with him, and manipulates his muscles and limbs, under the guidance of the hospital's physical therapist, to keep them from atrophying.

When I ask her to tell me what Motti was like before he went into a coma, she says, "He was very sweet," but then immediately adds, "He's still very sweet." It's not that she lives an illusion. She understands that he hasn't regained consciousness, and may never do so, but is convinced that on a *neshamah* level he's there for her to communicate with and take care of. (See box)

She's at his bedside every day from 10 a.m. until 1:30 p.m., then returns home to care for her other seven children. Her brothers and her husband take turns coming every night to say *Krias Shema* with him, and *Tehillim*, and to read him some stories about the Baal Shem Tov. When she leaves on Friday, she tells him she won't be back for Shabbos — she lives too far

away to walk — but that someone who lives nearby in Givat Shaul will come to see him.

Though, to the outside observer, Motti doesn't appear to be responding to his mother's words or touch, there are instruments today, like functional MRIs and EEGs, that show increased brain activity when she greets him or kisses him. She and the medical staff at the hospital and his teacher Michal are dedicated to providing him with constant stimulation, to enhance his quality of life.

"The hospital is very attentive to Motti's needs," his mother says. "Whatever I ask for they try very, very hard to provide."

Across from Motti is Leah. She's 16 but the size of a 4- or 5-year-old. Her teacher is tapping out a tune on a xylophone in tandem with a song he's playing for her on a computer. Her arms are stiff and contorted, her motions spastic, but you can see the joy and excitement in her eyes, at the smile and encouragement of her teacher and the sound of the xylophone and music.

The prize pupil on the ward is Tzvi. He's hooked up to a respirator and sits in a wheelchair that has been rigged to allow him to move independently, though he tends to go around in circles. Michal shows him how to use a computer with a touch screen that helps him communicate better. Her long-term goal is to get him to use his wheelchair more effectively, so that he can move in a straight line, and to respond with "shalom" when she greets him.

"Every teacher here has a number of students and for each student there are a number of goals, just like any other special-ed program," she says.

Another comatose patient, Itzik, is propped up on his bed with gauze in his mouth to hold his tongue in place. He's 18, and his eyes are closed. Michal places her dog Mogli on his bed and moves his stiff hand to rub the dog's head. Within minutes, his eyes start to open slightly, enough so you can see his eyeballs move from side to side.

"You see," Michal says, "he's responding!"

* All names of children have been changed.

I had been warned by Professor Gale that I might find my visit to the department depressing, but I found it humbling. To be in the presence of teachers like Michal, who get excited by even the slightest sign of progress, and of doctors like Professor Gale and mothers like Motti's who stop at nothing to enhance the quality of life for children who seem to have so little life, is inspiring.

'Anne Frank With A Different Ending'

Some 30 years ago, there was no such thing as long-term respiratory care because patients weren't able to survive for extended periods on respirators, which take over lung functioning.

"When I was in medical school people were put on respirators during surgery, but there was no such thing as a patient on the ward being on a respirator," Professor Gale recalls.

But medical advances, which make it possible for a child like David, who was born without a full brain, to remain on a respirator for years, have raised ethical questions: What's society's responsibility to such patients? Can it afford the cost of round-the-clock long-term hospital care for patients who have practically no prospect of getting better? And how about the parents? Is it fair to ask them to make the sacrifices involved in caring for these children, often at the expense of other family members?

The answer is, it depends on the society. According to Professor Gale, who did her advanced training in preemie care at Stanford University, doctors in the United States encourage parents not to hold on to such children. "Why allow a child to suffer his whole life? He'll never be like everyone else," they say. "You're young, you'll have more children."

The approach reflects an overall attitude toward life, whether it involves brain-damaged children or elderly parents. Professor Gale recalls a lab director at Stanford, a native of Holland, who announced that he'd be traveling the following week to attend the funeral of his mother, who had dementia and was on a respirator. How could he be so sure that she'd die the next week? Because the family had decided on a date to pull the plug that was most convenient for them.

But in Israel, it's different. Life, even when it's being hung onto by a thread, is precious.

"Our Sages tell us, 'Whoever saves one person it's as if he saved an entire world,'" says Dr. Yechezkel Caine, director general of the hospital. "And since we have no way to prophesy whether a child

'Hakadosh Baruch Hu Has His Own Literature'

Before arriving at Herzog, Motti spent two months in an intensive care unit at a well-known hospital in Yerushalayim. At one point, the doctors declared him brain dead and asked his parents to allow them to "harvest" his organs for other children.

"We wouldn't hear of it," says his mother. "And two weeks later brain activity returned."

Herzog Hospital and Motti's mother are on the same page, as far as Motti's prognosis. Both are in the here and now, making sure his condition doesn't deteriorate, and not thinking about what's up ahead.

"The medical literature says

one thing," she says, acknowledging that doctors aren't hopeful, "but *Hakadosh Baruch Hu* has His own literature."

Motti is making progress. He loves to listen to music — his favorite song is "Bar Yochai" — and, in general, seems more responsive to his mother's touch and voice, though she admits there aren't any clear external signs.

Where does she find the emotional and physical strength? It takes two buses to get to him and then return home, to take care of her other seven children. "The strength comes from the *Ribbono shel Olam*. I made a deal with Him; He's a partner in all

this. I need the strength to fulfill all my roles. I *daven* for this a lot."

It hasn't been easy for Motti's mother to balance her responsibilities to Motti and those at home. "In the beginning, the children used to complain about all the time I dedicated to him. I said to them, 'What do you want? I'm with him four hours a day and at home with you 20 hours.' And they said to me, 'You're here physically, but you're still with him.' I thought about it, and they were right.

"I had to learn to disconnect. I use the time on the buses home to make the mental and emotional switch, so that I can be there fully for my other children."

will recover, we give each the best possible treatment."

Herzog recently built a beautiful, spacious wing for close to 60 young people — the only one of its kind in the world — comprising two separate units, one for young people till the age of 21, and the other for older patients. There's a waiting list of children on respirators needing such care, which costs thousands of shekels a day and is only partially reimbursed by the health funds.

Thirty percent of the patients are Arab.

When Professor Gale came to the powers that be in the government and the Ministry of Education and demanded that the law providing for free education for all be applied to her children as well, they agreed to pay for teachers to staff an educational program in the hospital.

"Our culture makes it inconceivable that we should give up on such children," Professor Gale says. "There's someone there [even with a child in a coma] and I want to help him, to enhance his quality of life. I believe that life is the most precious thing."

She traces her attitude to her experiences during the Holocaust, when as a 6-year-old in Poland she and part of her family went into hiding ("I was an Anne Frank story with a different ending").

"They never gave hope," she recalls of her mother, aunt and grandmother who took care of them. "We were three young girls. This was 1941-42. They had the strength to carry on and the faith that it would come to an end."

In a similar way, Professor Gale doesn't give up hope on children who are minimally responsive. She's upbeat, full of youth and

vigor and excited about her work. "There's someone there and I want to help him, to enhance his quality of life," she says.

The average length of stay for a child at Herzog is five to 10 years. In rare cases, children have "graduated" to Alyn for rehabilitation, an enormous achievement, but most never leave. The cause of death is usually infections relating to the respirator, which needs water and attracts bacteria.

In the past 10 years, 18 of the unit's 68 children have died, 16 of them due to infection. How does Professor Gale deal with these deaths? "You know what? I'm at peace with it," she says. "My mandate is not to extend their lives, but to improve the quality of what life they have."

And that's done with the help of physical therapy, speech therapy, occupational therapy, social workers and, now, special-ed teachers, in addition to a dedicated medical staff.

"My husband couldn't understand why I spent two years trying to get teachers," Professor Gale says. "He said, 'These children lay there, not doing anything. Do you expect them to learn math?'"

"But people don't understand that there is nonverbal communication, and that you can connect with the child in many ways. We know this scientifically. We have functional MRIs and EEGs that show that the child is responding to various stimuli.

"If a boy doesn't move, people think his head doesn't work. That's not true. The head works. And this puts a great responsibility on us, not to let him lay there."

To be sure, the teachers don't teach math or geography. Instead,

they use music, and storybooks and petting animals to stimulate brain activity. "There's enormous added value to the school," says Professor Gale. "The children wait for their teachers. With some, you can tell by their motions how happy they are to see them."

My time at the Herzog School of Special Education left me with two thoughts.

One, this is the time of year when children are going back to school, the conventional kind. As parents, we have expectations of our children and of the yeshivos that sometimes produce tension and anxiety. Of course, it's important to try to make the best decision as regards the *chinuch* of our children, but we need to keep perspective.

In his commentary on *Chovos Halevavos*, Harav Avigdor Miller, *zt"l*, writes of the importance of appreciating the gifts that Hashem gives us. It achieves two things, he says: "First, you make yourself happy. Second, you express your gratitude to Hashem."

If we appreciate what it means to be able to send healthy children to school, with all of their learning and behavior issues, we will be a lot happier and feel a lot closer to Hashem.

Two, watching Motti's mother talk to her comatose son, in the hope that he might open his eyes, reminded me of how important it is to continue talking to our spiritually unresponsive children, in the hope that something will sink in and that they will wake up.

"We believe and hope and *daven* for *yeshuos*," says Motti's mother. May her *tefillos*, and those of all the parents at Herzog, be answered, speedily in our days.