



Dr. Julia Namestnic: 'They are not dying, and we love them. Everybody on the staff has a favorite. Perhaps some day there will be a way to help them.' (Photos: Judy Siegel-Itzkovich)

No greater love

In a pediatrics ward at Jerusalem's Herzog Hospital the staff care for probably the most tragic patients of all

BY JUDY SIEGEL-ITZKOVICH

This very special Jerusalem pediatrics ward is colorful, orderly, clean and... chillingly silent, except for medical staffers' calling the patients' names - even though they know they'll get no answer. The doctors, nurses and paramedical staff can only dream of a child shouting for joy or making a mess. In Herzog Hospital's "Ventilated Patient Unit C," the 18 "children" aged four months to 20 years are either in a deep coma or semiconscious. It's clear that no one will improve enough to be discharged and enjoy a normal life.

Although the unit was launched three years ago when a 16-year-old Jerusalem girl with a genetic metabolic disease went into a coma, the psychogeriatric hospital (www.herzoghospital.org) hasn't yet listed the unit on the wall in the entrance foyer.

"I hadn't realized there is no listing,"

says Dr. Yehezkel Caine, the 330-bed institution's director-general, former surgeon-general of the Israel Air Force and a specialist in aerospace medicine. "But it's true that we didn't publicize its existence because the families are very sensitive. Our unit isn't a secret; all Jerusalem-area hospitals know, and they and the health funds refer patients to us. There is enormous pressure to admit more patients, and we have to turn them down."

The only other institution in Israel that can care for such patients is Tel Aviv's Reut Hospital, which is larger.

Herzog Hospital, known for its care of the elderly, demented and mentally disabled, invited *The Jerusalem Post* to tour the children's unit and interview the devoted staff. This resulted from a disclosure by the media that one of its patients is the three-and-a-half-year-old son of a Jerusalem mother of eight who, along with her "rabbi" Elior Chen allegedly abused him, putting him into a vegetative

state. The staff are not allowed by court order even to talk about him, and I am not allowed to see him.

There are a few more who suffered severe child abuse, but others lost consciousness due to accidents and falls, metabolic diseases, congenital defects such as being born without certain parts of the brain, a shortage of oxygen at birth or a sudden brain hemorrhage after being a normal child. All the cases are tragic, says Prof. Rena Gale, senior pediatrician and director of the ventilated children's unit.

ALTHOUGH PATIENTS like these would be disconnected from their respirators in Sweden or Holland, where active euthanasia is accepted, Herzog staffers "never think it would be better to die," she says. "We still remember the Holocaust; we would never do selections. There's a slippery slope. Maybe we would feel differently if a child were forced to

suffer. But we don't let them suffer. We give them drugs and treatment. They are attached to monitors. There are objective and subjective ways to determine whether a child, even a baby, is suffering," said Gale, a neonatal expert invited to head the department two and a half years ago. "When there is something bothering them, their pulse speeds up or they grimace. We don't expect them to get better tomorrow, but we do give them quality of life."

"No patient in this unit comes under the definition of the Terminal Patients Law," adds Dr. Julia Namestnic, a senior physician who arrived from Tashkent 17 years ago and specialized in treating elderly people attached to ventilators. "They are not dying, and we love them. Everybody on the staff has a favorite. Perhaps some day there will be a way to help them," Namestnic suggests. "In the meantime, we care for them as if they were our own."

Fortunately, the health funds cover all the hospitalization costs of their members without complaint. Herzog's unit is much cheaper than pediatric intensive care units in the general hospitals, and beds for acutely ill children are freed up by the existence of the chronic-care ventilation unit.

"We were nervous about taking the first patient when the Hadassah intensive care unit asked us because we had experience only with elderly patients in comas," said

died, recalls Namestnic with sadness, as infections can't always be overcome. Ventilated patients can live for many years. "We have a 91-year-old coma patient who has been in the geriatrics ward for years; some have been on a ventilator for seven or eight years. Just look at Ariel Sharon at Sheba," she notes, referring to the former prime minister who has been in a coma since January 2006.

Herzog, which currently has three or four children on the waiting list, accepts

patients for temporary assessments and also admits less seriously disabled but ventilated children whose families want to go on vacation.

The staff do a lot of hard physical work, as it takes strength for an orderly or nurse to turn over teenagers. The older ones also have special air mattresses to reduce the risk of sores. Every other day, says Geudj, "the children are given baths in their beds; the mattresses are waterproof. Most are fed via tubes to their stomachs, but those who can swallow are spoonfed. We try to stimulate them with music and color. We always speak to them and kiss them. There is no one that we don't love. We braid and put ribbons on the girls' hair."

"When we ask the hospital management for medical equipment, we don't have trouble getting it. We are the most 'spoiled' unit in Herzog," Gale says, "because's it's hard to say 'no' to us."

NEVERTHELESS, some luxuries are still unavailable, such as enough customized wheelchairs for taking the children out. Each child is a different size, and the chair

has to be suited for the ventilation machine as well as the position of the patient. Herzog does not have its own workshop for building such wheelchairs.

Geudj says she and her colleagues would like a mobile Snoezelen facility to provide controlled multisensory stimulation, as patients can't be brought as far as the hospital's impressive Snoezelen room, installed in 2006, with its soft music, waterbed, glass tubes with bubbles rising, pleasant odors, spotlights, vibrating cushions, stuffed animals and revolving mirror balls.

The hospital will soon begin building a new wing, which will offer space for an expanded pediatric ventilation unit, says Caine. The staff hope that eventually there will be space and money to construct a therapeutic pool.

The families come from all ethnic groups and backgrounds, adds Arbaboff. "Some travel long distances to get here, even though they know they won't even hear a 'hello.' Some place photos of their kids the way they were before they became comatose, and that is the saddest thing to see."

Guedj encourages family members to celebrate the children's birthdays or other family occasions in the wards if they wish, or to bring a favorite toy or blanket. There are parents who help staff give the children baths; they get a good feeling from participating.

The hospital organizes lectures for families twice a year.

As for the staff, they have learned not to take their job home, even though their work is so intensive.

"All of us have children. Daniella is also a grandma," says Arbaboff. "At first we couldn't help talking about patients at home, but we separate the two aspects of our life now. At first, I used to tell my own child I loved him all the time; I would cry and get hysterical, but I got over that."

"You learn to separate the two," adds Guedj, who helps the staff work out their anger when a child whose coming could have been prevented is admitted. "I didn't want my family to be saddened by the personal stories I encounter here." ■

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Namestnic. "This was pediatrics. We knew how to run ventilators, but we had a lot to learn. We learned the ropes from other departments and still have numerous medical advisers in various specialties from other hospitals."

"THE STAFF are so devoted," says Caine, and indeed, that fact is evident throughout. "The strain is intense, as in a neonatal intensive care unit. You don't do these things because it's your job, but because you have a warm heart. I have no words to describe their dedication."

In fact, it was difficult to persuade other doctors, nurses and auxiliary workers to come to the pediatric unit, but once they became acclimated, no one wanted to leave. Some even use their days off to draw pictures to hang in the ward.

Daniella Geudj, a Paris-born social worker who has worked at Herzog since 1982, is one of them, and Sigalit Arbaboff, in charge of the unit when it opened, is now the hospital's clinical supervisor and regularly involved in its activities.

Although the young patients don't talk, and many barely move, they are treated as if they were well functioning; they get vaccinated against children's diseases according to the Health Ministry schedule. They are placed on special wheelchairs so they can go out into the garden, and are exposed to music and TV. But when in bed, they have to be turned every two hours to prevent pressure sores. They get respiratory and physiotherapy; secretions in their throats and lungs have to be suctioned out, says Gale. Some of the patients are able to smile. "Sometimes there are slight improvements, and we are overjoyed by positive reactions."

Nevertheless, a few have

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Naji Shuiki (auxiliary staffer), Dr. Julia Namestnic, Prof. Rena Gale and social worker Daniella Geudj pose for a photo holding stuffed animals because their charges cannot be photographed.

