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take him HOME, there's NOTHING we can do

Hospitals and doctors are in the business of saving lives — **until they're not.**

Our new health care reality means both professionals and institutions are taking a different view of terminally ill patients, one in which those tottering on the edge of life are costly liabilities

BY ***Eytan Kobre***
PHOTOS ***Meir Haltovsky***

If ever someone was qualified for the title of living legend, it was Mrs. Miriam Lubling, the diminutive powerhouse whose advocacy for patients in New York's hospitals benefited thousands over decades. Hers was a ubiquitous, almost revered presence in hospital wards, where, dressed as if on her way to a wedding, she spent countless hours every day raising the spirits and ensuring the first-rate care of the innumerable patients she called her "cousins."

The stories of how her selfless resolve and firm but winning demeanor produced impossible-to-get appointments for consultations and operations for people she'd never met are legion. This is the lady who once raced to the airport to confront a leading pediatric neurosurgeon heading off to vacation: "You can go on vacation, but if you don't operate on this child's brain tumor immediately, *he* never will."

And as Rabbi Israel Rosman, NYU Hospital's Jewish patient advocate, relates, "She stuck so clearly to halachah. She spent 30 years on the floor with doctors and she never shook hands with any men, no matter what. If a phone call came in while she was *bentshing*, she didn't rush."

Less than a year ago, the woman whom Rabbi Moshe Sherer called "Klal Yisrael's angel of mercy" entered the hospital with an infection at age 96. The level of care she received from both doctors and nurses was second to none; after all, she was in the hospital she touted to be world-class.

But when her infection did not respond to antibiotics, and she lost consciousness and required intubation, the Lubling family found themselves at the mercy of the ominous new reality in American health care: The doctors balked at continuing treating her infection aggressively, advising her children instead — in what has become an oft-heard euphemism for ending all life-prolonging efforts — to "let her be... make her comfortable and let nature take its course." The family consulted their *posek*, who, despite the doctor's assessment of a less than ten percent chance of recovery, ruled that in the absence of mitigating factors like excessive pain, aggressive treatment should be continued.

Ultimately, says her son, attorney and communal *askan* Chanoch Lubling, "the doctors who said that her staph infection would not subside were wrong — it did abate and she died from something else. After being unconscious for weeks, my mother regained some awareness, and on Purim day, when some of her grandsons sang and danced around her bed, she acknowledged them and squeezed their hands. Two days later, she left the world."

Welcome to the grave new world of American medicine, in which "quality of life" reigns supreme as the yardstick doctors use to determine what "quantity of life" will be allotted to the elderly and chronically ill. And, for these arbiters of life and death, a life of limited function and mobility inherently lacks sufficient "quality" for money and effort to be spent to prolong it. Undergirding this approach is a secular worldview that doesn't allow for the existence of an eternal soul or a view of life that sees every additional day in this world as precious and worth fighting for.

As Chanoch Lubling puts it, "To some doctors, if the patient won't resume eating steak, it's not worth continuing treatment because the patient will never regain a quality of life they recognize. One doctor told me, 'Your mother used to run and do — she'll never return to that.' But I said, 'Could she enjoy her grandchildren?' and he acknowledged that she might. The doctors don't mean bad," Chanoch says, "they mean well. They believe that continuing treatment when the patient is not likely to recover is not in the best interests of the patient. They really think the family doesn't understand and that they are just having a hard time letting go of their loved one. But it's they who don't understand: As I told the doctor after hearing our *posek*'s ruling, 'For 90 years she followed halachah, she sacrificed to follow it, and now we should ignore it?' "

"Throughout my training years ago, I'd constantly hear: **'THIS PATIENT'S LIFE IS NOT SALVAGEABLE.'** It was as if they were deciding whether an abandoned boat should be sent to the scrap heap" —*Dr. Paul Rosenstock*

Dr. Paul Rosenstock is the founder and medical director of Brooklyn-based Doctors on Call — a medical provider that sends physicians on home visits — and an urgent care center called Quality First that's designed to keep people out of the hospital, because, he says, "the ethical environment in today's hospital makes it a dangerous place." Doctors on Call works with Medicaid to allow patients who can be treated outside of a hospital setting to come straight to its center rather than an emergency department. "This way, we can see the patient and send him back home where he'll be seen the next day by Doctors on Call."

Rosenstock says that an experience he had as a fellow in oncology at New York's Memorial Sloan Kettering Hospital first made him aware of the chasm separating the Torah's outlook on life from that of secular society. "Dr. Yashar Hirshaut [a well-regarded oncologist in New York] was my attending, and a woman from a very prominent South Jersey Jewish family, who had metastatic breast cancer, had lapsed into a coma. She had stopped eating and the team administering intravenous nutrition approached Dr. Hirshaut and said, 'Look, there's no point in doing any more for this woman.' But Dr. Hirshaut, an eternal optimist who taught me that you never give up, replied, 'No, you've got to continue.' He got hold of a new experimental drug and started her on it. The woman woke up, eventually left the hospital, and lived for a full year, even learning to play tennis. I stood at her side at the bris of her first grandson."

Rosenstock says that the ICU has its own unwritten ethos in which a resident — whose own ethical views are unknown to the patient — judges whether one's life is worth "salvaging."

"Throughout my training years ago, I'd hear this phrase constantly: 'This patient's life is not salvageable.' They were speaking as if deciding whether an abandoned boat in the ocean should be sent to the scrap heap."

The prevailing ethos, he says, is that the life of an old person who is not interactive with his or her environment is worth less than that of a healthy person. "They put a value on the quality of life, which they don't judge based on the *neshamah,* because they don't recognize that we each have one. So if the patient can play tennis, he has quality of life; if he's a so-called vegetable, he has no quality of life and we can now feel free to decrease his quantity of life, because his quantity has no quality."

Although in society at large, "death with

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dignity" is a catchphrase of the new medical ethics landscape, when doctors appeal to families of *frum* patients they invariably couch it in terms of a desire to minimize the suffering of someone who has already lived a long life. Often, they add the assurance that "If it was my grandmother, I'd take her home." But in an article in the *Atlantic* last month, Dr. Ezekiel Emanuel, a leading bioethicist, makes the case even more personally, with a piece titled "Why I Hope to Die at 75."

Emanuel writes that once he has lived to 75, "my approach to my health care will completely change. I won't actively end my life. But I won't try to prolong it, either... [I] will stop getting any regular preventive tests, screenings, or interventions. I will accept only palliative — not curative — treatments if I am suffering pain or other disability." He acknowledges that his decision "drives my daughters crazy... [m]y loving friends think I am crazy," and that they "will continue to try to convince me that I am wrong and can live a valuable life much longer."

But it's not just those in the outside world who take this limited view of the value of life, and of each individual life. "This philosophy," Rosenstock observes, "has permeated even the Jewish psyche, because you hear people saying, 'I don't want to *mutcher* her anymore.' I had a case involving an amazing lady who, when her husband died young, opened a cigar stand in a building in Manhattan that enabled her to put all her kids through yeshivah.

"In her 80s, she developed an intestinal obstruction, and she was going in and out of lucidity. Her kids said, 'Please don't *mutcher* her, she's semicomatose.' But I insisted, 'This woman can be saved.' I prevailed upon them to allow her to be operated on and got a great surgeon who managed to find the obstruction, enabling her to live another ten years. *Ten years*."

No one wants to suffer, Rosenstock explains, or cause suffering. But Jews understand that HaKadosh Baruch Hu runs the world and if a person suffers in This World, maybe he will suffer less in the Next World. "But if you don't recognize that ethical stance, then suffering has to be eliminated completely."

Rosenstock explains that regardless of what a hospital ethics committee may say, in the middle of the night, when an inexperienced medical resident is making the rounds, there's "no such thing as a medical ethics committee." The subtleties of deciding whether to admit a particular patient to the ICU are not codified. The question of whether to send a patient home with an active bacterial infection is not written anywhere, he says. "When an intern sees his senior resident doing it this way, that becomes the unwritten ethical standard."

Moved to Action The rich tenor of Rivie Schwebel is immediately recognizable to connoisseurs of Jewish music, but his own unfortunate encounters with the medical system have moved the Flatbush businessman and communal figure to use that voice to speak out on what he sees as a crisis with end-of-life issues that will eventually affect everyone in the *frum* community. Two years ago, on Erev Succos, Rivie's father, Rabbi Aharon Schwebel *z"l*, was involuntarily discharged from a leading New York hospital with a raging and potentially deadly *Clostridium difficile* infection, purportedly because his bed was needed for another, healthier patient.

That was only one incident among many in which the Schwebel family got a close-up look at how the medical system in 2014 treats the elderly and terminally ill. What they saw was deeply unsettling. At one point, as Rabbi Schwebel's physician was breaking the news of the patient's passing to his family, a nurse came running down the corridor from his room shouting, "Doctor, he moved his hand and opened his eyes." The senior Schwebel lived on until the following Chanukah, grateful for each additional day Hashem had granted him to enjoy, surrounded by a loving family.

Rivie's experiences taught him that the character and outlook of the doctor makes all the difference in the treatment of the patient. "We searched for doctors who were world-renowned, but that's not always the best choice," he says. "Those doctors have their statistics and their standings, and they don't necessarily want to take on patients whose prospects are uncertain." Schwebel instead advises that one should choose a doctor who respects the sanctity of life. "Doctors who are not at the very top of the list can still be extremely competent and devoted, and will probably pay more attention to their patients' cases and try harder for them."

During his father's illness, Schwebel also observed that, "*Rachmana litzlan*, if someone over the age of 75 is in the hospital and has no advocate, he's finished." He saw for himself how a handful of "unbelievably dedicated *frum* doctors, tzaddikim really," would walk around the hospital every night until one or two in the morning checking their patients' charts and making sure they were getting the proper treatment. These same doctors, Schwebel says, also fought the hospitals, at great personal risk to their careers, to prevent them from discharging some of these patients.

"It needs to be said clearly that hospital staffs do great work and we're very thankful for what they did for my father," Schwebel continues. "But at the same time, no one, but no one, should ever be left in the hospital alone. I have seen how nurses have not given water to patients and slowly let them die. I've gone to the nursing desk — although there's just so much I can do to be involved in someone else's case — and asked about a patient who I noticed was deteriorating. 'Why aren't you giving him water?' So they came and gave him water."

Having a family member with the patient sends a clear message to the staff that this person is important, that he's needed and loved.

Paul Rosenstock concurs: "I've seen IVs run out, triggering an alarm, but the alarm is ignored. A hospital is a *makom sakanah*, and not because of the illness. The in-house patient liaisons they have nowadays are insufficient. You need to have a bedside *shomer*. We should have an army of volunteer *shomrim* coming in for patients."

Follow the Money As immediate past chairman of Agudath Israel's board of trustees, Rabbi Gedaliah Weinberger is no stranger to *klal* work, but he speaks about the challenges of the contemporary medical environment with unusual passion. He agrees that a secular, soulless view of the value of human life underlies the prevailing attitudes of today's medical establishment, and he's had his share of firsthand experience with it too.

But he also believes that "the philosophy follows the money, not the other way around, so we need to follow the money." And that trail leads to the insurance companies. Going back to the 1970s, he says, Medicare changed its method of reimbursing hospitals, coming up with something called "DRGs," or diagnostic related groupings. The idea behind DRGs is that a patient is allotted a certain amount of time in the hospital based on an initial diagnosis. If the patient's hospital stay is within that predetermined range, the institution will receive a flat rate. For example, if the hospital time allotted for appendicitis is three to five

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—Rabbi Shmuel Lefkowitz

days, and the patient is there for that amount of time, the hospital will get paid in full. But if the patient stays longer, the hospital will receive a reduced per diem rate. The financial incentive to limit stays is obvious.

"By pressuring their doctors, perhaps not officially but practically, to get people out, they went from an average length of stay of ten, eleven days down to five, six," Weinberger says. "Each day's reduction is worth $10,000 to $15,000 to the hospital," depending on location.

"Even though the doctors will tell you it's not true, that they practice medicine with the patient's interests in mind, whether it's done fully consciously or partially subconsciously, it's done."

A second major financial factor driving hospital policy is the link between mortality rates and decision-making on patient admission and discharge. Weinberger was present at two White House meetings at which federal officials admitted that because they monitor hospitals' performance, including their mortality rates, an unintended consequence is that hospitals seeking to avoid a negative ranking will simply refuse to admit patients who don't have sufficiently high prospects for successful treatment or will discharge them prematurely. When the patient comes into a hospital's ER, they have to accept him, but if he's being transferred from another hospital, they can refuse to admit him.

Doctor, Rabbi, Patient With challenges as daunting as these, what can be done on behalf of families who are trying to navigate an unsympathetic system to secure life-extending treatment for their loved ones, or, even more often, who simply need guidance on the interplay between the halachic and medical aspects of their situation?

Rivie Schwebel's encounters with the health care system motivated him to get involved in Chayim Aruchim, an Agudath Israel of America–sponsored initiative chaired by Rabbi Weinberger that, since its founding three years ago, has been actively pursuing a multifaceted agenda on behalf of Jewish patients and their families. Rabbi Shmuel Lefkowitz, Agudath Israel's longtime vice president for community services and a key figure in Chayim Aruchim, describes an important legislative victory recently won by the group. A study showing that New York's NYU Hospital was among the nation's leaders in providing high-quality care in a patient's last year of life, attributed that high score to the attitude of doctors, who saw it as their mission to help patients live longer.

In response to this study, in 2008 New York passed the Palliative Care Information Act, which requires doctors to offer their patients the option of palliative care. Technically, that term refers to care that eases pain, but it's used nowadays to mean replacing aggressive treatment intended to heal the patient or extend his life with a program to manage and reduce pain by medicating the patient as he proceeds toward an inevitable end. Rabbi Lefkowitz sits on New York State's palliative care council, and advocated successfully to amend the law in 2013 to require doctors to offer the patient both the option of palliative care and that of aggressive, life-prolonging treatment, with the involvement of the family's clergy if they so desire.

But, Reb Gedaliah notes, "even after the change, I had the families of two patients come along to a meeting with the medical director of a major New York–area hospital, where they described how they had not been offered the option of continuing treatment for their loved ones. I said to him, 'What do you say now?' He said, 'I admit that we may have violated the law, and it won't happen again.'"

Lefkowitz, Weinberger, Schwebel and other members of the Chayim Aruchim board have been working to circumvent the disregard for traditional values at the level of the ER and ICU by going straight to the top, meeting with the leadership of medical institutions, making them aware of the beliefs, values, and needs of the Orthodox Jewish community.

"In these meetings," Reb Shmuel explains, "we present hospital officials with a letter signed by the *dayanim* of the two Satmar *kehillos*, Rav Shmuel Kamenetsky and Rav Dovid Feinstein, the Skverer *dayan*, the chief *rav* of Hatzolah, and Chayim Aruchim's own halachic advisor." The letter asks for three things: Present patients with all their options; allow the patient and his family to make the final decision; and involve the patient's rabbi. "We don't have to spell it out for them, but these people know very well that their medical centers draw a not insignificant percentage of their clientele from our community and that the signers of that letter are the leaders they follow."

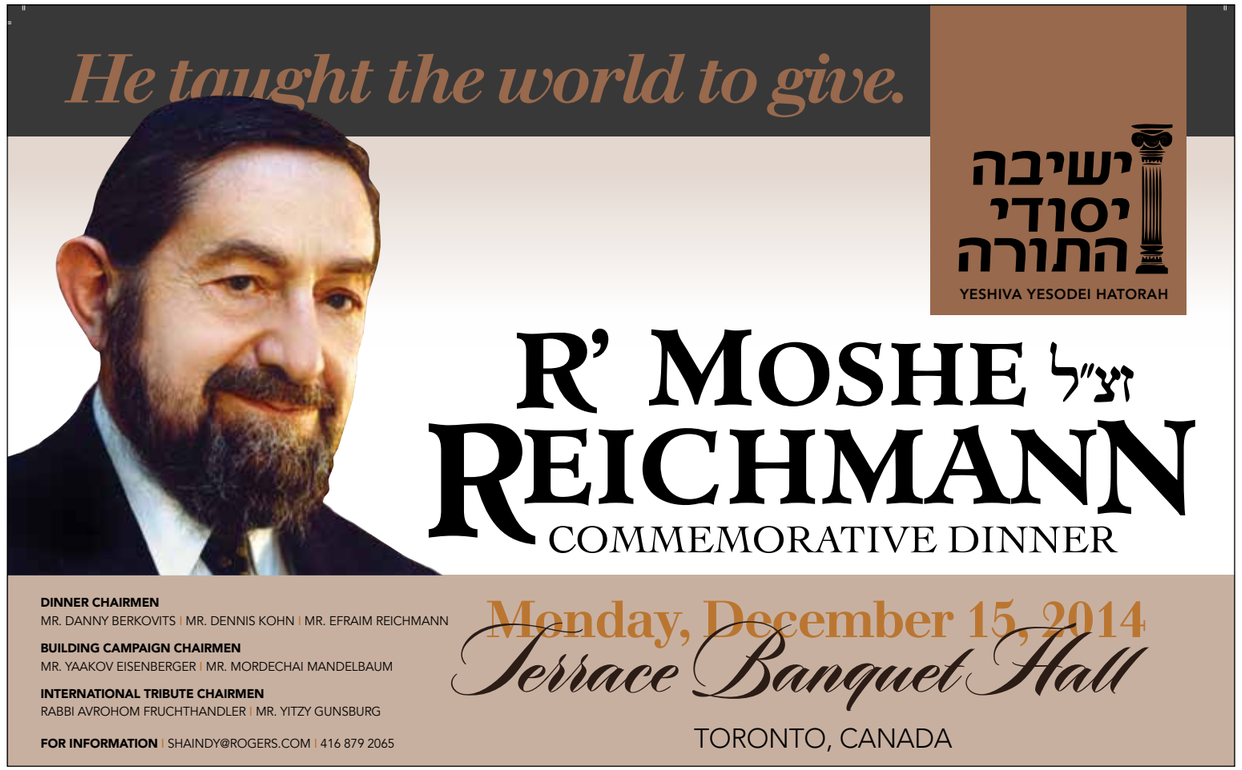
According to Rabbi Lefkowitz, these meetings have borne significant fruit. Two major hospital systems — North Shore-LIJ, which encompasses no fewer than 11 separate hospitals, and Columbia Presbyterian — have amended their brain death protocols for religious objectors to prohibit "pulling the plug" on patients who have respiratory function, continuing instead to provide nutrition, hydration, and medication, until consulting with the rabbi of the "brain dead" patient. The president of Mount Sinai Hospital, David Reich, has also been, says Rabbi Lefkowitz, "a great friend and very sympathetic."

Perhaps Chayim Aruchim's most important achievement to date has been the creation of Machon Refuah V'Halacha, comprised of *talmidei chachamim* who serve as halachic consultants and intermediaries to help bridge the cultural gap between patients and their families and their doctors. They attend dozens of training sessions given by both doctors practicing in diverse specialties and *poskim* with expertise in end-of-life issues.

When a call comes in to the Machon's 24-hour hotline, these *poskim*-in-training speak with the doctors involved to get the exact diagnosis and all relevant medical facts, and then, together with Rav Hershel Ausch, Chayim Aruchim's *rav*, work through the application of the halachah to the situation at hand. Their emotional distance allows them to deal with the doctor more dispassionately than the family would, and their familiarity with the medical aspects enables them to explain things to the *posek* better than the family would. Rabbi Lefkowitz says that the advocates are chosen not only for their halachic expertise but also for their people skills. "We have found that most doctors will respond, 'I'm going to work with you, I'm going to try to help you.' "

"And sometimes," Rabbi Weinberger adds, "our advocates provide more than just halachic expertise." In one case, a well-known Brooklyn *rav* had recommended hospice care for a brain tumor patient who seemed to be out of treatment options. "But one of our *rabbanim*, Rav Zishe Ausch, said, 'Hold it. There's a new drug that will help him. The hospice won't give it to him because he's not covered for it there. Put him instead into a nursing home and I'll get the doctor from NYU to give him this medication.' As a result, the patient lived three months longer, and more comfortably as well. The *rav* in Brooklyn had no idea about this drug, but our *rabbanim* are very familiar and up-to-date with the medical literature."

Remember Who You Are The area in which it seems a great deal of work remains to be done is that of educating



Take Him Home, There's Nothing We Can Do

both the Orthodox and medical communities before crises arise. Religious Jews need to learn the importance of having a health care proxy who can make decisions for them when they can't, and that they should not sign DNR (Do Not Resuscitate) orders without speaking first with a *rav*. And medical professionals should learn about the Orthodox Jewish view of life: that we possess both body and eternal soul; that every moment of life, however compromised or fleeting, is invaluable; that there are delicate, case-by-case decisions to be made about how much suffering is too much and when an inexorable process of dying has begun; and that we need to have a rabbi involved and a physician who understands our concerns.

Dr. Rosenstock of Doctors on Call believes an online program sponsored by Chayim Aruchim would go a long way toward providing the cultural sensitivity training needed. "We ought to be able to say to them, 'Here's the site, go online for ten minutes and you'll see that we understand the needs of hospitals and insurance companies, but that these are our positions based on a 3,000-year-old tradition.' This should be an address to which anyone, at any level — a hospital board, an intern, a patient's family — can go to understand where we're coming from."

The year of *aveilus* for Reb Aharon Schwebel is long over, but the memory of the ordeal the family endured hasn't dimmed in son Rivie's mind. "We had a doctor who is number three in the country for stomach cancer, and we had to beg, literally beg him to treat my father with even light chemotherapy. Everyone in the hospital said, 'Why are you wasting your time? He's 84 years old.' This, about someone who three months earlier was active, driving on his own, going over the davening with me.

"I had to get on my knees — literally — and cry to the doctor, 'Take care of my father.' With tears in his eyes, he relented. Three months later they took another scan and the tumor was 25 percent smaller. The doctor, who at the outset of treatment would've been happy if it had just not grown, said, 'I can't believe it.' I sent the report to a prominent doctor at Sloan Kettering and he couldn't believe what he was seeing either."

If the Schwebels learned anything, it is "not to feel uncomfortable defending your rights as Torah-observant Jews. It's so easy to fall prey to all the talk that occurs in the hospital setting. It's easy to forget what we know to be true when we are surrounded by so many who speak to the contrary. Whenever we were faced with decisions, we said, 'Our father has lived his entire life as an observant Jew and we must be consistent with his life's choices. We will not change now.' "

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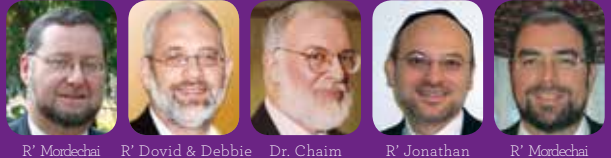

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