

THE RIGHT TO LIVE

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Nearly 1,000 Israelis are waiting for organ transplants. Many will die before suitable donors are found. See story with related boxes.

Twelve-year-old Nathaniel Peretz lies in a glass-enclosed isolation room in Sheba Hospital at Tel Hashomer. His tiny, 26-kilo body is hooked up to monitors and whirring machines that work around the clock to keep him alive.

A breathing tube snakes down his throat to pump the air in and out of his brand-new lungs, which he received barely two weeks earlier to replace his own, which were racked by the genetic disease cystic fibrosis, with which he was born.

Until early on the morning of December 31, Peretz's lungs belonged to Jonathan Tokaryev, 12, a new immigrant from Russia who lived in Kiryat Shmona.

Tokaryev died the night before of a massive brain hemorrhage following a stone-throwing accident at school. But because of his parents' magnificent act of loving kindness, his lungs were transplanted hours after his death into Peretz's body, giving new hope to a sick little boy whom doctors said had only months to live. It was the first double lung transplant ever done in Israel, and the first lung transplant performed on a child.

Tokaryev's heart went to a 15-year-old boy who was mid-flight to a transplant operation in Belgium when the pilot received instructions to turn the plane back to Israel, where Tokaryev's heart was waiting.

His liver, pancreas and kidneys gave new hope for a normal life to three other Israeli children.

"What mother ever thinks of donating her child's organs?" asks Tokaryev's mother, Dina, in an agonized phone conversation a week after she buried her son. "A mother can only sit by her child's bedside and pray to God to save his life.

"But when three separate doctors told us Jonathan was dead, that there was no hope of his ever waking up again, I thought, if these other mothers are also sitting by their child's bed, praying to God just as I was, why shouldn't I try to save them from the same terrible fate I've suffered?" she recalls. "Why shouldn't I give life to five other precious children?"

Nathaniel Peretz is one of the lucky ones. There are more than 950 Israelis waiting for organ transplants today. Many will wait in vain.

Ninety-five people are waiting for new hearts; last year, 16 heart transplants were performed. More than 800 are waiting for kidneys; last year, 56 critically ill patients received new kidneys, compared to 83 the previous year.

Not only is Israel's rate of organ donations dangerously low, but there were less kidney transplants performed in 1995 than in 1994.

"Fewer kidneys were available for transplant last year," explains Dr. Pierre Singer of the Rabin Medical Center-Beilinson Campus, who is head of information and education at the National Transplant Coordination Center

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(NTCC).

What happens to those people who don't receive the organ transplants they need? All will continue to suffer. Many will die.

"Those waiting for kidneys can stay on dialysis for a very long time," Singer says. "Five to 10 percent will die. Those who live will enjoy a very poor quality of life, especially the children.

That's why children have the highest priority for transplants."

Why were fewer kidneys available for transplant in 1995 than in 1994? It's part of Israel's disturbing record as the country with the lowest percentage of organ donors in the Western world, according to NTCC figures.

"The situation has reached critical proportions," Singer states. "Despite tremendous progress made in the technical aspects of organ transplants, organ donation is still at a terribly low level."

In 1994, Israel had 9 donors per million people. Contrast that with France's 14.5 donors per million, Spain's 30 per million, Austria's 35 per million and the US's 22 per million.

Israeli hospitals are equipped to perform organ transplants on every patient who needs one, and the operations are covered by national health insurance. Successful kidney transplants have been performed in Israel since 1966. The first liver transplant was in 1986, the first heart in 1987, the first pancreas in 1991, and the first lung transplant in 1993.

But if families aren't prepared to give hospitals the green light to remove their loved one's organs once doctors have verified brain death, organ banks will remain dangerously low.

In the absence of donor organs available at home, Israelis are going abroad for private transplants.

It's expensive. A liver transplant in the US can cost \$1 million, including related expenses.

And it may be dangerous in some Third World countries. Kidney transplants cost \$3,000 to \$5,000 in India and Egypt, significantly less than in other countries, Singer says, making them the countries of choice for Israelis in search of new kidneys, but the operations involve considerable health risks. Recipients of kidneys in these countries are often given no immuno-suppressive drugs, and can suffer infections and contract terrible diseases, including malaria, hepatitis B and AIDS, from infected donors. Sometimes the new kidneys have to be removed once the patient returns home.

And it's getting harder and harder to arrange organ transplants abroad. Transplant centers in every country are feeling public pressure to keep their organs for their local populations instead of selling them to wealthy foreigners. Last year, the French national transplant center was shut down and completely reorganized in the midst of great scandal after it was revealed that more than 30 percent of its 370 liver transplants were for foreign visitors.

"The doors abroad are already closed for livers," says Prof. Ami Barzilai, chairman of surgery at Rambam Hospital and president of NTCC. "Hearts are still being done in Belgium, but that door will soon close. Israelis should not try to arrange transplants abroad on their own, but should do everything through our center."

NTCC was established two years ago to increase public awareness of the need for organ donation, and to regulate the organ transplant process by creating one national registry.

"Until the center was established, it was a jungle," Barzilai notes. "Whenever an organ was available for transplant, the various medical centers would fight for it. Now we are responsible for maintaining one national registry of patients waiting for transplants, and of organs available from potential donors. We match donors to recipients according to an impartial list, not like before, when organs sometimes went to those with money or connections."

Strict impartiality is the new rule in organ donations, he says. Although young patients get priority, all other considerations male or female, Arab or Jew, rich or poor are irrelevant.

"Recently we had a potential donor, a religious Jew, whose family said they'd donate if we promised the organs would only be given to Jews," Barzilai relates. "We did not accept that condition."

On the other hand, he continues, an Irish soldier serving with the UN forces in Lebanon was killed in the line of duty, and brought brain-dead to Rambam Hospital. His wife agreed to donate his organs, so long as one kidney went to a Jew and one to an Arab.

"It was true UN style," Barzilai says. "That condition we accepted. Anyway, we have more than enough Arabs and Jews on the waiting list for kidneys."

Until the NTCC was established, Barzilai continues, if a potential donor died in one hospital, usually only those organs needed on the spot were removed and used. Today, because of the national registry system, the five major organs used in transplants heart, lungs, liver, pancreas and kidneys are all removed from a donor, and distributed among the six Israeli hospitals for implantation into waiting recipients.

Also, organs are now transported to the patients, rather than patients to the organs. That's the way the rest of the world operates, Barzilai explains, adding that "it's more logical."

Dr. Ben Shmueli, head of liver transplants and organ retrieval at the Rabin Medical Center-Beilinson Campus, points out that kidneys can be transplanted up to 30 hours after removal and livers can wait 16 hours, though lungs and hearts must be transplanted within four hours.

The NTCC works with a national tissue-matching laboratory for kidney transplants at Sheba Hospital, run by Prof. Ephraim Gazit. The lab began operating in 1973, but established its national list only a year ago.

All Israelis waiting for kidney transplants are registered with it. Gazit collects blood samples, to assess tissue type, and draws monthly serum samples from every patient on the waiting list, to determine the best match between recipients and potential donors.

The lab is on 24-hour-a-day call. As soon as a kidney is located, all vital statistics from the potential donor are fed into Gazit's computer, and the hundreds of transplant candidates are ranked according to specific criteria: age; compatibility with that specific kidney; length of time on the waiting list; and certain immunological criteria.

The top names on the list are given to Barzilai's team at Rambam, which begins arranging the transplant operation. If the first person on the list has died or gone abroad for a transplant the second person receives the precious organ.

"Order is maintained, and the available kidney is not awarded according to the personal preference of any particular physician," Gazit says. "It's absolute justice."

As of this month, there are 801 kidney transplant candidates on Gazit's list. No similar tissue-matching labs exist for patients waiting for other organs.

Gazit explains that a match between the serum samples of recipient and donor is not a prerequisite for successful transplant of other organs. Routine anti-rejection drugs are usually able to ensure survival of the transplanted organ.

But more importantly, while dialysis enables people waiting for kidney transplants to function for an unlimited time, patients waiting for new hearts, for example, are often in a much more critical state.

"The availability of hearts for transplant, and the emergency need of the patient for that heart, makes doing a match of secondary importance," Gazit notes. "If you have the heart, you don't play around. You do the transplant, and you take your chances."

Benny Basevich, 52, of Kiryat Haim, is waiting for a heart. Despite the odds, it has to be better, he feels, than what he's going through now.

Born on Kibbutz Kfar Giladi, Basevich was strong and healthy. He served in the paratroopers, and fought with the unit that captured the Old City of Jerusalem in the Six Day War. After his military service, he married, had two sons, and began working as a truck driver for a national moving company.

On March 10, 1985, without any prior warning, he suffered a severe heart attack. He was changing a tire on the road near Ein Gedi, when he felt tremendous pressure in his chest and back, his vision blurred, and he slumped to the ground. Another trucker pulled over to see whether he was all right.

"I had all the classic signs of a heart attack, but such a thing had never happened to me, so I didn't recognize it," Basevich recalls. "I told him I was fine. It was a macho thing."

Basevich kept on driving, and the pain and dizziness increased. He pulled over, got out of the cab, and fell to the ground again. For several hours he tried to pull himself around the truck to alert passing drivers. Finally a man who knew him from Kfar Giladi stopped and took him to the clinic at Mitzpe Shalem, where they diagnosed his heart attack.

"From that day, my entire life changed," Basevich notes. "I used to be a real workaholic, going from 4 a.m. to 9 p.m. every day. I hardly saw my children. Now I hardly leave the house."

For four months after the heart attack, Basevich rested at home. Then he spent 18 months as the shift manager for the moving company before his boss laid him off. Since then, his only work has been as a clerk in an auto parts store, which recently closed.

Last February, he was fitted with a pacemaker at Beilinson and put on the waiting list for a heart transplant. The pacemaker corrects only part of his heart problem, he explains. It doesn't correct irregular beating, which is filling his left ventricle with blood, causing his entire heart to elongate and enlarge.

Basevich now spends most of his time at home. He walks slowly, but can't climb many steps or do any lifting. He watches his salt and fat intake, to keep his weight down.

"It makes a big difference if your heart has to support 80 kilos versus 100 kilos," he notes.

And everywhere he goes, he carries a beeper, which will alert him when a donor heart is found. When the beep goes off, he's supposed to head straight to Beilinson.

Gazing sideways at the small black box, Basevich admits he's "terrified" of hearing that beep.

"My rational side says, a new heart is exactly what you need, but my emotional side is terrified of the operation," he says. "Still, I'm even more afraid of not hearing that beep. It's been more than half a year, and nothing. I read about transplants in Israel all the time, and I wonder, why not me? I feel like there's an hourglass hanging over my head, and I'm scared to see how little sand is left in the top part.

"I'm afraid of the operation, and I'm also afraid that years will pass and no suitable heart will be found. I wish the operation was over. I know I'll be able to handle whatever problems I'll face afterwards. It's the waiting that's so hard."

The most difficult part of it all for Basevich, he says, is being forced to depend on the kindness of strangers. He has nothing but praise for the country's medical system, which he says has done "everything possible" to help him.

"Now I feel like the guy standing on a street corner with a cup in his hand, begging people to drop in a coin," he says. "Only I don't need money, I need them to give me something far more precious. I need a heart. It's so hard for me to ask for that. Who am I to ask someone else to solve my problem? Why should they care if I live or die?"

There are three kinds of donors for organ transplants. Living donors, usually close relatives, are routinely used for certain transplants, such as kidneys and bone marrow. People can live quite well with one kidney. Unfortunately, this has led to the widespread practice of poor people in Third World countries selling their kidneys to wealthy foreigners.

Cadavers, or people whose hearts have stopped functioning, used to be the main source of kidney donations. No other organs can be transplanted from a heart-dead patient.

The most desirable organ donor from a purely medical perspective is what is referred to as a brain-dead patient, a patient whose brain-stem functions have ceased, meaning consciousness will not return, but whose heart continues to beat for a limited time.

Because the physical body remains "alive" for some hours after the brain has expired, the internal organs can be removed during these few hours and transplanted.

Determining the exact moment and irreversibility of brain death is a controversial subject and has led to opposition to the current methods of organ removal from brain-dead patients in certain haredi circles.

The process of determining brain death is carefully regulated according to procedures set down by the NTCC. After the attending physician has determined a patient is brain-dead, the same tests are repeated by a committee of at least two physicians (three in the case of a child) who have not treated the patient to eliminate any suspicion of prejudice.

Once the committee has confirmed the initial physician's diagnosis, a physician goes together with a social worker to inform the family that the patient is brain-dead. Only after that information has been given and absorbed by the family, does the doctor or social worker gently ask whether the family is willing to donate their loved one's organs for a transplant.

"It's a very sensitive process," Singer says. "Only after we are absolutely sure they understand that the patient is

brain-dead, do we give them the opportunity to donate."

Tali Yohanes is a social worker at Sheba, where she is in charge of all contact with donor families, including the first terrible discussion where she must tell them of their loved one's death and then ask them to donate organs.

"The family goes through an enormous trauma," she says. "These cases usually involve a young person who has died suddenly in a terrible, unforeseen accident. Just a few hours earlier, they had a healthy, normal child, and now they're hearing that their child is dead, and I have to ask them to donate parts of his body to save other lives.

"I go over all their questions 100 times if necessary, until they understand exactly what's happening. I explain that brain death is not like a coma, where the patient can wake up even years afterwards. In brain death, the patient will never wake up.

"And I have to ask them right away, when the pain is greatest. The window of opportunity is very small, sometimes just a few hours. Once the brain dies, the organs begin to deteriorate quite quickly."

Singer says that nationwide, only 40 to 50% of families agree to donate their loved one's organs when the hospital asks them to do so. That rate varies from place to place, but in general is much lower than rates abroad.

Yohanes says 75% of families asked at Sheba agree to donate the organs, a relatively high rate of consent which she attributes to the clear and humane way families are informed of their loved one's death by the hospital's special team.

Why do some families refuse? Yohanes says it's mostly for "irrational" reasons. Some families believe the organ removal will be conducted in a brutal way on their dead relative's body, so Yohanes explains that isn't so, the operation is conducted with the same care and respect as with a living patient.

Some families base their refusal on pseudo-religious reasons some mistakenly believe the body must be buried in its entirety, or the dead person will be denied redemption. In these cases, Yohanes will often bring in a sympathetic rabbi or mullah, for Moslem families to talk to the family.

"Halacha supports donating," Singer points out, noting that the chief rabbis of Israel agreed to permit organ donations from brain-dead patients in a 1987 ruling. "But in people's minds, Halacha is against donating. Or maybe that's just their excuse."

"Sometimes the family says, 'he's already suffered enough,' as if removing the organs after death would lead to further suffering, which is nonsense," Yohanes says. "We try to gently persuade them of this, but it doesn't always work."

Yohanes often deals with cases where a husband or wife, for example, will say they never discussed the possibility of organ donations at home, and they don't know what their loved one would have wished.

That's the hardest of all for her to deal with, because it's a problem so easily avoided by signing the pre-death consent form provided by ADI.

ADI was set up in 1978 by the parents of Ohad (Adi) Ben-Dror, who died while waiting for an organ transplant. ADI, which is now run by the NTCC, distributes organ donor cards together with driver's licenses or renewals. Signing the card means you give your consent to the removal and transplant of your organs in the case of brain death.

Although every hospital in Israel still requires family consent at the time of death in contrast to Belgium and Austria, where signing the donor card is sufficient permission the knowledge that their loved one has already agreed makes the terrible decision much easier, Yohanes says, on a family already confused by sudden grief.

Last fall, ADI and the NTCC began a massive public-awareness campaign to encourage people to sign donor cards. Posters were put in bus stations and on billboards, and radio and TV spots were aired.

The response was overwhelming. "Just before the campaign, we had the lowest level ever of people calling us, about 200 per month, instead of the usual 600 to 900," Singer says. "In the two weeks of the PR campaign, we got 2,500 calls and signatures."

Seventy-three thousand Israelis have signed the ADI donor card; 3,000 of them since this latest campaign.

"Organ donation is a mirror of Israeli society," Singer maintains. "It's no coincidence that when ADI subscriptions were at their all-time low, Rabin was assassinated. It's a reflection of what's going on in society."

When social awareness and feelings of "belonging" are high, so are organ donations, Singer says. Kibbutznik families have a 100% rate of agreeing to donate their loved one's organs, which indicates the degree of responsibility they feel toward society. In contrast, at the beginning of the massive immigration from the former Soviet Union, these new arrivals had just an 18% consent level. Today, that rate has jumped to 58% nationally.

"We asked both groups why, and the early group said, we're not integrated into the country, we don't feel a part of things, we have no reason to donate," Singer says. "Today, they feel more a part of the larger Israeli society."

Sometimes, it takes knowing someone who needs a transplant to encourage others to sign ADI donor cards.

Miri S. is a 30-year-old graphic artist from the Tel Aviv area who desperately needs a new kidney. She had one transplant five years ago, but the kidney deteriorated, and she's been on home dialysis for five months while she waits for a second transplant.

"You never feel more than 75% well on dialysis, but after a transplant, you can feel great again," she says. Since her first transplant, Miri's husband, family and friends have all registered as ADI organ donors.

"Don't wait until tragedy strikes your family. It's enough to visit a transplant center, and watch people who need kidneys be wheeled in and helped up the stairs, then see those same people a week after the operation walk out of the hospital under their own steam.

"Please, keep your minds open. You have no idea the significance this gift could have."

Basevich has become active in ADI since being put on the heart-transplant waiting list a year ago. He spends time pleading with people to sign donor cards.

"I don't understand why people won't sign," he says, shaking his head. "Maybe some people think acknowledging the possibility of their own death will somehow hasten it.

"I need a heart. Something they won't need anymore when they die, something that goes into the ground with the rest of their body, could save my life. I'm asking people to sign that card now, so if, God forbid, some terrible tragedy occurs, their family will be able to find the strength in that awful moment to say 'yes,' to make the special effort to save the lives of other people.

"I have no right to tell any family: 'Your loved one will live on in my body.' All I can do is lay my request before them on the table, and say: 'Please. You ask about rights? What greater right do I have than the right to live?'"

ADI can be reached at the Rabin Medical Center- Beilinson Campus in Petah Tikva, Tel: (03) 937-6950.

Illustration

5 photos; Caption: Tissue-matching center head Prof. Ephraim Gazit: 'It's absolute; Credit: Sarit Uziely, Jonathan Bloom

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Abstract (Document Summary)

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