

Women to Know

LIVES:
Jerusalem

AGE:
Early 60s

OCCUPATION:
Director of
Tikvah for Parkinson

Mrs. Debbie Shapiro

“I need to think about every movement I make, at least if I want to do it right.”
— Debbie Shapiro

Parkinson's is a very isolating disease. Your world grows smaller and slower, while around you, the people you know and love are rushing, accomplishing, doing, at what seems like a dizzying pace.

It's hard to explain to anyone not battling the slowness and stiffness of Parkinson's what it's like to wake up in the morning and literally have to force your feet to move. You want to crawl into bed, curl up under the covers and do nothing, but you know that doing this would be a death sentence, that it's crucial to get up and go, be with other people, exercise, work, and accomplish.

So begins one of the articles Mrs. Debbie Shapiro has sent me in preparation for our interview. In contrast to these depressing words, my conversation with Mrs. Shapiro, who speaks in a gentle, lilting voice, leaves

me upbeat and grateful. There is something about this young-at-heart grandmother in her early sixties that is refreshing—a groundedness, an eagerness to do and accomplish, a sense of being in the here and now, yet with a vision for the future.

She is part dreamer, part visionary, but she definitely has both feet planted on the ground—though with Parkinson's, at times even that is an accomplishment.

Debbie Shapiro made *aliyah* from San Francisco in 1971. She had complained of aches and pains for several years but chalked it up to exhaustion, stress, and general aging. However, when the aches and pains became more pronounced and began to affect her balance and her ability to walk, she could no longer shrug them off. Instinctively, she knew she had Parkinson's disease.

Debbie described her reaction to the doctor's matter-of-fact diagnosis. He

simply told her she had Parkinson's and recommended that she do tai chi exercises. He prescribed medication and told her to return to his office in three months. He said this calmly, as if he were discussing the weather or his upcoming vacation.

"I burst into tears," Debbie recalled. "Then I told the doctor, 'I'm probably the only idiot who has cried in your office.'" The doctor smiled and said, 'Actually, most people have a total meltdown.'"

SINK OR SWIM

Debbie knew she could either allow her disease to engulf her, to destroy her vibrant, youthful spirit and turn her into a frightened patient who was terrified to leave home, or she could use her inner strength to triumph over her diagnosis.

She took the latter option. She decided that she would not allow her condition to limit her life; instead, she would work to broaden it.

She began to research the side effects of Parkinson's, what to expect, and how to counter the effects. The more she read, the more she realized that it was vital for her to begin exercising, keep her muscles supple, and maintain an active social life and a positive attitude. And she did. She chose courageously to be open about her condition, speaking about it with candor.

After breaking the news to her husband, Debbie decided to tell her children calmly, as the doctor had recommended. She and her husband took them to a restaurant in Yerushalayim to discuss the situation. As usual, Debbie saved the day with her humor. She recalled, "While my kids were sitting there eyeing each other, waiting for someone to speak, I asked, 'So what's this about? You want to talk about the will?' The ice was broken, and we could laugh instead of cry."

Their devoted children decided to get together with them once a month for *melaveh malkah* to strengthen the family

bonds. They pitched in to help make Debbie's life easier and invited their parents for Pesach.

Debbie learned through trial and error to pace herself, not to undertake more than she was able to. She began to exercise religiously, pushing herself to keep up with the 20-something-year-olds who frequented the women's gym. She went to the supermarket, cooked dinner and kept house, though these activities sapped her of her strength. Often, even after a simple outing, she would have to lie down for an hour or more.

And through it all she wrote, keeping a daily log that candidly recorded her experiences. She described the roller-coaster existence of a patient with Parkinson's, who might be feeling on top of the world one morning and then so sick in the evening that it is impossible to get out of bed. All her plans and ideas might dissipate in a puff of smoke, teaching her once again that



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we are never really in charge. We just have to do our share and leave the outcome to the *Ribbano Shel Olam*.

Because Debbie was so honest about her challenges, she began receiving phone calls and emails from women around the world who were dealing with Parkinson's. They shared their struggles, their pain and confusion. Debbie became an unofficial address for people with Parkinson's and their bewildered families.

Debbie learned more and more about the disease, and she began to see what it did to people, forcing them to stay at home out of fear and shame, making them afraid to be honest about their condition. She realized that something needed to be done.

Someone had to educate the public, to provide resources to people whose lives had been upended by the diagnosis and offer support to their families.

A PARKINSON'S COMMUNITY

Debbie was struggling with her own limitations, learning, for example, how to walk with a cane. She was involved with her children and grandchildren, and she was also writing and counseling people over the phone. Despite all these activities, she found the time and energy to create an organization from the ground up.

She envisioned Tikvah for Parkinson shortly after returning from a life-altering trip to Oregon last September, where she attended the World Parkinson Congress, a gathering of patients, doctors, researchers, medical professionals, and representatives of the many organizations that deal with Parkinson's disease.



Debbie recalled, "I heard about the conference from my sister, who is an advocate and patient with Parkinson's, and was planning to attend along with another sister. How could I miss an opportunity to spend time with my two sisters? But the conference was very expensive. The only way I could go was if I received a scholarship. The organizers of the conference had several scholarships available for people they felt would use their knowledge and insight to help others.

"I filled out some paperwork, telling the organizers that I ran a phone support group and had written a series of articles educating people about Parkinson's. Thankfully I was accepted, and I eagerly booked my ticket."

Debbie found the trip exhausting but

emotionally uplifting. Although it was hard for her to sit through hours of speeches, meeting others with Parkinson's, some of whom had been sick for two decades, was eye-opening.

"I met people literally fighting their disease, running marathons, dancing, boxing, whatever they could do to maintain their health, and almost all of them were involved in helping others in the community," she said. "At the WPC, I was with thousands of others like me. I didn't have to feel embarrassed if it took me a few moments to walk across the room or find the courage to step onto the escalator. The people there understood me. We were battling the same enemy.

"But it wasn't just the camaraderie, the sense of belonging. The air was charged with optimism; it pervaded every conversation, lecture and workshop. We felt unified. We all knew that it was our obligation to do everything in our power to keep ourselves healthy, to continue living our lives to the fullest despite our limitations. It was like being part of a gigantic cheering squad, urging me to stretch and do my utmost. When I came home, I was filled with fire, determined to do something to help the

"Shortly after Sukkos, Debbie reached out to Rabbi Moshe Gruskin of Lakewood, the founder of Sparks of Life."

Parkinson's community in Jerusalem."

According to Dr. David Arkadir of Ha-dassah Hospital, there are some 10,000 people with Parkinson's in greater Jerusalem, but there are almost no services available for them.

"I attended a physiotherapy group at one of the hospitals," Debbie said. "We met once a week. Some days there were only four of us. The therapist seemed to be more interested in her smartphone than in the exercises. Someone told me that my Kupat Cholim had a physiotherapy group for women with Parkinson's, but when I went to find out about it, it had closed."

Debbie soon realized that she needed to fulfill the dictum "In a place where there is no man (or woman), become that man." She consulted with medical *askanim* who told her that many people in the *chareidi* community view Parkinson's as a death sentence. They are so afraid that people might find out that they have this dreaded disease that they isolate themselves, which only makes the depression associated with the disease worse. Without exercise, the disease progresses much faster. The only thing proven to slow the progression of Parkinson's disease is intense exercise, but who wants to exercise when they feel slow, sluggish, and stiff all over?

Debbie explained, "Parkinson's creates the ultimate mindfulness. I need to think about every movement I make, at least if I want to do it right. For example, when I walk, I must consciously pay attention to what I'm doing and tell myself, 'Lift the foot, step big, swing the arm.' If I don't, I end up walking stiffly, with tiny steps, like a rusty toy soldier.

"Because all our muscles become stiff and we lose the ability to use them, we must exercise all parts of the body. In our Monday-morning speech therapy session [which Debbie organized as part of the Tikvah for Parkinson rehab program], the speech pathologist instructed us to move our tongues all around our mouths, and then stretch them to the side. We looked

so silly and it seemed so futile, but it's really lifesaving. That's because the tongue is basically one huge muscle. If it isn't exercised, it becomes stiff, and as a result we are more prone to inhaling food and liquids, which is the leading cause of death among people with Parkinson's. So the name of the game is awareness and concentration. But it's not easy."

Shortly after Sukkos, Debbie reached out to Rabbi Moshe Gruskin of Lakewood, the founder of Sparks of Life, a renowned organization that offers *chizzuk* to American patients with Parkinson's. Rabbi Gruskin, a long-term Parkinson's patient, had a gym in his house and exercised regularly every day. He gave Debbie generous amounts of time, advising her on how to proceed.

At the same time, Debbie was spending her days giving *chizzuk* to other Parkinson's patients, running her household, writing, and exercising.

"I need the gym. It's a lifeline for me, so I can't give that up," she declares. "I realized the importance of it when I skipped the gym for close to a month because of a family *simchah*. Every morning when I wake up, my upper body tilts to one side, but within a short time I'm able to straighten up. But after those few weeks without exercise, I woke up one morning completely bent over to one side. I couldn't even stand up or walk without assistance. I was terrified that I'd have to spend the rest of my life in a wheelchair.

"Eventually, with the help of medicine to relax the muscles, massage and a private physiotherapist who made house calls, I was able to straighten out again. The physiotherapist gave me some simple exercises to do to make sure it wouldn't happen again. They were all exercises that I had been doing daily—except that I hadn't!"

In between visits to the gym and caring for her family, Debbie kept answering the phone because more people were calling for encouragement and advice. "You have to do something for us," they pleaded. "We

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don't have any resources here.”

Out of these phone calls, Tikvah for Parkinson, the first organization of its kind in Eretz Yisrael, was born.

“To break the stigma surrounding the disease, I decided to host an evening of information. I asked Professor Nir Giladi, the esteemed chairman of the Department of Neurology at Tel Aviv Sourasky Medical Center, if he would come speak.” Professor Giladi is one of the foremost experts in the field of Parkinson's and has a waiting list over half a year long.

“I was positive he would refuse, but he immediately agreed,” Debbie continued. “I was shocked. Now I had no choice. I was committed, and I actually had to organize something.”

Debbie arranged for three distinguished *rabbanim*, each from a different *kehillah*, to provide words of *chizzuk*. The Sadigura Rebbe and Rav Moshe Brandsdorfer, a leading *posek* in Jerusalem, wrote warm letters of approbation. She spoke with people at the local community center who agreed to let her use their sports hall, hired a person to set up the sound system and another one for the video, and asked a few women to set up the hall.

“Everyone I spoke to told me to expect 30 to 50 people at most. But they also pointed out that although a lot of people wouldn't come, the people in the community with Parkinson's would all find out what was said. I decided to be optimistic and set up close to 100 chairs. *Baruch Hashem*, my son and grandchildren were there because people just kept pouring in. They ended up setting out over 260 chairs, and people were standing in the back! My son had to extend the *mechitzah*. I realized I had only touched the tip of the iceberg.

“Everyone at the event was incredibly excited that an organization had finally been established to help them. But that organization was just one woman with Parkinson's who had limited energy reserves and virtually no budget.”

TIKVAH OPENS

Debbie didn't let this daunting task faze her.

“The need was, and still is, very great. The more I did, the more there was that needed to be done. I ended up working eight to ten hours a day, but the *siyata diShmaya* was so palpable that I couldn't stop. Things just seemed to fall into place. Within less than a month of our initial evening, we established an entire program for people with Parkinson's in Jerusalem. Everything we do is under rabbinical guidance, and our goal is to reach the *frum* community. But we are open to everyone who respects our adherence to *halachah*, and many non-religious people participate in our programs.”

At present, all of Tikvah's programs take place at Yad Sarah, the medical organization. “The people there have been incred-

A FULL AND MEANINGFUL LIFE

Tikvah for Parkinson is dedicated to helping people with Parkinson's disease live a full, meaningful life for as long as possible. We believe that people with Parkinson's have a right to understand their disease and to receive the emotional and physical support they need to maintain a healthy lifestyle, including multidisciplinary patient-centered treatment. All our activities are conducted according to *halachah* and are under rabbinical guidance, with an emphasis on turning a physical challenge into a tool for spiritual growth and self-actualization.

OUR PRINCIPLES

- **KNOWLEDGE:** With knowledge, we can be proactive about our own health care.
- **SUPPORT:** To face this challenge, we need the support of our families and friends, as well as the mutual support of other people with Parkinson's.
- **ADVOCACY:** As a group, we can advocate for better health care.

OUR GOALS

- To encourage people with Parkinson's to lead a healthy, active lifestyle with an emphasis on exercise, which has been shown to slow down the progression of the disease.
- To give people with Parkinson's information so that they can be proactive in dealing with their disease.
- To provide emotional support to people with Parkinson's.
- To facilitate mutual support among families challenged by Parkinson's.
- To raise awareness of Parkinson's disease and the special needs of those who have it among the general population and among relevant government bodies.
- To advocate for a multidisciplinary approach to treating Parkinson's.
- To make resources accessible to the Parkinson's community via a Parkinson's information specialist.
- To translate and distribute accurate and positive information on Parkinson's disease to the Parkinson's community.

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ibly helpful in assisting me to set up our rehabilitation program and letting me use their auditorium at cost.”

Tivkah for Parkinson is still growing, but it has already come a long way.

“So far we’ve had three very successful evenings, with prominent lecturers in the medical field and renowned inspirational speakers. After the event, we sell discs with speeches and information, which are highly popular. We’ve had people come from Bnei Brak and Netanya just to buy the discs!

“In addition to providing education about the disease, we’ve started an intense rehab program for people with Parkinson’s. At present we have three groups with over 30 Parkinson’s patients...and we have a waiting list! The three-and-a-half-hour program includes gym, group exercise, speech therapy, physiotherapy and a support group. In addition, we have a support group for wives of Parkinson’s patients. Because our groups are presently full, we’re adding another two groups after Pesach.

“In addition, the rehab program will be expanded to twice a week and will include tai chi, dance, boxing, occupational therapy and a women’s choir group, which all the women are really excited about! The whole thing is completely crazy. We only achieved legal status as a nonprofit organization last week! We’re literally working out of a shoebox.

“One of the most exciting developments took place as a result of our outreach. Herzog Hospital invited me to speak to its CEO and prominent Parkinson’s specialists. Because of what we’re doing, they decided to give priority to helping people with Parkinson’s and plan to create a comprehensive multidisciplinary Parkinson’s clinic in the near future. They will be working with Tikvah to assure that the services are suitable for the *chareidi* community. Meanwhile, they are encouraging us to develop our rehab program.

“We’ve come a long way, but there is still so much to be done. People are actually ashamed that they have Parkinson’s! At one of our recent events, a woman sat the entire time with her face to the *mehitzah* so that no one would recognize her. Women often ask to meet with me privately, and after we share our experiences, they tell me that this is the first time they’ve actually talked about what they’re going through. They tell me how difficult it is for them to keep their condition a secret, sometimes even from immediate family.

“That’s why education is so important! We need to make people aware of the disease and help them realize that it’s a



*Simply
Beautiful.*

Debbie admits that her schedule these days is punishing.

challenging, life-changing condition, but not a death sentence. We're *frum Yidden*. We should be ashamed of our *aveiros*, not G-d-given challenges!"

Debbie is trying to shatter the stance that Parkinson's is embarrassing by serving as a proud example. She recently wrote after a lecture, "When the taxi driver dropped me off in front of Yad Sarah, he asked me if I was going to volunteer. I responded that I run an organization that helps people with Parkinson's and that tonight we were holding a lecture. 'Nebach. Such *miskeinim*. What a horrible disease.' I could almost hear the driver cluck his tongue. 'There's nothing that anyone can do to help them. But it's a real *chesed* to try and bring some happiness into their miserable lives.'

"That's exactly the misconception we want to shatter," I said. "It needs to be changed, not just among the public but in the way we look at ourselves, or at family members with Parkinson's. We are not *miskeinim*. We are not *nebachs*. We are people faced with a challenge, and we are doing our utmost to stay as healthy as possible for as long as possible. And Tikvah for Parkinson is here to help us accomplish that."

Debbie admits that her schedule these days is punishing. "Until Tikvah becomes more financially stable, it's a one-woman show. But it's taking a toll on me. Following a recent event, I had a physical melt-

down. I literally didn't have the strength to continue," she recalled. "I desperately need a secretary, someone who can take on a bit of the burden. I am not capable of working so many hours. But how can I slow down when there's such a great need?"

There is also the question of money. Many patients with Parkinson's are not in a position to pay exorbitant sums for therapy and exercise. But Debbie takes it all in stride, one day at a time. "The *siyata diShmaya* is incredible. Who ever heard of something like this happening in such a short time? I feel that Hashem is literally holding my hand and guiding me, and that's what keeps me going.

"As I mentioned, I go to the gym every day. There is a group of women who come every morning, straight from *davening vasikin* at the Kosel. When I told one woman, a *chasidiste* of Karlin, how impressed I was with their diligence, she responded, 'Every morning I beg Hashem not to forsake me in my old age. How can I ask for this without making myself into a healthy vessel to receive the *brachah*?'"

"Her words capture the basic philosophy of Tikvah. As *frum* Jews, we understand that nothing is really in our hands and that we must turn to Hashem for our salvation. At the same time, we are obligated to do our *hishtadlus* and make ourselves into vessels to receive that blessing." ■

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