

A Million Red Lights

Preventative Health Care and Patient Support Options for Women with Cancer

by Leah Kotkes

Ten years ago, "Rivka" had cancer. Today, she's alive and celebrates life one day at a time. *Baruch Hashem*, the cancer has been removed, treatment is over, and she has a clean bill of health. This news is definitely something to acknowledge and celebrate.

Any woman diagnosed with cancer will tell you that she chooses to fight for life. But without a caring medical, physical, spiritual, and emotional resource and support system, the battle is almost impossible. When a person is diagnosed with cancer, *lo aleinu*, attitude counts. It's important that the cancer patient's world doesn't fall to pieces. The attitudes of the patient, the doctors, immediate family and friends, and anyone else on the fighting team makes a significant difference to someone who is looking cancer in the face.

Up to fifteen years ago, if someone was diagnosed with "the *machalah*," hushed

voices and pessimistic faces were usually all that greeted the patient from the increasingly darkening corner of her new world. Any ray of hope had the hardest time penetrating the society, community or family. Self-imposed walls of guilt, shame, and silence were often built to protect or hide a cancer patient and her immediate family.

Baruch Hashem, today this despairing state of affairs is a rarity rather than the norm. Advances in human resources and communication, as well as a global pooling of curative and preventative medical resources have transformed the situation, increasing patients' options. The percentage of cancer patients recovering completely through conventional, or combined conventional and alternative healing resources, is greater each year. The percentage of women who are utilizing preventative services to avoid cancer's onslaught (though still not enough) is increasing each day. Today, a positive outcome is possible and tangible. All-clear recoveries, modern-day miracles, are reported daily.

For those who do not recover, end-of-life care has developed into an all-encompassing support resource. The patient and family members can now be eased into their reality with

as much care, comfort, and kindness as is humanly possible. Today, the world is a more manageable place, both for those diagnosed with cancer and for those close to the sufferers, whose lives will never be the same.

Recently, a close friend from New York telephoned to tell me that her husband had been diagnosed with cancer. "I don't know who to speak to here. I don't know who to call for support, for my husband and myself."

I heard the anxiety in her voice, the fear and confusion. She had vital questions that needed priority attention. I gave her the telephone number of Beit Natan, here in Israel, praying that they would refer her accordingly.

Beit Natan, the Women's Cancer Support and Resource Center, based in the Bayit Vegan neighborhood of Jerusalem, offers a multifaceted array of health education programs and support for women coping with cancer. Their purpose is to inform and educate, as well as to support the needs of religious women with cancer in Israel. (Israel Cancer Association statistics show that one in nine women in Israel contracts women's cancer.)

When Rivka was diagnosed ten years ago, her doctor predicted that she had perhaps five years more to live. It was her atti-

tude, her surgeon's attitude, plus the support of friends and family, that helped her to fight for her life. Against the odds, Rivka is now cancer-free. Today, she's a volunteer peer-counselor for Beit Natan's Lev Rachel telephone Help Line.

"Most recovered cancer patients try to forget the painful issues they had to deal with when they had cancer. I thought I had taken care of them. But when I connect with my hotline peer, I realize that the cancer is still alive in my memory. A person who had cancer never forgets the suffering. When I'm matched up with someone with cancer for Lev Rachel, I take the role of the listener. I don't tell my story, unless the other person expresses an interest in knowing something specific. If the relationship develops, I may say, 'If you'd like me to tell you anything about my story, let me know.' This way, I can choose to leave out the very difficult parts of my treatment and recovery process.

"When I went to my doctor that first time, concerning something physical that was worrying me, a million red lights should have gone off in his head, as he examined me. His nonchalance created nonchalance in me; I didn't make an urgent effort to get a second opinion until twelve months later. The second doctor took my concerns seriously, but I was already quite

far along with cancer by then. That's when I started to experience a living hell.

"I was forty-two, married, with three children. It was obvious that the second doctor who diagnosed me was just as scared and nervous as I was. He tried his best to play down the diagnosis, but within a few days I was in surgery fighting for my life. When I woke, silent, sad-looking faces surrounded me. "Do I have a serious cancer?" I asked a close friend, who sat next to my mother-in-law. But I knew the answer from her face, and I broke down.

"I was given a fifty percent chance of living for the next five years. I decided, that day, that I'd been dealt a rotten card. It took me time to transform that attitude. I was angry at G-d, angry at the world, and I was frightened. Later, I would understand that these were normal emotions — emotions that I had to learn to accept before I could let go of them.

"The biggest *brachah* of my first surgery was that, despite pressure from all sides to take an oncology surgeon, I decided to take a different surgeon, instead. He cut out all the cancer that he found, which was way beyond what we'd anticipated. By getting all the cancer out in one go, he was the *shaliach* who saved my life. I'm constantly amazed by the *siyata d'Shmaya* that we were *zocheh* to see."

Rivka's first six months of chemotherapy gave her an opportunity to reassess her life, and to live each day to its fullest potential. Her husband remained suspended in a state of emotional shock for the duration and could not offer her much support. After surgery, Rivka's friends took over; they helped her and her family in every way, anticipating every need.

"Every situation is unique. In my case, my women friends gave me the support I needed. I was told that many people were davening for me, and that made a big impact on me. I wasn't able to listen to advice from lay people about my situation. I couldn't deal with it.

"After chemotherapy, my life went back to some semblance of routine. My doctor gave me the all-clear, but I was a different person. I still needed support. I felt like a toxic waste dump. I had never wanted to have chemo, but that was the only option for me with Stage III cancer. I had complemented my treatment with alternative medicine, which included a system of vitamins and tinctures. Someone close to me recommended that I try guided imagery therapy, which helps to release tension and free your mind. This was fantastic. I believe it really helped me let go of feelings and fears that were detrimental to my recovery. I tried eating a macrobiotic >>>

diet, which means fruit, vegetables, and grains cooked in a certain manner. I read many reports that this helps tremendously (both as a preventative and as a curative treatment). But I only ate this way for a little while. It takes so much self-control and skill to follow this eating regime. I wasn't up to it. My main focus was to survive, and that took all my *ko'ach*.

"A person with cancer becomes self-focused. My friends and the people of my community took over my family life, because to survive what I was enduring, I had to focus on my health. Since I'm an *olah chadashah*, without too much family in Israel, my community filled in the gap. They helped with medical expenses, food for my family, and cleaning help. A person with cancer needs unconditional, unlimited support. I couldn't have managed all the needs of my family, while going through chemo. After chemo, it's sometimes impossible to get out of bed for days. It's an exhausting process.

"I had to create my own will to live, and that took all my time and effort. Nothing else mattered to me. You have to firmly believe in yourself, if you want to win a war with cancer. Cancer is such an individual thing. I know that now. But at the time, I believed that the only way to live was to focus and fight the cancer with everything I had, mind, body, and soul. I believed that Hashem would grant me more years. I believed in my professional medical team. My doctor believed I would make it. He believed it one hundred percent. I felt that support. When I was well enough, I *ma-mash* davened from the depths of my heart. All this was reciprocated.

"I'm happy that I can be part of the volunteer peer-system at Beit Natan, and give something of myself to women who are facing the same challenges that I faced. Often, I will speak with a caller only once or twice, if this is her particular need. Other times, I might talk to a caller for the duration of her chemo treatment. I find I can give the most support to someone who is experiencing the same type of cancer that I had."

The trained women volunteers who answer the Lev Rachel Help Line are all recovered patients themselves, or have experienced cancer within their family. These women provide help and hope for over 600 callers a year. Using the peer-group support model, a caller is carefully paired with a volunteer, who is compassionate about her circumstances. Complete confidentiality is assured.

Chana, who lost her daughter to cancer and is Lev Rachel's co-founder, ex-

plains: "After my daughter was *niftarah*, I wanted to do something for women like myself, who were experiencing the trauma of cancer and needed someone to talk to who could understand their pain. *Min ha-Shamayim*, I was put in touch with Beit Natan, and we held our first volunteer training-program. Today, we have eighty volunteers, with about thirty active telephone mentors. In the merit of my daughter, *aleha hashalom*, women with cancer and their families now have the opportunity to receive compassionate and confidential peer support."

In addition, Beit Natan holds support groups at the Center. These groups, facilitated by an oncology social worker, offer an opportunity for cancer patients to meet

"The biggest *brachah* of my first surgery was that I decided to take a different surgeon. He cut out all the cancer that he found, which was way beyond what we'd anticipated. By getting all the cancer out in one go, he was the *shaliach* who saved my life"

in a private and confidential setting, to learn new coping skills, get more medical information, and to share and discuss the secrets on their heart with women facing similar challenges.

Preventative initiatives are essential. They can save lives. With all her strength, Rivka advocates preventative measures. "I'm convinced that if the doctor had caught my cancer at Stage I or II, rather than at the advanced stage of III to IV, which are the final stages of cancer, before hospice care, *lo aleinu* — my recovery would have been less complicated and quicker."

She is the first to admit that she wishes she hadn't waited a year to check out a recurring health issue that had bothered her. "Nobody is going to look after your own body except yourself," she emphasizes. "Our bodies house our souls. They are a gift from G-d. A very precious gift. If we neglect the house to our soul, we'll get into trouble. We can't live in this world without our bodies. In Israel, and the rest of the world too, we experience enough anxiety

from every standpoint that we can't control. This being the case, we have to take control over what is in *our* power and what is *our* responsibility."

Tragically, the importance of this mitzvah, in particular as it applies to preventative care concerning cancer, often seems to elude religious women. A national survey, *The General Health Habits of Chareidi Women*, initiated and just completed by Beit Natan, and commissioned by the Ministry of Health's Policy and Research Department, supports this observation.

Orthodox women from all over Israel were interviewed. They were between the ages of twenty-two to seventy-five, the median age being thirty-six, with an average of five children. (About thirty-seven percent have seven or more children; about twelve percent have ten children or more.)

A startling fifty-six percent of the women had never taken a mammography. (For women over fifty, the cost for an annual mammography is covered by Israeli health funds.) Eighty percent of the women had never had a clinical women's cancer-detection examination (recommended to be done annually). Seventy-one percent admitted that they do not do self-examination (recommended to be done monthly).

Their reasons for this preventative-care inertia? Thirty-five percent of the women said that they're afraid, not interested, forget, or find the process unpleasant. Some twenty percent said that they didn't know what a self-examination is. Thirty-one percent said that they don't know how to do it. The remaining thirteen percent excused themselves from any sort of preventative care due to being pregnant, nursing or "too young to be thinking of such things."

Hadassah Ein Kerem Hospital in Jerusalem reports that chareidi women come for cancer treatment at later stages than other members of the populace; that if these women were more informed and detected early warning signals, they wouldn't have to deal with Stage III or Stage IV cancer, which is far more difficult to heal than the earlier stages. *When diagnosed in its earliest stage, there is a ninety to ninety-five percent recovery rate.*

These positive statistics alone should be enough to motivate the women of the Orthodox community. Unfortunately, this doesn't seem to be the case. Perhaps if more women obstetricians and gynecologists were available in the hospitals and Health Fund services, this might make a difference. Indeed, seventy-one percent of the women surveyed said that they'd prefer a female obstetrician or gynecologist. Currently, sixty-nine percent of these doc-

tors are male, and forty-one percent of the chareidi women interviewed have male obstetricians or gynecologists.

"Our attitude has to advance," insists Chaya Heller, founder and director of Beit Natan, in response to this apathy. "In the old days, when someone said they had cancer, everyone became scared and it was hushed up. Cancer remains a scary disease. Ultimately, Hashem decides "who will live and who will die," but we can humble ourselves before this challenge and do something about it. There are women living with cancer today. They're challenged by cancer, and everything that it brings in its wake. This disease, like everything else in life, is a tailor-made *nisayon*, and consequently, an opportunity for growth for each individual. Many women get to a place of acceptance and then start dealing with it. A person has to make her efforts with preventative medicine, but we have to remember that ultimately our recovery is in Hashem's hands.

"In my work at Beit Natan, I know I cannot take the fear and pain away from a woman who has cancer. These are emotions which she will, at least temporarily, learn to live with. Everyone has her own personal emotional responses to the disease, most of which are very normal. What we can offer her at Beit Natan is peer support through Lev Rachel, and social encouragement in our weekly support group. In a safe and calm setting, the cancer patient can work through her feelings, clearly understand her treatment options, and get all the understanding she needs as a person. *There is a person behind the disease.*

"With advances in technology combined with personalized support care like this, a woman can experience healing and recovery. She can live a full life, during and after cancer. To make the right choices and decisions, a woman with cancer has to become an informed and educated person. We can give her all this support at Beit Natan. We have the staff and the resources."

Sarit, Beit Natan's oncology social worker, facilitates both the support groups and the annual retreat. She explains, "The debilitating effects of illness and treatment can often leave patients and their caregivers exhausted and frustrated. Beit Natan's annual two-day retreat provides respite and care for women who, in spite of their medical condition, often are still working and caring for others. Accompanied by a social worker, oncologist, and other professional facilitators, the women take part in Torah classes, self-awareness workshops, deep relaxation breathing, and exercises. Good food, plenty of rest, and a few days away from rou-

tine, means that the women return refreshed and exultant, recharged enough to continue in their battle.

"This year, we're offering the option for patients to be joined by their husbands and families for a Shabbaton. Last year, we didn't have the necessary funds for this; we hope we will this year."

Some women contact Beit Natan with a conscious or subconscious knowledge that they're in the final stage of their life. For a year and a half, Devora Corn, an experienced occupational and family therapist, has been managing Beit Natan's Home Hospice and Bereavement End-of-Life Care Program. Volunteers, trained in a specially-designed fifty-two hour course, visit patients once a week to bring companionship to them and their families.

"We look for volunteers who've had experience with cancer in their own lives or a loss in the family, along with maturity, as well as time to commit to the service.

If these women were more informed and detected early warning signals, they wouldn't have to deal with Stage III or Stage IV cancer. When diagnosed in its earliest stage, there is a ninety to ninety-five percent recovery rate

Their commitment after training will be about two to four hours a week at the patient's home. Patients may want a cup of tea, an errand run, or their apartment straightened. Each visit will be different. The volunteer may become the mediator in a family conflict, or be in a position to suggest a mediator who will come in to give the patient and his/her spouse more support.

"In one situation, the cancer patient and his wife decided that they wouldn't tell their children that he was dying. After he was *niftar*, the children were very upset, because they hadn't had an opportunity to say goodbye to their father. They vented all their frustrations and anger on their mother. In this situation, it might have been advisable if someone would have discussed options with the patient and his wife, for the good of the entire family. Often, a patient in the hospice stage has a limited perspec-

tive on the effects of his passing. Although each situation is unique, anguish might be prevented if professional or rabbinic guidance is given at the appropriate time.

"Often, a hospice patient may be nervous, self-conscious, or afraid to talk about death. A volunteer can help her with transition or suggest a suitable third-party to ease her fears and give her the necessary support. Because they're in the patient's home, volunteers can objectively and professionally gauge all sorts of situations. They can bridge the gap between the patient and his or her family, and provide information that may help the family to give more care, attention, and love to the patient. When a patient is given an opportunity to be more honest, he can have his needs met by his family."

Devora is also responsible for the volunteer supervision meetings, which are essential for the hospice program's effectiveness. The volunteers report back their experiences to the group; this is their place to express personal feelings about what they're experiencing in response to their work. The group supports the group. A volunteer will usually need extra support when her patient passes away.

"Our volunteers have all said at some stage: 'When you sit with a person who's dying, you gain a perspective on what is really important in life.'"

Beit Natan is a proactive organization. They know that they have their work cut out for them. Since 1997, they've been initiating programs for religious women, for the early detection of women's cancer, speaking to thousands. In 2004, their health education programs expanded to include direct telephone outreach to chareidi women over fifty. There's still a lot of work to do to inform religious women of the opportunities that exist for early detection. Educational and informational programs which focus on preventative care and wellbeing are always on Beit Natan's agenda. The results of their recent survey are propelling them towards their action agenda for 2005/6.

Beit Natan's motto is "Choose Life," for life is the most beautiful and precious gift that we have. Beit Natan receives personal rabbinical direction from Rav Yisrael Gans, *shlita*, of Mattersdorf, Jerusalem, with endorsements from all sectors of the chareidi and religious community. Their Keren Nina Fund provides financial assistance in cases not covered by government or public health agencies. ■

*Those who wish to contact Beit Natan may do so through **Mishpacha**.*