

"SEEING THE LIGHT"

Written by Tal Laor and published in Maariv Magazine



Hodgkin's Lymphoma has a very high cure rate, but when it strikes young people between the ages of 16 and 30, who are also at a time of life when crises prevail, coping with the disease becomes even more complicated. Tal Laor, a survivor of the disease, describes the support that patients receive, for example in the "Young Adults Embarking on Life" Group.

"Do you see the small scar on your neck?" pointed the nurse in the Hematology Department at the miniscule mark beside my clavicle bone, proof of the biopsy surgery that I underwent to remove my lymph node. "They say that Hodgkin's children are special people. As if God were wandering about, leaving a small peck on their neck. A keepsake of what they went through and the strength that they possess", she explained to me while attempting to lift my spirits at the height of one of many chemotherapy treatments.

Nearly eight years have elapsed since I was diagnosed with Hodgkin's Lymphoma, a lymphoma cancer that damages the lymphatic system (the lymph glands) in the body via malignant cells that originate from B lymphocytes; a disease from which I completely recovered after a dramatic and difficult year - and coping with the disease during that particular period changed my entire life and the way I see things.

I was in my mid-twenties at the time, in the midst of my bachelor's degree program at university. Back then, like many others, I didn't know what Hodgkin's was, aside from the fact that it was a disease that sounded nice and that Charlie Salinger, the protagonist of the famous American TV show "Table for Five", was beset by this illness.

This year will mark the discovery of the disease 180 years ago; an illness which many have coined "young people's cancer" because it is prevalent mainly in teens and young adults in the age range of 16-30. In most cases, Hodgkin's Lymphoma manifests itself in enlarged and swollen lymph nodes in the neck area without any pain, and additional clinical signs such as high fever, excess perspiration during the night, weight loss and other symptoms. Additionally, there is also lymphoma of a slightly different type called non-Hodgkin's.

Not many people know this, but the person who discovered this disease in 1832 was an English pathologist by the name of Dr. Thomas Hodgkin, who was also Sir Moses Montefiore's personal physician and friend. In 1866, while accompanying Sir Moses Montefiore on a visit to Israel, Dr. Hodgkin's died of dysentery and was buried in the Protestant cemetery in Jaffa. Montefiore erected an obelisk in his memory bearing the following inscription: "in commemoration of a friendship of more than 40 years and of many journeys taken together in Europe, Asia and Africa."

According to Israel Cancer Association (ICA) statistics, Hodgkin's constitutes 10-15 percent of cancer diseases among children and young adults. As 2009 drew to a close, 92 children and young adults were diagnosed in Israel with Hodgkin's lymphoma and 95 children with non-Hodgkin's Lymphoma.

The Gift of Life



"The hardest part was when they told me that my hair would fall out and that I would be bareheaded, and everyone would know I was sick", recounts Lihi Shoshan Bergman of Raanana, who developed Hodgkin's when she was 22. The disease struck her as she was completing her studies, precisely when she began working as a make-up artist on TV.

"My greatest fear was that I wouldn't be able to give birth in the future. It sounds awful, but today I know that I went through this difficult experience in order to understand that nothing is to be taken for granted. Life is a gift." Today Lihi is 30 years old and a mother of two.

In most cases, conventional medicine's procedure for treating the disease consists of chemotherapy treatments, which vary according to the stage at which the disease is diagnosed, as well as radiation therapy. It is also important to point out that this disease has a high treatment success rate.

"The prognosis of patients diagnosed at an early stage is excellent, with a 95 percent long-term survival rate ", explains Prof. Michael Lishner, a senior hematologist at Meir Medical Center in Kfar Saba. "Among patients who arrive with an advanced stage disease, the overall survival is very good and ranges from 75-90 percent. Self-donated bone marrow transplantation can save a significant portion of patients with recurrent disease".

It is no coincidence that the disease was nicknamed "young people's cancer". Unlike the case of various sectors of the population coping with cancer, when young people are beset by the disease it carries additional implications.

In contrast with small children and adults, who are supported and cared for in hospitals and special departments designed for this purpose, and for the most part are supported by their children or relatives, young people who have cancer sometimes fall between the cracks. At the same time, these years, characterized by dilemmas and natural crises revolving around forming identities and making future decisions, are complicated in of themselves, and cancer constitutes another difficult component in the daily struggle.

"These are young people who are at the point of departure of forming their adult identity and finding their way in the big world, whether it's being drafted into the army, or making a decision about what they are going to study or becoming part of a couple. They encounter the disease during an overloaded and complicated period of life", explains Orit Spira, a social worker and Director of the Rehabilitation and Welfare Department at ICA. "Additionally, signs of regression suddenly appear. After they've left home, traveled around the world, and served as commanding officers in the army, they find themselves in a weak position again. They move back in with their parents. This is a complicated and vulnerable emotional state, apart from the physical and medical struggle".

Upon identifying the unique difficulty which young people experience when returning to their normal routine after having completing treatments, in 2000 the ICA decided to establish a special group called: "Young Adults Embarking on Life", geared towards young adults between the ages of 20-30 who have survived cancer.

The group serves as a supportive social setting, in which young people from all over Israel meet once a week for a year, accompanied by psycho-oncology social workers. In addition to the weekly meetings that are held at the ICA Offices in Givatayim, these young people enjoy joint activities, such as trips and jeep tours in Israel and abroad, workshops, performances, parties, etc.

Regaining Control



Guy, a 31 year-old certified public accountant from Jerusalem, who recovered a year ago from Hodgkin's disease, recounts that the group helped him during a difficult period after the disease, and to this day he tries not to miss any meetings: "The period after [recovery from] the disease is the most difficult in my opinion. During the course of the illness you are engaged in the physical battle, living from treatment to treatment. Then there is suddenly a collapse. Where do you go from here? The group lets you unload your burden and share [your story with others]. It's a chance to meet people who have been through exactly what you've been through. The group and the staff really lifted me up from the depths".

One of the greatest difficulties that a person who has the disease experiences is to share what they're going through with their close surroundings. The people who support you the most and who are closest to you don't fully understand what you are going through.

"That is true. And then in the group you meet people whom you never met before, who are actually quite similar to you and have experienced exactly what you felt and know exactly what happened to you. You come and hear stories. The social workers from the ICA who accompany us are incredible. They care and handle things with sensitivity. This is a very important process from my point of view".

It's a commitment to travel every week from Jerusalem to Givatayim.

"That's right, and it's very important to me, so I make the effort".

What other activities do you do within the group setting?

"Two weeks ago we went on a two-day trip to Mitzpe Ramon. We slept at an alpaca farm, went on a hike with an instructor from the 'Eggarim' Society, made a bonfire outside and made a potluck dinner. It was terrific. Slowly but surely we begin to enjoy life again".

"The fact that this is a group on a national level, and that the activity is conducted in one place provide added value", adds Spira. "People come and meet friends from all over Israel, they have to plan the trip; sometimes it involves public transportation. They slowly begin to reclaim their independence and get the sense that they are regaining control".

What other content does the group address?

"We discuss a plethora of issues that are relevant to life after the disease, for example, couplehood and intimacy. How do I get back to the dating scene? In the wake of the disease, personal and physical self-confidence highly deteriorates at times. At what stage do I tell people about my disease and how exactly? We talk about it and explore it together in the group. We touch upon the subject of sexuality as well. It isn't easy getting into bed and exposing yourself after the disease. It's very different from a situation in which one has a husband or a regular partner".

It seems as though young people who have the disease are suddenly coping with problems experienced by older people.

"Of course; the issue of fertility is a case in point. Women are used to the fact that they don't have to make a decision about fertility at the age of 20. It isn't a typical decision during this stage of life; or young men who are suddenly coping with the question of whether to freeze their sperm or not; young women who are suddenly coping with menopause and have to understand that they are perfectly normal".

Can you measure the group's success over the past 12 years of its existence?

"Of course, people report that they suddenly have more confidence, are less anxious, and we see this all the time right in front of us. When people show up with a "healthy" kind of depression – depression that isn't necessarily bad and that you can grow from – and suddenly open up and talk, that's already progress. The magnitude of this group is that it allows members to talk about things, about their fears and thoughts, with people who have been through the same thing or similar things and to know that they are not alone when they're with them".

"When I approached the Director of the Bone Transplantation Department at Tel Hashomer Hospital for consultation, he explained exactly what Hodgkin's cancer is", Lihi sums up with a smile. "At the end of the meeting he told me and my family: "if you were to put all the different types of cancers in the supermarket and they would make you choose which one you'd like, grab Hodgkin's with both hands, because this is a tumor that has the highest cure rates. It is important that I convey the message that there is life after the disease, even if it involves a difficult period. It is always important to be positive because there is a light at the end of the tunnel, and it is there that must aim to reach".

For further details, or to join the "Young Adults Embarking on Life" Group, please contact the Israel Cancer Association Rehabilitation and Welfare Department at: +972-3-572.16.78, or via the ICA website at: www.cancer.org.il . These activities are held free of charge.