

# נשמהלה

Sharing Our Special Experiences: Chizuk & Inspiration

# Neshamale

## magazine



**MAAYAN,  
A WELLSPRING  
OF EMUNAH /6**

**WHATS, WHYS & HOWS  
OF EPILEPSY /11**

**HAIRCUTTING TIPS! /24**

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Dear Readers,

Support. For some, the word evokes feelings of warmth, caring, and validation. That's the way it should be. But for others, it evokes a feeling of neediness and weakness. We may have had unpleasant experiences that have given us a bad taste. That's the way it was for me.

Since Avrumi was a baby, I yearned to meet and talk with other mothers dealing with similar situations. Being totally consumed with my son's needs, I certainly didn't have the time for such an "extravagance," but nonetheless, I put in the effort to try to locate such a group. I made phone calls and asked questions. It turned out that, at that time, there were no such support groups in my town.

So, when I received a message one day inviting me to a lecture by a mother of a special needs child, I was ecstatic. I blocked out the date on my calendar and booked my babysitter. I walked in with high expectations, and at first, I was not disappointed. Just to walk into a room full of women who were all looking happy and normal was a big boost for me. When you are in a situation that is unique to most of the people around you, it feels very isolating. The mere sight of so many others, whom you know are dealing with similar circumstances, is cathartic, even without talking to them!

But it was sort of downhill from there. The speaker was charismatic, funny and insightful, and most of the mothers looked like they were really enjoying her talk. But it didn't speak to me. I had been told in advance that the speaker had a teenager with Down syndrome, but was assured that her speech would be applicable to all types of children with special needs. I didn't feel that was so—most of what she said concerned children who walked, talked, and were even able to read and write. At that time, my son did none of the above, and we were doubtful if he ever would. As the speech continued, I found myself sinking lower in my seat, feeling more isolated than ever before.

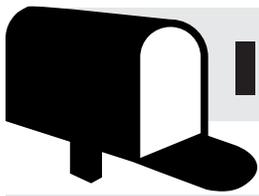
Then they began discussing how to entertain their children when school was out. When ideas were being offered to the tune of: "Pack *Tomchei Shabbos* boxes together" or: "Send them to *Bnos* with a shadow," I just stood up and walked out. "Bad idea!" I berated myself. "Why did I ever think I could relate to a bunch of mothers of high-functioning, adorable kids with Down syndrome?" (Please forgive my untrue generalizations in my moment of pain!) Until then, I had imagined meeting other mothers and instantly connecting and understanding each other. This was a real let-down, and created an (untrue) belief in my mind that most people out there would never understand me. I was totally turned off and did not consider trying a different support group, not then, nor in the future.

This explains why I found Yitti Berkovic's article about her first support group experience (page 14) so refreshing. As you will read, she came in utterly uninterested and was happily surprised to have gained and enjoyed so much. I guess that teaches me, for one thing, that it's better to start things with lower expectations! The main lesson I learned is that it's ok to try again. One or two negative experiences don't have to rule out something completely. Support is an important tool in our box of coping mechanisms; we shouldn't give up on it so easily.

Of course, support groups are not the only way to tap into this essential resource. There are many other ways to create relationships with people in similar situations. In lieu of a support group, I did reach out to other families and received much *chizuk* and practical advice from them. Working on this magazine, I have been fortunate to meet and speak with many inspiring people and have gained tremendously from each encounter. I also realized that it helps to focus, not on the details of someone's situation (as I did during that speech), but rather on the overall attitudes and themes that come through their stories.

I am still consumed by Avrumi's needs, and life has only gotten busier since that day. But I have learned that support is essential and cannot be considered an "optional" activity. When feeling overwhelmed, worried, or in despair, I pick up the phone and call someone. I always hang up feeling calmer, lighter, and more optimistic. So, when you have one of those days (or better yet, let's try to pre-empt those days!), pick up the phone, go to a support group... or sit down with a coffee and read the latest edition of *Neshamale Magazine*.

Wishing all of our readers a *Chag Kosher V'Samaech*,  
Chayala



# INBOX

Wow! Another masterpiece! Thank you so much! I enjoyed every article immensely! It definitely puts things in perspective when I see the tremendous challenges others are going through, and not just surviving, but growing and thriving. I read it literally cover to cover and enjoyed every word, especially the light and humorous columns and the beautiful poems. The question for the social worker was spot on; I could so relate—I could've written it exactly word for word myself. The answer was helpful too, though easier said than done. It helps me to realize that there's no easy answer. Sometimes there will be hard feelings on either end, but it's all part of the *nisayon* we have to pass. May we find the strength! I also loved the "Toys to Buy" article, especially that they were so easy to get and inexpensive. Now I just have to figure out where to fit a swing room in my house :)!  
T.S.

I want to express my gratitude to the producers of *Neshamale*, the superb email magazine that we receive. It is beautiful to see so many people working together to create such a masterpiece, chock full of inspiration, practical advice, and education, well written, and with beautiful graphics and layout. Truly an enjoyable read!

I would like to respond to the terrific and thought-provoking article by Rabbi Klein: "Is This My Fault?" The article was well written and brought to light a question we all must ask ourselves when faced with any difficulty in life. However, the article was written with a strong undercurrent of being apologetic and almost defensive, giving the reader multiple opportunities to "skip this, because it is not for you." This has unfortunately become standard in today's day and age, to sweep under the rug the all-important foundation of our *yahadus: schar v'onesh*, which we talk about at length in the *Shema* three times a day. We live in a "pat on your back" "you're A-Ok" society, where one can do no wrong which would actually deserve punishment.

Let us, however, examine two *Gemaros*. The first in *Eirachin* 16b, where the *Gemara* discusses what are considered *yissurim*. The *Gemara* gives four examples, along these lines: 1- Someone orders a shirt from Land's End and it doesn't fit properly. 2- Someone orders a coffee at Starbucks and it's not hot enough. 3- Someone puts on his undershirt inside out. 4- Someone reaches into his pocket for a quarter and comes up with a nickel. Basically, any

amount of discomfort, inconvenience, or frustration that we experience in this world is considered *yissurim*.

Let's be frank: anyone who has a child with special needs is constantly experiencing a great deal of *yissurim*, regardless of how much we love and enjoy our child. Don't we go through frustration when our child doesn't meet the developmental goals that were set for him/her? That's *yissurim*. Don't we have to pay oodles of money for therapy, expensive medical equipment, and medications, as well as lost income from all the work we have to miss in order to take our children to hospitals, doctor appointments, and therapy sessions? That's *yissurim*. Don't we feel uncomfortable when people stare at us, or ask us silly questions, or make ridiculous comments? That's *yissurim*. Don't we feel pain that our child will never get married, have children, or perform *mitzvos* properly? That's *yissurim*. And the list goes on and on.

Now, why are *yissurim* brought upon a person? For this we have another *Gemara* in *Brachos* 5a, which Rabbi Klein mentioned. If a person sees *yissurim* coming on him, he should examine his ways for sins. If he did so and didn't find any sins, he should assume that they are coming because he is wasting time from Torah study. If he found no wasted time, he may assume that they are *yissurim shel ahava*, in order to accept the *yissurim* and be rewarded for it. So, unless Rabbi Klein's article was written to a select group of great *tzaddikim* who examined their ways and found no sin nor wasted time in their lives, then this article is very much for us!

While it may be true that any amount of *aveiros* that I committed did not cause my child to be born with special needs, the fact that I have a special child is certainly the cause of many *yissurim* for me. And although there may be some great *tzaddikim* who can say that these must be *yissurim shel ahava*, unfortunately for myself, and I think the rest of us common folk, we do have the obligation to ask ourselves: "Is This My Fault?"

So, thank you, Rabbi Klein, for explaining to us so clearly that *yissurim* are to be looked at as the *refuah* not the *makkah*. We have always embraced our Eitan, and never looked at him as a "yissurim giver"—yet now we can view the inevitable challenges and difficulties that come along with raising him with the same love and acceptance as we have given to our son himself.

Sincerely,

Y.J.



Why in the world is Naftali's bed empty?!



דברי חיזוק וברכה  
מאת הרב מיכאל יארדלי שליט"א

Words of Inspiration

Given Especially to Our Readers

From HaRav Michael Yardley, *shlita*

Rav of Bais Medrash Yeshuas Pinchos

and Posek of Bais Medrash Govoha, Lakewood, NJ



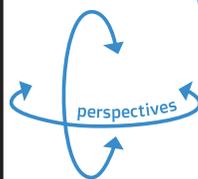
Rav Yeruchem Levovitz *zt"l* (*Da'as Torah, Parshas Beshalach*) explains a very interesting idea about *tefilla*. We are under the impression that when you have a difficulty, a *tzara r"l*, you *daven*, and the *tefilla* removes the *tzara*. We think that you have a *tzara*, therefore you have to *daven*. In truth, it's the opposite: You have to *daven*, therefore Hashem brings a *tzara*. Rav Yeruchem brings the *medrash* that says that when *Klal Yisrael* left *Mitzrayim* and were no longer crying out, Hashem said: "I miss hearing your voice!" So He brought the *Mitzrim* to chase after them; hence *Klal Yisrael davened*. The purpose of a *tzara* is to bring you closer to *Hashem Yisborach* through *davening*. The more difficulties you have, the closer you can come to *Hashem Yisborach*. And when a *rabim* davens for someone, the *rabim* becomes closer to Hashem, and that's a *zechus* for the person they're *davening* for.

There's a powerful story I heard from Rav Yitzchok Sorotzkin, *shlita* about a doctor in Cleveland. A person came to the hospital with a disease *r"l* and asked the doctor: "Doctor, what are the statistics for my survival?" The doctor said to him: "For religious Jews, I don't give statistics. I used to, but then these ladies come with their prayer books and their psalms, and they turn everything over! So, I stopped giving statistics for them."

There's an interesting *Malbim* at the end of *Sefer Malachi*. The *pasuk* says that *b'sof hayamim*, "אז נדברו יראי ה' איש אל רעהו", at the end of time, people will talk to each other about *emunah* and be *m'chazek* each other in *emunah*. The *Malbim* says that "נדברו" is also a *lashon* of "דבר", a plague. He explains that *b'sof hayamim*, there will be a *dever* and people will be worried. These words describe the challenging times that we have been living through this past year. However, the *geulah* has to come from working on *emunah*. Working on *emunah* means that when you see happenings that challenge your *emunah*, then you know the *geulah* will come from the *zechus* of having real *emunah*.

The *Alter of Kelm* explains this idea further. *Moshe Rabbeinu* told *Klal Yisrael*: "I am coming to take you out of *Mitzrayim*." The Torah first says that *Klal Yisrael* believed *Moshe Rabbeinu*; after this, he went to speak to Pharaoh. It would have been a lot easier had *Moshe Rabbeinu* first gone to Pharaoh, performed a few *makos*, and only then, gone to the *B'nai Yisrael*. In that case, he could tell them: "See these *makos*! I am going to take you out of *Mitzrayim* to serve *HaKadosh Boruch Hu*." The *Alter* answers that it certainly would have been a lot easier for *Klal Yisrael* to accept it that way, but that the *geulah* comes only if you believe when it's challenging.

Difficulties give us the opportunity to *daven* and to strengthen our *emunah*. The only way for us to get anywhere is through *yissurim*. I heard from Rav Yitzchok Sorotzkin *shlita* that it says in the *Gemara*: "There are three *matanos*, three gifts, that *HaKadosh Boruch Hu* gave *Klal Yisrael*: *Torah*, *Eretz Yisrael*, and *Olam HaBa*—and the only way you get *Torah*, *Eretz Yisrael*, and *Olam HaBa* is through *yissurim*. When it seems that we are having a lot of *tzaros*, we should know that it needs to be this way; we are actually getting *matanos*! We should be *zoche* to be *mechzek* in *davening*, be *mechzek* in *emunah*, have *simchos* and *yeshuos*, and see the *geulah shelaymah*.



From the perspective of:

**A SPECIAL  
CHILD  
I'm A Person Too**

Yitty

The world that's all around me  
Shows its sorrows and its joys  
Sometimes by saying or writing it,  
But mainly by making noise.  
I have so much inside me,  
That's aching to be said.  
But my lips just don't cooperate,  
And it stays inside my head.  
People often speak to me  
Like a little girl of two.  
Slowly showing and explaining to me  
How and what to do.  
They also think that I can't hear,  
Just because I cannot talk.  
They say thoughtless things 'bout what they think  
'Bout me, my face and walk.  
If people knew and thought about  
The value of their voice,  
They'd think lots more before they'd talk,  
'Bout what's the right and wrong choice.  
I often watch as people speak,  
And it's really quite absurd  
They waste their precious gift of sound  
On streams of empty words.  
How I wish I could make a *bracha*,  
Or make someone else feel good.  
Why would I waste my words away  
Just because I could?  
So here's a message from me to all  
And then this poem will be done.  
I'm a person who can hear and feel,  
So please treat me like one.

# Maayan:

## A Wellspring of Emunah

Devorah Hadassah Liebermann  
As told to Sara Lieberman

I sighed in relief as I lay down with my baby. It had been a busy day, caring for my three little ones, but my heart was full. I had just put the kids to bed, and my baby was drifting off to sleep. Blessed silence reigned in our tiny apartment in Neve Yaakov. My husband was out *davening*, and I briefly let myself rest next to my gently snoring baby. Turning to check on Maayan, my 2 year old, I gasped and jumped up. Her bottle had fallen from her tiny hands and milk was streaming out of her nose and mouth.

I grabbed her, and screamed at the top of my lungs. “Help!” I shouted desperately, running to the door. As new *olim*, we didn’t know the emergency numbers, my door was locked from the outside, and I didn’t have the key. Trapped, pacing, shaking, clasping my limp daughter to my chest, I cried and screamed for help. Neighbors gathered outside of my apartment door, shouting unintelligibly.

Her small body lay lifeless in my arms, as I begged Hashem to help her. With a huge gasp, her eyes fluttered open, and her pale face flooded with color. The next second my husband thundered through the door, panic stamped on his features, with *Hatzalah* medics behind him. *Hatzalah* checked her and pronounced her stable and well. It was only later on that we learned from the neurologist that this had likely been Maayan’s first seizure.

### Darkness Descends

It wasn’t until a year later that we had another scare. “Look!” Maayan pointed, “A slide! And a swing! Mommy, I wanna go to the park!” I held her warm hand in mine as we walked to her

gan, “Soon sweetie,” I murmured, smiling at her exuberance. Suddenly she froze, stared at the sky, and fainted, her body rigid like a board. I crouched down, but she bounced up after a few seconds, seemingly unaffected, resuming her bouncy chatter.

When I described what happened to her pediatrician, he referred me to a neurologist. My heart pounded in fear as we waited to hear his report. “Epilepsy,” he said dryly. “She’s going to need to wear a helmet...” His words swirled around me as my thoughts raced. What will be her future? Will she ever drive? Will she need a shadow in school? I felt deeply embarrassed, and wanted to keep the diagnosis private. Now I think: “Oh, how I wish it were just epilepsy!”

At age 3, Maayan started having trouble with her speech. She went from saying full sentences like: “I wanna go to the park,” to: “Want park,” and then to one word: “Park.” At the age of 5, her last words were “Amen” (to a *bracha*) and “Abba.” She loved saying “Amen” to *brachos*. Even if she heard the *bracha* from afar, she yelled “Amen!” from the other room. Maayan started using the word “Abba” for everything. My husband would joke: “I think I need to change my name.”

Together with this speech regression, she started having trouble walking. It was such a frightening time for us. She started to stumble and fall—all the time, not just from seizures. At the age of six, Maayan stopped walking. It was a slow process, from walking, to stumbling, to becoming confined to a wheelchair.



Shortly after that, her swallowing began to go. I'm a speech therapist, so I caught on fairly quickly that she wasn't chewing and swallowing properly. We switched to pureed foods, and she underwent surgery to put in something like a g-tube, but more sophisticated.

One day, when I went to feed her, I came up to her, brought the spoon close to her mouth, and she clutched my arm. I had a sinking feeling and called out to my husband: "There's something wrong! I don't think she sees us!" When we learned that she was blind, I was devastated. Each stage of decline was excruciating to watch, but this one hit me the hardest.

### *A Wellspring of Emunah*

Maayan was one year old when we made *aliyah*, and someone gave us an incredible book called *Garden of Emunah*. When Maayan started to get sick, we connected to *emunah* as a life raft in a sea of uncertainty. We said to each other: "Hashem does only good—let's find a way to thank Hashem from this, and let's be open to seeing miracles!"

It was bewildering to see our daughter go from a healthy, energetic toddler, to a child with complete loss of functioning. We were in Israel with no family for support, but we supported each other and tried to see the good in everything. I see it as a *chesed* of Hashem that each stage of loss came in slowly. It wasn't everything at once, but each year brought more loss and regression.

We watched our daughter stop walking, talking, swallowing, seeing, and then breathing. Maayan is now blind, eats via machine, has a trach, and is connected to a ventilator that breathes for her. We could not have managed if we weren't attached to Hashem—He is breathing life into us. We made a conscious decision to thank Hashem, focus on positivity, and create a warm, loving atmosphere in the home.

My husband, Yochanan Betzalel, was instrumental by guiding us on the path of *emunah*. He led us via example to have *bitachon* and *emunah*, and to realize that Hashem does only good. I started a gratitude journal and held onto *emunah* in Hashem with all my strength. I went to *shiurim* by Chava Dumas, a well-known lecturer and author in Israel, who introduced us to the teachings of Rabbi Twerski, *zt"l*. His teachings greatly influenced us, and touched us with his wisdom and positivity.

### *A Wellspring of Hope*

It wasn't until Maayan was 9 years old that we discovered what was really going on. We had not been looking for a diagnosis, we just wanted a way to help and cure our daughter. We didn't even want an end diagnosis. We sat down for an appointment with our third neurologist. She took one look at Maayan and said slowly: "What Maayan has—it's a lot more than epilepsy. It's an extremely rare condition—and I think I know what it

is—I wrote my doctoral dissertation on it." They ran many tests, and confirmed her diagnosis of Batten's disease. Batten's is one of a rare group of nervous system disorders called neuronal ceroid lipofuscinosis (NCLs), that tend to worsen over time.

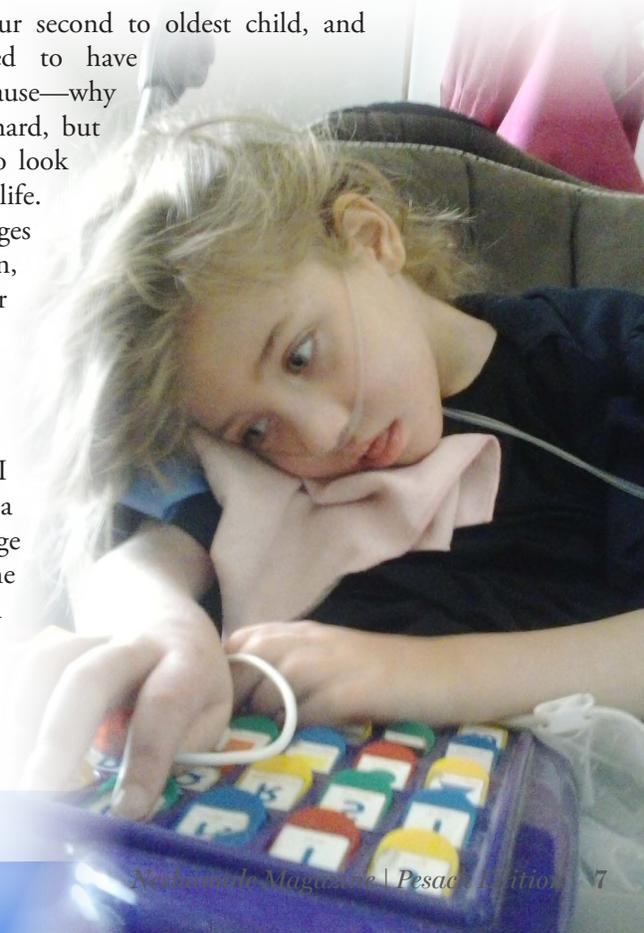
Batten Disease is a genetic disease. It is autosomal recessive, so both my husband and I are carriers. They don't test for it, due to its rarity of occurrence. I felt very mixed emotions when I heard this information. Is it my fault? Was there something wrong with me and my husband? I felt bewildered and sad. There is no history of this disease in my family. For a long time, I didn't feel comfortable admitting that it's a genetic disease.

There are few cures for genetic diseases. We wanted to create a space that was filled with hope, trust, and ripe for miracles, not focus on statistics and probability. For the years that followed, I chose not to talk to others about the hopeless diagnosis, because most people didn't realize that innocent words and questions can chase away hope and *emunah*.

We had to battle doctors who insisted that there was no hope. One of Maayan's first neurologists said to me: "You're an amazing mother! I see how you take care of her. I also see that you're religious. Mom, don't have false hope—just have another baby to ease your heart." This was more or less every doctor's message. In hindsight, I would rather not have known exactly what the diagnosis was, thereby being given messages of doom with each doctor visit. It was easier to be positive when doctors weren't telling us at every turn that we should hang up our gloves.

Maayan is our second to oldest child, and we continued to have children because—why not? It was hard, but we wanted to look forward in life.

In all her stages of regression, I had another baby in my arms. When she was finally diagnosed, I was pushing a baby carriage down the street, and was in a late stage of pregnancy, when I got



the call from the hospital: “Your daughter was just diagnosed with Batten disease—would you consider an abortion?” I dropped the phone and it clattered to the floor—I stared at it in a daze. How could they even suggest that?!

Not all the doctors and staff were like this. *B’chasdei Hashem*, He has surrounded us with many loving, competent messengers. Now, Maayan is being cared for by an excellent team of doctors and staff. They are part of a special unit for rare diseases at Har Hatzofim Hadassah Hospital. Dr. Brooks, the head of our team, has been phenomenal throughout the process, always there for us so we could ask questions and be guided medically.

### *A Wellspring of Love*

Once, Maayan had a devastating seizure that racked her body. She started choking, so we rushed her to the hospital. While we were flying down the highway in the ambulance, all her systems were crashing. My husband and I both cried out to Hashem, begging for mercy, and *Baruch Hashem*, she made it. We discovered that she had developed severe lung disease, and her lungs were generating large amounts of phlegm. Furthermore, because she lost the ability to swallow, she started choking regularly.

We came to Har Hatzofim hospital so often, that it became our home away from home. They have beautiful gardens there called “Healing Gardens.” Many times, I have walked through these gardens breathing deeply, focusing on gratitude, and using creative outlets for my feelings. Some of my coping methods are journaling, writing poetry, and composing songs.

We are always hoping and praying for a miraculous *yeshuah*. Hashem gave us the gift to believe in Him, for without that—where would we be? Hashem loves us unconditionally, and even though I might not be worthy of miracles, I believe Hashem will bring this *yeshuah* because he loves us! It’s only Hashem; *Ein Od Milvado*. Our thoughts dictate our realities, so when we commit to seeing the good, Hashem continues to allow us to connect readily to the good.

Since Maayan was a baby we felt that she was extraordinarily full of life. So, when the disease took over, it wasn’t hard for us to remain attached to her special gift. In the early days of our journey with Maayan, I started a chat called “Emunah Upgrades with Maayan.” Boruch Hashem, we now have over 100 women on the chat, a beautiful support network of women from all over the world, who are touched by the light of *emunah* that shines from Maayan. Through the chat we have initiated many projects, both to engender *zechusim* for Maayan, as well as to raise money to cover the costs of her care. One of the initiatives is called “Modeh Ani with Maayan”. I share a video of us saying Modeh Ani together, thanking Hashem for granting us another day of life. Many women have told me that this has transformed their own Modeh Ani.

How can it be that a little girl who stopped eating, walking, seeing, talking, and breathing is bringing such a bright light all around the world? How is it that she inspires grandmothers and young girls alike to connect to hope and determination, to see life’s challenges through, and to find the good in their most dire circumstances?

This is the light that my daughter brings into the world. I feel *zoche* to be her mother and to see the light she shines into every hospital, classroom, doctor, volunteer, dietician, nurse, ambulance driver, neighbor... I watch her transform everyone’s lives with her special touch! We believe in the value of her life. Her imperfect body reveals Hashem and brings us closer to Him. Whoever sees Maayan, sees Hashem. I couldn’t be more proud to be her mother and I feel blessed to be here along for the ride with my angel.

*Devorah Hadassah asks everyone to pray for Maayan’s recovery, do acts of kindness, learn Torah and spread unity amongst klal yisroel as a zchus refuah shelaima for Maayan bas Devorah Hadassah.*

### *A Wellspring of Inspiration*

*Here are some personal accounts from women of all walks of life, who have been inspired and changed from meeting Maayan, or connecting to her through “Emunah Upgrades”:*

“My sister, a true *tzadekes*, died 4-1/2 years ago after suffering from cancer. How could I follow G-d when He let her suffer and die? I wasn’t okay with His plan, and started slacking off in my observance. Last year I started working as Ma’ayan’s physical therapist, and something has changed in me since then. I see how Ma’ayan’s mother accepts her child’s suffering with love, and I am affected daily to see the hand of G-d amidst the greatest of suffering.

*-Avigal*

I have personally gone through some traumatic situations, and Ma’ayan’s Chat is literally my therapy spot—a place where I go to drink from this awesome well of *emunah*! There were times when I would be paralyzed with despair and Ma’ayan was able to revive my parched soul. The Liebermanns are the most potent source for *emunah*—people who live and breathe awareness of Hashem’s love and “*Kol mah d’avid Rachman Utav avid.*”

*-Anonymous*

I was a classic teenager with narrow views and expectations, and Ma’ayan taught me that being thankful changes everything, for both the blessings and the dark moments. Maayan showed me that Hashem is in the struggle, and that if it came from Hashem, it has to be good. She taught me that Hashem loves me more than anything, and being around Maayan, I felt that love. I’ve learned from Maayan and her family that, during periods of darkness, in order to live life and not just survive, we need to talk to Hashem.

Countless mitzvot have been done in the merit for Maayan's *refuah*. Seminary girls gave out food and got more than 800 "Amen's" in one day. Others sponsored children's *Tehillim* groups to daven for her. Part of a *mikvah* was donated in her merit, and even the air-conditioning in shul for *Shavous* was sponsored on her behalf.

Maayan taught me to never give up. Once, when her body was being wracked by seizures, we cried out to Hashem and saw the most miraculous shifts in her breathing, coming back from near death experiences.

One Shabbos, when my brothers began to sing *zemiros*, Maayan opened her eyes, lifted her head, and literally shined. I also saw how davening *Hallel* strengthened her. Her whole existence is one big *kiddush Hashem*.  
-Batsheva Phaff

We are blessed to know Maayan, who teaches us that anything is possible, and continues to push us to yearn for miraculous salvations and a true, full healing, for Maayan and for the world. My girls daven for her in school every morning and whenever they have the opportunity. Her mother's messages of *ahavat chinam* help me reframe many challenging perspectives.  
-Yocheved Shull

My 11 year old daughter asked to come with me to hear Devorah Hadassah speak about having a child with severe disabilities. She listened to every word and was so inspired she announced: "I want to help Maayan!" Together with her best friend, they decided to raise money for Maayan's care as their *Bas Mitzvah* project. They went door to door collecting, and proudly presented the money to Maayan's mother. At my daughter's *Bas Mitzvah*, she asked our guests to consider giving to this worthy cause. The joy and satisfaction of real giving was a priceless gift and lesson that Maayan gave to my daughter.  
-Ganendi

Maayan and her mother have been a true inspiration for me. Four years ago, we lost my granddaughter, a healthy 5 month-old baby. It was a terrible, devastating loss for us. We were grieving and not understanding, and one day it hit me— Devorah Hadassah was saying: "*Ein od milvado*" (There is nothing but Hashem)—and I was trying to sue the hospital and blaming people. I thank you for teaching us that everything is only from Hashem, even when we don't understand why.  
-Sara

Devorah Hadassa is true, living *emunah*. When I listen to her messages on the chat she created for Maayan, I am in disbelief at her unwavering *emunah*, knowing that everything is from Hashem, and that everything He does is good. She lives it, knows it, and believes it with her whole being, and it is this level of faith that I aspire to live by.  
-Wendy Zinman

Maayan has enriched my comprehension of the spiritual aspect of life. I have a new appreciation for every living creature; for every tree, every cloud, and certainly for every human being. It's special to see my family members remembering her in their *tefilos*, or saying a *kapitel tehillim* for her, including her in their hopes for the day.  
-Penina Leah

Ma'ayan is a very precious soul, one of the angels here on earth. Her existence has touched me deeply. I am part of the group that Devorah Hadassa set up for friends to get updates about Ma'ayan's wellbeing. We hear when to pray for her oxygen numbers to go back up, or when to pray for a specific hardship she is enduring. I draw so much inspiration from Devorah Hadassa, to live a holy life filled with doing Hashem's will, and to make our families and homes a holy sanctuary. Ma'ayan's life has inspired me to connect with Hashem on a deeper level, and the group reminds me many times a day to stop and appreciate the good that Hashem has given us, even (if not especially) during the hardships.  
- Anonymous

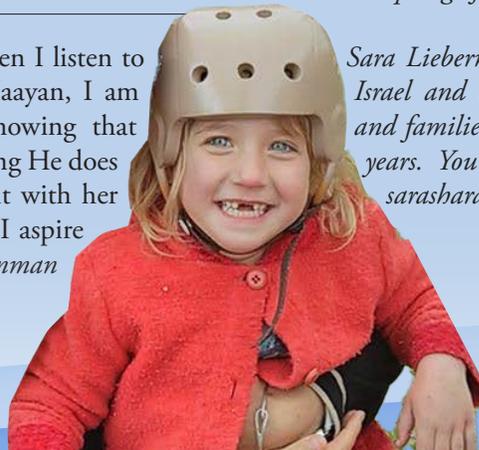
Being a part of Maayan's world has inspired me to become a kinder person, do more *mitzvos* and *daven* more. I'd say my G-d consciousness has increased one million percent! I think of Hashem throughout the day; I've been inspired to invite G-d into my life and request that He deal with me with compassion.

I was part of a world-wide group of ladies *davening* when we lit our *Chanukah* candles for global healing and personal prayers. We recited a prayer that Maayan's family wrote, based on Maayan's inspiration.

In merit for Maayan's healing, I've taken upon myself to say *Asher Yatzar* with greater *kavanah*. I was also inspired by Maayan to do the mitzvah of *tzedakah*—I helped to organize a *Chesed* Fund Page, called the 613 Project, for people to give *tzedakah* in her merit, and to help pay for the considerable costs involved in her care. We are shooting for 613 people to join in giving \$18 a month (see <https://thechesedfund.com/maayan> to join).  
-Devora Benarroch

*Devorah Hadassah Liebermann, better known as "the mother of Maayan," is the mother of 5 children, and works as a Speech Therapist as well as a Motivational speaker and Life Coach. You can contact her at [www.wellsofmaayan.com](http://www.wellsofmaayan.com).*

*Sara Lieberman, LAC is a psychotherapist living in Israel and has worked with special needs children and families in different capacities for the past eight years. You can contact her at 443-415-8798 or [sarashara25@gmail.com](mailto:sarashara25@gmail.com).*



# From The Doctor's Desk

## | *Epilepsy: The Whys, Whats and Hows*

Chayala Tawil

I interviewed Dr. Marissa P DiGiovine, MD, a pediatric neurologist practicing in Philadelphia, PA.

### **Is there any difference between a typically developing child who has a seizure disorder and a child with special needs whose seizures are only a part of his diagnosis?**

There is no difference in the seizure precautions themselves. Everyone with epilepsy will have an individual action plan, regardless of whether they have special needs or not. However, knowing if the epilepsy is coming as part of a specific syndrome can help us determine which medications have a better chance of working. In patients with special needs, we also focus on getting them as many therapies as can be beneficial to their overall development.

### **What is so bad about a child having seizures on occasion? Is it so important to medicate, or can we just live with it?**

There are a lot of reasons why we would want to treat seizures, yet it's also true that in some cases we will decide not to medicate.

In cases where we know the cause of the seizure, it is better to treat the cause, which will eliminate the seizures themselves. For example, if we see that a diabetic patient has seizures when they have low blood sugar, it would be wiser to treat the blood sugar problem rather than to medicate for epilepsy.

We can say that brief seizures don't damage the brain, but frequency plays a big part in this. If a patient has a short seizure once every three years, it may not be worthwhile medicating. But if a child is having short (3-10 second) staring spells hundreds of times a day, that could mean they are missing out on all of that learning time, so we would want to have this more controlled. The main thing we are concerned about is the loss of consciousness, not the seizure itself.

Another concern is that a patient who is currently having short seizures is at a higher risk for having a sudden full-body convulsion. We don't want to risk having a bigger seizure, due to both the risk to brain, as well as to the body that can get hurt in the process. Additionally, a patient who experiences many nighttime seizures is at a higher risk for SUDIP (sudden unexpected death in epilepsy). These risks that we are mentioning far outweigh the risks of taking medication.

### **There are so many medication options out there. How does a doctor determine which medication to try first, second, etc.?**

I always say that I tend to think of seizures in two basic forms: focal and general. Focal is when the seizure starts on one side of the brain and then spreads. General is when the whole brain is affected at once. Different medications treat each of these types more effectively.

Another consideration is the side effects profile. Usually patients adjust to the medications and experience no side effects at all. But we would take certain factors into account. For example, if a patient is underweight, we would avoid a medication that can decrease appetite. In this case, we may even choose a specific medication that is known to increase appetite, in the hope that it will solve two problems at once.

### **How common is it for medication to be effective in successfully controlling seizures? How many tries of different medicines are typical?**

If you group all types of epileptic patients together, then about two-thirds of patients will respond to the first medicine they

try. (This includes those who may need to adjust dosages, due to fatigue, allergies, etc.). Of the third for whom the first medicine doesn't work, about 50% will see success with their second medication. Unfortunately, after that, there are less and less successes. However, there are no limit to the number of medications that we will try. We can also try combinations of different drugs to see if that will work.

One thing that may change as time goes on, is that we adjust our expectations. When a patient has hard-to-control seizures, we need to balance the seizure frequency with the side effects of the medications. In this case, even frequent seizure control would be considered successful.

It's important to remember that new medications are constantly coming out. You may think you have reached the end of the road, but there may now be a new route to try.

### **What are common side effects of medication and is there anything that can be done to counteract them?**

The most common side effect is sleepiness. This is because a seizure is essentially an overactivity of the brain, so often the medication attempts to make the brain less active, causing the patient to feel drowsy. Usually after a few weeks the brain adjusts and the patient does not feel tired anymore. Other side effects are very dependent on each specific medication.

There are times that we can do things to negate a side effect. For example, if a medication is hard on the liver, we will give another medication to protect the liver.

### **What is your opinion on using alternate methods of seizure control, such as the keto diet, instead of, or in addition to, medication?**

I think that there is a place for alternatives to medication. At the same time, it is essential that these things are used under a doctor's guidance. In some cases, the medication can be even safer than the diet. For example, keeping to a strict Keto diet can lead to kidney stones (especially if there is a family history).

Depending on the case, I often advise to try two medications first since medications are often the safest and simplest way to control seizures. If that is unsuccessful, then I would recommend trying the Keto diet.

### **What is the next step in treating seizures if the medications and the Keto diet are not working?**

There are three main ways to treat epilepsy, aside from medication: diet, avoiding lifestyle triggers (such as sleep deprivation), and surgery.

Surgery is used to remove the part of the brain that is triggering the seizures. In cases where this would not be possible, there are some

new devices that can be helpful. One example is The Responsive Neurostimulation, or RNS, which is implanted in the brain to try to change how the brain's network functions. The Vagal Nerve Stimulator, or VNS, is another device that we use to decrease seizure frequency, but this one is implanted in the neck. These devices have been showing success in lessening seizures.

### **If a child's seizures are currently under control, are there any specific activities/situations that should be avoided in light of the slight chance of a seizure occurring?**

Yes, definitely talk to your doctor about seizure precautions. In short, I will say that the child should not do anything where it would be very dangerous if he passed out suddenly. Examples of these activities would include: bath/water play without supervision, climbing heights without a harness, or riding a bike without a helmet—although no child should ride a bike without a helmet!

### **If a child does have a seizure: What is considered an emergency, where one should call 911? What is considered important, to be reported to the doctor immediately, or what can wait until the next appointment?**

The answer to that is figuring out an action plan with your doctor, as it is very case-specific. To give a very broad answer, call 911 if the child is injured, is not getting back to themselves in between seizures, or if a seizure lasts longer than five minutes.

### **Do you have any practical tips or advice to offer parents based on your many experiences?**

The most important thing to know is that you are not alone. People don't realize how common epilepsy is. There are a lot of support groups that can be very helpful, even if you don't think you need one. When children realize that other kids their age are going through the same thing, it can make a big difference. Speaking to other parents can help you navigate this challenge better, too.

Another thing I want to mention is that technology is changing and evolving constantly. There are new seizure detection devices, and online seizure diaries that the medical team can keep tabs on. Once a year, ask your doctor to update you on the newest advancements in this field.

It's important to be prepared in case of a seizure. For a younger child, keep a list of his medications in his briefcase in case you are not around during a seizure. For an older child, keep this list in his briefcase or wallet. If he has a cell phone, consider setting up his home screen with emergency phone numbers and information on it.

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*This discussion was meant to be in broad terms, and is not meant to replace medical advice from your doctor. Since every child is unique, please speak with your neurologist about any neurologic concerns.*

Q

Dear Shira,

## IN SESSION

I have an adorable, loving, 5 year old son with a seizure disorder and behavioral issues. I am struggling with how my other children (ages 10, 9, 7, 3, 2) deal with their special sibling.

Although neighbors tell me how kind my children are to their special sib, I actually feel they should play with him and include him more, and be kinder and more patient with him. He doesn't have friends, so he loves playing with his siblings, but it seems like I am the one who has to entertain him all day. How much can I expect of my other children?

While I do reward them and try to give them extra TLC (especially when their brother is out), they often get frustrated with his destructive and embarrassing behaviors. Because he is on the very restricted keto diet, his siblings can't eat whatever they want in front of him. They also resent the amount of attention he needs.

How much do I empathize and allow my children to vent? Although I know they need to do this, it very quickly becomes a very negative discussion ("He's not normal..." "I wish he wasn't in our family..." "You're always busy with him..." etc.). Most of the time, I step in to say that it's hard but it's not so bad, and shortly after, they'll usually say he's adorable and they do love him (which I know they do!).

How do I get the perfect balance? Is that even possible? Thank you so much,

T.S.

A

Dear T.S.

Your question requires a lot of answers, some that are specific to your child. I will try to answer so that you can have meaningful answers, although I must generalize for the sake of our readers. Some of your questions are similar to previous questions and answers discussed in past editions of *Neshamale*, so I would refer you to those for further advice.

In brief, I suggest that you provide your children with information appropriate to their age level regarding their special sibling's diagnosis. While no one can be defined exactly in a 'diagnosis box,' there is information that is accurate and general, so that your children can understand what a 'seizure' (or any other disorder) means and its ramifications. Please make sure you are giving 100% accurate information, as trust is essential. Allow your children to ask questions and 'leave the door open' for further questions. Tell your children that you might not have some information, but will try to get it if possible.

Your children's needs must be validated! If their belongings are getting ruined and/or destroyed, it is vital to validate their feelings and be as proactive as possible to prevent further occurrences.

You asked how to get the 'perfect' balance. Since Hashem is the only being that is perfect, perhaps we can substitute that word for:

1) Doable    2) Agreeable    3) Mutual    4) Healthy    5) (Fill in what works for you)

As parents, we want only the 'best' for our children and family, but setting realistic expectations that are doable and achievable ARE the best! Allow me to offer a plan that perhaps can work for you, with an example that probably occurs in every family. It will show, in a very concrete way, how to implement this recommendation. Then we will try to apply it to your situation.

Almost every family has a special chair/location/position at the Shabbos table where more than one person in the family wants to sit. What is the prime location at your table? Is it the dining room chair, arm chair, at the end/head of the table, next to a parent? Suppose that both Avi and Sarala want to sit there. Every Shabbos there is an argument/disagreement. It is very difficult to resolve and can disrupt the entire Shabbos atmosphere from the get-go.

Introduce the concept of win-win, win-lose, lose-lose. Lose-lose will result in neither being able to sit in that spot and both being upset, which will further disrupt the atmosphere. Win-lose means that one child is the winner and the other is the loser. While the winner is very happy, the loser is NOT!

*continued on page 15*

# VALIDATION Corner



David Rose

## ♥ VANITZAK! – CRY OUT!

“There’s a fifty/fifty percent survival rate for this surgery, on a healthy child. Your child,” the doctor added grimly, “is *not* a healthy child.” I remember exactly where I stood when I heard those chilling words from the hospital’s top surgeon—at the desk outside our son’s NICU room, listening on the hospital phone. The doctor was describing the surgery he felt there was no choice but to perform.

Our dear son Zevy’s abdomen and chest were fast filling up with fluid, and the medical team had no idea where it was coming from. The fluid build-up was putting extreme pressure on Zevy’s lungs, requiring him to be hooked up to the strongest ventilator in the hospital. The head surgeon said they would have to perform a procedure comparable to open-heart-surgery, to find out where the fluid was coming from and then decide, mid-procedure, if and how they could fix it.

The prospect of having this procedure done was terrifying. I felt utterly overwhelmed. How did I react? I cried and silently screamed out to Hashem from the very depths of my heart—in English. “**Please** Hashem! Help us make it through yet another of the challenges You are putting us through with our dear *zeeskeit*. This challenge seems so much harder than all the rest! **Please** Hashem! Give us the strength we need so much. And send a *refuah shelaymah* to our dear Zevy.”

As we approach *Pesach*, the words from the *Haggadah*, “*Vanitzak ... el Hashem*” (“And they cried out to Hashem”) come to mind. Many commentators point out that the crying out of the Jews in *Mitzrayim* was what merited their *geulah*. These emotion-laden words at the *seder* have great power to bring personal *geulah* into our own lives, as well.

At a *Shabbaton* I once attended, I heard Rabbi Fishel Shachter say the following poignant thought: In *Shemos* (2:23), where

it discusses the Jews crying out in *Mitzrayim*, the *pasuk* says: “*Vay’eanchu b’nai Yisrael ... Va’taal sha’avasam el Ha’Elokim min ha’avoda.*” (“And the children of Israel groaned...and their cries rose up to G-d from the labor.”) This relates the special, powerful moment when the Jews cried out and were *zoche* to the *geulah*. What did the Jews cry out about that was so special in G-d’s eyes? Were they crying out lofty ideas like “*Gam Zu leTova!*” (“This too, is for the best!”) or “*Yissurim shel Ahavah!*” (“[We bear our] suffering with love”)? The Ohr Hachaim and Siforno both say: “NO! The Jews were crying out solely from pain! They were saying “Ow! It hurts!” It was these simple, pure cries which merited the *geulah!*”

***They were saying  
“Ow! It hurts!”  
It was these  
simple, pure cries  
which merited the  
geulah!***

This shouts out to us a monumental message: All you must do in a difficult time is to cry out! We can talk to Hashem 24 hours a day,

even non-verbally, in any language! Tell Him about the difficulty you are having. The story of the Jews leaving *Mitzrayim* shows us that Hashem hears this simple cry of pain—and He answers. We have a connection directly to Hashem’s private line!

Back to our story: The surgeon told us that the latest he could wait to perform the procedure would be three days. *HaRav* Aharon Feldman *shlit”a*, my *Rosh Yeshivah* at Ner Yisroel, told us that we should wait until the third day to make our decision. On the third day, the medical team decided to do one last test before the surgery, in order to rule out any other possibility of the source of the fluids. A very ‘high maintenance’ IV had recently been placed into Zevy to give him the vitamins and nutrition he needed. They checked that IV and, lo and behold!—the IV had been leaking! All of the nutrition and vitamins which had been flowing through the IV were pouring into Zevy’s body. After confirming this, they immediately removed the IV, and the fluids stopped. The terrifying, life-threatening surgery was not necessary! As in *Mitzrayim*, we cried out from pain—and Hashem answered our cries!



# My *Sisters* in Arms

Yitti Berkovic

I made the decision for all of the wrong reasons: *Good food. A full night's sleep. An affordable vacation.* But I would soon learn that even the worst intentions can yield magical results.

When my husband and I were invited on a weekend retreat for parents of special-needs children, we all but rolled our eyes. We were NOT the support-group type of people and we were NOT going. We'd rather just stay home and avoid being *on* for an entire Shabbos. I'd wear my robe and my snood and read magazines on my couch – that's my brand of therapy.

Besides, my husband and I have always seen each other as trench mates, the only two people who can completely understand our challenges, the only people who can give each other the support we need. No matter how much people sympathize, they can't fully understand the challenges unique to our family – the same way I can't understand the challenges unique to theirs.

So why bother kvetching to people who don't know us when we can kvetch to each other? (We won't discuss what happens when one of us is more likely to kvetch than the other (yes, that's me) and the other one (yes, that's him) has run out of creative ways to say "I completely understand and I am trying to validate your feelings").

Support-group phobia notwithstanding, our kids were not invited on the retreat. So what exactly were we supposed to do with the entire gang – including Naftali – from Friday morning until Sunday afternoon? So we checked off the box that read "Thank you, but we will not attend," and we were pretty sure the decision would stick.

But that was before my mother got wind of the invitation. WARNING: Do NOT attempt to change my mother's mind – especially when she thinks she knows what's good for you. My mother insisted we go: *You don't realize how badly you need*

*it. You don't realize how helpful it will be for both of you. Maybe this will be a life-changing experience.*

Resistance was futile. Any argument we made to the contrary fell on deaf ears. And when my parents agreed to move in to my house and watch all of my kids for the extended weekend, there was no way we were going to refuse that. Like I said: *good food, a full night's sleep, and an affordable vacation* – for that, we could suffer through a few boring support groups.

When we first arrived on Friday afternoon, we were certain we'd made a really big mistake. We were a little bit late (of course), so the first session was already underway. It was a handwriting analysis seminar. Our inner cynics were having a field day. *Handwriting analysis?* Now *that* was going to help when Naftali has a bad day. After only thirty seconds of trying to keep a straight face, I texted my husband: "This is not for me. Let's check out the tea room instead." We snuck out of the conference room, praying no one noticed, and ran to find some good chocolate-chip cookies.

That's how I thought the weekend would go. My husband and I would be like high school kids – cutting classes and hoping not to get caught – but at least we would have some good food to keep us company. *I could not have been more wrong.*

Friday night, after candle-lighting, I was herded into a group of women who had special-needs children my son's age. I was feeling more than a little bit awkward. I didn't recognize anyone. It was like the first day of school where everyone knew each other except for me, and I wanted to hide under my desk and cry. "Thanks, Ma," I mumbled to myself. *Why on earth had I come?*

But a funny thing happened. The conversation picked up and I found myself glued to every word. Everyone was warm and inviting. Everyone wanted to know about me and about my family – and they were *genuinely* interested. Everyone seemed to *get it*. I quickly discovered what should have long been obvious to me: *Hey! I can relate to these people's struggles! They really understand what I'm going through! They even have some ideas that might help!*

The conversation centered on our boys' upcoming *bar mitzvahs* – and the women had a lot to say. *Do we make a party our son most definitely won't enjoy? Is it a lack of hakaras hatov to Hashem and all of the people who help us if we skip the simcha altogether? Do you think your son will be able to wear tefillin? Is it worth the fight?*

I felt like a geyser that had suddenly be released. I had SO much to say. I was with my comrades. My sisters in arms. People who understood the nuances and bumps in the road

that are unique to my circumstances – they got it! WHY had I resisted this for so long?

These conversations picked up all weekend long. Everywhere I went, people had a desire to talk – to share – and cynical old me drank it up like I had been in the desert for forty years. *How do you cope with the frustrations of your other children? How do you react to the insensitivity of relatives who should know better? How do you decide what to share with others and what to keep within the confines of your home?*

I felt infinitely lighter – infinitely freer – when I could unburden myself in a way I never do when I am around my friends and my family. I don't consider myself a martyr, but I also don't want people around me to see me as a kvetch. I'd rather have a stiff upper lip than be seen as a whiner, but when I keep everything bottled up, it can have a corrosive effect on my soul. This I realized while eating delicious potato kugel and sharing a piece of my heart with women I had met only that day.

And it wasn't just me. When my husband and I met back in our hotel room to debrief, I discovered that the men – the macho *who-needs-support-groups?* men who had come only to support their wives - were also VERY chatty. Maybe it was even more cathartic for them because they have fewer social opportunities to share their feelings and even their fears. My husband returned to the hotel room completely re-energized

– he too had discovered a new world of people who GOT it.

Perhaps the most eye-opening moment occurred as the stars lit the night sky. As we waited for Havdalah, I saw an anxiety on everyone's faces that perfectly matched my own. We all had that gnawing feeling in our stomachs. *How did our special-needs child manage without us over an entire Shabbos? Were there any emergencies? Any difficult challenges? Had we made the right decision to leave them for this getaway?*

*Hey! I can relate to these people's struggles! They really understand what I'm going through! They even have some ideas that might help!*

Even as I waited nervously to retrieve my cell phone, I felt an indescribable ease. I was with people for whom my normal was their normal. I finally understood that the loneliness I often feel while trying to navigate Naftali's challenges is a self-inflicted pain I was ready to let go of. From beginning to end, the retreat was like nothing I'd expected. Sure, the food was delicious, the good night's sleep was heavenly, and it was a vacation my husband and I needed more than we realized.

More than anything, it was a learning experience that – yes, my mother was right – changed my life. I learned that seeking support doesn't make me weak or whiney. That there's nothing heroic about fighting alone. That I'm infinitely more powerful when I join ranks with my sisters in arms.

*This article was originally printed in The Voice of Lakewood.*

### ***In Session*** continued from page 15

How will win-win be achieved? Problem solve with the children. Perhaps one child can sit there on Friday night and the other Shabbos morning, or one for the first part of the seuda and the other for the second part, or maybe one week someone can sit there for the entire Shabbos, and the next week the other will do that. The key factor is that win-win means that neither child gets to sit there the entire time, but getting it for part of the time is mutually acceptable, so it feels like win-win.

Let's address your specific scenario: how to involve your children with your child with special needs. You know what lose-lose looks like, and probably what win-lose feels like.

How can win-win be achieved? Problem solve with your children for options that will be mutually acceptable and feel like win-win. Although no one will have their 'way' the entire

time, it will still be win-win.

To be more specific, are there certain times that your children will be more willing to include their sibling? Are there certain activities that are more acceptable? Who might they include to make it feel like win-win? Be creative and open to suggestions and options, without staying fixated on a specific expectation.

Wishing you nachas from your special child and the rest of your family.

Shira Speiser

*Shira Speiser is a social worker in Lakewood, New Jersey and has helped children and families for many years. You can contact her with your own individual concerns and needs at: (732) 367-1503 or shira732@live.com*



Dear *Neshamale* Sib Spot,

First, I would like to show my deep appreciation to your wonderful, amazing magazine!

Thanks a million!

Next, I would like to share a story with the other Sib Spot readers.

It was 8:00 pm, way past the usual bedtime for my brother Dovy, who has special needs. Why wasn't he asleep, you ask? Well, that's because his blanket was missing—and there's no way Dovy Weiss goes to sleep without it!

My family searched high and low, in every nook and cranny for the blanket, but to no avail. It was getting really late and we did not know what to do.

Finally, my mother took a crying Dovy out of his crib until we could find it. She started getting my other siblings ready for bed, while I went downstairs to do homework.

When my mother came downstairs, she started laughing. I looked up and saw Dovy happily hugging his blanket!

"Where in the world did you find that?" I asked my mother. But she just laughed: "Dovy must have found it himself!"

So now you know why I think that my brother has magical powers! He can find his favorite things, even when no one else can!

From: Rachelli Weiss



# PRE PESACH MEALS

By Devora Arnstein

## Activity Time!

### SMOOTHIE BAR

If you've never tried it before, you might think that making something yummy in the kitchen is not the type of activity that you'd invite your special sib to join you in. But if you try it now, you may just be surprised! There are so many easy and fun ways to include special sibs in fun food activities. Choose a recipe that you think would be easy enough and not too messy to handle. The main point is to have fun along the way and not be concerned about how the finished product will come out.



One of the favorite parts of baking or cooking for all kids is the chance to "put something in the bowl." If you are worried about spills and incorrect measurements, you can first measure out the ingredients into a large cup with a spout and then let your sib (or assist him) in pouring it into the mixing bowl from there.

A Smoothie Bar is a super-easy idea for a fun Chol Hamoed (or any day) kitchen activity.

**Step 1:** Take frozen fruit out of the freezer and let it sit out for about 20 minutes. You can buy

bags of frozen fruit or cut up fresh fruit and freeze in advance. Examples of good smoothie fruits are: strawberries, bananas, mangos, kiwis, blueberries, pineapple, and peaches.



**Step 2:** While the fruit is defrosting, you can make it more exciting by decorating the cups that the smoothies will be poured into. Use plain white cups as your base and decorate with markers and stickers. Now is also a good time to label everyone's cups with their names.

**Step 3:** Now you are ready for the fun part! Bring the blender to the table and give everyone a turn to create their own custom smoothie. Start by offering a base of liquid: milk or orange juice works well for this, but you can be creative and add any sort of drink you think may taste good. Then pick out which fruits you would like to include in your drink. Other optional add-ins are yogurt, sugar, or lemon juice. Make sure to put the cover on tightly before you turn on the machine! Blend until smooth and pour into your beautifully decorated cup.



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# Sibs Spot Interview: Elisheva, Detroit, Michigan

Fraydel Dickstein

**I am so honored to be speaking with you, Elisheva! I heard you started “Sister’s Corner.” It sounds incredible and I want to hear all about it. Before we discuss that though, can you tell me a little about yourself and your family?**

I live in Detroit. I am in 9th grade and I am the oldest in my family. I have 6 younger siblings, including my special brother.

My brother Yosef is ten and he has a rare syndrome that affects his 22nd chromosome. It makes him delayed in many ways.

**Can you tell us a little more about Yosef?**

The truth is that children with his syndrome are usually much more severely impaired than Yosef. Chasdei HaShem, he can walk and talk. He is fun, happy, loving, social, and sometimes a little bit wild. Sometimes he likes to say the same things again and again.

**Which school does Yosef attend?**

He is in public school. I wish that he could go to a Jewish school, but there is a frum after-school respite program called “The Spot” that he goes to and LOVES!

**Can you tell me about an interesting moment you had with Yosef?**

My mother was taking a walk with Yosef. It was icy outside and my mother showed him how he could break the thin ice over a puddle. He smashed the ice with his foot and said: “To remember the *Bais HaMikdash!*” Breaking the ice reminded him of the glass that they break at a *chuppah!*

**What is something special you gained from having Yosef as a brother?**

Thanking HaShem! There is so much he can’t do that I can do. This makes me realize how grateful I need to be for everything.

**This is a funny question I like to ask siblings: What are you brother’s favorite foods, toys, and activities?**

He likes to take tons of ketchup with anything he eats! He likes to play with Magna Tiles, Mentchies, and trains. He also loves to open books and “read” them to himself by heart. You will often find him wearing a blanket as a tallis and “davening in shul.”

**Yosef sounds like a real cute personality! Now that we can picture a bit of your life with a special sibling, can you share with us what motivated you to start this new program?**

During lockdown, I was talking with one of my friends, who was saying how this is such a hard time for those who have special needs siblings.

We decided we wanted to do something, but at first, we didn’t know what. At the beginning of this year, I thought up an idea and put it on paper. Within a couple of weeks, my friend and I launched the Sister’s Corner hotline.

We spread the word by telling girls we know, as well as advertising through special needs programs throughout the country. We now have a big group of girls signed up from all over the world. There are girls from Phoenix, Baltimore, Lakewood, and many other cities.

We started Sister’s Corner as a way for teenage girls to give each other *chizuk* (and to have some fun along the way) with this unique challenge.

**Wow! It is amazing that young girls can pull off such a thing! Can you tell me more about the hotline?**

There are six options: Updates and General Information, Girls Like You, Conference Recording, Music, Personal Experiences, and Weekly Words of *Chizuk*.

**Can you explain what some of these are?**

“Girls Like You” is where we have girls leave messages with *chizuk* for others. It can just be an inspiring thought or a short story. We ask them to keep it under a minute. For instance, a girl once said how someone found out that she had a special needs sibling and was making her feel like a pity case. At first, she was really upset, but then she realized that there was no point in getting upset about it.

One song on the Music option is one that I wrote with a friend. The song is from the perspective of a sister talking to her special needs sibling, telling him how much she learned from him. Call and you will be inspired!

*(Fradel: I couldn’t help but call and boy, did it warm my heart! The line about greeting Mashiach had me in tears!)*

“Weekly Words of *Chizuk*” is an inspirational recoding touching on many topics in life, including having a special needs sibling.

“Personal Experiences” are recordings from sisters of special needs siblings detailing their struggles, triumphs, joys, and

experiences. Often these experiences are recorded by the Sister's Corner teens themselves.

We also have live conferences, and we made a live Chanukah *chagiga*. We did it over the phone line, not only because of Covid, but because we have girls from all over the world who want to take part. We had a theme of "Doughnut judge a book by its cover." We had a guest speaker, Miriam Cohen, who has two special needs nephews and works with blind and visually impaired students. The *chagiga* was very successful. We got a lot of positive feedback from the girls who were on. We have recordings of the live conferences on the hotline.

**The hotline is just phenomenal. You mentioned you are starting a monthly newsletter! Can you share some details about that too?**

Yes, we sent out the first issue on Rosh Chodesh Shevat! We will be distributing it once a month. It contains inspiration, teens' poems, stories, discussion questions answered by girls, interviews, etc. We email it out, but we can mail it out to anyone who doesn't have email. I do the graphics and my sister (who is 11) helps me type it up.

**Wow, wow! You must be super talented! I love putting out Neshamale, but it's lots of work—and it's only a quarterly! How do you find the time and the momentum to keep going?**

I personally gain so much from running Sister's Corner. Also, thinking about how many girls it's impacting gives me a push. Whenever I get positive feedback from participants, I feel

re-energized and it encourages me to keep on going. That's all—aside from the fact that I love doing it!

**Can I ask you to share how you developed such a positive attitude about your brother that is now spreading to so many others?**

I was always very proud to have a special brother, but I never fully appreciated it. A few years ago, I became friends with a girl who is obsessed with her special needs sibling and volunteers with other special needs kids. Her positive outlook impacted the way I view my situation.

**What is the main message that you are trying to spread through your program?**

First of all, you're not in this alone. There are so many others in the same situation as you. Secondly, there is good in every situation, you just need to find it! You can't always choose what music life plays for you, but you can choose how you dance to it.

**All I can say is "tischazek!" You are doing something so wonderful! Please share how all of our sibs can access The Sister's Corner hotline and newsletter.**

Here is our information:

Our hotline number is (641) 715-3800, ext. 557130#

To sign up for the newsletter, email: [specialsisterscorner@gmail.com](mailto:specialsisterscorner@gmail.com) or leave us a message on the hotline.

\_\_\_\_\_ *Please contact us if you would like to be interviewed for the Sibs Spot.*



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**Step 4:** You can quickly rinse out the blender in between turns so as not to mix flavors. When everyone has had a turn, hand out colorful straws, make a *bracha* and enjoy!

## Variations:

You can choose one person to be the "smoothie maker." They stand by the blender and fill the "orders" for everyone's favorite smoothie recipe. If your special sib can do this job, they will feel really special and important!

A different way of doing this is for you and your special sib to be the only ones involved in making the smoothies. You can decorate cups for everyone in the family and make one large recipe. Pour into cups and have your special sib "deliver" a surprise drink to everyone in the family.



# Don't Judge

Excerpt from the Sisters Corner Newsletter

They sit before me  
these works of art,  
painted by the One  
Who is perfect from the start.  
Nevertheless, I wonder  
since their bodies seem marred  
They seem so different—  
Who are they? How do they star?

They sit before me,  
precious gifts from Hashem  
I turn to Him and ask:  
“What is it that’s in them?  
There must be something more,  
something I can’t see  
behind their seemingly imperfection,  
please help me find the key.”



They sit before me,  
but I look yet again  
and realize that each one  
has a part of Hashem.  
They’re completely pure and precious,  
their *neshamos* shining through—  
like a seashell in the ocean,  
there’s a pearl inside them, too.

Sometimes when it happens  
that the outside looks so dark,  
it’s *davka* to preserve  
the beauty of the inner spark.  
*Al tistakel b’kankan,*  
do not judge by the wrapping or bow,  
the inside is the thing that counts,  
*ella ma she’yeish bo.*



## Your Special Neshama

(Girls can call the Sisters Corner Hotline to hear this song!)

Your genuine smile, pasted on your face  
Your laughter fills the world with joy and delight  
Bringing happiness to those surrounding you  
Your charming smile lights up your face.

You look around, oblivious to the world  
With innocence only you can claim  
You accept everyone for who they are  
‘Cuz you have a special Neshama.

Chorus:

Never having done anything wrong  
Despite all the challenges that came your way  
When Mashiach arrives will you take me along  
As you lead the way can I hold your hand

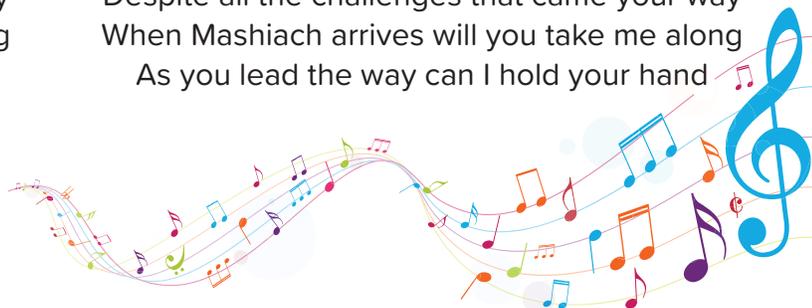
אל תסתקל בקנקן

The outside is not what we judge you by  
אלא במה שיש בו  
Rather the Neshama in you.

So many lessons you have taught me  
With your love, acceptance, and happiness  
A lifetime of thank yous would never suffice  
You have a special Neshama.

Chorus:

Never having done anything wrong  
Despite all the challenges that came your way  
When Mashiach arrives will you take me along  
As you lead the way can I hold your hand



# What Would You Do?

Sometimes my neighbors tease my sister because she sounds funny when she talks. I feel so bad for her, but if I tell them to stop, then they'll make fun of me, too. What would you do?

I would rather them make fun of me than make fun of my sister.

MB, 8 years old

I would tell my mother.

Rivky, 7

You can tell the neighbors: "Please stop bothering my sister. I know she talks funny, but she is still a person."

Bracha, 7

I would explain, in a nice way, that having a special needs sibling is really cute, and if you get to know them they are so, so cute, even when they talk funny.

Malky, 13, Tehila, 12, Devora 11

I would tell them to stop, and not care if they tease me.

Rikki, 8

When she's not around, I would explain to them how teasing her is wrong. If it didn't help, I would try to keep my distance from those neighbors, and keep my sister away from them.

Malky, 11

I would tell the neighbors that it's not nice, and that they can get punished by Hashem.

Yehuda, 5

I would tell them to stop—"because she's a lot more special than you."

Devorah, 10

Question for next issue:

**What is something that you like to do together with your special sib?**

Please send in your answers to Sibs Spot! We can't wait to hear from you!

# How Will I Ever Manage?

Rabbi Ezra Klein

Many of us tend to worry a lot about the future. It's normal, of course. Parents of special needs children don't have a typical or predictable future ahead, neither for their child nor themselves. However, envisioning the future in all its "glory," with all the potential challenges, stresses, embarrassments, disappointments, and failures, can become overwhelming. Dwelling on how current challenges are only a drop in the bucket compared to what there is to come, can paralyze us and prevent us from dealing effectively with our child right now.

Worrying excessively about the future can also rob us of the enjoyment of our many pleasurable, *nachasdike* moments, since we are too busy worrying about "what will be." *Neshamaleh Magazine* recently received this note from one of our readers: "A while ago I went through a period where I pictured everything I did, in the future. Like, if I was changing my child's diaper (when he was 2), I would picture myself changing him when he was 20! This was so overwhelming, and so silly and pointless, that it ruined the whole experience of enjoying changing my cute 2-year-old's diaper."

For some parents, just thinking about how they will ever survive and cope with future daily challenges is daunting. For others, the weight of the responsibility of navigating the confusing world of therapies and interventions can be crushing. No matter how much we do, it never seems to be enough. The guilt can be debilitating.

How do we avoid agonizing about the future and enjoy the here and now?

The truth is that, as parents, we have a conundrum about worry. On the one hand, as we discussed, worry can overwhelm us and prevent us from parenting effectively or enjoying our children. On the other hand, if we don't worry and plan for our children's development and future, who will? [see sidebar] So, what's the truth? Should we worry, or shouldn't we?

The definition of worry in the *American Heritage Dictionary* is: to feel uneasy about; be troubled. Worry is an emotion, not a

thought process. There is no real benefit to worry other than, perhaps, to motivate us to plan. In fact, short bursts of worry, better described as "concern," definitely spur us to take action to avoid future events that concern us. Planning, however, is a thought process. The definition of plan is: to formulate a scheme or program for the accomplishment or attainment of something. Planning has benefits. It enables us to accomplish great things.

If worry is merely an emotion, the question becomes: is it a good thing to feel uneasy or troubled for extended periods of time? The answer is obvious. It is not only detrimental to our mental well-being, it contradicts our belief in our kind Creator and Ruler, Hashem, Who has sustained us and kept us alive until now, Who has showered us with a multitude of blessings, will surely continue to protect and nourish us and our children in the future. There is truly no place in a Jewish heart for stressful worry.

Planning, on the other hand, definitely has a place in our minds and hearts. *Chazal* tell us in *Pirkei Avos*, איזהו חכם? הרואה את הנולד "Who is wise? One who sees into the future." We must think about the future in order to plan, and put into place safeguards, interventions, and systems to ensure our success physically and spiritually. But even planning can get out of hand.

There is a well-known maxim that says: אל תדאג דאגת מחר, loosely translated: "Don't worry about tomorrow." (Although I have not yet found a source in *Chazal* for this saying, it is quoted in many *sefarim*.) I understand this to be telling us something profound, that is: "Don't worry *tomorrow's* worry." Yes, there may be a time for worry and planning, but often we worry too early. Planning how to get our child into seminary is a valid concern, but not when she is six months old.

Worrying "tomorrow's worry" today serves no real purpose. We don't need to plan now for an event that will happen in the distant future. We have our hands quite full with today's concerns, and we will have ample time to think through solutions to future problems when the time comes. Additionally, circumstances change over time; by the time the object of your concern becomes an issue, it may not even be relevant in your new situation.

There is another reason not to worry about tomorrow's worry. Hashem always gives us the fortitude and wisdom to meet and succeed all our life challenges. But He only gives us that strength and wisdom when we really need it. If we start worrying about a problem too early, we will likely not come up with a viable solution. We will also likely stress about it, since Hashem has no reason to help us deal with a challenge that isn't even here yet.

## Worrying “tomorrow’s worry” today serves no real purpose. We don’t need to plan now for an event that will happen in the distant future.

I remember when Nechama, our daughter with Down syndrome, was born. Some people in the community were encouraging us to visit families who had grown children with Down syndrome. They felt this would help us see that even children with Down syndrome could have productive lives. I adamantly refused. I was not emotionally ready to see a grown child with Down’s and come to grips with the fact that my child was going to look like that one day. I was quite okay with our daughter at her stage of life right then. By the time she grew up, with Hashem’s help, I knew I would be able to love her as she was. But I wasn’t ready yet. That was tomorrow’s worry; not today’s.

Next time the worry bug strikes, we should ask ourselves these two questions:

Am I worrying—or am I planning?  
Is this today’s concern—or is it really tomorrow’s?

Avoiding worry and only planning about today’s concerns can go a long way to achieving peace of mind—something we could all use more of.

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*Rabbi Klein is using a pen name. He can be contacted through Neshamale Magazine.*

### **Question: Should we rely on our child’s school & therapists to map out his or her future?**

**Rabbi Klein:** I would say—Absolutely not! Taking responsibility for our child’s development is our duty and our duty alone. There are three reasons for this:

1. No one knows and understands our child as well as we do. *No one even comes close.*
2. No one cares about our child as much as we do. *No one even comes close.*
3. Usually, there is no one person who spends as much time with our child as we do.

If we genuinely care about our child and want to help him reach his potential, we have to be actively involved in planning, obtaining, and implementing the interventions necessary to reach this goal. We don’t have to do everything ourselves, and we don’t even have to get everything done. But we do have to decide what our priorities are, and the most effective means to accomplish them. Then we must follow through.

The exact extent of our active involvement depends on many factors, including the degree of our child’s disability and the availability of outside services. But even if we live in a community in which our child goes to a special school for most of the day, we must realize that “the buck stops here” – that’s us. We are our child’s “case manager;” brainstorming, planning, and overseeing all that needs to be done. Don’t feel up to the job? Don’t worry – Hashem decided that you were the perfect candidate! He will surely be at your side, coaching and helping you along the way.

Deep down, we all know this is our responsibility, and that’s exactly why we become worried and nervous about the future. Being in denial of this truth is how some of us deal with this burden, but this denial is not very effective. Facing our responsibility head-on, and alleviating our stress with the suggestions included in this article, will help us plan, take action, and feel empowered. This will surely lessen our feelings of anxiety, not increase them.

Great question! Glad to hear we're not the only ones... :) After too many traumatizing trips to different barbers in town, we decided to learn to do it ourselves! The haircuts may not look perfect yet, but we're getting better and better each time.

N. L.



## Tips From The Experts *hey! that's us!*

**My son is terrified of getting his hair cut! He goes crazy from the noise, and even from the sight of the machines. He starts screaming when I just drive by the barber shop! None of the barbers want to deal with him. Any tips or advice to make haircuts easier?**

I am a teacher of our special *neshamales*. I don't even bat an eye when a child comes to school with a botched-up haircut! It's just the opposite—we teachers marvel at the patience you, the parents, must have, to go through this minor but necessary task!

Leora Gorin

I would like to answer about the haircut issue, as it's very challenging. I took a small portable machine and followed Yehuda around the house. Not being attached to a wire helps.

Fraydel

I stand my son in front of the bathroom sink filled with water, and he becomes so distracted splashing and playing that, if I work fast, he barely notices that I am trimming his hair.

Anonymous

Try haircuts at home (by a professional or even a parent), followed by a trip to 7-11 for a Slurpee!

Seth Merewitz

After going through what can possibly be described as minor surgery at the barber shop (lollipops don't work as well as anesthesia!), I can only share what has worked for us: I started to cut my son's hair myself, in the comfort and familiar surroundings of his home. The following tips might be helpful to you:

Buy a good quality machine which is fast and smooth, such as Oster (I have an Oster Quick Feed which was about \$60 in DB Electronics). Make sure to keep it well oiled.

Before the haircut, familiarize him with the sight and sound of the machine. Build up to having him feel it as it vibrates, then go on to placing it on his body (backwards!) as it vibrates: on his back, shoulders, and finally head.

Choose a time when he's tired and lethargic, such as late at night. Strap him into a chair, such as a highchair. Use the shoulder straps to help hold him in place.

If putting on a cape will make him nervous, just skip it and take off his clothing instead. Everything can be swept up afterwards, and if he gets itchy, you can use a blow-dryer or brush to clean him off. A hat brush works quite well for this, and many kids really enjoy the sensation!

Don't try to style the haircut with scissors, as this may well end up looking like a disaster. Use one uniform size on the whole head, such as a 4 (If you really want to leave some more hair in front, you can switch to a larger size just for the front).

Here's the #1 Tip: Don't try to hold him still! Let him twist and turn! When he turns one way, cut off a chunk from the opposite side. He will then naturally turn the other way, exposing the other side, and then you can cut off from the other side. If he is trying to use his hands to cover his hair, try giving him something squishy or fun to hold. I do not recommend distracting him with nosh, because it gets hairy!

Don't try to "square off" the back. This is very difficult with a fidgety child. You can use a smaller size clip to taper off the back.

Happy Cutting! Raphael

Here are some suggestions:

Maybe try earplugs, or noise-cancelling headphones.

Most of the hair can be cut with scissors to lessen the time the trimmer needs to be used.

Let him feel the trimmer on his hand first, and practice at home on a doll (one that can take the abuse without getting ruined).

Show him a video of a boy getting a haircut—he will see what to expect, but not have the volume of noise as in real life.

Have him suck a lollipop during the haircut, as sucking activates the body's calming reflex.

If you want to try to cut his hair at home, that might be better, as the environment is familiar and he only will need to deal with the trimmer situation.

I hope these suggestions are helpful!

Ita Rosenblatt, OT

It is likely that this child has had negative sensory and emotional experiences with barbers (whether due to the sights, sounds, or feeling of the haircut itself).

Therefore, the goal would be for the child to associate the haircut with positive emotional feelings. So, for example, perhaps the child can be brought to the barbershop after hours, when there are no other customers and the equipment is off. He can touch the chairs, the silent equipment, etc. Perhaps he would want to use the equipment and cut a doll's hair. The barber can explain what the equipment is and let him touch and feel the equipment, turn it on/off, etc.

Since the goal is for the child to associate entering the barbershop and getting his hair cut with positive feelings, it is important for the parent to be calm, happy, and relaxed while going through this process.

Lots of luck with this and all the best, Rivky Steinberg, OTR/L

My son is 3-1/2. He hates the haircuts (I think it tickles him more than anything). It takes two people to hold him down, etc.

Although I do not usually resort to videos, this is the only thing that has helped us to distract him for most of the haircut, and it makes it so much easier for all of us.

A few Shwekey/Mordechai Shapiro songs and we are done and still breathing! B"H!

Good luck!

R.K

You can try bringing along some favorite toys or gadgets (that are hair-friendly of course!). For instance, our son finds it calming to play with a vibrating massager while he's getting his hair cut. He enjoys having his hair blow-dried when we're finished, so the promise of that, plus a lollipop at the end also helps him.

Our son once went four months without a haircut! What may have led to our *yeshuah* in finding a person/method that worked, is remembering that Hashem is with us in ALL issues, great or small. We asked Hashem for help finding the right *shaliach*, a good barber who would connect with our son, and that our son should find the experience pleasant.

Hatzlacha! E.R.S.

Find someone who will do a scissor cut if he's scared of the machine!

Also, get recommendations from other parents in your area for someone experienced in cutting hair for other kids with special needs; they usually have more patience and understanding.

Chaya Chazanow

Question for the next issue:

**I find the most challenging time of the whole week to be the Shabbos Seudah. Between serving, eating, clearing and trying to give everyone some attention (parsha questions or just making conversation), I am overwhelmed just trying to juggle it all. Then my special needs son acts up by throwing food and screaming, and the meal dissolves into chaos... Any tips for how to set up a better system?**

Please send us your answers to: [neshamalemagazine@gmail.com](mailto:neshamalemagazine@gmail.com) or text your answers to: 848-299-2908

# Illuminations

## *Karpas – A Time to Ask*

After we wash our hand for *U'rechatz*, we dip a vegetable, known as *karpas*, in salt water. A number of reasons are given to explain this custom: Some mention that it is done to whet our appetite for the *matzah*; the *karpas* is an appetizer of sorts for the upcoming main course. A second reason is that the vegetable dipped in saltwater serves as a reminder of the bitterness of the exile which we experienced prior to enjoying freedom. This is also why we are supposed to have in mind the *marror* when we make the *bracha* of *Borei pri ha'adamah*. A third explanation is that we are encouraging the children to ask questions by doing something that will arouse their curiosity.

I once heard that the three explanations – the appetizer, the bitter salt water, and the desire for children to question – are really one and the same, as follows: In response to the child's question, we are to answer that freedom by itself, represented by the *matzah*, is not special. If one is always free, he does not appreciate his freedom. Only after partaking of the appetizer and experiencing the bitterness of slavery via the *mei melach* (salt water), signifying the tears of the Jewish people, can we begin to savor freedom – the main course and the goal of our existence.

All the answers echo that same theme. One leads to another. Appetizers allow us to appreciate the main course. Slavery helps us savor our freedom.

The idea of questioning, wondering, and being patient until the answers come is central to the history of the Jewish people. It is told that a *maskil* once posed a powerful question to the Ksav Sofer. Rattled by the question, he came home to his father, the Chasam Sofer, to ask for an answer. But the Chasam Sofer waited three days before answering. "*Fun a kasha shtarbt men nisht. We don't die from questions.*" Sometimes we have to wait for answers.

This is the concept we wish to convey to our child on this most special night. Results do not come instantly in this world. There might be hardships and pain, tears and frustration. At times one might feel trapped, a slave of sorts. There will inevitably be tears. And yes, there will most certainly be questions. But that should not stop one from moving forward in life. The answers will certainly come. We will yet savor the taste of true freedom.

*The anguished parents had tried everything for their little Tovah. At birth she had seemed normal, but at three months she began to suffer from seizures. Essentially, she was experiencing shock waves to*

*her brain many times throughout the day. After going from specialist to specialist, and trying various treatments, all unsuccessful, the parents heard of a new type of diet that might be able to help her. It had to work; the pediatric neurologist specialists had told them that unless the seizures stopped, Tovah would suffer irreparable damage. The poor little girl was already blind and deaf, and she was facing additional brain damage unless something was found to arrest the illness. The magnitude of the problem was almost too much to imagine. How could such a little baby girl be so sick... But this time, they hoped, they had found something that would work. Sadly, after an initial stage of recovery, even the special diet failed. In fact, not only was the baby not improving, she was deteriorating.*

*Tovah's parents had unusual strength, caring for a baby who could neither see nor hear their expressions of love, as well as tending to the many needs of their five other children. It was an awesome task, trying to give each child sufficient attention, when one of them required so much of their time. Juggling it all was challenging and at times overwhelming, but Tovah's parents were careful never to complain or to let their children feel that they were overwhelmed with this challenge that Hashem had sent their way. However they tried, and as understanding as the older children tried to be, the parents often wondered what effect all of this was having on them. On one particularly difficult day, they discovered the amazing answer to that question.*

*Returning from the doctor's office with the disappointing news that the latest treatment had failed, and that Tovah's condition was actually worsening, they resolved that they would try to remain strong for the other children – but they had to tell them the gloomy news. The children had been davening for their little sister ever since she had become ill, and hoped that they would hear good news. Tovah's mother and father spoke softly to their four sons and one daughter, carefully choosing their words to let them know the latest treatment had not worked, but also trying not to alarm the children.*

*One of Tovah's brothers, Meir, was a bit slower than the others. Sweet and loving, but not as sharp as his brothers, he was playing with his siblings when his parents came home and gathered the children to tell them the latest developments. The children were close and would need one another more than ever now. When told that his sister Tovah was not getting better, Meir's eyes filled with tears. The other children took the news stoically and, as children, seemed to just want to go on with their day. At this point, Meir put his arm on his older brother's shoulder. "It's all right. I promise you. Hashem has a plan... He always does..."*

*Tovah was in great need of Hashem's mercy, but her parents, watching their small children comfort one another, knew that Hashem had also given the family the strength it needed to get through whatever He had in store for them.*

## The Perfect Imperfection

*Tishah Yarchei Leidah* – Nine are the months of pregnancy.

The “*Echad Mi Yodei’a*” list almost exclusively contains allusions to Hashem, Torah, and Biblical personalities. It seems a bit odd to include this item. Rav Shimshon Pincus can help us find a deeper meaning in this phrase.

Rav Shimshon begins by discussing the ninth chapter of *Tehillim* which begins: “*Lam’natzei’ach al mus la’ben mizmor L’Dovid.*” Rashi brings four explanations as to what “*al mus la’ben*” (“about the death of the son”) is referring to. The first explanation is that *la’ben* is Avshalom, who caused David much anguish in his lifetime, and about whom David composed this *mizmor*. A second explanation is that *la’ben* was Naval (both words are composed of the same letters), who was an enemy of David. A third explanation is that “*al mus*” refers to the alamos, a musical instrument, and “*la’ben*” is from the word “*binah*” (understanding), implying that the instruments gives understanding to the song. Yet a fourth explanation is that there was an individual by the name of Laben who was an enemy of David. Upon his death, David composed this *mizmor*.

Reb Shimshon brings a fifth explanation – that “*al mus laben*” refers to the death of David’s infant son, who died soon after his birth. David had fasted and prayed for seven days for the recovery of the child. When the child ultimately died, David wrote and sang a song. How was this possible?

Let us try to understand. When we think of perfection in this world, it is the number ten which comes to mind: The ten utterances of the Almighty created the world; the Ten commandments are our guide to life; the ten Emanations (*Sefiros*) are a way by which we understand how the Almighty relates to us in this world; ten men are needed to form a minyan.

But, interestingly, when it comes to life itself, it is during nine months of pregnancy that the child grows in his mother’s womb.

These *tishah yarchi leidah* are one short of ten. But there is a powerful message here: We cannot understand Hashem’s “rules” of perfection; childbirth, which takes place after nine months (i.e. imperfection) is, in fact, perfection.

This thought is a powerful reminder of Whose world this is, and Who is the ultimate engineer of all we see around us. And when something “imperfect” comes along, we must recognize it as being “perfectly” in line with Hashem’s plan for the world.

This is the realization that David came to in this ninth chapter of *Tehillim*. It is only when his son, the child for

*continued on page 30*

# את פתח לו

Leah Tawil, SLP

You have it in you to help your child open his mouth, so to speak, and enable him to communicate. Here are some tips to incorporate even more communication into what you are already doing during your day. Try to establish predictable routines throughout your day which naturally present built-in communication opportunities.

## Seder and Sequences

The Pesach seder has a very specific sequence, as we all know. But are you aware of how much of our daily lives are governed by sequences? Almost everything we do happens in a specific order! *First* this, *then* this, and *then*... In past issues, we talked about how important routine is, and how useful it is for incorporating language. Today, let’s focus on some of the language and basic concepts that surround sequencing.

To teach these sequences, try stressing the words *first* and *then*. I like to use an easy First-Then Board, like the one pictured below. You may want to Velcro simple photos, symbols, or pictures to it. Or you can simply stick it in a sheet protector and use a dry erase marker to write or draw quick sketches. (Disclaimer: No artistic talent needed!) When referring to the board, be sure to use your words “*first*” and “*then*,” again and again...and again!

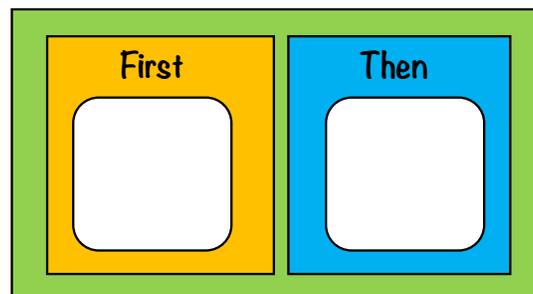
With Yom Tov around the corner, we are sure to find some recurring sequences that we can use to teach these concepts:

For cleaning: first spritz, then wipe

In the kitchen: first pour/dump, then mix (adjust words to fit what you are doing)

Setting the table: first plates, then cups (lots of options here...)

Shabbos table: first *kiddush*, then *challah*; or: first *Totty*, then Mommy



# Smart & Safe

## Bathrooms

Fraydel Dickstein

I estimate that 50-100% of special needs parents have some level of difficulty dealing with the bathroom and all that it involves. I would love to share a thought that helps keep me sane and even helps me feel uplifted. One of the most exalted tasks in the *Bais HaMikdash* was that of offering the sacrifices, the *Korbonos*. I wasn't there, but I am sure it was not too clean, as animals tend to be messy. I like to think of my home as the *Bais HaMikdash*, with me serving as the *Kohen Gadol*, so I try to think about this when I am mopping up the bathroom for the umpteenth time. On this note, I feel privileged to further our journey through the house and zoom in on the bathroom, another loaded "Smart and Safe" topic.

For starters, if your child is not toilet trained and training is not currently in your cards, keep your bathroom locked. Perhaps an inside combination lock can work well here. If your child is trained, semi-trained, if you want them to have the exposure, or, for whatever reason, locking the bathroom is not an option, let's explore some other bathroom solutions.

### Toilets

The toilet can be a safety hazard, as well as an unsanitary toy. I have seen multiple strap locks put on the tank cover. Putting on multiple locks makes it that much harder to break.



**Child Safety Strap Locks** (4 Pack) for Fridge, Cabinets, Drawers, Dishwasher, Toilet. 3M Adhesive, No Drilling - Jool Baby (\$9.95 on Amazon)

To secure the seat itself, there are toilet bowl locks.



**Toilet Seat Lock, Child Safety. Universal Fit for Standard Flush Toilet, 2 Pack** (\$12.99 on Amazon)

I personally have no experience with the above two locks. I have not tried them, since I feel that these are really child-level locks and a child who is stronger and older can break them. I

would definitely suggest putting multiple locks on each side of the tank and/or toilet seat. On the bright side, for many of our children, the toilet is not dangerous, but simply unsanitary.

### Sink

If your child, like mine, likes to spill water or perhaps make floods, you can simply shut the sink water off. There are valves under the sink which should not be hard to turn off.



### Bathtub/Shower

The water in the tub is another story. Firstly, I would like to say that if you are afraid of your child making the water too hot, to the point where they can burn themselves, you can control the temperature of the whole house's water. This is usually done by adjusting a knob on the water heater. Your plumber will know where your water heater and temperature adjustment knob is if you can't locate it yourself.



I have done lots of research as to the possibility of locking the shower knob. Perhaps a professional can figure it out, but I was not able to. So as of now, we don't have a way to keep the tub off, other than by shutting down the water main. That being the case, we needed to find solutions for Yehuda taking baths without flooding the house.

We are currently very lucky, as we have recently waterproofed Yehuda's bathroom and put in a drain. It was costly, but worth every penny. We put fiberglass down on the floor and a few inches up the walls. We put a drain in the middle of the floor. These renovations are similar to making a bathroom accessible for a child who needs to be wheeled into a tub. We were told we need a mosaic tile to slant towards the drain. I got the cheapest one out there and it was still costly (at least \$4 a square foot). The total cost of these bathroom renovations was under \$2000.

Drains are incredibly helpful. If you happen to be doing over your bathroom, keep in mind that putting in a drain is a cheap and easy

way to save a lot of heartache and damage. Depending on your specific bathroom, adding a drain should cost no more than \$100. Just make sure to explain to the worker why you are putting it in, so they pitch it on a slant, causing the water to flow into the drain on its own, before it seeps through to the floor below.

I bought a “sponja stick” style rubber broom which I use to push the water down. It’s pretty incredible. I also mop the floor that way; it’s fun and easy.



**MR.SIGA Soft Bristle Rubber Broom and Squeegee with Telescopic Handle - 12.4” Width** (\$19.99 on Amazon)

I will share with you what we did about the flooding prior to our bathroom renovations. Shower curtains are helpful, even though they scared Yehuda terribly for a while. I am totally petrified of glass doors, but if you are not afraid of them breaking, it’s probably the best anti-flood method. It always helps to turn the shower head towards the wall, so the water stays more in the shower. You can buy corner shields to put on the corner of your tub. This helps if your child loves to splash in the bath.



**Tidee Tubb Splash Guards, Ultra Clear** (\$12.99 on Amazon)

Baths are so much fun and such a great sensory activity. I have always been shocked that our Yehuda does not look like a raisin with all the baths he takes! Unfortunately, one of Yehuda’s favorite activities is to fill the bath all the way up to the top, and then to move up and down, sending gallons of water onto the floor. I remember being so exhilarated when I found these flood cloths:

**Best Water Absorbent Mats (20-Count) New and Improved Water Absorbent Pads - Wringable and Reusable** (\$35.00 on Amazon)



The first time I used them, I spread them outside Yehuda’s bathtub, confident that this would absorb all of the water, so I let him splash away. Then, my daughter came to tell me that her carpet was wet! Sure enough, I checked the two

rooms adjacent to the bathroom and was in for quite a shock to see that the carpets were wet. I realized that, since the bathroom did not have wall tiles and my flood towels did not allow flooding, the water slipped out of the sides underneath the base boards. I ended up putting flood towels along the walls as well, which prevented future floods. For the existing mess, I sprinkled my carpet cleaner along the

walls and vacuumed with a cheap wet vac. You can vacuum with a regular vacuum, but it doesn’t work as well and the water can cause problems with the vacuum cleaner. I vacuumed a few times until the powder stopped getting wet and remained perfectly dry. *Baruch Hashem* the carpets stayed beautiful and never got smelly and moldy. I must say that I thank Hashem every day that I now have only hard flooring in my home!

**WORKSHOP Wet/Dry Vac WS0255VA Compact, Portable Wet Dry Vacuum Cleaner, 2.5 Gallon Small Shop Vacuum Cleaner, 1.75 Peak HP Portable Vacuum** (\$44.99 on Amazon)



I cannot wrap up the bathroom without mentioning a meal time favorite: shampoo! Yehuda is happy as a lark when he gets his hands on the shampoo, because he likes to eat it. I have always wondered what tastes so good about it—upon speaking to other mothers, I have concluded that it’s a secret our children share, as they all seem to like it! However, I have found that when Yehuda eats a lot of it, he can seem upset afterward, and I often will hear him coughing. All in all, the eating bothers me. I like my children, especially Yehuda, to eat wholesome meals and this does not fall into that category! We also like there to be shampoo left for the baths and showers of the rest of the family.

I think a simple solution would be to put a child safety lock on your bathroom cabinet. The shampoo will be safe in there, and is easily accessible when needed. In our house, we keep the shampoo either in the locked laundry room or in the locked master bathroom. The children that are able to, keep their shampoo, toothbrushes, and toothpaste in their own closets. Another idea someone mentioned to me is to use only sample-sized shampoo and toothpaste so that there is never too much around to spill.

I always tell my kids that the Dicksteins suffer from being human, and that means we make mistakes! Every so often, the shampoo is left in an accessible spot, and we get treated to a skating rink on the floor. I am no cleaning pro, but basically, I wipe it up as best as I can with a towel, then wash it down with minimal water. If you use too much water, it can take a long time to get rid of all the bubbles. It may stay a bit sticky for a while, but at least it smells good. It’s Hashem’s true *chesed* that I have never hurt myself from falling from all the shampoo around.

May we all be *zoche* to keep our children safe and to genuinely appreciate their *heilige neshamas*.

*Please feel free to send any questions or topics you would like covered to: neshamalemagazine@gmail.com. I look forward to hearing from you soon!*



# Lets Get Educated

## The Masgutova Method

Tzivy Szmidt, MAT

It's amazing how many reflexes we are born with without even realizing it! Some well-known reflexes are the Moro reflex (when a baby senses he is falling, he instinctively spreads out his arms), and the rooting reflex (when a baby's cheek is stroked, he turns his face to that side and opens his mouth). The following is a discussion of the Masgutova Method, a reflex-based therapy that may prove beneficial for your child.

### When did it all begin?

While preparing for her thesis in 1989, Dr. Svetlana Masgutova became fascinated by the history of, and the effects of reflexes. Time spent in archives researching articles from before 1900's, spurred her on to explore the impact of the maturation of reflexes and its effect on development. Her research led to the Masgutova NeuroSensory Reflex Integration (MNRI) Method; often called the Masgutova Method.

### What is it?

Originally developed for people struggling with trauma recovery, the Masgutova Method is a neurologically-driven approach that focuses on restoration and maturation of reflexes, coordination, and brain functioning, sensory/motor integration. It is widely used for children, teens, adults, and the elderly.

Reflexes begin to develop in utero and continue to develop until age two. The reflexes integrate into the body and develop into more mature automatic movement patterns (ex: rolling over, crawling). While the Masgutova Method is not scientifically proven, observations have noted that by consistently using

this method, one whose reflexes did not naturally mature or integrate properly can reach developmental milestones.

### Who administers this method?

One can find a variety of therapists at the Masgutova Method training programs, including occupational therapists, physical therapists, educators, and parents.

How does this method work? A clinician trained in the Masgutova Method will complete an assessment to determine if primary motor reflex pattern is active (not integrated) or not (integrated). If there is no response, the clinician determines whether or not the reflex has ever emerged, or first needs to be activated and then integrated. After the assessment, treatment consists of integrating exercises.

### The Masgutova Method in Action:

*Shuli has a weak pencil grip. Her school-based OT uses certain strategies of Dr. Masgutova to help develop patterns. For example, the OT will work on certain MNRI restorative techniques such as the Grasp reflex, the Robinson Hands Grasp reflex, and the Babkin Palmomental reflex, which provide sensory-motor input to the hands for better grasp strength and patterns. There are also exercises that parents can do at home with their child to support his development.*

*The Masgutova Method identifies reflex dysfunction and works toward integration. This results in an overall improvement in function, allowing children to become more successful in all that they need and want to do.*

*Thank you to Sylvia Hershkowitz, OTR/L for reviewing this article.*

### *Illuminations continued from page 27*

whose recovery he cried and fasted, finally dies, that he is able to realize the inherent "imperfection" of the world and sing about the ultimate "perfection" of God's Master Plan.

And this is what life is all about: always striving to serve Hashem better, to become as close to perfection as we possibly can, is what moves us. The challenges we face are given to us so that we can appreciate what we have and see things in a fresh, and different, light. Then we will realize how much we have been given, and appreciate everything so much more.

The nine months of pregnancy mentioned in "Echad Mi Yodei'a," the song at the end of the Seder, serve as a bridge between the "eight" days of the *bris milah* – which is an act of perfecting in itself – and the "ten" of the *Aseres HaDibros*, the Ten Commandments. It is for us to internalize the lesson of the *tishah yarchei leidah*, the nine months that produce "perfect imperfection."

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# From *Great Expectations* to *Peaceful Acceptance*

B. Pritzker

We all have great expectations in life, especially when it comes to a newborn baby. Holding that fragile, tiny bundle of life just beginning, we anticipate the first time he'll recognize us. The first smile; the first meaningful interaction. Engaging in circles of communication. The first time he'll verbalize that special word Mommy; friendships, family time together; the milestones of *upsheerin*, school, *Chumash*, etc. His life is yet unknown, waiting to be discovered.

When Meir was born we expected the same things we expected from our oldest child. As Meir developed, or should I say *didn't develop*, we started getting worried. It was nice to comfort ourselves with the many pieces of advice we received. "Don't worry, my Yitzchok was so behind in everything, but once he started catching up we couldn't keep up with him." "He reminds me of my nephew who was *so* slow, but turned out to be so intelligent." "He's probably just thinking a lot." "You've been speaking to too many therapists; every kid develops at his own pace." However, that feeling that he was just not connecting to us and his surroundings persisted.

As time progressed, it became clear (to us at least), that the issues were real. We got him Early Intervention so he could "catch up" while there was still time. Yet, although he did make progress, he was not "catching up."

We frantically tried to get him diagnosed to get to the root of the problem. The word "spectrum" entered our lexicon. Then began the search for the magician with the magic wand who would "set him right." OT, PT, ABA, Speech, Floor time, Water, and Music therapy, this agency and that expert. Between them all, there's got to be a way to cure our child and put him back on the path "he was supposed to be on." Someone! Please! Give us clarity and show us where to go and what to do!

Truthfully, as Meir grew older, we didn't always have the time or energy for these pursuits; we were busy surviving. Surviving the tantrums, the *mushed* up food, the rolling up of unrolled toilet paper; making sure he was safe and didn't run into a car, drown in the pool, or ingest an entire bag of sugar. Our family equilibrium was thrown off balance. Nothing seemed to be normal again. Going away for *Yom Tov* was no picnic with

Meir; never mind doing errands. Getting him to try on new shoes without wreaking havoc on the shoe store was impossible. How do you function as a family with a child who is verbal—yet you don't understand him and he doesn't understand you?

Throughout all this we were still burdened with the nagging worry – what is going to be with this child? Where is he heading, and what does that mean for us? Through our journey with Meir, our thinking has slowly evolved. We have gradually learned to accept the reality that he is not on the conventional track. He doesn't have to catch up to anybody, nor is he behind anybody. A mainstream school should not be our goal for him. At best he can survive (with a lot of help), but he will not thrive. Yes, we are still pursuing the best options for him and still trying to tackle another day with our special child. However, our focus has shifted. Our goal is no longer to force him into the mold of a typical child; rather it is to encourage him in his areas of strength, and support him in his areas of weakness. This attitude has altered our state of mind from frantic to peaceful, from turbulent to calm.

We must help him thrive and reach *his* potential. Not in the manner we anticipated, but in the way Hashem, in his infinite wisdom and goodness, set out for *him*. Instead of *kvelling* over his siddur party, we *kvelled* over the time Meir came to tell us with pride in his voice that he got a high score on an electronic game. We were thrilled when he expressed fear about his first shaky tooth, when his tantrum ended with expressions of sadness, when he finally learned object permanence and started comprehending time and sequence of events.

We still hope and pray for the best but we prepare for – well, there is no worst, but rather, we prepare for whatever Hashem has preordained for him. We hope and pray that our son will understand that there is a Creator Who runs the world and loves him dearly. That he will appreciate how much we love him and be able to reciprocate. That he will understand his life and not just be sunk in a foggy haze. That he will be capable of true friendship and serve Hashem with joy. That he will continue to meet with, and be helped by, loving, talented people who see him as we do – a precious *neshama* full of light.



# When Erev Pesach Falls Out on Shabbos... *in the Hospital*

C. Tawil



When *Erev Pesach* falls out on Shabbos, it is always a unique experience. Whether you eat your *HaMotzei* on the deck, in the basement, or hunched over a bag at your Shabbos table, it usually involves some arrangements, some stress, and some laughs. When I looked at the calendar this year and saw that we would again be having this schedule, it brought back memories of an *Erev Pesach* many years ago that involved a lot of arrangements, a lot of stress, and yes, also a lot of laughs.

My story begins about two weeks before *Pesach* when my youngest sister, Shira, went into cardiac arrest. She was an 11 month old baby with Down Syndrome and a heart condition. The week before the cardiac arrest, she was seen by her cardiologist who saw no reason for any immediate concerns. But Hashem had other plans. She was now in the PICU on life support. Despite emergency surgery the week before to try to patch things up, she was still in very serious condition. *Pesach* was coming, and we needed to figure out how we could celebrate *Yom Tov* at home with the family, while not abandoning her in the hospital.

Being that the hospital was a 2 ½ hour walk from our home, it was not simple to arrange shifts. However, being that Shabbos was on *Erev Yom Tov*, making *Pesach* into a sort of “three-day *Yom Tov*,” it would not be feasible for someone to be alone at the hospital for three days, either. After much discussion, it was decided that I, then 18 years old and the oldest of the siblings, would go with a friend for the first 24 hours. Then, on Shabbos afternoon, my mother would walk in to spend the first two days of *Yom Tov*, while we would walk home in time for the first *Seder*. I found a friend who generously offered to accompany me, and we started packing.

The hospital where my sister lay was not generally populated by the *frum* community, and there was absolutely no *Bikur Cholim* room, no kosher food, and no accommodations for *frum* families. We were on our own. We packed food for all three Shabbos meals, labeling everything with double seals. The food would have to be stored in the communal fridge and there was no way to have any hot food.

After a very hectic day of *Biur Chometz* and *Pesach* cooking,

we arrived at the hospital in our Shabbos finery, carrying a large black garbage bag full of food. We tied up the bag and stored it in the communal refrigerator. We went to the family sleeping room, where I *bentched licht* on a pair of electric candlesticks, to the stares of the Hispanic couple sharing the room. We then spent some time at the bedside of my very sick sister. We davened and sang *Kabbalas Shabbos* to her, then decided to head over to the cafeteria to eat our meal.

The hospital had strict regulations that we were only allowed to eat in the hospital cafeteria. We took our large black garbage bag and made our way down the seven flights of stairs. The hospital cafeteria was almost empty at this time of night, although the TV was blaring full force. We made our way to an empty table on the side of the room and started unpacking: a plastic tablecloth, paper goods, a *Kiddush* cup and grape juice. I filled the *kos* and stood up. I opened the *bentcher* and began to recite *Kiddush*. It was probably the first time in my life that I was making *Kiddush* on Friday night. Halfway through the words, my emotions overtook me: the overwhelming fear of what could happen to my sister, the sleepless weeks of stress and tension, the difficulty of not being with my entire family for *Pesach*—I just broke down and started crying.

My friend looked at me and became teary eyed. I tried to continue making *Kiddush* but the words just stuck. Suddenly, the incongruity of the scene hit me: making *Kiddush* against the background of a blaring television, wearing Shabbos clothes amidst a totally secular atmosphere—it was really such a strange sight, that my tears turned into laughter. Soon we were both laughing, with tears rolling down our cheeks! I finally finished *Kiddush* and we ate our meager, cold meal (even the soup that my mother had lovingly packed in a thermos was only what you could call “slightly warm”). We ate hurriedly, as we really wanted to get back upstairs to my sister as soon as possible. We hiked back up and spent a few more hours at her bedside. Then we informed the nurse that we would be down the hall in the family room.

I had never slept in this room before. On all of the other nights that I had spent in the hospital, I had slept (or not

slept, depending on the night) on a reclining chair at Shira's bedside. However, from experience, it was difficult to fit even that one chair next to her bed, and there was no way that we could fit two. It would not be fair to ask my friend to sleep by herself in the family room, so the only thing that made sense was for both of us to sleep there together.

In case you don't know what a family room is, it's just what it sounds like—a room where all the families sleep. If you have never been *zoche* to this experience, just picture a large room, filled with about 40 reclining chairs, all lined up in rows, almost touching each other. Yes, this was where we two young girls found ourselves, much to the shock of our cultural sensibilities. We finally found two chairs next to each other and managed to fall asleep, despite the strangeness and the noise surrounding us.

It was not hard for us to wake up early the next morning. We eagerly left the family room and went to check up on Shira. At about ten o'clock, we retrieved our big black garbage bag and

and packed up our bag. Since we could not afford the time it would take to go up and down seven flights of stairs between meals, we went out to the courtyard and davened *Mussaf*, then came right back into the cafeteria to have our *Shalosh seudos* as quickly as possible.

I guess we davened a pretty quick *Musaf*, because the cafeteria looked the same as when we had left. It was still jam-packed, with no empty tables. The only seats available were the very ones we had just vacated. The problem was that the group of doctors was still sitting there! I looked at my friend, who just shrugged and said: "Let's go!" We went.

The group became still as we approached once again. Trying to control our embarrassed giggles, we reset our end of the table and went to wash our hands for *HaMotzie* once again. This time around, the doctors didn't even try to hide the fact that they were staring. I'm sure they could not possibly understand why we had set up, ate and left and room, only to come back and reset and eat 15 minutes later. We were

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***But we could not afford to wait, because we had to eat both of the seudos before the z'man, when you are not allowed to eat any more chometz on erev Pesach.***

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tramped down the stairs to the cafeteria. The room looked nothing like it had the night before. Now, it was bustling and jammed full of doctors, nurses, and hospital personnel. At first, we couldn't even find an empty table. But we could not afford to wait, because we had to eat both of the *seudos* before the *zman*, when you are not allowed to eat any more *chometz* on *erev Pesach*.

We walked around and finally found a long table in the middle of the room that was occupied on only one side, by a group of four doctors having a conference. We seated ourselves on the opposite end of the table and started spreading out our tablecloth. Without looking up, I could feel the stares of four pairs of eyes on me. Trying to appear nonchalant, we proceeded to set up our *Kiddush* once again. This time, I got through *Kiddush* without an emotional outburst, just a slight blush up my cheeks from being the center of attention in an alien atmosphere. Then, we left the table to wash for *HaMotzei*.

The sinks were a long distance from the table and the doctors were probably wondering where we had disappeared to, without cleaning up! We made *HaMotzei* and ate a piece of fish, being closely observed all the while. Then we *bentched*

definitely more entertaining than whatever medical topics they had been discussing!

After our third meal, we packed everything up once again and proceeded to the bathroom on the main floor. We had been instructed that the *minhag* was to dispose of the crumbs in the toilet, so we had to do this—even in the public bathroom! Though it was hard to control our laughter, we flushed those crumbs down the toilet. We were quite relieved to be finally finished with our meal ordeal. We made our way back upstairs with a much lighter bag, joking that we were practicing "going out of *Mitzrayim*" with the big bag that we'd been carrying around the hospital!

The rest of the day proceeded smoothly, according to plan. We spent a few hours in the PICU, then headed downstairs to the main entrance. We met my mother at the entrance, just as she was walking up to the hospital (great timing!), and began our 2 ½ hour walk home. It was a beautiful day and we tried to enjoy ourselves, despite our aching feet. We had lots to discuss, especially our recent adventures in the hospital. Despite the difficulties and uncomfortable moments, I was proud that we had the strength to do the right thing and be *m'kayem* the *halachos*, and even the *minhagim*, of when *Erev Pesach* falls out on Shabbos—even in the hospital.

# *MindField*

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Elky Handler

Life's a constant uphill battle  
And I'm addled by this war.  
But I'll stay astride my saddle  
And I'll fight it to its core.

It's a struggle for survival,  
It's a war I daren't lose.  
And I won't! I'll stay alive!  
All Demons dare me? I'll refuse.

No, I don't know why He's done it,  
And I cannot see His plans,  
But I'll fight it 'til I've won it,  
From my perch inside His Hands.



## GLOSSARY OF HEBREW TERMS APPEARING IN NESHAMALE MAGAZINE

Note: All words are in Ashkenasic (Eastern European) pronunciation. (Y) indicates term is Yiddish (A) indicates Aramaic

**Abba** – Father (A)  
**Ahavat chinam** – “free” love, whether deserved or not  
**Aliyah** – (lit: to go up) 1) to move to Israel, 2) to be called up for the Torah reading in synagogue  
**Amen** – So be it!  
**Asher yatzar** – blessing after using bathroom, thanking G-d for physical health  
**Aveiros** – sins  
**Bchasdei Hashem** – with G-d’s kindness  
**B’sof haYamim** – at the end of days  
**Bais haMikdash** – the Holy Temple  
**Bar mitzvah/Bas mitzvah** – Jewish rite of passage: 13th birthday for boy, 12th for girl  
**Bentch** – to bless, or to say Grace after Meals (Y)  
**Bentched licht** – lit (and said blessing over)  
**Shabbos/Yom Tov candles** (Y)  
**Bentcher** – booklet containing Grace after Meals (Y)  
**Bikur cholim** – visiting the sick  
**Bitachon** – trust (in G-d)  
**Biur chometz** – destroying leaven before Passover  
**B’nai Yisroel** – the Children of Israel (the Jewish People)  
**Bnos (groups)** – girls youth group  
**Borei pri ha’adamah** – blessing before eating vegetables  
**Bracha** – blessing  
**Bris milah** – circumcision ceremony  
**Chag Kosher V’Samaech** – greeting for Passover: “Have a kosher, happy holiday!”  
**Chagiga** – holiday party  
**Challah** – special bread for Shabbos and holidays  
**Chazal** – our Sages, of blessed memory (acronym: Chachamim Zichronom Lvracha)  
**Chesed** – acts of kindness  
**Chizuk** – strength, encouragement  
**Chometz** – leaven  
**Chumash** – the Five Books of Moses  
**Chuppah** – wedding canopy  
**Daven/davening** – pray, prayer (Y)  
**Davka** – specifically  
**Dever** – plague  
**Ein Od Milvado** – There is no one but Him (G-d)  
**Emunah** – faith  
**Eretz Yisrael** – the Land of Israel  
**Erev Pesach**  
**Frum** – religiously observant (Y)  
**Gan** – nursery school  
**Gemora** – Talmud / Gemaras (pl) (A)  
**Geulah/Geulah shelaymah** – Redemption/ the Final Redemption  
**Haggadah** – guidebook for Passover seder  
**Hakadosh Boruch Hu** – The Holy One, Blessed Be He (G-d)  
**HaKaras haTov** – appreciation (lit: recognition of the good)  
**Halachos** – Jewish laws  
**Hallel** – prayers of praise to G-d  
**HaMotzei** – blessing before eating bread  
**Hashem Yisborach** – G-d, may He be blessed  
**Hatzalah** – Jewish Emergency Medical Service  
**Hatzlacha** – success  
**Havdalah** – concluding ceremony of Shabbos  
**Heilige** – holy (Y)  
**Kabbalas Shabbos** – welcoming in the Sabbath  
**Karpas** – vegetable on Seder plate  
**Kavanah** – intent (ie: concentration in prayer)  
**Kiddush** – sanctification; recitation over wine on Sabbath and Holidays

**Kiddush Hashem** – Sanctification of God  
**Klal Yisroel** – the Jewish People  
**Kohen Gadol** – High Priest during Temple times  
**Korbonos** – sacrifices during Temple times  
**Kos** – cup  
**Kvelling** – expressing pride and joy (Y)  
**M’chazek** – strengthening  
**M’kayem** – fulfilling  
**Makkah** – striking (ie: with plague)  
**Marror** – bitter herbs eaten at Passover seder  
**Mashiach, Moshiach** – the Messiah  
**Maskil** – proponent of the Enlightenment movement  
**Matzah** – unleavened bread  
**Medrash** – explicatory stories and parables  
**Mentchies** – little people (toy figurines) (Y)  
**Minhag/minhagim** – traditions  
**Mitzrayim** – Egypt  
**Mitzvah/mitzvos** – Torah Commandment/s  
**Mizmor** – song  
**Mussaf** – Shabbos and Holiday “Additional” Prayer Service  
**Nachasdike** – inducing pride  
**Neshama/neshamos** – soul/s  
**Nisayon/nisyonos** – test/s  
**Olam haBa** – The World to Come, Afterlife  
**Olim** – immigrants to Israel  
**Pesach** – Passover  
**Pirkei Avos** – Ethics (lit: Chapters) of the Fathers (section from Talmud)  
**Posuk, Pasuk** – verse (of Torah)  
**R”l** – Rachmana l’zlan; May G-d have mercy  
**Rabim** – the public (lit: many)  
**Refuah/Refuah shlyamah** – Healing/Speedy Recovery  
**Rosh Yeshiva** – Dean of Yeshiva  
**Schar v’Onesh** – Reward and punishment  
**Seder** – ritual Passover dinner service, lit: “orderly”  
**Sefarim** – books  
**Seudos** – meals

**Shabbaton** – Sabbath weekend retreat  
**Shabbos** – the Sabbath  
**Shaliach** – agent, messenger  
**Shalosh seudos** – third Shabbos meal  
**Shechina** – the Divine Presence  
**Shema** – foremost Jewish prayer, which declares the oneness of God  
**Shidduch** – marital match  
**Shiur/Shiurim** – Torah lecture/s  
**Shul** – Synagogue (Y)  
**Siddur/Siddurim** – Jewish prayerbook/(pl)  
**Simcha** – joyous occasion  
**Tallis** – prayer shawl  
**Tatty** – Daddy (Y)  
**Tefilla/tefillos** – prayer/s  
**Tefillin** – ritual objects used by Jewish males during morning prayer  
**Tehillim** – Psalms  
**Tischazek** – May you be strong  
**Tomchei Shabbos** – organization that provides food for Shabbos to the needy  
**Torah** – Five Books of Moses; inclusive term for body of Jewish observance and life  
**Tzadekes** – female tzadik  
**Tzaddik/tzadikim** – righteous person/(pl)  
**Tzara** – pain, difficulties  
**U’rechatz** – ritual hand washing during Passover seder  
**Upsherin** – 3 yr old boy’s first haircut ceremony (Y)  
**Yahadus** – Judaism  
**Yeshuah/Yeshuos** – salvation/s  
**Yissurim** – punishments  
**Yissurim shel ahava** – “punishments of love”  
**Yom Tov** – Jewish holiday  
**Z’mán** – time  
**Zeeskeit** – sweetie pie (Y)  
**Zemiros** – special songs sung at Shabbos table  
**Zoche** – merit (verb)

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