

נשמהלה

Sharing Our Special Experiences: Chizuk & Inspiration

Neshamale

magazine



MARI, MY PRINCESS/4

The Song
of his *Soul* /10

A graphic of musical notes on a staff, positioned to the right of the text 'The Song of his Soul'.

ISSUE #2 // PESACH EDITION תש"פ

Sibs
SPot /16

The logo for 'Sibs SPot' features the text 'Sibs' in white with a red heart above the 'i', and 'SPot' in white with a red silhouette of a child jumping below the 'o'. The background of the logo is red with white stars.

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Dear Readers,

Welcome back to the second issue of *Neshamale* magazine! I want to personally thank each and every one of you who read and responded to our inaugural issue. It's a pretty scary thing to send out a piece of your heart into cyberspace, not knowing where it will end up and how it will be received. Your feedback was so encouraging and very much appreciated!

The question in last issue's "Tips from the Experts" column asked you to share a one-liner that uplifts you and keeps you positive when life with a special child feels particularly overwhelming. The responses, as you will read, are as varied as they are helpful. It is so interesting to see what inspires people!

Along those lines, we received a lot of feedback from the first issue, with readers often mentioning their favorite columns. As I read through the comments, I noticed that mention of the favorite columns covered every *single column* in the magazine! It amazed me that, although we are all in similar situations, reading the same magazine, different articles speak to different people in different ways.

I hope that we will continue to uplift our readers with a variety of articles and ideas. If there is a slant that you feel is missing, please let us know or consider filling that void by contributing your own experiences or ideas.

When we received the diagnosis for our special needs son, Avrumi, we spoke with my husband's rebbi HaRav Dovid Shustal (*Rosh Yeshiva* of Beth Medrash Govoha in Lakewood). Among many things, he told us one idea that stays with me always. He said: "The *Ribbano Shel Olam* is a *Kol Yachol*. He can do anything. But there is one thing that He cannot do. He cannot make a mistake!" He explained that if my son is missing a gene, it's not a fluke. It's not an accident. It *had* to be this way!

Sometimes this is so clear and obvious. When I walk into Avrumi's room every morning, greeted by his delighted smile and sounds of excitement as he catapults himself into my arms, I am filled with joy, and thoughts of "mistakes" are not on my radar at all. When I see Avrumi's siblings come through the door and greet him lovingly, it's clear that he is a beloved member of our family who was placed with us for a purpose. When I think of the many, many lives he has touched with his purity and joy, it's clear that there are no mistakes.

But then there are other times. When he cries and screams for hours and I have no way of knowing WHY?!, and he can't tell me, then questions do cross my radar. When he brings his sibling to tears by pulling their hair, or destroying the school project they spent hours working on, I wonder why they need to grow up with a special sibling. When his needs are overwhelming and it seems like we're not making progress in crucial areas, I feel despondent and need some *chizuk*.

That's when I fall back on *my* answer to the mantra question: "Hashem can **not** make a mistake." And though we don't understand *why* it had to be this way, it is comforting and empowering to believe that it *does* have to be this way.

Where would we be without our *Emunah*? I was inspired by the interviewee in this issue who shared: "I find the *bracha* of *Shehakol* very uplifting...you are saying that everything is according to Hashem's plan. We say *Shehakol* throughout the day, and it's like *emunah* booster shots." Imagine if every time we made a *Shehakol*, we thought about this and engraved this message into our hearts: It's all good! There are no mistakes!

Emunah is one of the main themes of the upcoming Yom Tov of Pesach. How were the *Yidden* finally redeemed from the slavery in *Mitzrayim*? Only with their *emunah*, as the *posuk* (Shemos 4:31) says: "ויאמן העם", "and the nation believed!" They believed that Hashem did not forget them, and that all of their suffering was for a good purpose. But they also believed in *Tefilah*. When we read the *Hagaddah*, we talk about the enslavement and suffering of *Bnei Yisroel*. Then we tell about the *makkos* and *yetzias Mitzrayim*. What happened in between those two events? "ונצעק אל ה'" "and they cried out to Hashem." That cry was the catalyst that set the redemption process in motion.

This represents one of the trickiest balancing acts that we are required to master: we need to believe it's all perfect, yet at the same time keep davening for a *yeshua*! This applies to so many situations in our lives, but especially to life with a special child—there is just so much to accept and so much to daven for! We offer a beautiful perspective on this theme in the "In Session" article.

In Hoshea (2:22) it says: "וארשתוך לי באמונה", "and I will betroth you to Me through your faith", which the *medrash* (Yalkut Shimoni 519) explains to mean that the *Geulah* will come through the *z'chus* of *emunah*. May we be *zoche* to have this *emunah* and be worthy of our own personal redemptions, as well as the collective redemption of our entire nation with the coming of *Moshiach*, *bim'hayrah b'yameinu*, *Amen*.

Mari, my princess

Shevy Nachum



I should probably begin by making a disclaimer: there are two things you should know about me before reading this. One, I am a positive person by nature. It's not something I had to work on; it was a gift handed to me by Hashem, along with my senses of sight and hearing. This impacts a lot of my story and I know how lucky I am to have this gift. Two, I am the textbook definition of a Type A personality. Everything begins with making a list, my spices are alphabetized, and my snack bags are color coded. I like when things fit neatly in their boxes, but five years ago, I had to create some brand-new boxes.

Looking Back...

Mari was born on *Erev Rosh Hashana*. It seemed that, from the very beginning, every single thing that happened was tailor made for us and our family. For starters, we knew about some of her challenges before she was born. I often think how lucky I was to have had that time. We were able to spend the pregnancy preparing both practically and emotionally. As someone who takes comfort in planning, I made sure everything we could do in advance was done.

I remember leaving that big sonogram and thinking: "I can do this, but how in the world will my other kids cope?" The next day, my 5 year old twins came home from school all excited about the new unit they began—a unit on special needs. As they began telling me that special children are just like us, and they need love just like us, for the first time, I fully understood when people say they felt Hashem physically holding their hand. And from that moment, it felt like He never let go.

By the time Mari was born, we had already had four months to process our new reality. We were ready to love and accept her wholeheartedly. Thank God for that because, from the moment we had her, the people around us were taking our cue

on how to view her, how to love her. So when they realized we weren't "pretending to be ok" and that we actually fully viewed this as a simcha, they followed suit.

Mari was born with physical, medical and cognitive challenges. At about three months old, we went for a sleep study and were sent straight to the emergency room when the results showed her losing oxygen over 30 times per hour. The fact that she had survived those first 3 months was nothing short of a miracle. Her doctors performed a mandibular distraction, which basically extended her entire jaw, opening her airway considerably. Once her airway was enlarged, she wasn't as good at protecting it while swallowing, so she had to have a G-tube (feeding tube) placed.

Because one problem kept leading to the next, we ended up staying in NYU for 6 weeks. During that hospitalization, my husband and I took turns staying with her. It was not easy, but we got it down to a science. When it was time to switch shifts, we would meet in the hospital and overlap for twenty minutes and have coffee together. That way we knew that we had seen and spoken to each other that day!

For the sake of our other children, we felt it made the most sense for us to divide and conquer, making sure one of us was at home at all times. We've used this system during subsequent hospital visits, and we've definitely had our share! Between a palate repair, cardiac issues, and gastro difficulties, Mari keeps things interesting!

I know people always say: "Hashem gives you what you can handle." But I believe it's more than that. I think when He gives you a challenge, He simultaneously gives you the tools you'll need to ace that challenge. So when I was given Mari, I

was also given a strength I never before possessed. I was given a husband and kids and siblings, each one playing their role to perfection. Trust me—I do have my moments and I cry plenty. I remember when Mari turned 2, and left the official “baby stage,” it felt like a punch in the stomach. But even when it’s hard, I feel a sense of “I got this.” I might need ice cream and good chocolate, but “I got this.”

Enjoying The Present...

Today, Mari is five years old. She has three older brothers who protect her with their hearts alone. When I said before that I feel our situation was tailor made for my family, the fact that Mari was born when my children were so young is a perfect example of that. Five year olds are pretty accepting and basically fully trust whatever feelings they read from their parents. So from the time Mari entered their lives, there was never a question to them that she is anything short of perfect. To them, she’s just Mari, our family’s princess. I know that now they are still so innocent and don’t yet know the world isn’t as accepting as they are. But one day, when they are faced with that reality, they will be able to look back and be proud that they never felt anything less than pure unadulterated love for their sister.

One night when I was putting my seven year old son to sleep, he turned to me and said: “We’re so lucky! Because when *Moshiach* comes, our family will get to greet him first... all cause of Mari.” Naturally, I assumed he must have heard this from a *Rebbe*. With tears in my eyes, and very proudly, I asked: “And do you know why that is?” He looked at me as if I was the strangest person on the planet and responded: “Yeah! Cuz we can park in handicap parking!” Mari is their normal, just another member of their team.

Mari has a very angelic look to her. When looking at her, it’s hard not to notice the soul looking back at you. She sometimes seems like she isn’t aware of her surroundings but then, she has these moments of complete awareness—where you know she knows exactly what’s going on around her.

Music is something that seems to affect the deepest parts of Mari. She can follow any beat to perfection and her eyes seem to dance along as well. My mother spends hours singing *Tehillim* songs to Mari. Watching her whole face light up while she claps along never ceases to amaze!

Mari spends hours learning the basics in physical therapy. She works with Henny Roberg, a CME therapist, and a gift straight from Hashem. CME therapy isn’t for every child, but for Mari, it has been our greatest hope and we have seen unbelievable results. We can’t wait for the day she finally takes her first steps! She has the most incredible staff at SCHI, who not only push her to be as awesome as she can be, but truly love her.

After school, she goes to The Special Children’s Center, a bubble

of pure joy and happiness, where she can just have fun and enjoy herself. She comes home from the Center showered and in pajamas, practically gift wrapped for us. Between SCHI and the Center, our move to Lakewood feels constantly justified.

People sometimes call to ask me if I can talk to a parent who had a special needs child. I am hesitant to do this for two reasons. One, I feel that this journey is so personal, and the same way I have my own challenges, I also have advantages that most people don’t have. I have a family where we are no strangers to special children. I have a 12 year old adorable niece with Down syndrome and an incredible nephew, a few months older than Mari, who has special needs.

Twelve years ago, my sister paved the way for our family, who were totally unfamiliar with the concept, about what this new world meant. She painted it as a beautiful place, where you have the option to either be pitied or respected—but never both. I don’t know if she made a conscious choice, but it was a GENUINE choice, one that left the rest of us looking at her daughter as the best thing that ever happened to our family.

Family support is everything to me and I cannot imagine the suffering that a person must go through if it isn’t there. Knowing that any time Mari is in the hospital, a sister is with me (including every single Shabbos) so that my husband can stay with the other kids, or relying on in-laws to cook full *Shabbosim* in my absence, or knowing that so many people would drop everything to be there for Mari, means everything.

My second reason for hesitating before calling other parents is that when Mari was first born, a well-meaning stranger called and told me how excited she was because, after a lot of work, her five year old son had just learned to crawl. For the first time since Mari’s birth, I experienced gut wrenching fear. I couldn’t imagine a world where I would be excited to see my five year old child crawl! I looked at my perfect little girl, asleep in her swing, and had to tell myself not to forget this was OUR journey, no one else’s. Granted, I would be over the moon if Mari would start crawling today, but my 5-years-ago-self didn’t know that. So when I do end up speaking to people, I try not to get bogged down in the details of my personal journey, because they need to live their own.



Without Mari, I would never have had some of my favorite experiences. One was the opportunity to work with my sister and co-write “A Mother’s Promise,” an incredibly emotional song by Yaakov Shwekey. Yaakov approached us at a *Shabbaton* for the Special Children’s Center and told us: “Write the perspective of a mother on what it feels like to have a special child. You write it; I will sing it.” Neither of us are writers and we initially turned him down, but something inside us decided to try telling our story. It was our way of being able to sit down and pen our deepest emotions, in a safe place, a place we knew other mothers have been. I can’t even describe the emotion in writing that song, and I will forever be grateful for having had that opportunity.

Another project I just began working on is the MARI undershirt. When you have a child with special needs, there are always complications cropping up. Thanks to Amazon, there are creative solutions for almost any problem. For example, recently we went through a phase where Mari was very unhappy. She would irritate her G-tube and scratch her ears. I ordered splints for her to wear on her elbows which do not allow her to fully bend her arms. This effectively stopped her from irritating her G-tube and ears, but it caused her to start attacking her other hand and really harming it. Once again, Amazon to the rescue! I bought a bikers glove which protected her other hand. These few little things made a huge difference and Mari is so much happier now!

But when I needed an undershirt with snaps on bottom for Mari, one larger than the standard baby size, Amazon came up empty. I knew I wasn’t the only one looking, because anyone with a child who isn’t toilet trained, or has a child with a G-tube, could benefit from having everything neatly secured with snaps. So I reached out to June Aboksis, owner of Junees (a clothing store)

and a good friend, and together we created larger undershirts. I’m hoping other parents will become aware of this product and check it out. You can find us online at iwearmari.etsy.com.

Aside from bringing out a creative side that I had no idea I even had, Mari has taught me a thing or two about my own strengths. Being a parent to a child who has so many challenges, you end up wearing hats you never considered. You become a therapist, a nurse, a teacher, and sometimes even a surgeon, apparently! That last one happened one Friday, 5 minutes before Shabbos, when we were out of town, and we realized Mari’s G-Tube button had fallen out. The pediatrician wasn’t an option, so my only choice was to go to the ER or to figure it out on my own. All I can say is: “Thank goodness for Youtube!” Because that Friday, I learned how to replace my child’s button!



Looking Toward The Future...

It’s amazing that, although I am such a Type A personality and always have everything planned to the last detail, somehow, I don’t worry much about Mari’s future. On a practical level, I only think about it when I absolutely have to. I don’t find myself worrying about things like: “Who will care for her when I’m gone” or “What if she’s 15 and still can’t walk?” I believe this (totally out of character) ability was given to me as another gift, because the questions have no end once they begin. So I just focus on today, on this morning’s outfit, on her awesome week in therapy, and just how much joy this princess has brought into our lives.



Dreams of perfection dance around in my mind
 A miracle of life so beautifully designed
 As I hear your first cries, my heart fills with love
 You’re placed in my arms, a gift from above
 Then come the words that forever change my world
 Something’s not right with your sweet little girl.
 I hold you even tighter, as old dreams just seem to
 fade away
 I know I will love you, protect, and keep you safe
 “We will be alright” I tell you with a soft kiss...

I promise I’ll be your eyes when you cannot see
 I promise to be your voice when you cannot speak
 I promise I’ll be your legs when you can’t bear the weight
 I promise to be your heart when the pain gets too great

Deep in the night, when I watch your eyes close
 The mother in my heart is desperate to know
 When those big blue eyes open, is it me that you see?
 Will your sweet little arms ever reach out to me?
 When you hear laughter, is it just empty noise?



Do you feel you’re all alone in pain and joy?
 Will you ever know the feeling of my love that
 really runs so deep?
 Dreaming of tomorrow, we softly drift asleep
 “We will be alright” I tell you with a soft kiss...

I promise I’ll be your eyes when you cannot see
 I promise to be your voice when you cannot speak
 I promise I’ll be your legs when you can’t bear the weight
 I promise to be your heart when the pain gets too great

I promise I’ll be there
 Through triumphs and through tears
 To be the spark in the dark
 I promise I promise I promise!

La la la... la la la... la la la...
 We will be alright
 La la la... la la la... la la la...
 We will be alright



From The Doctors Desk

| THE INS AND OUTS OF G-TUBES

Chayala Tawil

I interviewed Dr. Marcos Alfie, MD, a Pediatric Gastroenterologist with Meridian Medical Group, NJ, about the use of Gastrostomy feeding tubes, or G-tubes, as they are commonly called.

Q: What are some of the circumstances that would make a doctor recommend a G-tube for a patient?

A: The most common reason a child would need a G-tube is to prevent aspiration, which means that food is going into the airway. In this dangerous situation, the G-tube is considered a medical necessity. There are other less common situations, such as dysphagia, where the esophagus is underdeveloped and interferes with swallowing safely.

The second most common reason for a G-tube is when a child is not gaining weight. Unless there is a case of severe malnutrition, this is considered an optional medical intervention. Here the doctor's skill and experience come into play. The doctor must carefully monitor the patient and decide whether it is advisable to insert a G-tube to increase calorie intake.

Q: What are some of the complications and how are they dealt with?

A: The most common complication after the insertion of the G-tube is dislodgment, when the tube falls out. This usually occurs during the night, while the child is asleep, and is not discovered by the parents until the morning. This is problematic, because the incision can close quickly, even within 1-2 hours. If the hole closes completely, the child will need another surgery to reinsert the tube. To avoid this situation, it's very important to keep close tabs on the tube and make sure it isn't loose or falling out. If you do realize that the tube fell out, try to reinsert it (without the balloon) and tape it down until you can reach the doctor. If you cannot reinsert it, put anything sterile there, just to keep the incision open, and head to the closest emergency room. Always keep a spare tube with you in case of emergency.

Another complication is when tissue grows around the incision. This can be cauterized by a doctor in the office. Cellulitis, an infection, can sometime occur, and is treated with antibiotics.

Q: Have there been any recent advancements in this area?

A: One of the problems with the standard G-tube is that those with severe reflux can still vomit. A more recent innovation is the J-tube, which feeds directly into the small intestine, instead of the stomach. Although it is usually more ideal to feed through the stomach, this is very helpful for reflux sufferers and is becoming more popular.

Q: What are some of the common misconceptions that people have about G-tubes?

A: The main misconception that parents have is that they think a G-tube is permanent. They are afraid to take the step of inserting a G-tube, as they feel that it will change the life of the child forever. This is completely untrue. A G-tube can be temporary and is completely reversible. Sometimes it is only needed for a short while because of developmental immaturity. When the child grows up and is able to eat, the tube can be pulled out in the doctor's office and does not require any additional surgery. The incision closes on its own.

Please note that this article is for informational purposes only. Please do not take any actions without the guidance of your child's personal doctor.

Q

Dear Shira,

I have a beloved 9 year old autistic son. Chaim had a late autism regression. I find myself struggling with fully accepting Chaim today. I feel that if I am not miserable about his autism then I will become complacent and I won't have the drive to do all that I can to help him. On a deeper level, I am worried that I won't cry and daven as much for him, which I believe can change his predicament. I feel that this lack of acceptance is holding me back from experiencing the special joys that can be part of raising a special child. Any advice?

Chaim's Mommy

A

Thank you for your very honest question.

Before I answer, please take out the biggest blank piece of paper you can find. In the center of the paper, draw a small dot. Show the paper to a few people and ask them what they see. Typically, almost everyone will respond that they see a dot. People don't notice the biggest part of what they're seeing – the white.

This experiment was demonstrated on a huge auditorium size screen. Although the white was exponentially many times greater than the dot, all anyone noticed was the dot. This metaphor is symbolic of a child with special needs. People tend to focus on the special need – the dot – and they do not see the greater part of the person. It sounds like you are starting to see the “white” that is Chaim, and that's exciting, but scary.

There is so much that EVERY parent of a neurotypical child or atypical child has to address. A parent has to build a relationship with their child that includes accepting the child with the unique raw material, and guide them to develop to the best of their abilities to reach their full potential. The balance is like a seesaw—how much to give to each side, which side is too heavy, and which side needs to be lightened.

Fully accepting Chaim and doing everything within your power to get him what he needs are not mutually exclusive. You will always be *davening* to Hashem, because without His help, nothing will be accomplished.

I agree with you that a lack of acceptance may hold you back from experiencing the special joys that can be part of raising a special child. You need not allow this to take away from your doing all that you can to help him. Presently, you might be feeling that the ‘white’ in the above exercise represents the special needs Chaim has, rather than the reverse.

I suggest making a list of all of his wonderful abilities and uniqueness. Make it as comprehensive as possible and don't leave anything out. Don't forget to add the purity of his neshama and all its ramifications. For example, he is able to communicate, but he does not speak *loshon harah*; he can see, but he does not look at inappropriate objects. Add all of them to one side of the seesaw, and then put his needs on the other side. What are you noticing?

You will always have the drive to do all that you can to help Chaim, and you will never stop crying and davening to Hashem for him. You don't need to be “miserable” about Chaim's situation for that to happen. You may be surprised—as you come to fully accept him, rather than becoming complacent, you may have an even greater drive and daven even harder!

Wishing you much *nachas* from this child and the rest of your family,

Shira Speiser, LCSW

Shira Speiser is a social worker in Lakewood, New Jersey and has helped children and families for many years. You can contact her at 732-367-1503 or shira732@live.com



Let the good times roll!





A Special Simcha

Dovid's Upsherin

N. Lipson

Our son's third birthday was approaching, and we were making plans for his *upsherin*. But this was not a typical *upsherin*. Our beloved son, Dovid Simcha, has Down syndrome. He spent much of his life in the hospital with many medical complications, and *Chasdei Hashem*, we were so grateful that he was home and well, and reaching this milestone. However, regarding the *upsherin* formalities, our son wasn't quite there yet. He is not yet walking, and understandably, not up to recognizing the *Aleph Bais*, so we dismissed the option of doing the customary *honig-leken* (licking honey off Hebrew letters) in a *cheder*. Yet, as the day came closer, something was niggling us about skipping this event. We went through different variations of trying to see how this could work, but we came up blank. It wouldn't make sense to take him to a *cheder* in front of a full class. It just wouldn't work.

But on the Friday before his birthday, we somehow found ourselves calling Rabbi Eisgrau, the *menahel* of our older son's school, Cheder D'Monsey. We left a lengthy message on his machine explaining the situation, acknowledging the fact that we were calling so close to his birthday, and that his birthday was four days before Pesach—a most hectic time in all classrooms. We asked if he had any possible ideas about how we could do a condensed version of an *upsherin*. Maybe there was some other option that could satisfy the situation.

When Rabbi Eisgrau called us back, his response contained the most heartwarming words we had ever heard.

“Could you please bring your son to the *cheder* on Monday? We want to see him. We really want him to come. It will mean so much to us to have him here and do his *upsherin* in the *cheder*.”

We were speechless.

“But what about the *Aleph Bais*? And in front of a whole class? He can't talk yet, so how will he respond? Besides, Monday is four days to *Pesach*...”

“Monday is perfect!” said Rabbi Eisgrau. “And don't worry about anything. We have it all worked out. We'll have him lick

a lolly dipped in honey from the *Aleph Bais*. We won't ask him to say anything. The class will sing ‘*Siman Tov u'Mazel Tov*’ – It will be so beautiful for them! And one more thing – please send us a picture of Dovid!”

We hung up the phone and tears filled our eyes. We were completely blown away by his response. Suddenly, the mode switched. Instead of focusing on what *wouldn't* happen, we were actually looking forward to a meaningful day in the *cheder*.

Monday morning arrived, and we cut little Dovid's hair. We then placed a *yarmulke* and *tzitzis* on our sweet little boy. We wrapped him in a *tallis*, and like any other family, we headed towards the *cheder*. Arriving there, we were greeted with smiles from staff and *talmidim* alike as we walked towards the first-grade classroom.

The first thing that welcomed us was the bulletin board, displaying a beautiful *Mazel Tov!* sign with Dovid's pictures prominently posted along with his name. After Rabbi Pieprz and Rabbi Engel gave us a warm welcome, Rabbi Eisgrau sat down in the Rebbe's chair and began.

The boys sang “*Baruch HaBab*” with smiles and enthusiasm. Then Rabbi Eisgrau introduced Dovid and explained why today was a special day. He took out a personalized *Aleph Bais* card with Dovid's name and picture, and he placed honey on the *Aleph*. He took a bright red lollipop, dipped it in the honey, and gave it to Dovid. He then showed Dovid and the class a customized coloring book with *upsherin* pictures to color, along with Dovid's name and picture on the cover. After continuing with an engaging lesson on Torah and Mitzvos, the class erupted in an enthusiastic “*Siman Tov u'Mazel Tov*,” all the while sitting, so as not to highlight the fact that Dovid cannot dance yet.

While they were singing, the *menahel* of the older grades joined at the back of the classroom, followed by other staff members. We felt embraced by the *cheder* family, and we could not get over how they went all-out to make this event a most meaningful experience for us and our children.

As our son Boruch, the proud older brother, gave out the *pekalech*, the class sang a slow and heartwarming “*V'hei She'amdah*.” Our eyes and hearts filled; we were touched by the *cheder's* acceptance and love, how they truly viewed each and every *neshama* as a shining star.

An upsherin and a bar or bas mitzvah are always a momentous occasion. But when the star of the show has special needs, we may need to plan the celebration with unique considerations. Please share your experiences with us, as to how you made your child's upsherin and/or other simchas a truly special event.

The Song of his Soul



Yitti Berkovic

This year, when we reach the end of the Pesach Seder, I know one thing for sure: I'm going to cry. *Tears of joy? Tears of sadness? Tears of longing?* It's hard for me to know that myself. But I know that when my family begins our rousing rendition of "*Lshana haba'ah b'Yerushalayim*," the tears are going to come, fast and furious. And it won't just be the wine talking.

The tears will tell a story I hadn't dreamed possible, a story that fortified my *emunah* in a way I didn't know I needed. I hope my story will move you the way that it moved me.

Sometime last summer, my husband and I decided to make our son Tzvi's February bar mitzvah in *Eretz Yisrael*. Even in the planning stages, it felt like a miracle. I had not been to *Eretz Yisrael* since seminary, 18 years ago. My husband Yossi had not been back since his yeshiva days, 19 years earlier.

Like many of you, we'd never imagined we could afford to take our entire family across the ocean - looking at airline prices alone gave us sticker-shock. But now the timing felt right. *Everything* about the trip felt right.

We would be spending the money anyway, and though it would cost us at least as much as making a local bar mitzvah, it felt like money better spent. Every penny would go toward introducing my children to the land of their forefathers - toward making memories to last a lifetime.

Plus, we wouldn't be doing it alone. Many of our family members were just like us - hardly the jet-setting type - and they were thrilled to have a reason to travel to *Eretz Yisrael* to join our simcha. Only one issue gave me considerable anxiety: How would Naftali, our son with special-needs, manage a trans-Atlantic trip and such a jarring change to his schedule? *Probably not very well.....*

Many well-meaning people encouraged us to leave Naftali at home, offering to pitch in with the babysitting. They pointed

out all the things we knew to be true: *He needs structure. He doesn't do well in unfamiliar settings. He hates crowds. How will he manage all the walking?* So, when it came time to book tickets, I began to panic. Maybe everyone was right.

Maybe bringing Naftali wasn't fair to Tzvi. Maybe Tzvi deserved his bar mitzvah to be about *him* - without us holding our breath to see how Naftali would behave. But Yossi wouldn't hear of it. "Naftali is Tzvi's brother, and this is a family *simcha*. He comes with us, even if it means we plan our trip around him. That's part of life with a special-needs sibling."

Part of me knew Yossi was right, but part of me also thought he was making a real mistake. I didn't tell this to Yossi, but when we boarded the plane, I had a list of experienced babysitters in my pocket. When Naftali inevitably had his first meltdown, they could spend the day in our apartment with him.

But here's the second part of the miracle: *I never even opened that list*. In fact, I threw it away almost as soon as we landed. Because from the moment our plane touched down in *Eretz Yisrael*, Naftali became a child I did not recognize.

As we whizzed down the highway to *Yerushalayim* for the first time, he stared out the window with a smile that reached all the way up to his eyes. Naftali craves familiarity and sameness. The sights outside should have all been foreign to him - *intimidating* to him - and yet he seemed more at home than I'd ever seen him.

When we reached the Old City, still exhausted from the flight, he pointed through the taxi window and said: "That's where the third *Bais haMikdash* will be built."

What?

He said it calmly - but with eerie certainty - and his words took my breath away. *How did he know? What did he even know*

“If there is anyone who does not believe in the existence of the neshama, all he or she needs to do is look at a picture of Naftali standing with his hands against the Kosel’s cool stones, the song of his soul playing gently on his lips.”

of the Bais haMikdash? He hasn’t been to yeshiva since he was 6 years-old – nearly ten years ago! Clearly, he saw something I could not see; without being taught, he knew something I could not know.

A few minutes later, we walked through the Old City to reach the Kosel for the first time, and I held my breath again. There were stairs – endless, winding, stairs – and Naftali hates stairs. He hates long walks. But he practically danced down the steps – laughing to himself the entire time.

Who was this child? And what was he thinking? What did he feel here that he did not feel in America?

My sensory child, my child who won’t push through a crowd or touch things he’s never touched before, marched up to the Kosel and leaned up against the cold stones as if to give them a hug. In truth, he embraced the entire country in that very same way - like he’d found a part of himself that had been missing for too long. For the rest of our trip, our son - who can be stubborn, oppositional, difficult – did whatever we asked of him – and with a smile.

He traveled from cemetery to cemetery, standing patiently as the adults around him *davened*. He waited on line for more than an hour – in a cramped, claustrophobic stairwell – to receive a *bracha* from Rav Chaim Kannievsky, *shlita*, still smiling even as the adults around him griped. “I went to see the *tzaddik*,” he told me proudly when he got home.

No complaints. Only joy. *What was happening?*

The most remarkable moment occurred at *Mearas Hamachpela*. The men in our group had gone to daven mincha, so Naftali stayed with me and the other women to wait. Some Israeli men looking to form a minyan of their own noticed Naftali and tried to wave him over to join them. “I’m so sorry,” I offered in my broken Hebrew. “He is autistic. He can’t be counted in your minyan.”

The men laughed jovially. “Ima, this is *Eretz Yisrael!*” one man insisted. “Every Jew is welcome to join the minyan!” *How could I argue with that?* With bated breath, I watched as Naftali followed this perfect stranger to the side of the room where mincha was beginning. I watched in disbelief as Naftali pulled up a chair and sat quietly with a *siddur* on his lap as the men swayed in concentration around him.

No protests. No outbursts. No attempts to run back to where I was sitting. Instead, he opened the *siddur* and read out the *alef-bais*, his “prayer” mingling with the prayers around him. Only after the last kaddish, when the men dispersed, did he return to me with a grin. “I davened *mincha* so nicely,” he beamed. My eyes filled with tears. *Yes, you did, Naftali. Yes, you did.*

That glow stayed with him all trip long, and he showed me, time and again, beyond any doubt, that his connection to our land is far deeper than mine, far richer than mine. The joy that emanated from him as he traversed our *Eretz haKadosh* was mysterious and mystical and almost other-worldly.

The truth was undeniable: *In Eretz Yisrael, he sees what I cannot see.* He feels what I cannot feel. If there is anyone who does not believe in the existence of the *neshama*, all he or she needs to do is look at a picture of Naftali standing with his hands against the Kosel’s cool stones, the song of his soul playing gently on his lips. He is not just a special *neshama*; he is *ALL neshama*, and he is teaching me to connect better with the pureness of my own soul.

So now you understand why, when I say “*L’Shana haBa’ah b’Yerushalayim*” this year at the *Seder*, I will cry. Not tears of joy or sorrow or longing; no – they will be tears of prayer: Please, *Hashem*, help *all* of us see what Naftali sees – help *all* of us feel what Naftali feels. May our prayers be as sweet as his so we can be worthy of the *geulah shelaima, bimeheira b’yameinu. Amen.*

This article was originally printed in The Voice of Lakewood.



On the Lighter Side... The Perks

Rikki's Lucky Mom

"You are so lucky!" "What a zechus!" "I'm in awe..." Do you ever get these type of comments? I do. The commenters actually sound jealous of me, the lucky mother of a child with severe special needs. Sometimes I wonder why.

I mean, *I know I'm lucky*. I just wonder why *they* think so. Do they actually *want* this gift? No one has ever offered to take my daughter for any amount of time. I've come to the conclusion that they are simply jealous of the perks that come along with a special needs child. *Perks*, you ask? Well I've thought it through and I realize that there are so many of them. We need only recognize and appreciate them. I will try to enlighten you, so that you, too, can realize just how lucky you truly are.

The handicapped parking sign. For the shopping-lovers among us, this is definitely #1 on the list! Before I had a handicapped child, I used to spend my time search for parking spots. On the fourth circuit around the lot, I would longingly eye the three empty handicapped parking places and fantasize about sliding into one. Of course, before the thought could finish processing, I would be thanking Hashem that I couldn't park there. Nonetheless, one day I did become the proud owner of a handicapped parking sign. (There is just one small problem. The only way I can go shopping is without Rikki. The only way I can use the sign is *with* Rikki. Well. At least I get to use it for doctor appointments!)

Lots of attention. When you have a child with special needs, you will never be lost in the crowd. If you are ever feeling lonely, simply go to a crowded area with your special child. Everyone will notice your child, and by extension, his or her superhero parent! Don't worry, not everyone will stare. There are those who will actually look the other way and only glance back every few moments in an effort to fix their hood, check the clock on the wall, or pick a piece of lint off their back. Those more honest will comment, share a story of their sister-in-law's nephew who also uses a walker, or ask you what your child's diagnosis is. They may then suggest that you switch to their sister-in-law's nephew's doctor.

Lots of pity. It's a package deal, two for the price of one. Along with the attention, comes pity. "How do you manage?" "I don't know how you do it." "Do you need help?" Whether they verbalize it to you, or just send you the vibes, it will be delivered on a consistent basis. It comes from all sides: from close family members... neighbors... close family members of those neighbors... the lady in the robe store... they *really* mean well. No longer will you need to dramatize your daily living experiences in order to garner sympathies; your circumstances are dramatic enough as it is. In fact, your drama-quota is now on auto-fill.

The best excuse. I remember learning in 4th grade that Rachel yearned for children so that she could blame things that went wrong on her child. I'm sure that's a simplified version of the real meaning, but it does tell you something. Nothing is inexcusable anymore. Can't make it to your nephew's *simcha*? Your washing machine is broken again? You forgot to make the *cholent* for Shabbos? There's a one-word answer: "Rikki!" (I have found that no "outsiders" really have a come-back to this one. It may have something to do with that pity thing, see above.)

Free stuff. I know, it's hard not to be jealous of free stuff. Especially if it is very valuable stuff. When I tell people that Rikki's walker cost (her insurance, not me) \$5,500, they gawk. When a friend bragged about her expensive bugaboo, I couldn't resist telling her that my daughter's stroller cost \$7,000 (again, her insurance, not me). Should I mention the fact that I don't pay a penny for her tuition or therapies? The color green is not so becoming on people's faces, so I'll stop there.

I hope this list has clarified for you just what perks there are and why some people get wistful when they see your child smiling in his (\$10,000 covered by insurance) wheelchair. May we all be *zoche* to appreciate the blessings in our lives!

Please understand that this article was written in jest, although you are still welcome to send irate letters to the editor.



Badge of Honor



Food for Thought

Part 1 in a series

Shalva Sauer, SLP

Shimmy has been nursing for 8 months, but his weight gain is slowing and the doctor is concerned. Introducing solids has been a disaster, with weeks of trying to teach him how to take a spoon. Shimmy's tongue keeps pushing out the food and most of it lands on his bib. Shimmy will not accept bottles. Mealtimes have become very stressful, compounding the pressure of all the therapies and appointments for special needs children.

Malkie is turning two. She has mastered pureed food, but that is all she is capable or willing to eat. Malkie subsists on yogurt, jars of baby food, and baby oatmeal. If she can be convinced to eat pureed soup, she gags on any tiny piece of chicken or vegetable that her little tongue detects and vomits her entire meal. Malkie sucks and gnaws on crunchy chewable foods like pretzels or cookies, but then either spits out the pieces or dissolves them in her mouth. She is getting hungrier as she grows, but needs enormous amounts of pureed food to keep her satisfied.

One of the most emotion-laden issues for Jewish mothers everywhere, and particularly for parents of children with special needs, is keeping our children well fed. It is so important for mothers to know that their children are getting enough nutrition and are growing and gaining weight. When feeding milestones are not met and a child's nutrition is at risk, the stress takes a toll on everyone involved.

When a child is struggling with feeding issues, it's very important for the family to be supported by professionals who validate their challenges and are responsive to their concerns. A doctor or therapist addressing feeding issues should listen carefully, take the parents' concerns seriously, and provide good referrals and positive strategies. If a professional is dismissive of a parent's anxiety, parents should find a second opinion and be sure they are comfortable with the recommendations provided.

It's imperative to recognize that when a baby is born, his brain is wired to seek and take in the necessary calories for him to grow and develop. If a baby does not seem to be doing that, he has a good reason. During infancy, we must be careful not to label a child as "behavioral," even if a doctor or therapist claims that this is the case. If a baby is not getting the nutrition he needs, the correct approach is to ask questions and explore: "What is holding back my baby from eating?" "What is the barrier to this child's ability to nourish himself?"

There are many reasons why a baby may not be eating adequately. He may not have the necessary skills to coordinate the very complex act of eating. Maybe there is a structural/anatomical problem which is getting in the way of successful eating. He may experience a high level of discomfort every time he tries to eat and knows it will be painful to try again. It may take a team of specialists or just a discerning pediatrician to get to the root of the issue, but there is always a valid cause for the feeding difficulty.

As time progresses, if the issue is not resolved, the baby will not experience typical oral experiences and may not even mouth toys. In this case, the baby can develop sensory difficulties surrounding food, and may be unable to tolerate many tastes and textures. Mealtime can take on negative patterns, and then we have a child with overlaid "behaviors." Even at this point, the child is usually not "sensory" or "behavioral," but rather, is challenged with sensory and behavioral outgrowths of a feeding issue which was more medical or motoric at its root.

Shalva Sauer, MS, CCC-SLP is a speech-language pathologist who specializes in pediatric feeding therapy in Lakewood, NJ.

Do you have questions about feeding therapy? Send them to us and they will be answered in a future column.



Shimmy, Our Shining Star



SPECIAL PARENTS

of SPECIAL CHILDREN:

Sara Lieberman

A Talk with Mrs. Haller from Baltimore, MD

Sara: Hi, thank you for agreeing to be interviewed. What can you tell us about yourself?

Mrs. Haller: I grew up in Brooklyn. I never interacted with children with special needs in the community and didn't know much about them. If I happened to see someone with special needs, I would shy away and be unsure of how to interact with them. So I was totally unprepared to have a special needs child, because I had no prior experience whatsoever.

Sara: Can you tell us a little about your son with special needs?

Mrs. Haller: Boruch is 19 years old. He was diagnosed with a rare condition that affects him in many ways, including his developmental and physical growth. He's extremely short for his age and looks different. He communicates with his own vocabulary—using sounds, signs and gestures. You can't understand him unless you take the time to learn his "language." He's a very happy, outgoing person and loves to talk and connect with family and friends—even strangers, like cashiers at the supermarket. He loves going out to stores and calling people on the phone. He has plenty of friends at school, including staff. He definitely has his opinions, like which hat he wants to wear and where he wants to go, and he's pretty insistent on getting his way. He has a great sense of humor and loves making mischief. He also loves when we act silly with him, and talk in funny voices. He has a huge, yummy smile and a contagious laugh. He's a big personality and has great energy and a zest for life. He loves to color and play with his toys.

Sara: What are some of the day-to-day challenges that you deal with?

Mrs. Haller: My son goes to a public school for special needs children. He needs me to get him dressed and needs 24 hour supervision. He has fragile bones and walks with a walker, so we really have to watch over him. He needs to be entertained and requires help with daily living tasks. He gets meds in the morning and night, and has a g-tube for feedings.

Sara: What are some tools and strategies that you use to help you cope with your challenges?

Mrs. Haller: I have come to learn that it's not my plan, it's Hashem's plan, so I go according to His plan. It's not easy when things don't go my way, but I work on accepting that I'm not in charge. Like the time when we were all ready and excited to go to a *Shabbaton*—Boruch had a seizure and we couldn't go. It's hard and disappointing, but acceptance of Hashem's plan is a big game-changer. We have gone through so much that really wasn't according to my plan that I composed a song to help us adapt and accept.

Sara: Great! Can you share it with us?

Mrs. Haller: Sure! Here goes:
(*TTTO*: ?)

Low: Where to go, when to go, how to go,
We know.

Hashem we follow:

Al Pi Hashem Yisau, V'al Pi Hashem Yachanu
That is what we do.

Hight: And you should know,
and you should know,
and you should know
Shehakol N'heiyeh Bidvaro.

Sara: Thank you! It's so catchy! There are certainly many times when I will need to sing this myself!

Mrs. Haller: Yes, it helps us be flexible—which is the second step after acceptance. If plan A didn't work out, do plan B.

Another tool that helps me is: Don't compare. I frequently hear parents comparing their children's disabilities. This is not healthy, because you'll always want your child to perform better, and we need to accept our special children for who they are. I actually have it easier in this area because my son has a rare disorder, so I don't have many to compare him to.

Sara: This can apply to every life situation; it's a great reminder. Which brings us to my next question: What חידוק do you draw upon when going through a hard time?

Mrs. Haller: I find the *bracha* of *Shehakol* very uplifting. In the *bracha* you're saying that everything is according to Hashem's plan. We say *Shehakol* throughout the day, and it's like *emunah* booster shots. It's helpful for me to think: "It's not what the doctor said, it's not what the therapist said, it's what Hashem says." This supported me one summer when I was in the hospital with Boruch. I was alone and scared and I found comfort in this *bracha*; it gave me so much *chizuk*. After that summer, I gave my employees a *Shehakol* treat every Friday with a poem.

Also, in *Al Hamichya* and *Birchas Hamazon* it says "*Hu Mativ*." When you think about it, you are saying that Hashem is all good! When something seems bad, it's not that it is bad. When I eat and say *brachos*, just focusing on what I'm saying is like having this built-in connection to Hashem every day. I can't believe I said these *brachos* for so long without tapping into their power.

Speaking about *brachos*, I'm very into treating myself. Slush coffees, milk chocolate, anything with peanut butter and chocolate—Hashem made these treats for us to enjoy!

Sara: Treats are great pick-me-ups. What are other ways you stay positive and upbeat?

Mrs. Haller: I draw strength from quotes and inspirational messages. I especially like short quick phrases—they say so much, and it sticks. When I was sitting *shivah*, a few people took pictures of the quotes I have posted on my walls.

Sara: I'm sure surrounding yourself with positive messages affects the whole family in a good way as well. What perspectives did you give over to your other children about having a special needs sibling?

Mrs. Haller: Parents are really role models for the kids.

Whatever attitude you have will spill over to your children. If the parents are embarrassed or withdraw socially because of their special needs child, the kids will learn from that and follow suit. When Boruch had surgery and had a huge prominent scar running across the top of his head, his younger brother was in kindergarten. He had a friend over and he told his friend: "Wanna see his head?" He was not embarrassed that his brother looked different. He thought his scar was cool, and

wanted to show it to his friend. On *Simchas Torah* he dances with Boruch, and in other public places he feels totally comfortable with his brother.

Sara: Baruch Hashem, you gave over good messages to your children. How do you balance work with the needs of your family?

Mrs. Haller: I'm still working

on that! You really need to find the balance that works for you and your family. I read this quote in the last issue of *Neshamale*: "If Momma ain't happy, ain't nobody happy" and it's really true. You can't stretch yourself too thin. Years ago, we discussed with a developmental doctor our thoughts about moving to New York to gain access to more services and therapies. He said to us: "The most important thing is to live in a community where people are happy!" Some people turn their world upside down to get every therapy possible, but I think Hashem wants us to do normal *hishtadlus* and be happy. If you're going crazy, then maybe you're doing too much *hishtadlus*.

Sara: Thank you so much for sharing your story with us. Your *emunah* and positive messages are inspiring!

Mrs. Haller is using a pseudonym. She can be reached through Neshamale magazine.



To my dear sister Esti,

You are physically disabled,
You can't control your movements.
Your legs can't hold you.
Hashem controls you.

You can't talk,
You can't play, jump or sing.
You are unique.
Hashem chose you to fulfill this mission.

You are in front,
In front of everyone
Trying to reach perfection.
You already are perfection.

Though the world doesn't think so,
You are ahead of everyone.
Lying and waiting
For when Mashiach will come
To take us out of this false reality.

You'll jump out of where you are,
You'll sing and dance.
You'll be so happy
With the Master Plan.

E.C.



Activity Time!

Pesachdik Potato Heads



What food do you think of when you think of Pesach? Potatoes, of course! Though I'm sure you've eaten many different forms of potatoes on Pesach, I'll bet you've never eaten a Mr. (or Mrs.) Potato Head! Here's how to do it:

Supplies:

- Potatoes, cooked or baked until edible, but still firm
- A variety of sliced vegetables (ie: peppers, olives, pickles, baby tomatoes, mushrooms)
- Toothpicks



Instructions:

Slice off the bottom of the potatoes so they can stand upright. Set up plates with a potato on each one, and the cut-up vegetables and toothpicks in the center of the table.

Now it's time to get creative! Using toothpicks, attach different vegetables to make Mr. Potato: you can make a hat, shoes (the bottom of a pepper works well for that) eyes, ears, nose, mouth, arms.

Snap a picture of your creation and send it to us!

Eat your Mr. Potato Head with some honey-Dijon dressing on the side!

Variations:

Depending on how many children are doing the activity and what their abilities are, there are lots of possibilities.

If you have a lot of cousins together, make a Potato Head Contest for *Chol HaMoed* lunch! Choose someone special (maybe your *Zaidy*) to be the judge!

You can create a whole family: father, mother, sister, brother, baby, etc. Take a picture of the whole "family" together before eating!

Depending on your special sib's abilities, you can adapt the activity. If they can't do it on their own, help them out. Ask them to point to which vegetable they want to use, and you attach it for them. Explain the body parts. Many will find it humorous and enjoy watching you create a yummy, fun meal for them! Be sure to remove the toothpicks before giving it to them to eat.

Shloimy Helps Out

By Elisheva Dickstein



A HUG FROM HEAVEN



My name is Yoel and I have four younger siblings, one of whom, Refael, is autistic.

From what I've heard, until he turned two, Refael was a sweet, regular baby. Then Abba and Ima started to realize that he had issues. They received a diagnosis when Refael was two and a half. Ima described the way they stood there in the hospital corridor while Refael was still under anesthesia from his MRI. They heard the term "autistic," but didn't fully understand what it meant then.

But oh, what a disorder it is! When the doctors explained it to them, Abba and Ima were both in shock, and Ima cried for a long time.

When Abba and Ima returned home and told me about Refael's diagnosis, I immediately thought, *Why us? Why Refael? What will my friends say?*

I was confused and embarrassed, but I knew that I loved my brother and that I would do whatever needed to be done for him. Ima told me that Hashem sends these special souls to the best and most worthy families because only they can withstand the challenge. "Be proud of us," she told me. "We were chosen for an important mission."

The truth is that in those early days, when Refael was still a toddler and relatively calm, it wasn't hard to be proud of our mission. But as time passed and Refael got older, the difficulties grew along with him.

My whole family pitches in to take care of Refael: we feed him, dress him, and take him for walks down the street. Refael doesn't talk clearly and he needs constant supervision.

During the year there's a lot of work revolving around Refael, but when it comes to vacation time, our entire household goes into high gear. We're all part of the effort to look after Refael because he's at home for so many hours during that time.

The person most devoted toward Refael's care is Ima. There were nights when I saw her fall asleep on the couch sapped of all strength, days in which she couldn't cook because she didn't have the time. I once heard one of the neighbors say

that Refael is like thirty children combined. She had no idea how right she was.

During summer vacation there are days when Ima does not sleep. All of us try to help out, but there are many times when Abba is away at work, my sisters are at camp, and I am with my friends or at *Masmidim*. The only one always there is Ima.

There are some very hard days when Refael throws tantrums, and gets wild and out of control. This is especially hard now that Refael is a teenager and even stronger than Abba. It's very unpleasant and scary to be near him when he's angry. On days like that, Ima doesn't take Refael to public places or out on errands, because he can become volatile.

Last summer, Refael was fourteen years old. Regular boys that age are independent and mature, but for Refael it was not a simple age at all. His functioning is limited and he needs help in almost every area of his life. His body is big and strong, but he has as much common sense as a baby.

One day Ima needed to rush out to pick up a pair of glasses for Ruchama, my younger sister. Without those glasses, she suffers from migraines. I was at shul studying with a *chavrusa*, and Abba was out of the country for a week. Ima was in the stairwell of our building, getting ready to leave with everyone, when I met them on my way back home.

"Oh, Yoeli, it's so good that you came!" There was an expression of relief on Ima's face. "Come and join us. It'll be a big help." Ima handed the baby's carriage over to me and gestured to me to follow her.

I was nervous about going out with Refael, and I could see that my younger siblings were too. They were embarrassed by his behavior outdoors, but there was no choice. Ima had asked for our help and it was a *mitzvah*.

As we left the building, I saw that Ima was pale and trembling slightly. "What happened, Ima? Are you not feeling well?" I asked. Ima leaned against the wall, weak and tired. There were tears in her eyes.

"I'm a little bit nervous to go out with everyone," she said. "I'm worried that Refael will make trouble and become wild."

I'm suddenly feeling how hard things are with him. Abba isn't here and, aside from me, there's no one else who can take care of him."

Ima hugged me and then, suddenly, she added, "You know something? Hashem is with us. I should have remembered that. Hashem is our Father and He's with us everywhere. He gave us Refael as a present. He helped us raise him until now and He'll continue to help us. There's no better Protector than Him."

Ima looked heavenward and said: "Hashem, please help me with Refael. I need Your help!" I watched Ima become stronger as she spoke. The color was returning to her face, but there were still tears in her eyes. I could see Refael standing on the low wall around our building, waving his hands around, and I was scared that he might fall. "Come, Ima," I said. "Refael is getting impatient."

We all marched out. Ima and Refael stood at the front of the procession, with me and my baby sister in her carriage taking up the rear. My two other sisters stood in between us. Suddenly I thought: if Ima feels so comfortable speaking to Hashem like that, why couldn't I speak to Him, too, and ask Him what I need?

So that's what I did. I said it quietly so that no one would hear: "Father in Heaven, you know how hard my mother tries. She does everything she can to raise us properly, and to care for our special Refael. No one else knows what a major challenge this is. No one can even imagine what Ima is going through. You've seen, like I have, how worn-out she sometimes is, yet she still gives so much love and happiness to Refael. That's why I'm asking You, *Ribono Shel Olam*, to give Ima a hug. Send her a sign to show her how happy You are with her. You're a Father, and a father can hug his daughter. So please, Hashem, find a way to give her strength and to tell her that she's a good mother. The best mother. Thank You!"

I could feel my quiet speech strengthening me.

We started walking from store to store. We were on our feet for a long time, but Refael was amazingly calm the entire time. We took turns walking next to him, telling him stories, answering his questions, and making him laugh.

"Do you see, Yoeli?" Ima whispered as we walked. "Hashem is with us. Can you feel it too? Refael is behaving wonderfully."

Next to the optical store was a falafel store. "I want to eat something good," Refael said, drawn to the store. Ima decided to go along with whatever he wanted so as not to rub him the wrong way and cause a scene.

We all stood outside the store as Ima went in with Refael. I heard Ima patiently explain all the options with a small smile, the way one explains things to a child. "There's ice cream, there's falafel, and if you want something to drink, there's that too. You can have whatever you want."

Ima fixed Refael with a loving and questioning gaze, awaiting his answer. Refael fell silent, deep in thought.

The saleslady was an older woman with a pleasant expression. She looked at Refael and Ima and asked: "Is he your son?"

Ima nodded, and I could tell that she didn't notice the expression of amazement on the saleslady's face as she continued to help Refael try to figure things out. To us, Ima's behavior toward Refael, which demanded an abundance of inner strength and patience, was nothing unusual.

The saleslady turned to Ima, her voice filled with emotion, and said, "*Giveret*, you are such a good mother to this boy. You speak to him and explain things with such patience and love. You're a wonderful mother, and a wonderful woman. Your heart is golden. Hashem loves you and is blessing you. He will provide you with only good. If He gave you such an important life mission, then you are a hero."

The woman continued to praise Ima and then said: "*Giveret*, I need to give you a hug. I feel so good just seeing you."

"The truth is that I need that hug," Ima said.

The woman stepped out from behind the falafel stand and enveloped Ima in a huge hug. She kissed her on her forehead and continued to bless her. "You should merit *nachas* from all of your children, and especially from Refael."

"Amen," I whispered from the entrance to the store. I turned toward the wall so no one would see me cry.

Ima left the store, very emotional. Refael clutched a bottle of juice and a bag of fries, and appeared completely happy and calm.

When we got home, Ima spoke to Abba on the phone and told him what had happened. "In the fourteen years that we've had Refael," she said, "I've heard all sorts of reactions from people, some good and others better. But I have never encountered a reaction like this one. Never have I received such an encouraging hug; I'm still soaking up its warmth! And it all came from a woman I never met before. It was like a hug from *Shamayim*."

Overhearing that phone call, I thought: *It's the hug that I had the courage to ask for from Hashem.*

I saw with my own eyes how it's all possible, how our amazing connection with Hashem is all true.

Speak to Him. He listens.

Thank you to Tfutza Publications for allowing us to reprint this story from "Right in Front of Me: True Stories Seen by Kids Like You" by Koby Levi.

What Would You Do?

If you had the opportunity to tell your special sibling something and they could understand everything you said, what would you want to tell them?

Shevy, 7: I would say:
Avrumi, you are the best brother ever!
I love you soooooo much! I really, really, really do!!!
I love when you are happy and not sad!

Mordechai Y.: All I would say is: "I love you!"

Zanvil Grunbaum, 6: Shaya, you are cute! I want you to be healthy. You are already a little bit healthy, Boruch Hashem.

Liba, 9: You are the best brother! I love you so much!
How does it feel not to be able to talk? Do you like me?
Why do you love my room?

Yisroel, 8: I would teach him Chumash and also ask him what he wants the most.... and then I would tell my mother to buy it for him!

Nechama, 12: Really he is a good boy even though people sometimes tell him to go away and stop doing what he is doing. We love him and everyone else does too!

Chesky Grunbaum, 7: Shaya, you are so cute! I have the z'chus of having you in my family. Even though you think it is a tza'ar, it isn't because we get so much s'char!

Chani, 9: I want you to know that we understand your feelings like when you feel happy or sad. Do you know that we all care about you?

Question for next issue:

**Does your special sibling like to touch or take something precious of yours?
Tell us about how you deal with it!**

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

Now that you've told your special sibling what you wanted to say, here is their "response"

TO MY SPECIAL SIBLINGS

The time has come,
Now that I've turned three,
To share with my brothers and sisters
How much they mean to me.

My world is really boring,
Not full of excitement or fun,
Because, as you all know so well,
I can't talk, or play, or run.

When you joke, or play, or even fight,
I cannot come join in.
How I wish I could play a game with you,
And see if I could win.

But then one of you comes over,
To play and talk with me.
You can't begin to imagine
How that makes me so happy.

Every time that you remember
To give me some attention,
It means so very much to me,
Much more than I can mention.

To my sibs, I'm a special *neshama*,
But they're also so special to *Hashem*.
They do so much *chesed* for me each day.
They love me, and I love them.



Sibs Spot Interview: Yaakov T.

Hi, Yaakov. Can you tell us a little bit about yourself?

I'm 9 years old and in fourth grade. I'm popular in my class and kids look up to me. I'm the type of kid who comes up with good ideas. For example, when everyone is bored at recess, I'll think of a new game and get all the boys to play. I really enjoy playing sports. I also enjoy learning.

You sound like a great boy! What can you tell us about your special sibling?

Avi is my younger brother. He is four years old. He is very happy and always laughs. He is sensitive when people get upset at him. He loves getting his head rubbed. He can't talk but he tries to tell me stuff. So when he wants me to rub his head, he comes over to me and puts his head under my hand!

It's good that you understand him so well even though he can't talk! How do you feel about having a special sibling?

I feel *chashuv* having a brother who is full of *simcha* and has a special *neshama*.

Wow, that's beautiful. Are there also times when it's difficult?

It's hard for me when my brother hurts other people. I wish he could understand not to do this but he

really doesn't understand. Sometimes I feel bad for him and sometimes I want to play with him.

How much do you feel that your life is affected by having a special sibling?

I don't know the exact percent but for sure it is. I go out of my way to help him, to stop him from doing dangerous things, to play with him—and to rub his head!

You sound like a really awesome older brother. Are there any interesting stories that you can share?

One day my brother was playing on the deck, which has a gate. All of a sudden, my mother noticed that the gate was open and Avi wasn't there! She got very scared and yelled at all of us to go look for him. We all went running in different directions but we couldn't find him. Then someone thought of checking upstairs in the house. There he was, playing upstairs! No one had noticed him sneaking upstairs. Boruch Hashem he was safe.

Wow, that must have been a big relief! It sounds like Avi adds a lot of excitement to your family. He is very lucky to have such a caring older brother!

Please contact us if you would like to be interviewed for the Sibbs Spot.

Does Hashem Love MIE?

Rabbi Ezra Klein

In the car on the way to the hospital to give birth to our daughter, I tried to encourage my wife, Leah. “Remember, no matter what happens, think: I love my child —and I love Hashem,” I said. We knew for a while that there was a possibility that our unborn child had Down syndrome, as I mentioned in my previous article. We tried to think positive, but I wanted us to be ready for any possibility. Needless to say, when our daughter did turn out to have Down syndrome, we grappled with many *hashkafic* and emotional issues.

On the first day, after meaningful discussion about some of the issues, Leah turned to me with tears in her eyes and said: “I know I love my child, and I love Hashem. My question is: Does Hashem love me?”

It was clearly *hashgacha pratis* that I actually had an answer to that question. A few days before, I finally accomplished a task I was meaning to do for many months. We didn’t have pictures of all of our children hanging in our home. Some months earlier, we went to a beautiful botanical garden and I snapped some stunning photographs of each of our children. They were printed, but still waiting for me to find the time to hang them on the wall. The day before our daughter, Nechama, was born was the last day of *Chol Hamoed*, and we were looking for something to do. Having the children help hang the pictures seemed like the perfect activity. When we were done, I was pleased with how they turned out. They looked great— arranged in a geometric pattern on our wall, the individual portraits of all our children gave us tremendous *nachas*.

Leah’s question made me recall those photos of our beloved children. “Think about the picture arrangement,” I said to her. “Hashem gave us those precious, delicious *kinderlach* whom we love dearly. Can there be any doubt that Hashem loves us deeply? Surely the same Hashem Who was so loving and kind

when He gave us those amazing children didn’t suddenly change. He also gave us Nechama —with that same love and kindness!”

By focusing on the gifts Hashem gives us that we can more easily appreciate, we will recognize and feel the great love Hashem has for us. This will help us integrate the understanding that it’s the same loving Hashem Who gave us our special child.

It’s also important to recognize all the simple, yet significant, little miracles Hashem performs for us on a regular basis. For example, I appreciated how Hashem arranged that we put up those pictures the day before Nechama was born, since it helped us cope with our emotions. Of course, everyone needs to do this; whether or not they have a special child. But for those of us who have the daily challenge of dealing with the “gift” that Hashem sent our way, it’s even more essential, in order to preserve and nurture our loving relationship with Hashem— and to stay sane.

We also had to deal with our tremendous disappointment, that even after we put so much effort into our *tefillos* and received reassuring *berachos* from *gedolei Yisrael*, our daughter still had Down syndrome. What happened to all our *tefillos*? Why weren’t they answered? How can I ever daven again?

I recalled a deeply insightful comment I heard from a *bachur* in Lakewood many years ago. We were learning in the *Bais HaMedrash* a couple of days before Rosh Hashanah when this *bachur* turned around and with intense seriousness asked a few of his friends the following: “Last year I tried my best to do teshuva and daven to Hashem for a good year. Of course, I might have done a better job, but I made a pretty good effort. Yet, this past year, some pretty nasty things happened to me. How, and why, should I daven again for the coming year, if it didn’t work last year?”

Some of us knew what was behind this *bachur*’s question. He was engaged and presently going through an extremely difficult time. The engagement was on very shaky ground and was about to break up. He was undergoing tremendous stress trying to make the right decisions, with his dreams about to be shattered.

There was an awkward silence for a moment. What could we say? That his *tefillos* prevented him from having an even worse year? Perhaps there was truth to that concept, but we didn’t think it would be very comforting for him at that moment. And then the *bachur* himself spoke, answering his own question.

**What happened
to all our tefillos?
Why weren’t they
answered?**

“You know — I was wrong. My *tefilos* last year **did** work. If everything Hashem gives us is for the best, then my life’s events were the best thing that could have happened to me. We know that *tefila* works. This means that my *tefilos* made me “*zocheh*” to have these difficult things in my life. Without those *tefilos*, I may not have had these challenges. I would not have been worthy of having these things—which are really for my ultimate good.”

That *bachur* was 100% right. It’s true that we always get what’s best for us. But what is best for us depends upon who we are. If we daven, we become better people and more deserving of Hashem’s kindness. Our *tefilos* always work. We just don’t always receive what we ask for. But whatever we receive, we know that it’s better than what we would get if we didn’t daven. Perhaps it wasn’t very “pleasant” in the short term. But

it’s definitely what’s best for us, and what we ourselves would chose if we knew all that Hashem knows.

The same applied to the *brachos* we received from *Rabbonim*. They blessed us with good, and told us that we shouldn’t worry. That did not change. We definitely received “good,” and we certainly shouldn’t worry. It’s all from our loving Father.

Life with a special child can be challenging. But it is so much easier if we feel Hashem’s great love, if we realize how much He is doing to make life better for us, every day and every moment of our lives.

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

את פתח לו

By: 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.

OWLs at Breakfast!

“OWL”* is a technique you can use anytime. It will help you follow your child’s lead and motivate him to stay in the interaction with you.

Observe Wait Listen

Try this at breakfast time:

Observe what your child looks interested in, but don’t jump in immediately to give it to him! Perhaps you gave him some options of what he can eat.

Wait for your child to initiate. This can be hard! Try counting to 10 in your head while leaning in expectantly.

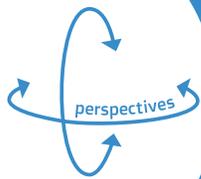
Listen to what your child communicates to you.

“Communicating” can be any attempt to let you know what he wants; it does not have to be verbal. Maybe he will turn his head or point in the direction of the food he wants to eat.

Once your child communicates, respond effusively! Praise, compliment, and grant your child his request. Try giving him just a little. Then, Wait again!

You can also try giving him something you know he doesn’t want and Wait for him to let you know that he doesn’t want that.

**The OWL acronym and idea is adapted from Hanen’s
“It Takes Two to Talk” program,
www.hanen.org.*



From the perspective of:
***A Respite
 Coordinator***

Shoshana Lob

The State of Michigan has arguably the fewest benefits, services, and resources for the Special Needs population, compared to other states nationwide. Partly due to the dearth of government funding available, and partly due to our relatively modest-sized community in Detroit, there is currently no *frum* specialized schooling option available for children with moderate to severe special needs.

A common option for these children is to attend the local public school in their district, or pay for prohibitive insurance premiums that allow attendance to private specialty schools, also secular. As a result, many families struggle with the multiple challenges of isolating their child in a non-Jewish environment, a less-than first-rate education, and erratic public school schedules, among others.

A few years ago, Elisheva Goldberg and I were privileged to be involved in initiating The Spot, a volunteer-based respite program with no fees, to address the dire need. The Spot's model does not focus on education; rather we strive to assist by reliably and professionally transporting and caring for children with special needs during the evening and other off-school hours, while at the same time providing a nurturing, *frum* environment staffed with devoted volunteers.

In the early days of the program, a mother expressed her gratitude for finally being able to benefit from the Spot's assistance. Hashem helped me properly verbalize my inner feelings, and I responded: "This is never something you need to thank anyone for. Your child with special needs belongs not just to you, but to the entire community. We as a *tzibur* must provide assistance and friendship to these children and their families. It is our obligation. These are our children."

This is a sentiment I truly believe. On many occasions, people assume that Elisheva and I must have our own children with special needs – why else would we devote so much time and energy to the cause? And I answer by explaining that it is a *zechus* to assist families in our town who struggle with the incredibly life-altering challenge of raising a child with special needs. No one needs to thank me – I am the one who is grateful and humbled.

There are many vital lessons that positively impact the lives of our volunteers in a unique way. A young adult who spends a committed two hours a week volunteering with a special child will have gained an experience that is priceless. The act of giving selflessly to others is very enhancing for anyone, especially for our teens who are beginning to expand outside their own selves and create their individual identity. I can testify time and again that our volunteers are...special. They are mature and thoughtful girls who know what to be grateful for.

My message to parents of children with special needs is: Please! Don't hesitate allowing others to assist you. And don't feel indebted or guilty that others are volunteering to help. You are gifting *them* with the amazing opportunity to interact with your child, to feel and experience the blessings of good health, and to fulfill their obligation to care for the children Hashem gave to all of us.

Shoshana Lob is the co-director of The Spot, a respite program in Detroit, MI.



Fraydel Dickstein

I would like to share with you some of what I call "Wow!" moments. These are moments when we realize just how special it is to have a special needs child, when we see the great impact they have on our families and others around us. These precious moments bring home to us that our children are perfect just the way they are and that their purpose is to bring us to perfection. I'd like to share a few of my own, as well some of my friends':

On the first night after our special son Yehuda left for camp, his brother Yisroel, with whom he shares a room, came into my bedroom and told me he is afraid to sleep without Yehuda! He told me that when Yehuda sleeps with him, he knows that Hashem watches him. I was so overcome with emotion to hear that my son, as well as my other children, truly believes this, —and so do I. I told them that since Yehuda is ours, Hashem will watch us in a special way, even when he is away at camp.

I was in the room with Yehuda and our daughter Liba, and was telling Yehuda that his teacher was going to have a baby. I gave a *bracha* that she should have a healthy, beautiful baby, and Liba piped in: "Or one like Yehuda, they are special too." I was so blown away that she really sees it this way. It was a deep Wow! moment for me.

Chayala, our 5 year-old, had a classmate over for a visit, and was taking her on a house tour. I overheard her in Chaim's bedroom telling her little friend: "This is where my brother with special needs sleeps, and he is really, really cute."

One evening I was talking to Bracha about the state of our couches and we agreed that only genuine leather would be able to withstand the constant staining we have. I mentioned that they are very expensive. Bracha said, "But Mommy, it's because of Leah so Hashem will send the money for it!"

Please share your Wow! Moments with us at neshamalemagazine@gmail.com or text to 848-299-2908. Let us share the nachas and the pride!

I received a magnet years ago that reads: "I try to take it one day at a time, but sometimes several days hit me at once."

I remember this when I need to laugh my way through something. Most of the time I try to remind myself that this is a *nisayon* from HKB"H, and that no matter how hard or difficult things get, if I couldn't handle it, it would not be happening.

---Adina

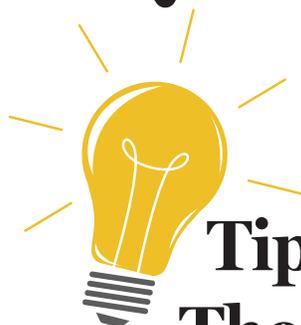
My son makes a lot of trouble. When I walk into a wrecked room, I try to sing instead of scream. We have a few versions of endearing songs that include my son's name and singing keeps me grounded while I clean up!

---Gitty

One very important thing I learned when you're going through any life challenge, is to make sure you look good and take care of yourself. My mother is a wise woman who encouraged me to start a diet. I did well B"H, and when you feel good about yourself, it automatically builds your self-esteem.

One line stands out from the many *chizuk drashos* (inspiring talks): "If Hashem chose me to take care of His special *neshamos*, He thinks very highly of me! And if Hashem chose me to have two (!) special needs kids, He really loves me!"

---Nechama Brisk



Tips From The Experts

hey! that's us!

"This child is my E-Z Pass into *Olam Haba!*"

--- C. T.

What is your "mantra" or one-liner that helps you keep perspective and ride the waves when things get stormy?

"Hashem is always with me and I'm never alone! He created Eli and will give me the strength I need to deal with him!"

---Anonymous

"One day at a time!"

"Keep on moving, keep on moving, please don't stop, please don't stop..."

---Fraydel Dickstein

I once read a secular book by a mother of a child with special needs. She wrote: "Who knows if in a different lifetime my son took care of me and now I'm paying him back?"

I was so surprised, as of course we know about the concept of *gilgulim* (reincarnation), but I didn't know that they believed it too. I think about this sometimes when things are hard.

We don't know the whole picture. Really, who knows who my severely disabled son was in a previous *gilgul!*

---N. S. N.

Two sayings that keep me going on our rollercoaster medical journey are: "Tracht gut vet zein gut" (Think good and it will be good), and "Gam zeh ya'avor" (This too, shall pass). If today is dark, there's always a chance for tomorrow to be brighter—and believe me, things are often a lot brighter!

---Esther Malky

When I feel weak and out of control, I think to myself: "I have a delicious boy. He is perfect in every way. Just as my niece was born with severe allergies, my child was born with a condition called Down syndrome. It's just a condition, it's not the person... He is not Down syndrome; he HAS Down syndrome!" This mindset takes me very far in stormy times.

---Chaya Perlman

My one liner is: "One day at a time, one hour at a time, one minute at a time... it's the only way!"---T.S.

Question for the next issue:

What are your tips and tricks on the topic of medication? Keeping track of dosages, getting it down without getting worn down... Let us know how the experts do it!

Please send us your answers to: neshamalemagazine@gmail.com or text your answers to: 848-299-2908

Smart & Safe

Doors and Locks

Fraydel Dickstein

Thank you for all the feedback I received about my last column on kitchen safety! One mother called to tell me that she is moving and wants to use some of the ideas for her new home. I feel that each successful lock we find can be life-changing in the peace of mind it gives us.

In this issue, I will focus on securing doors, which I believe is a very important safety topic.

INTERIOR DOORS: Locking the interior doors can be challenging. Our Yehuda loves my daughter's bed—whether he is clean or dirty. He likes Lego pieces and all kinds of exciting things. His siblings can get really upset when their linens are messed up or their puzzles are ruined, so we often lock the door knobs to their rooms and use keys to open them. The problem is keeping track of the keys! Also, they are hard to open and often require an adult. I plan to invest and put combination locks on the doors. My interior doors are solid, so hopefully this will work.

EXTERIOR DOORS: I remember the day when Yehuda mastered the slot lock at the top of the door. He figured out how to stack chairs to get to it. I was so scared, that I planned to sleep against my front door that night. My husband ended up pushing the couch against the door and setting up some kind of trap to prevent his escape, allowing me to sleep in my own bed. Since that night, we learned so much about locks and have become more saavy, affording us many freedoms we never thought possible (I must say that I also feel more protected against burglars with all our extra locks!). We can sleep away from home, too, as long as we bring the appropriate locks along. Below are some ideas that may work for you:

Eudemon Baby Safety Door Knob Covers Door Knob Locks (\$9.99 on Amazon for a 4 Pack)

These are the most basic locks available and are simply fantastic. They are actually not a real “lock.” Instead, they go over the doorknob, making it difficult to open. In the beginning, you will have to get used to squeezing it, but you will become a pro in no time. The biggest problem I have found is that the children learn how to break them apart. I have seen them nailed together and was told that it's super effective to do that.



Door Security Slide Latch Lock

(\$3.99 on Amazon for a 2 pack)

These are the classic metal slide and latch locks.



Uxcell 2 inch Cabin Hook Eye Latch Gate Door Swivel Window Door Hook (\$9.99 on Amazon for 20 pieces)

These are the classic metal hook and eyes.



Prime-Line U 9888 Flip Action Door Lock - Reversible White Privacy Lock with Anti-Lock Out Screw for Child Safe Mode, 2-3/4" (\$2.72 each on Amazon)

This one is not as common. The hinged portion of the reversible lock flips over the door to lock.



The next step is an easy-to-use lock. Here are three very basic locks, sold in local stores, such as Walmart, and online. All of these locks should be installed high on the door. Installation is pretty quick and easy.

When all of the basic locks became superfluous, I panicked and had a two-sided combination installed by a locksmith.

Double Sided Combination Lock

(The price fluctuates based on your local locksmith's installation price. Mine cost about \$200 for the combination and the installation.)

These combinations are very costly but it felt much safer to me. They are also very convenient, as you can open it from the outside, and I stopped having to stay up until my husband to come home so I could open the door for him. With the other locks that locked from the inside, I would be afraid to shower, nurse the baby, or do anything time consuming, as I had to be available to run and open the door.



I have to take a moment to say that for us, and for so many other parents, we look back at the day that we finally installed this much-needed lock as a special day. It really works and is so worthwhile. Our only regret is that we hadn't done it sooner! Being able to come in from the outside independently, not needing to climb to find a key or what not, is such a relief! *Note: We are very careful never to punch in the code in front of Yehuda!*

A great resource for more door locks is the Alzheimer's store. The link is: <https://www.alzstore.com>. They have many locks that can be used in all sorts of ways. Here is one of them:

Door Guardian (\$27.95 each from the Alzheimers store)

This ingenious, strong door lock requires no key and does not look like a lock. It works on doors that swing inward only. I have friends who use this successfully. They are far less costly than combinations and can be effective. My friend who uses this, locks the room from the outside at night, so she is not worried about a midnight get-away. I personally feel that our double combination lock has given me more security.



Another great idea, which I saw in Camp SCHI, is to put a second door knob all the way at the top of the door. It's really hard to reach up and to turn both of them together. Although a great idea, I definitely prefer our combination lock for exterior doors.

Most of the above locks install permanently in your home. But what about when you want to sleep away from home with your child? There is a way!

Major A100 KEE-BLOK for Knobs (\$34.30 each on Amazon)

The Keeblok metal die cast door knob is a doorknob cover that is metal and can only be removed with a key. It's a little scary that



the only way to open the door is with the key. However, it can be a real life-saver as it is transportable and dependable.

I truly say "Hodu L'Hashem!" for this lock! I take it with me whenever we go away with our son, and we can sleep; it's amazing!

No more need to push beds against doors and other such creative ideas. When I moved to a new house, I was able to use these until the permanent locks were installed. In many situations, having this available takes away the panic of: "What if a lock breaks...?"

I bought many other brands of this type of lock and they all broke, so I recommend only KEE-BLOK company. Bear in mind that it will not fit onto every lock, but I hope it works where you need it. They also sell them for lever locks.

Many people, in addition to using locks, also put in alarms, so if someone were to open the door at night, they would hear it.

Expandable Plug-In Door Alarm (\$49.95 each from the Alzheimers store)

The remote alarm comes with a high-performance transmitter and receiver set that can be customized to monitor a room or selected area, depending on your individual requirements. You can use one set to guard one door or buy extra transmitters for more doors. Additional receiver/alarms can also be purchased separately, and placed in different areas of the house to add extra assurance that no alert will go unheard. All of them will sound if any monitored door is opened. You can use these on cabinet and refrigerator doors, too.



Recently, one of Yehuda's therapists stopped at my front door and commented on the double-sided combination lock. She was blown away with how brilliant it is. She told me that she worked with a 15 year-old girl who would wake up at night. Her family feared that she would run out and the whole family's sleep was interrupted because of it. When I heard this story, I told her about this column and I was inspired to continue writing it. There are so many solutions for our challenges. Some are out-of-the-box and can be costly, but there is almost always a way. If you are experiencing difficulties of this sort, I urge you to contact me via Neshamale magazine. I know all too well what sleepless nights mean, when the whole family is negatively affected, and I would love to try to help in any way possible.

May we all be zoche to raise our children smartly and safely!

Illuminations

Rabbi Yaakov Moshe and Rebbetzin Chaya Sara Kramer were a holy couple who lived in Eretz Yisroel. Reb Yaakov Moshe was considered by many of Eretz Yisroel's gedolim to be one of the lamed-vav tzadikim in whose merit the world is sustained. Although they never merited to have their own children, they dedicated their lives to raising many children who were physically and mentally handicapped. Below is a peek into this part of their lives, excerpted from the book Holy Woman, by Sara Yoheved Rigler.

One morning in 1950, 26 year old Chaya Sara, following her usual routine, rose early in the morning and milked the cows. She had no idea that this day would prove to be the most momentous day of her life.

Late in the morning, a neighbor approached, pulling a red-headed 2 ½ year-old boy behind her. She asked Chaya Sara to do her a favor. She was taking care of this mentally handicapped child, the son of her cousin, who had divorced his wife shortly after their brain-damaged baby was born. Now she had to run an errand in town, and couldn't take the child with her because he was too unruly. He was so unruly, she told Chaya Sara, that she often had to tie him to the bed. Would Chaya Sara watch the boy for the afternoon?

Chaya Sara gladly agreed to care for the child, whose name was Avramele. When the neighbor returned several hours later, she found Avramele clinging to Chaya Sara's skirt, crying, and refusing to leave her. The neighbor, tantalized by the prospect of ridding herself of this unwanted burden, gazed at Chaya Sara and remarked: "Living with you would be *Gan Eden* for him."

Chaya Sara looked at the frightened, clinging child, then looked back again at the neighbor who had been tying him to the bed. She made her decision. She agreed to take the child. She would care for him, day in and day out, for the next 55 years, until her death. It was the most significant decision of her life.

While physically normal, Avramele was severely mentally impaired. Tested as a teenager, he was found to have the intelligence of a 3 or 4-year old. Despite attending the first grade of R' Yaakov Moshe's *cheder* year after year after year, he never learned the *alef-beis*. One neighbor recalls watching R' Yaakov Moshe trying to explain

something to Avramele. Rav Yaakov Moshe patiently repeated the point perhaps a hundred times. Still, Avramele didn't get it. And, as the neighbor had testified, the child was unruly. He would roll in the mud and tear his clothes. Once, when Avramele was in his teens, Chaya Sara ordered the services of a *shochet* to slaughter some chickens. Avramele stood by and watched. Later that day, trying to imitate the *shochet*, Avramele killed 18 chickens. Yaakov Moshe cautioned the abashed Chaya Sara not to reprimand Avramele because he was incapable of understanding. A full week later she had recovered from the loss enough to say to him nicely, "We don't do things like that."

Yet, as the neighbor had also predicted, living with the Kramers was *Gan Eden* for Avramele. Neither of his adopted parents ever raised a hand or voice to him, no matter how uncooperative his behavior. Yossi Shtiglitz remembers once coming upon R' Yaakov Moshe in a field as he tried – unsuccessfully – to convince Avramele to come home. Avramele was 10 years old and decidedly overweight. Finally, R' Yaakov Moshe fetched their donkey with the wagon and gently lifted the heavy child and set him into the wagon.

Miriam, the only child they ever raised who was neither physically nor mentally challenged, used to complain that Chaya Sara would discipline her but not Avramele. Chaya Sara would reply: "There's no one there to discipline."

Yet Avramele was not totally untrainable. When he was fully grown, he would still play with the little children of the moshav. This was a potentially explosive situation, because the little children often teased Avramele, and if he had hit them, he could have seriously harmed them. The Kramers, however, taught Avramele never to hit. And he never did.

In fact, he once saved a person's life. In the 1980's, a bus stopped at Kfar Gidon and Avramele and several other passengers descended. Only Avramele noticed one of the passengers, a deranged man, lie down in front of the bus's wheels. Even his limited intelligence understood what had to be done. He yelled at the driver: "Don't go! Don't go! There's somebody under the wheels!" and thus saved the man's life.

Like so much in the Kramer's life, Avramele was not what he appeared. Once R' Yaakov Moshe gave the Belzer Rebbe a *kvittel* with Avramele's name on it. The Rebbe, who did not know the boy at all, told R' Yaakov Moshe: "Be very careful with this child. He's a holy child. Don't ever hurt him."

Indeed, as Avramele grew up, both Kramers showed him an inordinate amount of respect. Sometimes, when people would

come to R' Yaakov Moshe for a blessing, he would send them to Avramele.

During the 1980's, Zalman, a man in a religious community abroad, went missing. Every day one of his worried friends phoned R' Yaakov Moshe to ask for a blessing for Zalman's safe return. One day, when Zalman had been missing for about seven weeks, R' Yaakov Moshe told his friend that he could stop worrying. Avramele had had a dream and announced: "Zalman is coming home tomorrow." The next day, Zalman returned.

When Rebbetzin Chaya Sara was in her 70's, I interviewed her for this book. Since I had learned that every soul comes to this world to effect a particular *tikkun*, I was trying to ferret out what Rebbetzin Chaya Sara's *tikkun* was. Despite my searching questions, I kept hitting a brick wall. Finally, frustrated, I asked her: "So why did you come to earth in this lifetime?"

She gave me a clear-as-the-nose-on-your-face look, and answered matter-of-factly, "Why, to take care of Avramele." "To take care of Avramele?" I asked, thunderstruck. This great soul, this spiritual master, had come into this world just to take care of a brain-damaged boy?

"Yes," she answered simply. "He's a *tzaddik*."

I had heard chassidic stories about *tzaddikim* coming back to this world as persons who are exempt from *mitzvos*, so they could fix one small mistake they had made in their previous *gilgul* without accruing any new sins. Hearing Rebbetzin Chaya Sara assert that Avramele is a *tzaddik*, I stammered: "Y-you mean he was a *tzaddik* in his last *gilgul*?"

"Yes," she answered. "And in this *gilgul*, too."

I wasn't going to let her get away with this. The 52-year-old Avramele, who usually greeted me with a smile, rocking from side to side and repeating: "Rigler, Rigler," had that day locked himself into the kitchen because he was afraid of the unknown woman I had brought with me. I pressed on: "In what way is Avramele a *tzaddik* in this *gilgul*?"

"He's does only good and never does bad," she answered with a shrug. She couldn't understand why I was having such a hard time grasping this.

"What good does he do?" I insisted. I had never seen him do anything at all.

"He says 'shalom' to people. That's an act of *chesed*."

"What else?" I challenged.

"Avramele does not like to touch or be touched," she explained. "But once when I fell, he put out his hand and helped me up."

I left her apartment in a state of total cognitive dissonance. How could it be that Rebbetzin Chaya Sara Kramer came into this world only to take care of this mentally impaired person, who is a *tzaddik* because he once reached out his hand and helped her up? I kept turning the idea over and over in my mind, but could not solve the enigma of Avramele and his part in Rebbetzin Chaya Sara's life.

What is certain is that she loved him very much. In 1984, Chaya Sara underwent an emergency hernia operation in Jerusalem's Hadassah Hospital. After her release, Yaakov Moshe took her for recuperation to the nearby apartment of their niece Pnina Kubitchek. Pnina remembers Chaya Sara lying in bed crying: "Avramele! Avramele! He's a *yasom chai* (an orphan whose father is still living)!" Despite her infirmity, she wanted to immediately return to Kfar Gidon in order to take care of the 36-year old Avramele, who had been left in the custody of Yaakov Moshe's brother Peretz.

Indeed, even at the end of her life, when she was ill and needed total care, she continued to place Avramele's needs above her own. I asked her why she didn't go to live in Bnei Brak with her adopted daughter Miriam, instead of being taken care of by strangers. After all, Miriam was clamoring to take care of her. Rebbetzin Chaya Sara replied simply: "Avramele doesn't want to go to Miriam's." And that was that.

Close to the end of her life, when Avramele had taken to locking himself in the kitchen most of the time, rendering it impossible for any of the Rebbetzin's caregivers to cook for her, she finally revealed an insight into the part he played in her life. She said to me: "Avramele helps me."

"How does he help you?" I challenged.

"He helps me because I love him," she replied. "A person cannot live without loving."

May this inspiring story be a z'chus for Chaya Sara bas Mendel Yosef whose 15th yartzzeit will be on 2 Sivan.

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Lets Get Educated

LGIT: Low Glycemic Treatment Diet

Tzivie Schmidt

There is a plethora of programs being used to help children with special needs, yet it can be challenging to get accurate information. In “Let’s Get Educated,” we present a very basic overview to help you figure out: “Is this for my child?”

Who are the target recipients? Those prone to seizures, regardless of age or seizure type. One-third of patients with epilepsy do not respond to antiepileptic drugs and may seek complementary and alternative treatment modalities, such as the LGIT diet. This diet is also used by diabetics and those looking to lose weight.

When did it begin? This diet was developed in 2005 to help control seizures in lieu of, or in addition to, the conventional approach of medication. It was developed in the MGH (Massachusetts General Hospital for Children).

What is it? The LGIT diet is similar to, but less restrictive than the Ketogenic Diet, a high fat, low carb program. A dietitian customizes a meal plan for each person based on his calorie intake. The glycemic index (GI) ranks foods based on how quickly blood glucose rises after ingestion of a particular food item. Most participants can eat between 40-60 grams of “low” carbohydrates daily.

How does it work? Scientists have found that abnormal glucose levels (too high or too low) can cause seizures. As carbohydrates are digested, glucose is released into the bloodstream. Minimizing sugar intake forces the body to produce ketones from fat instead of carbohydrates. The digestion of carbohydrates is slowed by other foods eaten at the same time that have either fat or fiber. Therefore, meals are planned to consist of fat, protein and a low glycemic index carbohydrate of 50 or less. The downside is the lack of vitamins and minerals in the LGIT diet. Supplements are recommended to compensate.

What are the results? Regulating the level of sugar in the body leads to better seizure control. One study found that after 3 months on the LGIT diet, 32% of the participants had a 50% reduction of seizures. In another study, 22% of the participants were completely seizure-free, and 73% had a reduction of seizures. The largest study of 76 epileptic

children on LGIT showed a greater than 50% reduction in seizures in approximately half of the children. The LGIT diet is becoming a more popular treatment for epilepsy due to its effectiveness and lack of significant side effects.

While it may seem overwhelming and constricting to follow the LGIT diet, the amount of (non-kosher) home delivery prepared meal options and recipes indicate that the LGIT diet is being used to help many avoid medication, and may be worth consideration.

LGIT in Action: *Shaya is a 14 year old with special needs. Among other issues, he also has seizures. Until recently, Shaya’s seizures had been under control through the use of medication (Clobazame). Recently, his seizures have become more frequent, as well as stronger. Understanding the parents’ reluctance to change medications, the neurologist suggested trying the LGIT diet while staying on the current medication. Shaya and his parents met with a dietician who was knowledgeable regarding diet therapy for epilepsy. They created a diet plan for Shaya that consisted of 1500 calories daily, with 60% fat, 30% protein, and 10% carbohydrates.*

The adjustment period was quite difficult. Shaya missed pasta, cookies, and his personal favorite, bakery challah. In school and at home, the adults also adjusted to giving prize incentives instead of the nosh they had used in the past. Over the next few weeks, Shaya got used to his new menu and his seizures did decrease significantly. After six weeks on the diet, the neurologist was happy with the results and determined that Shaya’s seizures were under control once again.

Sample daily menu from Shaya’s plan:

Breakfast

2 eggs, 12 almonds, ½ large banana

Snack

string cheese, 12 cashews

Lunch

3 oz. slice salmon with 1 tsp. olive oil and 2 T. chummus, small apple

Supper

3 oz. chicken cutlet, 16 olives, ½ cup applesauce

Snack before bed

celery or peppers with 2 T. natural peanut butter

This article was reviewed by Sarah Klugman, RD.

Yehuda Turns Two

Ricka Kirschenbaum, July 2019

I'm sitting in the NICU, with wires all around.
 Rocking you back and forth, back and forth.
 Tears flow from my eyes as I squeeze your tiny body.
 (The big question—are you? or are you not?—just answered.)
 “Will I ever love you the way I love your two brothers?”
 “Will my love for you be the same?” I wonder.
 A tear falls onto your tiny hand.

I'm sitting in your room, cozy and warm.
 Rocking you back and forth, back and forth.
 As I wipe your tears, on your birthday night, I wonder...
 “You're Two, Baby!” I whisper, as I rock you back to sleep.
 “Can I ever love you more than I do today?”
 My love is so deep, so strong, so fierce!
 As much as for your brothers.
 My heart is full.
 I give you a tight squeeze, I kiss your hair.
 A happy tear forms at the edge of my eye.
 We've been through so much in these two little years!
 How they dragged, yet flew by!
 We put so much effort into your tiny little self.
 And look what we have.
 My beautiful little Yehuda.
 I smile to myself as I rock....
 I wouldn't trade one day for anything else.
 Memories flash quickly through my mind.
 Rough days, sick days, the day you smiled...
 The day you learned to clap...
 No, I wouldn't trade one day of Yehuda
 For anything else in the world.



When We Wondered

Tzippy Mendlowitz

If only we could have heard him say his *Brochos* out loud and so proud...

When we wondered if we would ever have *Yiddishe nachas*.

If only we could have heard his laughter at his own sense of humor...

When we wondered if we would ever laugh again.

If only we could have heard some of his amazing *chochmos* that shock us at his understanding...

When we wondered how much he would ever understand.

If only we could have felt the joy bubbling out of him and overflowing as he dances at a *chasuna*...

When we wondered if he would only bring us sadness.

If only we could have seen his pride when putting on his *Tefillin* for the first time...

When we wondered if he'd ever do *Mitzvos*.

If only we could have seen him daven his own special *nussach* from a *siddur* with such fervor...

When we wondered if he would ever learn how to read.

If only we could have been knocked down by his bear hugs when he is so excited to see us...

When we wondered if he would always be so weak.

If only we could have seen him be in the same school with all his siblings...

When we wondered if he would ever feel a sense of belonging in the community.

Thank you Hashem, for all Your tremendous *chesed*,

For now we are aware of the things people usually take for granted.

My Son is Not a Case

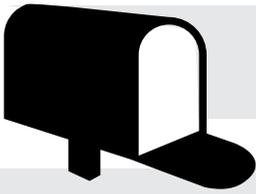
Elky Handler

It's true my child has delays
 because his tone is low.
 Agreed that when my baby plays
 his progress may be slow.
 His neck is tight, his hips are weak,
 but please look at his face,
 And choose with care the words you speak:
 Don't call my son a case.

He may need loads of therapy,
 an hour every day.
 You may not understand what he
 attempts, at times, to say.
 Granted that he doesn't walk,
 but crawls from place to place,
 But think of him please when you talk.
 Don't call my son a case.

My boy's just that: a person with
 a life, and with a name.
 A child who has issues is
 a child all the same.
 The little prince you're seeing
 isn't there to take up space.
 He's a thinking human being.
 So please don't call him a case.

This article was originally printed in The Voice of Lakewood.



INBOX

I read the magazine from cover to cover. Some articles made me cry, others made me laugh. I really enjoyed it, and would be happy to get future publications.

Tizku L'mitzvos!

Adina

Kol Hakavod and what a wonderful idea, so necessary! As a special needs mom, I so often feel the lack of appropriate support... it can get so frustrating reading magazines and hearing speakers discuss parenting and other family issues that are just so unrelatable to us and our lives. It's so helpful to have a place to hear from and connect with other parents of special needs. Also, I absolutely love that you included the sibling section! So often overlooked, and so, so important.

I actually started the first Jewish school for children with special needs in LA 3 years ago. I will definitely share this with our families.
Chaya Chazanow
Los Angeles

The magazine was really amazing! My kids all read it and got such chizuk!

Thank you so much!

Chava R. Bistriz

The magazine was just incredible!! It was so professionally put together, and my whole family really enjoyed it! Tizku lemitzvos! You are providing a tremendous chizuk to us all! I particularly appreciated the letter of approbation you got from the Rosh Yeshivah. It was very meaningful to me.

I'm one of those interesting people that need chizuk like the rest of us, yet shy away from publications and events that cater to the parents of special needs children. Not sure why, but it took me a week to be able to pick up your magazine, about a month

to open up the "touch of care" package I received after birth, and whenever I see events advertised, I cringe. I'm exploring this enigma and doing my own emotional probing. I wonder if there are others like me. I'm new on this journey. Maybe once, b'ezras Hashem, I'm more weathered, I'll be over this... Thank you again for your groundbreaking publication!

All the best,

Name withheld

Wow! I just received the Neshamale magazine via e-mail. I read the whole thing in one sitting. What a beautiful magazine and wonderful initiative. I loved that it was real but positive! Please keep them coming.
T.S.

Thank you so so much for the beautiful magazine! We really enjoyed reading it! The articles were interesting, informative, and, most of all, inspiring.

I LOVED the "Tips from the Experts" column. It's a great feeling that others have the same concerns and questions as we do! It was cute to see the column about safety locks; we too were very busy with that at one point!

Our special needs child is a ten-year-old girl and she's our oldest. The magazine gave us a really nice feeling that we're not alone in our challenges, and that there are others in our boat, so to speak.

My 8-year old son enjoyed the siblings column. I think he enjoyed the feeling of not being alone in the situation.

The magazine is much appreciated, and we're looking forward to reading more!

C. S. R.

Hi, I was in touch with Yaldeinu about my 3 year old and they sent me your magazine

Neshamale. I would love to subscribe. It had me crying. I feel such a lack of understanding about my child's needs from others and by reading this I felt so validated. I would love to start a support group for other parents with kids with sensory processing disorder and ADHD. Tizku Lemitzvos for such an amazing publication!

As the bubbly of a special needs child, I really enjoyed your magazine.

"On the Lighter Side" had me rolling. My grandson cracked eggs on the dining room wall, where they dripped onto the carpet, but four dozen eggs on the duvet cover really topped it. I don't know if someone without such delicious children would have found the situation funny, but it really touched me. The cream on the cake was Yehuda in the washing machine. We really have to admire the creative thinking of some of our children. The caption "Normal is just a setting on the washing machine" was the cherry on top.

I really look forward to seeing more of your magazine.

Sora Berman

Baltimore, MD

Dear Editor,

We'd like to spread the word about a new support group in Lakewood for mothers of children with seizure disorders. We meet a few times a year to give and gain chizuk, and just to schmooze and relax with fellow mothers in the same trenches. For info about the next meeting, or for details, support, or to give suggestions, please call or text: (347) 729-5448 or: (732) 733-3855 or email: coffeandfriends123@gmail.com We'd love to hear from you!
Tzipi and Tzippy

GLOSSARY OF HEBREW TERMS APPEARING IN NESHAMALE MAGAZINE

Al haMichya—Blessing pronounced after eating certain foods
 Alef-Bais—Hebrew alphabet
 B'Ezras Hashem—idiom: With God's help
 B'Meheira v'Yameinu—idiom: May it be soon, in our days
 Bachur—Unmarried Yeshiva student
 Bais haMedrash—Torah study hall
 Bais haMikdash—the Holy Temple
 Baruch haBah—idiom: Welcome!
 Birchas haMazon—Blessing after a meal
 Bnei Yisroel - Children of Israel, Jews
 Boruch Hashem—idiom: Thank God
 Bracha—Blessing
 Brachos—Blessings
 Chasdei Hashem—idiom: God's kindness
 Chashuv - important
 Chasuna—Wedding
 Chavrusa—Torah study partner (Aramaic)
 Cheder—Jewish elementary school (Y)
 Chesed—Acts of kindness
 Chizuk—Strength, encouragement
 Chochmos--Wisdom
 Chol haMoed—Intermediate days of Jewish holidays of Pesach and Succos
 Chumash—the Five Books of Moses
 Daven—Pray
 Emunah—Faith
 Eretz haKadosh—Israel (lit: the Holy Land)
 Eretz Yisrael—the Land of Israel
 Erev Rosh haShana—the Evening preceeding the Jewish New Year
 Frum—Jewishly observant (Y)
 Gan Eden—the Garden of Eden
 Gedolei Yisrael—Great Jewish sages
 Gedolim—the Great ones (sages)
 Geulah - Redemption
 Geulah Shelaima—the Final Redemption
 Gilgul--Reincarnation
 Giveret—Mrs.
 Hagaddah - Book used to conduct the Seder/Passover service
 Hashgacha Pratis—Divine Providence
 Hashkafic—Torah outlook
 Hishtadlus—Effort
 Hodu L'Hashem—idiom: Praise God!
 Hu Mativ—He (God) does good
 Kinderlach—Children (Y)
 Kol haKavod—idiom: More power to you! (lit: all the honor)
 Kol Yachol - Omnipotent; able to do anything
 Kosel—the Western/Wailing Wall in Jerusalem
 Kvittel—Note of request (Y)
 L'shana haBa'ah b'Yerushalayim—idiom: Next year in Jerusalem! (expression of hope for Redemption)
 Lamed-Vav Tzadikim—Mystical tradition of 36 righteous hidden in every generation
 Loshon haRah—Gossip
 Ma'aras haMachpela—Cave in which most of the Patriarchs and Matriarchs are buried
 Makkos - plagues (ie: in Biblical Egypt)
 Masmidim—diligent scholars
 Mazel Tov—idiom: Congratulations!
 Menahel—Principal
 Mincha—Afternoon prayer service

Mitzrayim - Egypt
 Mitzvah—Commandment; colloquial: good deed
 Mitzvos—Commandments (pl)
 Moshiach—the Messiah
 Nachas—Pride & joy
 Neshama—Soul
 Note: All words are in Ashkenasic (Eastern European) pronunciation. (Y) indicates term is Yiddish.
 Nussach—Version
 Pekalech—Goodie bags (Y)
 Posuk - verse (ie: of Torah)
 Rabbonim—Rabbis
 Rebbe—Elementary grade Torah teacher; Jewish spiritual guide
 Rebbetzin—Rabbi's wife (Y)
 Ribono Shel Olam—God (lit: Master of the Universe)
 Rosh Yeshivah—Dean of Yeshiva
 S'char—Reward
 Shabbaton—Sabbath weekend retreat
 Shabbosim—Sabbaths (pl) (Y)
 Shalom—Peace
 Shamayim—Heaven
 Shehakol N'heiyeh BiDvaro—Blessing pronounced before eating/drinking certain food
 Shivah—Seven day mourning period when family and friends visit to offer consolation
 Shlita—Blessing for long life (abbreviation), often appended to names of religious leaders
 Shochet—Ritual slaughterer
 Siddur—Jewish prayerbook
 Siman Tov u'Mazel Tov—idiom: Congratulations!
 Simcha—Joyous occasion, happiness
 Simchas Torah—Jewish holiday of Rejoicing with the Torah
 Tallis—Jewish prayer shawl
 Talmidim—Students
 Tefillin—Ritual objects used by Jewish males during morning prayer
 Tefilos—Prayers
 Tehillim—Psalms
 Tikkun—Repair, rectification
 Tizku l'Mitzvos—idiom: May you merit to perform more Commandments
 Torah—God-given code of Jewish life and law
 Tza'ar—Pain, difficulties
 Tzaddik—Pious, righteous person
 Tzibur—Jewish community
 Tzitzis—Ritual fringes on specific four-cornered garment worn by Jewish males
 Upsherin—First haircut for 3 year old Jewish boys (Y)
 V'hei She'amdah—Passage in the Passover service proclaiming God's support of the Jewish People throughout our difficult history
 Yarmulke—Skullcap worn by Jewish males (Y)
 Yartzheit—Anniversary of someone's death (Y)
 Yerushalayim—Jerusalem
 Yeshivah—School of Jewish study
 Yeshua - Salvation
 Yetzias Mitzrayim - Exodus from Egypt
 Yidden - Jews (Y)
 Zaidy—Grandfather (Y)
 Zechus—Merit (noun)
 Zocheh—Merit (verb)

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“ Don't go through life,
Grow through life ”

