

נשמהלה

Sharing Our Special Experiences: Chizuk & Inspiration

Neshamale

magazine



**EXPLORING:
FEEDING**
OUR SPECIAL CHILDREN /21

NEW COLUMN!
QUALITY ABA
WHAT DOES IT REALLY MEAN? /16

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Editor: Chayala Tawil
Contributing Editor: Fraydel Dickstein
Layout/Design: Adina Cahn
Copy Editor: Susan Tawil
Printed By: Ramapost

With much appreciation to our contributors:
Perry Binet Shira Speiser, LCSW
Yehudis Blavin, PA Faigy Stein
C. Mittleman Leah Tawil, SLP
S.M. Pitterman Gitty Waxler
Rabbi Boruch Rabinowitz Malka Weldler
David Rose Yehudis Wolpin

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CONTACT INFORMATION

E-mail: neshamalemagazine@gmail.com
Mail: 112 6th St. Lakewood, NJ 08701
Text: 848-299-2908 Phone: 248-752-6464

To subscribe for free e-version:

neshamalemagazine@gmail.com

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Dear Readers,

The question in our previous issue's "Tips from the Experts" column asked what to do with our special children during family *simchas*. I recently had a great experience bringing our son Avrumi to a *simcha* that I want to share with you. One of our very dedicated volunteers, who took Avrumi out every *Shabbos*, was getting married. I planned to attend the *chasuna*, to be part of the *simcha* and to wish *mazel tov* to this lovely girl and her family. The idea of bringing Avrumi crossed my mind, but I was unsure about it. Most of the girls who volunteer with him are high school girls, and this was the first time one of his "friends" was getting married. I wasn't sure if it was appropriate to bring him or not. As the day wore on, I just couldn't make up my mind. At the last minute, I thought to myself: "Avrumi has so few chances to do *mitzvos*. Here he has a chance to be *m'samaech* the *kallah*; how could I *not* bring him?"

I knew it wouldn't be the easiest thing, but at that moment I felt it was the right thing to do. I changed him into his *Shabbos* clothing (twice, because the first outfit got dirty before we even made it down the stairs!). When we got downstairs, it was raining, and his wheelchair had been left outside. I almost backed out at that point, but my husband came to the rescue with a blowdryer, and dried the chair in a few minutes. We finally loaded ourselves and our paraphernalia into the car and drove to the hall. I planned to arrive during the *kabalas panim*, wish "*Mazel Tov!*" to all, and leave before the *chuppah*. I thought we were running on time, but apparently not: after parking far away, and running through the rain, we finally walked through the doors only to hear the music signaling the start of the *badeken*. I was very disappointed—how would we get to wish *mazel tov* to the *kallah* now? Once the *badeken* began, I didn't think we could see the *kallah* until after the *chuppah*, and I wasn't sure how long Avrumi would last there altogether.

But, as soon as Avrumi heard the music and saw the crowds of people, he got so excited! He jumped up and down in this seat with a huge smile on his face! Another girl noticed us come in and realized that we had missed the *kallah*. She came over and said: "Don't worry, I'm going to make sure that the *kallah* sees Avrumi!" Sure enough, as the *kallah* was being escorted out of the room with her face now veiled, the girl ran to her and led her over to us. When the *kallah* heard that Avrumi had come to see her, she took off her veil and gave him a hug. He was beyond ecstatic and was laughing hysterically (which is how he expresses his joy). I told her that he is wishing her all of the *brachos* in the world, and I wished her a sincere *mazel tov*. She then put her veil back in place and proceeded to the *chuppah*.

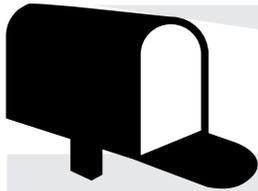
I would never in a million years have had the *chutzpah* to go over to a *kallah* who was on the way to her *chuppah*, but when Avrumi is involved, exceptions are the norm! All the guests understood that this was a unique situation, and I think everyone sensed Avrumi's tremendous joy in sharing in his friend's *simcha*. It was very touching, and afterwards many people came over to say hello to Avrumi. Avrumi seemed like he was enjoying himself and didn't want to leave so quickly, so I stayed with him right outside the *chuppah* room, and I davened my heart out that this very special girl, who had done so much for our family, would be *zoche* to build a beautiful family and home of her own. After the *chuppah*, we wished *mazel tov* to the rest of the family members, and then went home to put a very happy, tired little boy to sleep.

Bringing Avrumi to this *simcha* turned out to be a very positive experience (one that I would definitely do again—so may all of Avrumi's volunteers be *zoche* to find their intended and get married *b'sha'ah tova!*). I realized that everything had worked out well due to one important factor: I had one goal when taking Avrumi along to this *chasunah*: to bring joy to the *kallah*. And despite all of our little mishaps, we accomplished that goal. In the past, when I've tried to bring Avrumi to other *simchos*, things didn't go so smoothly, but maybe that's because I didn't have a single goal. I wanted to enjoy myself, or spend time with relatives, or get something to eat, or I wanted to dance... and I also wanted Avrumi to behave and enjoy himself. That's too many goals for one night out!

I suggest that the next time we decide whether or not to bring our special child to a *simcha*, we ask ourselves: "What is my #1 goal in attending this *simcha*?" How we answer that question should give us clarity as to whether we should bring our child, or get a babysitter or make other arrangements.

May we all be *zoche* to many joyous *simchos* in *Klal Yisroel!*

Chayala



INBOX

It was an article in the *Neshamale* magazine that inspired the idea. It was the determination of Toby, our Care Manager, who empowered us to go for it, and to not give up. It was the devotion of Rivka and Rikki, our Occupational Therapists, who spent their lunch break writing letters to convince our insurance company that this was medically necessary. And now, again, it's *Neshamale* magazine, with whom I want to share; to celebrate the special occasion of getting a Cubby Bed (previously named Boogaloo, featured in the Smart & Safe column of Issue #4) for Moshe!

Finally, we can say "Goodbye" to worrisome nights!

Gone are the nights of worrying:

What if Moshe jumps out of his crib and gets into trouble?

What if he topples his net bed tent to the floor and gets trapped between the bed and the tent?

What if he has a seizure and bumps his head into his bed frame?

What if he simply opens the tent zipper and escapes?

Finally, we can say "Hello" to calm, restful nights! Now we can all enjoy a good night's sleep! Moshe loves his new Cubby bed; it gives him freedom and space, while keeping him contained and safe. He loves the cool light inside, and the unwind/sunset feature which puts him to sleep in less than 5 minutes. And Mommy can rest calmly and not need to jump up to make sure he doesn't hit any hard surfaces while he's having a seizure, because there are simply no hard surfaces! Getting this bed is the best thing that ever happened; it's like having him sleep in his own little castle! Thank you, Hashem for this amazing bed!

Z.K.



Moshe having (dangerous) fun in this old tent bed



Moshe in blissful slumberland

Dear *Neshamale Magazine*,

Thank you so much for such an inspiring, encouraging magazine! I have a thought I wanted to share about the "Wow! Moments" column by Fraydel Dickstein. Regarding the mother whose neighbors came to help babysit on *Yom Kippur*, she wrote: "I knew that on *Yom Kippur*, those davening in *shul* are compared to *malachim*. I think that people like my neighbors definitely qualify as "angels" as well."

This story, together with the other stories in this section, are all phenomenal, and I just want to say that I feel those neighbors are not just "angels *as well*"—in Hashem's eyes they are even greater than angels! People who help families with special needs children (and, of course, parents themselves, who need to stay home from *shul* to take care of their child!) cannot imagine the *schar* they will get!

S.T.A.

Dear Special Needs Families,

I was surprised to hear from a friend recently, that she didn't know that Medicaid covers diapers. They do, and it's a huge savings!

I want to give some unsolicited advice (that I should listen to myself): Do your homework and find out what resources are available out there to help with your special children.

If you're like me, you may be overwhelmed and HATE paperwork, phone calls, and red tape, but once it is done, you will, hopefully, have the benefits for years to come.

I am sure our loving Father adds up all the paperwork and red tape we parents deal with and rewards us for this, and every other part, of our journey!

May Hashem give you all *koach, nachas* and *bracha*!

A reader in Lakewood, NJ

I got my copy of the Chanukah issue of *Neshamale* in the mail and it was so nice to sit down on the couch and enjoy reading it in print. Thank you!

In the past I used to print out the email, but couldn't always get around to doing it, and then the papers would get messed up, etc... Now, I received the glossy color magazine and there's no comparison! I hear from other mothers that they love the magazine but have the same experience—it doesn't always work out to print it and it's hard to read a full magazine on the computer.

I was thinking that if you stop offering the email option then people will be forced to subscribe! Yes, it costs money—but it's worth every penny and your readers will enjoy the magazine so much more. Most magazines require subscriptions and if you want the magazine, you make sure to subscribe. I don't think it's a lot of money to pay for such a wonderful magazine.

Just some thoughts...Thank you for what you do! *Tizku Lmitzvos!*

N.L.

Thank you so much for the feedback. I agree with you that the hard color copy is so much more enjoyable to read, and a lot easier to share with the whole family. At the same time, we would like to keep the magazine accessible to everyone, so we will continue our free digital delivery.

For those who prefer, hard copy subscriptions for future issues, as well as copies of past editions, can be ordered at: www.ramapost.com/neshamale.

VALIDATION Corner



David Rose

♥ THE RIGHT TIME AND PLACE

The story of *Pesach* is chock full of discussions of *emunah* and *bitachon*. It was then we became a nation of believers in Hashem. Of course, there is a proper platform for discussing these questions—everything at the right time.

As busy and crazy as things may get, we all generally make it from day to day, get into some sort of rhythm, and forge forward without thinking too deeply about our lives—most of the time. But then there are the really difficult moments, which many of us experience at various points in our lives. Nothing seems to be working out with—fill in the blank – whatever your personal circumstances may be. We feel overwhelmed, like we can't go on anymore. And then the doubts and questions creep in: Why me? Why did Hashem send me this child? Doesn't He know there is only so much I can bear? Etc.

The purpose of this article is not to delve into the answers to these questions. Rather it is to cushion the painful emotional turmoil which comes along with them. There are some very uncomfortable feelings which these questions may bring to the surface. Firstly, very often a person feels guilty. How can I question Hashem's ways? We may feel as if we are bad for having doubts in our *emunah* and *bitachon*. But the questions themselves can be very confusing, and it is during such times that the problems in our daily lives can become so difficult to bear.

It is imperative to realize that there is a time and a place for everything. Yes, there are for sure answers to these questions. But when you are going through a rough patch, that is exactly when it is **not** the proper time to contemplate these questions. When your emotions are stretched thin and you don't have any energy, the *yetzer hara* knows there is a huge weak spot in your armor, and that is when he tries the hardest to sneak in. At this time, it is most important for you to steer away from these doubts. Put all your energies into focusing on self-care. Push the questions aside, you can deal with them later, when things improve and you are feeling emotionally stronger. Take care of your emotional needs first.

And I knew I had to tell myself in firm, crystal clear terms, that now was not the time to ask this.

Like many others, I recently tested positive for Covid. But there was a big difference now. Most people I spoke to who got it felt a bit sick, maybe they were bedridden for a day, or even a few days, but it was relatively short-lived. Unfortunately, due to medical conditions that I have, when I got it, it was terrible. I felt like I was hit by a truck. I was exhausted, had trouble breathing and minor pneumonia, my doctors wanted to send me straight to the ER, etc. I don't remember ever feeling so awful in my life; it was traumatizing. And in the midst of it all, the questions started creeping in: Why did I get affected so terribly when so many other people I knew had it much easier? And I knew I had to tell myself in firm, crystal clear terms, that now was not the time to ask this.

As to the *misplaced* feelings of guilt, *Chazal* tell us: "*Ain HaKadosh Baruch Hu ba b'tronia im briyosav*," which basically means: "Hashem is not out to get us." Hashem doesn't think that we are angels! He knows that we have hard days when we feel we've reached the end of our rope. He knows, better than we do, that sometimes

we feel so drained that the questions creep in. Hashem does not judge us for being human!

This is one of the many great lessons we learn from *Pesach* and *Yitziyas Mitzrayim*. The well-known *Ramban* at the end of *Parshas Bo* expounds on the indelible message we learn from the spectacular *makos* and miracles that happened in *Mitzrayim*: Hashem cares about every single Jew and He has the power and uses that power to be involved in every aspect of our lives. This was despite the fact that the Jews in *Mitzrayim* had sunk to the lowest spiritual level possible. *Yitziyas Mitzrayim* shows us Hashem's Omnipotence, and the intent of the many related *mitzvos* is to remind us of this important point.

Hashem loves and accepts us no matter what. When things get tough, try to emulate Hashem—give yourself the love and acceptance that you so very much deserve!

Feeding Yitzchok



Our Son with Cerebral Palsy

C. Mittelman

Yitzchok was born almost nine years ago with brain damage leading to Cerebral Palsy, among other challenges. As a baby, he nursed successfully, B”H, and we didn’t realize the importance of food exposure at that stage. At nine months of age, he developed seizures. Unfortunately, both the seizures and the medications he required further reduced his environmental awareness, so he lost out on precious months of the exploratory stage in life.

We also struggled with daily medication intake that definitely added resistance to feeding later on. He was not eating regularly yet, so his meds were poured down his throat twice a day as he fought and cried. In hindsight, this was absolutely terrible; we feel this trauma made him reject all things, especially food, coming close to his mouth.

The true struggle began at around 18 months old. He was weaning off nursing entirely, but refused bottles, and showed no interest or ability to accept purees. We were under pressure to insert a g-tube, as his nutrition was unreliable. The situation turned into daily force-feeding of pureed mixtures. When Yitzchok was offered a pacifier (to make him open his mouth), he would get a spoonful inserted, but most of it would come straight back out. A big shout-out goes to Yitzchok’s *Bubby*, who spent the summer he turned two, steadfastly spoon-feeding him. He would cry, she would croon; time flew by, but the meals were eventually mostly eaten, and B”H, Yitzchok maintained his weight.

The routine settled into pureed meals (with very little interest on his side), interspersed with snacks. We offered him snacks so he would open his mouth, and then also gave him a spoon of puree. These difficult meals involved over half an hour of feeding, accompanied by tears and huge messes, with him swatting the spoon away. Then there were the countless times that he vomited straight after mealtime.

We were fortunate to have him evaluated by a feeding specialist at Columbia Hospital, who encouraged training him to drink out of a cut-out cup. This was something his therapists had been wary of, as they were unsure how well he would manage the liquids. This specialist assured us that, since he was not drooling excessively, he was already using a swallow reflex for his saliva. As cup drinking was a brand-new experience, never associated with negative emotions, Yitzchok was willing to work on drinking nicely out of the cut-out cup. At first it was a tiny amount, but gradually the ml’s increased and his risk of dehydration fell.

Similarly, Yitzchok learned to chew and swallow crunchy snack foods, as these were never force fed to him, and he took them at his own pace. He started with barbecue potato sticks; the tiny size and the spices made it a fairly easy food to manage. We would put the pieces of snack onto his back molars, so that after a few chews, he would easily swallow them. It took time for him to learn to move the food around his mouth properly, so if a piece of snack was stuck towards the back of his tongue, he would begin gagging. We learned to watch out for slight coughs and signs of choking.

Another highly stressful aspect was that Yitzchok refused to accept meals from strangers. Every single meal, every single day, had to be fed by a parent or his “lucky” grandmother. We would *daven* to Hashem to ease our stress and to help Yitzchok’s eating skills improve, but we could not imagine where and how this would happen. What additional *hishtadlus* were we expected to try?

B”H, the breakthrough began when Yitzchok was almost 8 years old. A volunteer with no professional background, but endless devotion, who had previously built a joyful connection with our son, challenged himself to help Yitzchok eat. Since there was already a trusting relationship between them, that

included many playful interactions and high expectations for success, he was able to approach Yitzchok with food. He started with pudding, and continued, trying new soft table foods, one at a time. The intense emotions we felt as we observed our son eat a scrambled egg, a piece of potato kugel, or a diced-up apple for the first time are unforgettable. We knew this was a miracle unfolding before us.

It's been a year since then, and the changes are many. Yitzchok is still spoon-fed every single meal, and he needs distractions in order to eat. However, the heavy pressure of keeping him adequately nourished, and the dread of dealing with every mealtime is GONE, B"H. He has simply developed a new, accepting attitude toward trying food.

The first practical improvement was that he started eating more at school. Until that point, all he would eat on school days was pudding, snack, and some drink—way too little to keep him energized. Also, this past summer, he was able to try out camp, finally! Until now, his food refusal simply ruled out the possibility. As well, he eats supper most days with our home health aide. In fact, astonishingly, he looks forward to playing and eating with her (Is this the same child?). We have also stopped buying cases of baby food—Yitzchok now eats whatever food is available in the house! We've hoped for this stage for so long! He will eat a bowl of Cheerios and milk for breakfast. Most foods are fine for supper, as long as they are not too crispy or chewy, and at Shabbos meals, he will actually partake of the same food everyone else is eating. We are thrilled to be out of the rut of endless pureed mealtimes, and look forward to further progress, leading to independent self-feeding and better acceptance of all food textures.

We want to share this message of hope to others: Whether your goal is improved feeding or another area, try to remain brave enough to hope for improvement, one tiny step at a time. Remember: as long as there is life, there is hope, and Hashem has surprising ways of sending a *yeshua*.

Yitzchok's Favorite Treat:

Yitzchok is happy with a bag of potato flutes any time of day. It's a super-satisfying feeling for us to give him a snack bag and watch him eat it independently.

Yitzchok's Favorite Meal:

When Yitzchok was only eating purees, his diet varied between baby oatmeal jars mixed with peanut butter or containers of chocolate pudding (which he preferred a lot more, but which we reserved for treats). He enjoyed the cold sweetness, and the texture was just right for him; not too runny, yet easy to swallow. If we ever traveled, or had appointments and knew that he would not be home at mealtimes, we made sure to pack Tenuva chocolate puddings so that we could feed him without problems and not create a public spectacle. These puddings are imported from Israel and are irregularly stocked in the grocery stores. When we would notice a new shipment had arrived, we would buy out the shelf, easily having eight packs of pudding at once in the fridge. Show him a chocolate pudding and earn a smile!

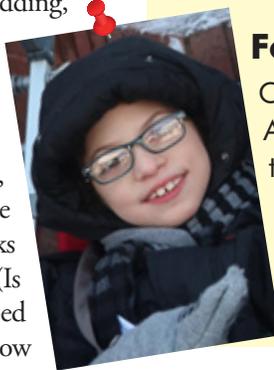


Food Yitzchok Absolutely Refuses:

Challah. Chewy bread is still not on his "Good Food" list. Also, strangely, lollipops! We await the day we will need to monitor his candy intake!

Our #1 Tip:

Strive to create positive associations to mealtimes and food exploration.



Some things we learned along the way:

- Never give up davening to Hashem. In our situation, help was sent directly to our door.
- Try to set up feeding therapy ASAP for any baby that is not exploring the environment independently. We would have benefited from this advice early on.
- We explored many resources and found some to be helpful. There is a website "feedingmatters.com" that is very informative. Responsive Feeding is a methodology that builds trust between child and caregiver, and supports and encourages positive progress with eating. I recommend a lecture given by Stephanie Cohen MA CCC-SLP, CLC and Karen Dilfer, MS, OTR/L on Speechpathology.com
- We also greatly benefited from seeing a pediatric nutritionist (through Early Intervention). Her expert advice on how to increase calories with limited puree intake helped us avoid a g-tube.



Feeding

The Ketogenic Diet

Yossi

Faigy Stein

The first disclaimer I want to make is that Yossi's diet is not the same thing as the fad Keto weight loss diet. You certainly can't try this yourself at home! This is a medical diet that Yossi's doctors put him on in order to try and control his seizures. The science behind it, is that a diet that is crazy high in fat and crazy low in carbs is good for people with seizures. On the keto diet, the body is forced to function differently. Instead of breaking down sugars to use for energy, the body uses the huge amounts of fat eaten, which go straight to the brain. This is supposed to eliminate, or decrease, seizure activity in the brain.

Yossi, our six-years-old, has epilepsy and has been on the Keto diet for two years. We definitely saw improvement when he started it, and B"H we were able to lower some of his seizure medication. Now, it's hard to know how much it's helping, but our doctor wants him to stay on it.

I wouldn't call it an easy diet. It's a completely different way of life. In the beginning, it was very overwhelming, and I felt like it took over my life. But then I got used to it, and it just became something else on my to-do list. The main work is preparing and weighing the food. Every morsel of food must be weighed in order to keep the fat/carb/protein proportions exact, which is how a state of ketosis is achieved. The scale that we use measures a tenth of a gram; it's actually meant to

weigh diamonds! Weighing the food can take hours and is very tedious. We always have to be prepared with measured foods for Yossi to eat.

The other hard part is that Yossi has to eat very specific foods, and can't have the normal food that everyone around him is eating. Most difficult is the fact that carbs are so severely restricted on this diet (think: pretzels, chips, candy, even fruit). This affected our entire family, as we had to start being very careful not to eat food around Yossi or leave food anywhere. We put locks on our food cabinets and refrigerator, as well. B"H, Yossi is generally very cooperative about it and is very proud of his self-control, but he still needs to be watched around food.

In the beginning, we tried not to eat any other foods around him, and worked very hard to have Yossi away from the table during meals, etc. Now, he's acclimated. B"H he's ok with having a different supper than the family, but we don't keep him at the table for long and don't serve his old favorites (like pizza or french fries) in front of him. We also save parties, desserts, and treats for when he's sleeping or out of the house.

So, what does Yossi actually eat? The diet plans are personally designed for each child and are regulated and adapted by the Keto team at CHOP (Children's Hospital of Philadelphia).



On Yossi's custom diet, all of his meals come along with a "chocolate milk" concoction made up of heavy cream, oil, and sugar-free chocolate syrup. I serve a lot of mayonnaise, oil, and/or margarine along with all of his meals. Most of the meal is fat, although he can also have a small amount of protein and a tiny bit of carbohydrate. For example, for supper he can have half a piece of chicken, smothered in mayo, and a pickle. I sometimes make him a dish of broccoli, cheese, cream cheese and mayonnaise. There are some products available that are low carb that we use as treats, in very small portions, like corn pops, cartwheel snacks, and protein chips. We use tiny pieces of "Carbolicous" bread for his *challah* on Shabbos. I also use it to make croutons and grilled cheese.

Yossi is generally not hungry in between meals, because all the fat he eats is extremely high in calories, and he's maintaining his weight. I try to be creative, although as creative as you try to be, there are just not that many options. Eggs, salami, and hot dogs are good options because they all have a high fat content. If you are thinking that these are not the healthiest foods, you are correct. This is not the healthiest diet for the body – it's the brain that we are catering to here.

Because of how 'unbalanced' this diet is, in the conventional sense, it can only be implemented under the constant care of a doctor, with continuous monitoring. We check Yossi's blood sugar and ketones frequently by doing finger sticks, we go for labs all the time, and he takes a lot of vitamin supplements.

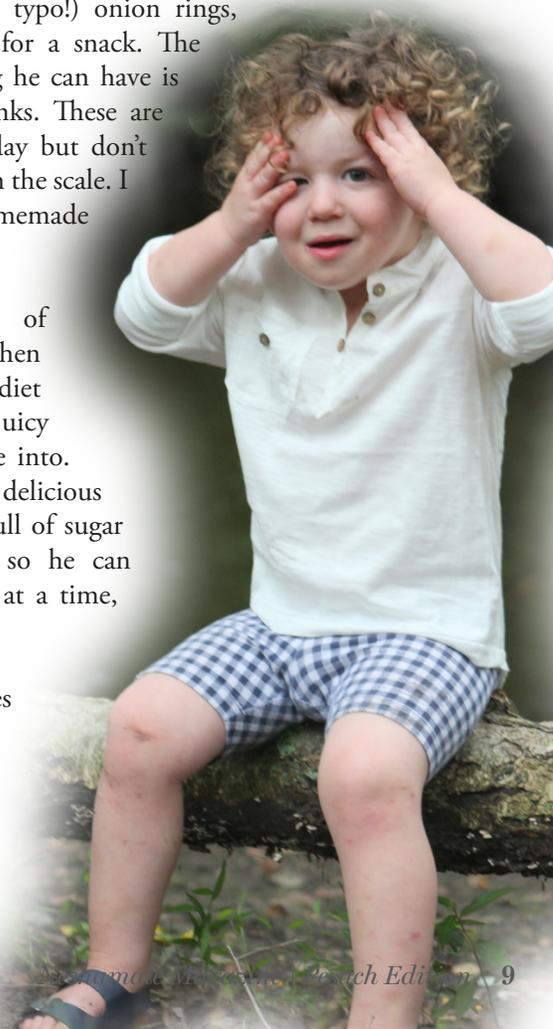
Yossi's favorite meals are chicken and chicken cutlets (mixed with lots of oil and mayo), grilled cheese made from protein bread, and other "normal" foods that everyone else eats. This is nice and (relatively) easy, but we're holding our breath, since his favorites tend to change every few weeks. At one point I was making "all in one" recipes that included all his protein, carbs and fats in one dish. These included keto pizza, broccoli quiche, waffles and even cookies. These recipes take a long time to prepare, but are easier to maintain, since I can make a lot

in advance, freeze them, and then just warm them up. The problem started when he refused to touch these foods. After a while, they had to be dumped. Now I am more careful to make only a few of what he likes at any given point. Aside from the *ba'al tashchis* issue, making his food is a ton of work, and throwing it away is very disheartening.

Yossi's favorite treats are homemade gummy bears (made from sugar-free jello and kosher fish gelatin imported from Israel), Rice Krispie Treats—minus the Rice Krispies (peanut butter, margarine, coconut oil and sugar-free chocolate syrup), and a concoction of oil, cottage cheese and protein chips. He also likes some cheeses and nuts. Yossi can have about 1 or 2 (that's not a typo!) onion rings, flutes or corn pops for a snack. The one "semi-free" thing he can have is caffeine-free diet drinks. These are limited to 12 oz a day but don't have to be weighed on the scale. I use them to make homemade slush, ices, etc.

The treat I dream of giving him one day, when we are done with the diet IY"YH, is a whole juicy apple for him to bite into. Yossi loves healthy delicious fruits, but they are full of sugar (i.e. carbohydrates), so he can only have a tiny bit at a time, which is a shame.

The food he misses most is—challah, hands down! Although Yossi generally doesn't



cheat, challah is one thing we can't trust him to be around. Once every child gets their challah at the *seudah*, the rest goes off the table and is put away (If a child wants more, he can come to the kitchen quietly to get it, and eat it discreetly out of Yossi's sight. By now, our other children are well-trained in being discreet!). Although Yossi has his own "challah" (a tiny piece of protein bread, fried in oil and spices, which he likes with mayo-based 'dips,' it just doesn't compare to the real thing.

In addition to his own special portions that were weighed before Shabbos, I try to serve other foods that Yossi can have: broccoli kugel instead of potato kugel, salmon instead of gefilte fish, no sweet sauces, and only diet soda. Other than that, we actually have a very nice, normal *seudah*. Our Shabbos *seudahs* have lots of singing, and focus less on the food. Yossi and his siblings really enjoy our Shabbos meals!

Unfortunately, the happiest days in our calendar are also the hardest for Yossi (and us). Think *Simchas Torah* (*nosh!*), *Purim* (*mishloach manos*), *Pesach* (grape juice for *arba kosos*), and Chanukah parties. We still don't have easy solutions to these, but we try our best to adapt to each situation, taking them one at a time.

While this diet is a great alternative to seizure medications because it doesn't have the same side effects as the meds, it does set Yossi apart, and causes him to feel different on many occasions. There are times that he misses out on the excitement, and there are events which we skip if we think he won't be able to handle the food. This is definitely something to consider if you are thinking about putting a child on Keto.

Although the diet is difficult and didn't give us exactly what we hoped for, B"H it has also enriched our lives. First, I've learned so much about *hishtadlus*, *emunah* and *bitachon*. I started the diet in desperation, thinking it would be the magic pill that would heal our son. I've since learned that, while we need to do our part, Hashem has many ways to bring about a *yeshuah*.

On the flip side, I'm happy knowing that I am doing all I can to help my son. I've also learned that I can do more than I think I can, and this whole experience has stretched me in many ways.

Yossi, too, has gained from this diet. He is extremely sensory and impulsive. He used to stuff food in his mouth and then swallow without chewing, resulting in frequent vomiting (especially on Shabbos afternoons). Now, he eats slowly and really enjoys his food. In the past, self-control was almost impossible for him. People who knew him thought he would never be able to stick to this diet. Today, I can show Yossi a container full of his favorite snacks and he chooses just one!

There are also times that he will bring me a cookie or treat he found, and proudly tell me: "I didn't eat it!" This boosts his fragile self-confidence as we cheer him on—nothing boosts self-esteem like making good choices. Also, the lack of sugar, flour, and processed food (which are severely limited on the diet) is very beneficial to his behavior, and is supposed to help with regulation and focus.

If someone wants to undertake this type of diet (Remember: it is dangerous to try without your doctor), my best tip is: Get help! I have a niece who comes for a few hours every *Erev Shabbos* to prepare and weigh Yossi's foods. Special high school girls take Yossi out on Shabbos so my other kids can enjoy a Shabbos party and dessert. I am also part of a Keto group in which we share ideas, recipes, and support. I would not be able to manage the Keto diet without the help and support of family and good (old and new) friends!

I originally heard about this diet by "mistake" – I overheard a few mothers discussing how well their kids were doing on the Keto diet. I was intrigued and spoke to my doctor. With his full approval and encouragement, we went ahead with it. Later, I heard from other women who had tried the diet, but did not see success. (Keto will significantly cut down on seizures in about 50% of people. About 15-25% become seizure-free. Unfortunately, it doesn't work for everyone). I feel that it was *Hashgocha Pratis* that Hashem led me to hear that initial conversation. We are grateful that we are able to follow the diet, and grateful for each seizure-free day that we have.

Faigy Stein is writing under a pen name. For questions about seizures and the ketogenic diet, she can be contacted through Neshamale Magazine.





Memorable MISHAPS

Compiled by Fraydel Dickstein

This column lets us laugh about the hilariously funny things our children do (although they may not always seem so hilarious in the moment!). It's also nice to know that this is our "normal", and that we and our families will be OK!

! The Erev Pesach Fragrance:

Meir loves smells. My mother once had a not-yet-religious guest over who smelled like an advertisement for the perfume store. Meir sniffed her and got so excited by her fragrant smell that he bit her! Needless to say, she was quite taken aback!

On *erev Pesach*, everyone was ready, the house was quiet and calm, and Meir was meandering around, doing his thing. Meir loves the smell of garlic powder and presumably did not realize that, while it's good in a bottle or in the soup, it's not so good on Bubbie's fresh carpet and couches! He sprinkled it everywhere to better spread the garlicky fragrance. What an exciting mess to clean right before Yom Tov! Apparently, Meir had very fond memories of this experience, because he did the exact same thing the following year at the exact same time—a half hour before *lecht bentchen* on *erev Pesach*!

! Yachatz Too Soon:

Shmuel is the most vivacious, adorable three year old on planet Earth. He has the cutest ideas, although while they are happening, they don't always feel that way. It was *erev Pesach* and the *matzos* were stacked neatly on the table, waiting for our *seder* to begin. Some of our children were taking naps in anticipation of the *seder*. Shmuel was not taking a nap, as we wanted a peaceful *seder*, with him in bed. When I came into the dining room, I saw my little boy perched on the table, frisbeeing the *matzos* one by one across the room!

(I wasn't sure which was worse—this, or when he frisbeed my mother-in-law's *sheitel* across the room.)

! An Outstretched Arm:

Binyomin loves chicken; it's one of his favorite foods. At the *seder*, I saw Binyomin eyeing the *z'ro'ah* time and time again. I gave Binyomin a different piece of chicken, but there was something about the *z'ro'ah* that he really wanted, despite our efforts to dissuade him—it was clearly on his radar. When my husband ran to hide the *afikomen*, I left to check on the baby

for literally one second. Lo and behold, when I came back, Binyomin was happily munching the *z'ro'ah*. Ever since then, I make a few *z'ro'ahs*, so in case we have a repeat experience, we will have backup!

! Dangerous or Hilarious?

Our special needs daughter Shaindy is now thirty five and, with our other children now grown and out of the house, my husband and I decided we would take Shaindy with us wherever we go. We decided we would not limit our trips either. A bit before Pesach, my husband, Shaindy, and I were on an airplane *en route* to *Eretz Yisroel*. In front of us sat an Arab, clad all in white—I thought he might be a sheikh, but I honestly wouldn't know. Shaindy wanted some soda, and when she finally got it open, the cola shot straight across the aisle. Our Arab friend, dressed in white, received a direct hit and was completely covered in the dark brown liquid. I wasn't sure if this would be the end—perhaps we had incited an anti-Israel riot or worse! I was petrified—who knew what would happen next? He just looked up and mumbled something that sounded like a prayer and indicated it was OK. Shoo—that was scary!

! Shhh! If You Won't Tell, I Won't Tell!

One *erev Shabbos*, a half hour before the *zman*, Chaim, my very involved special needs four year old, was 'helping' me in the kitchen. He took a pile of cucumber peels that was *en route* to the garbage, and dropped it into the fresh *erev Shabbos chulent*. I just picked it all out, and everyone enjoyed the delicious *chulent* on Shabbos without a clue about the 'new spice' I had used.

STRESS BUSTER TIPS

Take a picture! While you are running to get the camera, you may actually be praying that your son continues stomping on the eggs! Looking through the lens forces you to take a step back and see the humor in the situation. A year from now, you'll see the picture and laugh, so realize that it's not worth getting stressed about it now.

On a more spiritual level, think of Hashem taking **your** picture at this very moment. Smile your best as you redirect behaviors, sweep up the eggshells, or start up the bath.

Please send your Memorable Mishaps and/or stress-buster tips to: Neshamalemagazine@gmail.com, or text to: 848-299-2908. You can also leave a message. Give everyone a good laugh, and let us know that it's OK when these things happen—stuff happens to everyone!



Lets Get Educated

The Sensory Diet

C. Tawil

In conjunction with the feeding/diet theme in this issue of Neshamale, here is a different kind of diet that may help our children—one that is food-free and fun!

What is a Sensory diet?

A sensory diet is a group of activities that are specifically scheduled into a child’s day to assist with attention, arousal, and adaptive responses.

Who would benefit from a sensory diet?

The sensory diet is beneficial to children with ADHD, Autism, and Sensory Processing Disorder, as well as children with sensory issues but no formal diagnosis.

The activities can help calm an over-aroused or over-active child, increase the activity of an under-aroused/passive child, prevent uncomfortable reactions to sensory input, reduce sensory seeking (self-stimulation) behavior, increase productivity, provide comfort for the child, and teach the child self-regulation strategies.

How is a sensory diet determined?

It is essential to have a tailor-made sensory diet prescribed and monitored by an Occupational Therapist. On day-to-day basis, the plan can be implemented by a parent, teacher or caretaker.

The activities chosen for the child’s needs are based on sensory integration theory.

When is the diet administered?

The ideal plan is to have an individualized sensory diet incorporated throughout the day, on a consistent schedule.

When the use of specific types of input (including proprioceptive, tactile, visual, auditory, vestibular, gustatory, and oral motor) is introduced during various times of the day, it assists the brain in regulating attention and an appropriate level of arousal. These different types of input cause a release of neuro-chemicals that can last up to two hours. A sensory diet is designed to keep a steady flow of these neuro-chemicals in the brain throughout the day for improved functioning.

Why is a sensory diet helpful?

A sensory diet provides the necessary combination of sensory input to “feed” a child’s nervous system. When a child’s nervous system feels properly organized, the child is able to pay attention and perform tasks at a more optimum level.

When a child’s nervous systems are wired so that they do not efficiently process sensory input, this can contribute to behavioral and emotional problems. A sensory diet can provide or modify sensory input to help meet the needs of these children.

EXAMPLES OF SENSORY DIET ACTIVITIES:

Oral Sensory Activities:

- Chewy toys/Chewing gum
- Crunchy snacks
- Blowing activities (whistles, bubbles)

Proprioceptive Activities:

- Stacking chairs
- Push-ups
- Pushing or carrying heavy items
- Crawling over pillows
- Drumming

Olfactory Activities:

- Scented markers
- Essential oils

Tactile Activities:

- Sensory bins (rice, beans, etc.)
- Play with shaving cream, play-doh or water
- Brushing protocol (requires training)

Vestibular Activities:

- Swinging
- Scooter board (on stomach or seated)
- Riding bikes
- Jumping activities

Please note: All of these activities should only be implemented with the guidance of a skilled OT. Some of these activities may even be deleterious to the child’s development if they are not appropriate for the child’s particular needs.





On the Lighter Side...

Life Skills 101

Moishy's Mommy

Moishy's teacher made a grand announcement on opening night: "This year we have something new and very exciting. We have created a model home in a special wing of the building. We will be taking the children there once a week to work on life skills. We will teach them how to do basic household activities, such as making their bed or unloading the dishwasher."

Moishy doesn't talk. He is not toilet trained. He can't drink from a straw or eat with a fork. I thought those were pretty essential life skills for us to be working on. But as long as he will learn how to make his bed, I guess the other things aren't so significant. I know that in some homes making one's bed is rule #1. In my home, the concept doesn't exist. My own mother enforced bed making, which I grumbled about for twenty years. "When I'm a mother," I would say, "I won't make my kids make their beds!" Since I'm an honest lady, I've kept my word. (Ok, maybe it's because I still don't want to make my own bed.) I used to say, and I still believe, that it's silly to spend time making the bed look nice, only to crawl into it at night and mess it up again! I remember the day I had a girl come over to help me on Thursday afternoon. She gave the little kids baths and tidied up their rooms. My daughter came running excitedly into the kitchen to tell me that "Shira made the bed look soooo fancy!" I went to have a look and had quite a laugh. Shira had simply made their beds—that looked very fancy to my daughter, who was apparently missing this crucial life skill.

As far as emptying the dishwasher goes, Moishy wreaks enough havoc in this home without him being taught skills to make trouble in a more efficient manner. I can just see him swinging the glasses through the air, as he gleefully empties them, breaking one at a time. Emptying the dishwasher is another one of those time wasters, in my busy opinion. In our home, the dishwasher holds the clean dishes and the sink holds the dirty dishes. Once the clean dishes have all been dirtied, we can load up the dishwasher, and the fun starts

again. I understand that it is not socially acceptable to say: "If you can't find a clean bottle, just look in the dishwasher." That is why I am writing this under a pseudonym. Otherwise Moishy might have *shidduch* problems. Except that he won't, because even better than being a professional dishwasher-emptier is to be a happy dishwasher, which he certainly is. Many times a day, Moishy fills the kitchen sinks and washes all of the dirty dishes (along with the floors and counters). Who wouldn't want to marry such a helpful guy?

Now that we've knocked those two goals off Moishy's list, I'm wondering what other life skills he is going to be taught in this new model house? Perhaps doing laundry and ironing. Moishy is already quite the expert at laundry. He loves interrupting my washing machine's cycles and restarting them on the wrong setting. He loves stopping the dryer and pulling out the damp clothes in search of his favorite blanket. I won't lie and tell you that he also knows how to iron; I don't think he knows what an iron is. He certainly never saw me use one. It's just another one of those things that I don't know how people find time to do.

Perhaps this true anecdote will do justice to the genuine state of affairs in my home: A guest once requested an iron to use. I climbed up on a stool and took the dusty iron down from the top shelf.

Four year old: What's that?

Six year old: You don't know? It's an iron.

Four year old: What do you do with it?

Six year old: You don't know? It's for Perler Beads!

I take that as one of the best parenting compliments I have ever received. In fact, it pumped me up so much that, even upon learning that I am missing some basic life skills, I can still stand proud. Maybe my kids aren't that deprived after all.

The Sensory Diet in Action

Chani is seven years old and has ADHD and sensory processing disorder. She has difficulty following commands, staying on task, and sitting in one place. Her OT designed a program in which she takes a sensory break before each meal and snack of the day (about every 2.5 hours, 6-7 times a day). They created a visual chart showing choices of activities to do during these breaks. Chani gets to choose two to three activities per break. For example, during

one break Chani choose to blow bubbles, jump on the trampoline, and carry heavy bean bags around the room. After these activities, Chani feels calmer and more grounded, and is ready to sit in her seat for lunch and continue on with her day.

Thank you to Menucha Halberstam, OT, for reviewing this article.

The Other Side of the Desk

| *Spotlight on Medical Imaging*

Yehudis Blavin, PA-C

Q: Can you give an overview of the different kinds of medical imaging tests? What should I know about the main types?

A: Great question! Medical imaging, used to obtain “pictures” of what is going on inside the body, is extremely useful for guiding a medical team in diagnosing and treating patients. The different imaging modalities each have their own purposes and are used to view different body areas and tissue types. For example, X-rays are good for imaging bone, but ultrasounds are not. Let’s go through the four main types of medical imaging to hopefully provide a helpful overview.

X-rays

X-rays take a basic 2D picture of the inside of the body. They provide radiation, but are considered pretty safe, as the radiation is targeted to a specific area and is usually low-dose. They are inexpensive and easy to obtain, so they are good initial choices to get an idea of what is going on with a patient. X-rays are great for imaging broken bones or the spine, or for visualizing the lungs to diagnose pneumonia. They are less helpful for abdominal issues, but do have some uses—for example, diagnosing a bowel obstruction or visualizing an object that a child may have swallowed. A mammogram is also a type of X-ray. X-rays can be used to continuously image an area during a procedure, which is known as fluoroscopy. This provides the doctors with “real time” images to guide them during the procedure, but does subject the patient to more radiation than a single X-ray study.

CT scans

CT scans, or Computed Tomography scans, provide radiation-based, 3D images by taking multiple pictures of a body area

so that the area can be visualized layer by layer to evaluate for any abnormalities. CT scans take longer to administer than X-rays, and provide considerably more radiation. The images are significantly more detailed than X-ray imaging and provide more information about what is going on inside the body. CT scans are good for diagnosing abdominal issues, such as appendicitis or kidney stones. They are also used to evaluate trauma patients, to assess tumors, and to evaluate the brain for a possible stroke or bleed. CT scans are good for imaging lung tissue and can be used to assess for pulmonary emboli (blood clots in the lung vessels) or complex lung infections. CT scans are frequently performed after iodine-based dye, known as contrast, is administered to provide more detail. In CT angiography, dye is used to “light up” blood vessels and give information about potential blockages or vessel abnormalities. People with iodine or contrast allergies usually only get dye-free scans, but sometimes, if a contrast study is considered essential, they can be pre-medicated to minimize their reaction, and the dye is given under close observation.

Ultrasounds

Ultrasounds use sound waves, rather than radiation, to produce images. Ultrasounds are good at assessing the heart (known as an echocardiogram) and blood vessels. They are also used for assessing a fetus during pregnancy, since no radiation is delivered to the baby or mother. Ultrasounds can be used to assess for various abdominal issues, such as gallstones, appendicitis, or kidney and bladder issues. Ultrasounds are considered safe and cost effective, but are “operator dependent,” meaning the image quality may vary depending on the ultrasound technologist’s technique.

MRI's

MRI's use magnets to produce images and are great for imaging soft tissue and muscle. MRI's are good for diagnosing joint or muscle problems, or to evaluate spine or back issues. They are also good for imaging brain tissue and evaluating strokes. There is no radiation involved, but since the machine attracts metals, people with certain metallic medical devices, such as pacemakers, some heart valves, nerve stimulators, etc., cannot undergo the test. (Most recent joint replacements are made out of a metal that is MRI-compatible, but anyone with any metal in their body should alert the doctor or technician to ensure MRI safety.) The MRI machine is enclosed and the study can be lengthy, so people with claustrophobia may have difficulty and may require a special "open MRI" if an MRI is necessary.

Yehudis Blavin is a Physician Assistant who specializes in internal medicine and surgery.

Please note: The Information expressed in this column is for educational purposes—only and should not substitute for the advice of your personal medical professional.

Do you have a medical question that you would like answered? Send in your question to Neshamale and we may feature it in a future article.

Chizuk Boost #3

Rabbi Baruch Rabinowitz

HaShem appeared to Moshe and tasked him with the mission to speak to *B'nai Yisrael* and to *Paroah* in *Mitzrayim*.

“לא איש דברים אנכי”, Moshe countered. “I am not a speaker; I have a disability-- a speech impairment. How can I be the one to represent the *Ribono Shel Olam*?”

“מי שם פה לאדם”, answered HaShem. “I gave you the power of speech. I have chosen you, with your elevated *neshamas*, with your imperfection, to accomplish this mission.”

According to the Or HaChaim (*Shmos* 4:11), if a person has a disability, it is not a random occurrence. A person with a disability is designed and created by Hashem for a specific purpose. Everything HaShem creates is perfect, even if we cannot readily understand the good.

The Gemara (*Pesachim* 50a) relates that when the son of R' Yehoshua ben Levi recovered after being deathly ill, his father asked him what he saw when he was nearly in the Next World. His son replied that he saw an upside-down world, a world of עליונים למטה ותחתונים למעלה - those who are respected in this world were at the bottom there, and those who are at the bottom in this world were treasured in the Next World.

“No,” said R' Yehoshua ben Levi. “You saw a world with clarity - the real world!”

In *Olam Hazev*, we differentiate between good and bad. We perceive negative, and we cannot see the all-encompassing depth of HaShem's kindness. We say *Hatov U'Meitiv* (HaShem is good and does good) and we say *Dayan Ha'emes* (HaShem is the true judge). In this world, the name of *HaKadosh Baruch Hu* is hidden; we cannot say the *Sheim HaShem* outright. But in the next world, יהיה ה' אחד ושמו אחד - HaShem will be One and His Name will be One. We will say *only Hatov U'Meitiv*, that HaShem is good and does good.

I must try to connect myself to the next world, the real world. I can be a *Ben Olam Haba*, explains Rav Moshe Shapiro zt"l, if I live with the perspective of *Olam Haba* even in this world. I can work to feel the revelation of HaShem's true Name. I can know that all is good, no matter the circumstance. Even in this world, I can recognize that *tachtonim* (the ones at the bottom) are really *elyonim* (the ones at the top).

Those who are most precious in HaShem's eyes—our children with special needs, these special elevated *neshamas*—are *tachtonim* in this world only. We must appreciate that HaShem gave us the *zechus* to be *Bnei Olam Haba*, to see *elyonim* where others might not. May HaShem give us the wisdom, patience, love, and fortitude to see our children for the wonderful gift that each truly is.

Thank you to Malka Weldler for transcribing this article from the audio shiur.

This Chizuk Boost is excerpted and adapted from one of Rabbi Baruch Rabinowitz's weekly 10 minute Chizuk shiurim for parents of children with special needs. There are now over 130 recordings, which can be accessed on Kol HaLashon (718-906-6400, press 1, 4, 97, 2).



Sara Miriam Pitterman

ABA Therapy is one of those hot-button terms that is bound to get someone worked up—whether it’s because “Everyone gets it,” “It’s the best thing that ever happened,” or “It turns kids into robots.” When it comes to the field of Applied Behavior Analysis (ABA), there sure are a lot of opinions!

It doesn’t help matters that different systems (Early Intervention, Board of Education services, insurance-based model, and private pay) define and interpret who does the ABA therapy and how it is done.

There are a lot of skilled ABA therapists out there, and some not so skilled. While some practitioners, such as an RBT (Registered Behavior Technician) or an ABA paraprofessional, may have nothing more than a high school diploma and possibly a 40 hour training course, others are special education teachers (Master’s degree plus certification) with formal or informal ABA training.

Then there are BCBA’s (Board Certified Behavior Analysts) with a post-Master’s degree, 1500 hours of fieldwork, and ongoing training (LBA’s are BCBA’s who are licensed by the state in which they practice). Moral of the story: If your child is getting ABA therapy and you have questions, reach out and make sure you are getting quality work.

But what does quality ABA mean? What does an ABA session look like?

One of the most confusing parts of ABA is that it’s a teaching procedure for both skill-building and behavior management. It’s not a curriculum. ABA skill-building therapy can cover any or all of the following areas: communication, motor skills, sensory work, play skills, and social skills. It may address ADL skills such as toilet training, dressing, self-feeding, and hygiene. Sessions may target attention, academic, or community integration. They can range from classroom readiness skills to job training.

That’s a lot of different areas, and almost every child getting ABA will likely be working on some combination of those listed above. And that’s only for skill-building! ABA also address behavior management—treating behaviors that interfere with a person’s ability to function, that are socially meaningful to the clients or their families. This might include decreasing aggression, tantrums, elopement (running away), or emptying out the baking cabinet. It might include habits like nail biting or touching other people’s belongings.

In this upcoming new column, we will discuss the ABA process, from both your child’s and the therapist’s perspective, and help you learn to recognize quality ABA therapy.

Sara Miriam Pitterman is a BCBA working in Lakewood, NJ for Brainbuilders LLC, an insurance-based ABA company. You can contact her at: smpitterman@brainbuildersnj.org

Program Report: A Shabbos in Paradise

Fraydel Dickstein

“It’s gonna be the little *kinderlach*, the little, little, little *kinderlach*; it’s gonna be the little *kinderlach*, who’ll make *Mashiach* come...”

As we drive home after spending the past 36 hours in the oasis of the *Lev with Love Shabbaton*, this song is going ‘round and ‘round in my head. It’s clear to me that it is those with whom we just spent Shabbos, who will be the ones to bring *Moshiach*—both our special *neshmales* themselves, and their incredibly devoted counselors. Our special children generate remarkable *chesed* in our beautiful *B’nos Yisroel*. These girls selflessly put all of their energy into doing what is difficult or seemingly impossible. They stayed up whole nights watching children who didn’t sleep at all and need to be watched every second for safety. They lovingly cared for those who are already adults, feeding them and changing them as needed.

I have no doubt that when Hashem looks down at these scenes from His throne, (actually, I think He is already down here in this special place, in a most tangible way!), He shines His *shechina* on everyone. These special *neshamos* bring more *shechina*, hence, more *kedusha*. If you could visualize what we would see if we could see *kedusha*, the Hudson Valley resort that *Shabbos* was a like blazing, gorgeous Divine fire, too intense for the human eye to look at.

Let me backtrack a bit, and allow you to experience a tiny bit of the specialness that we merited to be a part of on this *Shabbaton*. As we approached the Hudson Valley resort on Friday afternoon, we were so excited to see *Lev with Love* picket signs surrounding the driveway. As we entered the lobby, we saw extremely patient volunteers, walking with their charges. One was gently coaxing a big girl to make a good decision, another was swinging her feet on a bench along with a sweet boy who needed the fresh air. An atmosphere of warmth and acceptance enveloped us, and we knew we were in the right place.

Inside, the walls were adorned with beautiful *Lev with*

Love posters alongside the event schedule. A delicious welcoming buffet was available with kugel, cholent, farfel, and more. There was ample staff, with clear signs indicating rotation schedules. Children who needed their own space had counselors happily sitting alongside them. Children who wanted to be part of the action had counselors cheering them along. Moonwalks were set up in one room for jumping.

There was a magic show on Shabbos after both meals, which the kids really enjoyed. Mrs. Armon, an experienced special education Morah, ran a beautiful group Friday night, which I was privileged to attend, and led another on Shabbos afternoon. Just being in the room, you could feel her love and reverence for each child.

The Shabbos afternoon performances, led by a number of the special children themselves, were so touching that I am sure they had the *malachim* singing along. A magnificent concert on *Motzei Shabbas* took the event to a whole new level. Every child was so well occupied and cared for; there was no detail overlooked. A dedicated *Hatzolah* member, Mr. Aboud, joined for the duration of the *Shabbaton*, available for any emergencies.

Even more impressive than the well-run program, was watching and feeling the abundant love and complete acceptance throughout. It was an oasis for our special children, what I would call a paradise on earth. The most magical part, for me, was observing the incredible patience of the volunteers. It was amazing to see how lovingly so many girls were caring for children who have many similar behaviors to my Yehuda. Where else is there such complete acceptance and awe for our children? (Hopefully in our own homes, but we all know how challenging that can be!)

Aside from the paradise created for our children, the experience for their families this Shabbos was also exceptional. One mother texted me that it was the first time her family has had a break since her son was born; their usual Shabbos does not allow for a moment's rest. How many families experienced the rare treat of sleeping for two whole nights, as they didn't have to stay up with their child?

For my family, this was the only time we could even consider going away (other than when Yehuda attends camp). The *Shabbaton* is literally one of the only times families like ours could get a breather, guilt free, as we knew our children were in such good hands. It did

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What Lev with Love Means to Me

I want to try to explain what Lev for Love means for my family on a personal level. My husband told me that he used to dread coming home from shul on Shabbos. He knew he would find the house in shambles, his wife wrung out, and nothing near a meal happening. Yehuda would spill and dump or wreck anything we would try to do. One day, Hashem took us by the hand and found us a new home, next door to Mrs. Cohen. She approached me after seeing my delicious Yehuda and said: "I have a rotation of girls in the neighborhood. I could send you as many girls as you need." I looked at her with my mouth agape; I could not believe what I was hearing. The moment is so deeply etched in my mind, that I can still smell the early fall air, I can picture her and the exact angle I was standing. She said: "Just tell me when, and I will send you girls." And she did.

They came Friday afternoon, Friday night, Shabbos morning, and Shabbos afternoon. I realized I could make a salad and put it back in my locked fridge. I could set a table. Sometimes I could even make challah on erev Shabbos, something that I greatly enjoy doing. My daughters would greet Shabbos in their robes with freshly washed hair, complete with ribbons. We started to feel like a family. Our family began to look forward to Shabbos. My husband was able to go out to learn on Shabbos, not feel like a prisoner in his home. I was able to take a nap, or just space out for a few minutes.

Yehuda loved the attention of the girls. He especially enjoyed the families that welcomed him into their homes. He felt so good to be involved—to be able to go to other people's houses, just like everyone else. He loved to touch their rugs and pictures. Once Shabbos changed for us, the menucha spread to the entire week. The volunteers changed our lives forever.

While Yehuda has come a long way, and we no longer need that volume of volunteers, we will never forget how much of a lifesaver—and life-changer—they were for us at that time. They gave us the ability to become a functional family once again. The chesed that Mrs. Cohen arranged for us continued to spread to other families as well, until it became a real organization, under the name Lev with Love. I hear first-hand from many, how dramatically Lev with Love has impacted families in our community. They have incredible volunteers who go week after week, to give families a break, or to take these special neshmalach out and give them some much needed attention—many families don't know what they would do without their volunteers. We are privileged to have these angels in our midst, and they are privileged, as well, to spend their time giving in such a selfless way, as they encounter the pure kedusha of our special children.



Illuminations

SOMEONE'S CHILD

This past summer in Camp Ma-Na-Vu, we were privileged to interact with an unforgettable group of children, a group that enriched our lives and touched our *neshamos*. They were the children of Camp Ahuvim, the only Jewish camp in the world for autistic children.

Before the summer, the director of the camp, Rabbi Shlomo Klein, asked me how I felt about bringing in this type of program. I was all for it. Naively, I thought that we would be able to add so much to the lives of these children. Little did I know that the opposite would be true. *They* would change *our* lives in a memorable way. Each – with his unique challenge – allowed us to see more clearly the goodness that abounds in our own lives.

The one who impacted my life the most was Leiby. I met him on the basketball court one day. As he frolicked with his counselor, I noticed his delight as he played with the ball and attempted to get it into the basket. He tried – and tried again – until he finally succeeded. And when he did, Leiby jumped up and down, clapping as if he had won the lottery. I admired Leiby and his simple joy in life. With his *peyos* swinging from the sides of his head and his sweet smile, he melted my heart.

When his parents came and I introduced myself to them, they asked me if there were any children's books in camp that Leiby could read. I told them that I had a few in my bungalow and gave Leiby *Touched by a Story for Children, Volume 2*. He promised me that he would read the whole thing. Sure

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so much good for us all—I know one family who said it was their first time going away for Shabbos in five years!



On this special Shabbos, *Lev with Love* brought together so many pure *neshmalach*, and the angels who are their volunteers. I have no doubt

enough, the following week, he had finished all 48 pages. Out of curiosity, I asked him if he had a favorite story. He told me that, indeed, he had one. It was “Someone’s Child.”

In short, “Someone’s Child” is a story of a couple enjoying their vacation in *Eretz Yisroel*. One day, suddenly, there is a thunderous noise as a squadron of fighter jets flies by overhead. While the couple looks up and thinks how “cool” it looks, they notice a woman nearby who breaks down crying. When asked whether her son might be flying in one of the planes they’ve just seen, she responds: “No. But it’s someone’s child.”

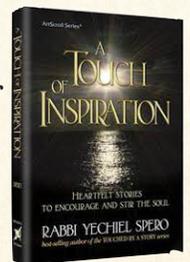
This was Leiby’s favorite story. It got me thinking. Why was this story his favorite? It is hard to know precisely the reason Leiby liked that particular story. Maybe it is as simple as the fact that he likes jets, or perhaps it is much deeper than that. Regardless, one message rings clear: We must treat every child with the knowledge that he is someone’s child. Or better yet, knowing he is Someone’s child – with a capital S. This is what I learned from Leiby. And this is what we must all learn from Leiby.

It is said that the Chazon Ish, Rav Avraham Yeshayah Karelitz, stood up for special children. He held them in high regard, since he felt that they have special, *heilige neshamos* (holy souls).

If we are blessed with a special child, then we already know the joy. And if we are not, then we must adopt all special children as our own. Not only in spirit, but in financial matters as well. We must support the local schools, camps, and programs for special children. We must look to get involved in any way we can. Because these children are not just any children.

They are Someone’s. Someone’s special child.

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that when *HaKodesh Boruch Hu* gathered His celestial court and said: “*Chazu banai* - look at my special children!” I know He meant the *heilige neshamos* of our children and those caring for them. After feeling the *Shechina* this past Shabbos, I am convinced I got a flavor of how it will feel when *Mashiach* comes—may we be *zoche* to greet him quickly!

“It’s gonna be the little *kinderlach*...it’s gonna be the little *kinderlach*, who’ll make *Mashiach* come.”



Activity Time!



Chayala Tawil

Skewer it!

Skewers are a really fun and appealing way to prepare, present, and partake of food. Threading food onto skewer sticks is a great OT (Occupational Therapy) activity for your child to practice fine motor skills. It may also encourage picky eaters to taste some new foods. According to the experts, kids eat best when they are involved in the food preparation. Experts also say that kids eat better when food is presented in an appetizing way. What could be more appetizing to a child than a look-alike lollipop?

Skewer sticks come in different colors and different lengths. There are really no rules except to have fun and prepare something that you'll enjoy eating. If having the kids do the actual threading makes you nervous (because of the germs or the mess or just because) you can have an adult prepare the skewers and serve it out.

Here are some ideas get you started:

Salad on a stick: Use raw veggies such as baby tomatoes, pepper chunks, olives, cucumbers, and pieces of lettuce. Thread desired items onto a short stick and offer salad dressings in small cups for dipping.

Deli sandwich on a stick: Try different deli meats (rolled up or folded), baby tomatoes, pickle slices, purple onion, and pieces of bread cut into quarters. Thread a piece of bread, followed by deli and veggies, and end off with a slice of bread. Serve with mustard and ketchup. (For a Pesach variation, leave out the bread.)

Fish course on a stick: Skewer salmon cubes in a variety of flavors (dill, pickled, etc.), white fish, etc., along with an assortment of grilled or raw vegetables.

Fruit salad on a stick: Try cubed melons, cubed pineapple, banana slices, kiwi chunks, and berries. You can also include some dried fruit options (dates, apricots, etc).

Dessert on a stick: Offer a variety of candies that are soft enough to be threaded onto the sticks, such as marshmallows, sour belts (ribboned onto the stick), cherry balls, and chocolates. Kids can get artistic and create patterns and designs out of nosh and turn it into a whole activity.

Here are several options for presentation:

You can stick the prepared skewers into a base of Styrofoam or a cardboard box, which you can cover or decorate with a pretty napkin or contact paper, if you wish. (The base would have to be prepared before Shabbos.)

For a Shabbos or Yom Tov meal, while messier versions (like the fish or fruit versions) are probably best to plate individually, neater versions, like the veggie salad or the dessert sticks, can be offered in a vase or tall cup.

Skewers can also be a great idea as a picnic food. Have the kids prepare a bunch of deli sandwiches on sticks for everyone to enjoy in the park.



Safety First!

There are some safety concerns to be aware of:

The sharp pointed ends can be a safety hazard for children. Be careful not to poke anyone while threading the items. After threading, you can slice off the point with a sharp knife to create a blunt edge. For some children, a stick (even without any sharp edges) will still present too much of a danger, so this activity may not be appropriate for everyone. You may be able to adapt some of these ideas using short paper lollipop sticks, which are a much safer option.

If you will be baking anything on the wooden sticks, soak them in water for 15 minutes before threading and baking so they don't burn.



Q

Dear Shira,

IN SESSION

Why is feeding so emotional? We are doing many therapies and exercises with our daughter, without great results, and I'm ok with that—but when it comes to feeding, I get so emotionally involved. If my daughter eats her breakfast or not can literally determine my mood for the rest of the day! There must be some psychological reason for my irrational reaction—could you please shed some light on this matter so I can understand what's going on?

Thanks,
A Confused Mommy

A

Dear Mommy Who is Trying to Do the Right Thing for Her Child,

To start, please read again to whom I am addressing this letter. You are trying to do all the right things as you raise your daughter. You want her to be healthy, and progress, and be the best she can be. Although that goal is the same for every child, having a child with special needs raises the bar. You are faced with therapies and exercises, with many people coming to your house, or with you taking her to the appointments.

Did you ever play the game of Limbo when you were a child? In the game, a pole is placed at a certain level, and everyone has to go under the pole without touching it. The stick is continually lowered, and everyone keeps trying to get underneath without touching. The lower it goes, the more challenging it becomes.

Who wins limbo? Usually the most flexible and/or most petite person will be the inevitable winner. Inflexible or tall people can still play and have fun, too, even though they probably won't win. However, starting the game with the stick on the ceiling (too high), or playing with the pole almost touching the floor (impossible), makes the game no fun for anyone.

The metaphor is that perhaps your stick is too low, and your expectations are too high to be met. Although raising a child with special needs is not a game (Limbo or any other), maybe your expectations and goals can be placed at a more realistic level. For instance: What constitutes a “nutritious” breakfast? Can it be modified so that it won't be so stressful, and be more enjoyable for everyone?

The following might be some suggestions:

Offer new foods (perhaps a protein bar, a cheese stick, or a squeezy yogurt).

Give choices (let the child choose which flavor yogurt and/or what color straw).

Make the food look exciting (how about a sailboat made out of a colorful pepper with a celery stick and American cheese for the sail?).

Food, in general, has a lot of different meanings for people. As an example, is there anyone in your family who was a Holocaust survivor? Because of the lack of food and starvation that people endured then, many survivors and their families feel that food should never be wasted, and that everyone's plate must be totally “clean.” What does it mean to you when your daughter doesn't eat enough?

The last part of this answer is that when parenting a child with special needs, parents lose a lot of control and the outcome is often unpredictable. There are so many therapists and programs with which your child must participate, and as you mentioned, the results aren't always what you hoped. Food may seem to be the one area that you, the Mommy, can facilitate and control.

When you feed your child, you feel you are contributing to her well-being, and you want good results. But feeding doesn't always have that possibility. Try feeding a baby a jar of peas, for example, and watch what happens—most babies will keep their mouths shut and the spoon will not go in! I suggest that you give yourself credit and support for what you are doing—for the therapies, appointments, and yes, the feedings—rather than focus on what you are think you are not accomplishing.

Wishing you much *hatzlacha* and *koach* as you continue raising your children,

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 with your own individual concerns and needs at: (732) 367-1503 or shira732@live.com



Feeding our Special Children



Recipe: A Recipe to Remember By N.M.

Prep. Time:
120 years +

Serves:
1 Special
Child At A
Time

Ingredients

In order to raise a special needs child,
Devoted parents are a must.
Add half a cup of empathy
And three-quarters cup of trust.

2 full cups of kindness
Is the basis to it all.
Add a dash or two confidence
To help you when you fall.

You'll need 3 or 4 good role models
To show you what to do.
Stir in a cup of knowledge
And a splash of curiosity, too.

Without 2 cups of patience
You simply won't survive.
Don't forget the passion
And gratitude to be alive.

Directions

If the batter turns out lumpy,
Sprinkle in a sense of humor.
A bit of laughter and some lightness
Makes the whole thing turn out smoother.

Now it's time to fill the baking pans
With overflowing love,
But first make sure to cover well
With your prayers to the One up above.

Mix and bake it fresh each day,
And serve it up in style.
Tastes best when served with a side of kiss,
As well as a hug and a smile.

Notes



Going Gluten-Free

C. Tawil

Many special needs children are on a gluten-free diet. Although not scientifically proven, many parents see significant improvements when their children with autism, ADHD, or dyslexia go gluten-free. The diet is known to improve social and cognitive behaviors and speech with many children. It may also help ease digestive symptoms, reduce chronic inflammation, boost energy and promote weight loss.

But—how do you do it? Aren't bread, pasta, and cake the main foods that our kids eat? Here are some tips (and a few recipes) from parents who are implementing this diet with ease. As one mother told me, "It's really, *really* not a big deal."

Baking

99% of cake and cookie recipes can be converted to non-gluten with no problem. Use this blend of flours for baking cakes and cookies:

Non-Gluten Flour Blend

- 1 bag (22 oz.) Bob Mills Tapioca Flour
- 1 bag (22oz.) Bob Mills Rice flour (brown or white rice)
- ½ bag (11 oz.) sorghum flour

Directions: Mix together and store in air-tight container. Substitute measure for measure for the amount of flour called for in recipes. Follow the recipe as usual, adding in 1 tsp. xantham gum per cup of non-gluten flour.

(Note: You can use any brand of these types of flours. We just like Bob Mills, because the bags come in these convenient weights, so you don't have to measure out the flour to create the blend.)

As to other recipes, you can make Oh Henry bars and other oat-based recipes with gluten-free oats. Recipes that call for almond flour are great for non-gluten desserts. For the shavuos cheesecake, you can simply make a crust-less version as most cheesecake batters do not contain flour. And don't forget to leaf through

your Pesach cookbooks for other gluten-free dessert ideas.

Here is a delicious non-gluten cookie recipe that everyone will enjoy:

Peanut Butter Truffle Cookies

- 1 cup chocolate chips
- 1 cup brown sugar
- 1 cup chunky peanut butter
- 1 egg
- 1 tsp. vanilla extract
- 1 tsp. baking soda

Directions: Mix all ingredients by hand. Drop by spoonful on an ungreased cookie sheet lined with aluminum foil or parchment paper. Bake 12 minutes at 350 degrees. Do not remove from cookie sheet until cool and firm.

Bread/Challah

A bread machine is a great appliance for a non-gluten household. Although you can buy non-gluten breads in the grocery store, they are not all that tasty. It is easy enough to throw the right ingredients into the bread machine before you go to sleep in order to get a fresh, hot loaf ready in time for breakfast.

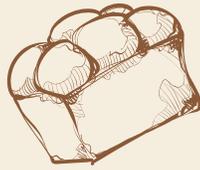
You can also make challah dough in the bread machine, and remove it before the baking cycle. Gluten-free challah dough is very sticky and hard to braid, so put the dough straight into challah pans right after mixing and let it rise directly in the pans. After rising, brush loaves with egg and sprinkle on seeds before baking to make it look more "challah-like."

For rolls, put smaller pieces of dough into muffins tins to rise and bake.

Two favorite types of gluten-free bread are made by Udi or Mountain Canyon, and can be found in health food stores, as well as Target.

Non-Gluten Challah

2 Tbsp. yeast
½ cup warm water
1 Tbsp. sugar
5 cups oat flour
1 cup non-gluten flour blend (see recipe above)
2 Tbsp. xanthan gum
¾ cup sugar
1 tsp. salt
4 eggs
1/3 cup oil
1 cup seltzer



Directions: Place the first three ingredients into the mixing bowl and let rest for 8 minutes. Add the rest of the ingredients and mix for 5-7 minutes until a sticky ball forms. Place into pans lined with parchment paper and let rise for 1 hour. Put on egg wash and bake at 350 degrees for about 30 minutes or until done.



Treats

If your kid is not a fan of gluten-free cake, try other desserts and treats that are naturally gluten-free. Walk down the health aisle in your local kosher supermarket and see how many snacks come in gluten-free versions, including pretzels and cookies. Muddy Buddies, jello, ice cream, fruit rollups, and candy are usually well received by everyone. A great tip a mother shared is to visit your kosher grocery store on *Isru Chag Pesach* and stock-up on gluten-free cookies (at 50% off!) for the rest of the year.

Here is a super easy and refreshing sorbet recipe:

Fruit Sorbet

1 bag frozen strawberries
1 cup sugar
1 cup orange juice

Directions: Blend in food processor until smooth. Freeze. For best results, re-beat again the next day. You can also substitute frozen mango for the strawberries. Or, make both flavors, and layer in a clear plastic or Pyrex container for an exciting dessert.

Meals and Sides

Non-gluten rolled oats and steel cut oats (such as available by Bob Mills) can make great winter breakfasts. There are plenty of non-gluten cold cereals, as well as other options like yogurt, smoothies, and rice cakes.

For supper side dishes, rice and potatoes are your new best friends. Pasta is one thing that will be sorely missed, but rice

pasta is a pretty good substitute (best served fresh). Quinoa is also a nice option.

Eating Out

Before deciding where to eat out, do your homework. Find out which venues will accommodate your needs. Some pizza stores sell gluten-free pizza. Some restaurants offer items that are certified gluten-free.

Swap it

Many recipes that call for flour as a thickener, such as soups and kugels, can be substituted with corn starch or potato starch. Use half the amount of corn starch than the flour called for in the recipe.

Breadcrumbs and cornflake crumbs (such as for coating schnitzel) can be swapped for crushed Corn Chex or other gluten-free cereals. There are also panko crumbs that are gluten-free.

Going gluten-free may not be easy, but it doesn't sound like anyone will be going hungry anytime soon, either. If your doctor or therapist recommends it for your child, give it a try. And let us know what great tips and swaps you come up with!

Thank you to Sara T., Rivky S. and Ruchie H. for their assistance with this article.

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Tips & Tricks for Feeding Tubes

Perry Binet

Disclaimer: I am not a nurse or medical professional. None of the information below should be used in lieu of advice from a medical professional. I am merely sharing some information that I have learned and picked up while on the feeding tube journey with two of my boys. I hope you find it helpful.

Feeding tubes are a *bracha*, although *brachos* come in many different forms. It can be scary to learn that your child will need a feeding tube, but realize that a feeding tube placement does not need to be a permanent solution. For the time being, a lot of stress can be eliminated by knowing that there is an alternate route of getting your child to eat, hold food down, or whatever the reason may be for the tube. Feeding tubes also do not need to mean that your child is critically ill. There are children who have feeding tubes for myriad reasons, including for medication, sick care management, back-up if the child does not eat, for supplemental nutrition, nighttime nutrition, fluids, and more. Speak to your doctor and decide together if this is the right step for your child. If it is, welcome aboard! Feeding tubes look a lot scarier than they really are, are way cooler than they look, and are also way, way more helpful than you can imagine!

Helpful Feeding Tube Items:



Tubie Friends-These are teddy bears that can be ordered with tubie ports and other medical equipment. Tubiefriends.com



Syringe feed holder-This is a holder for the syringe as the child gets a feed. It also comes with bag holders. Freearmcare.com

Extension cleaners-These are thin and narrow brushes that can clean extensions. (Pipe cleaners can work too!) Available on Amazon-search: "straw brush skinny cleaner."



Uni-solve wipes-These are wipes that remove tape marks from the skin in a simple and painless manner.

Feeding tube belt covers-These are belts that cover the site/tube/extension, etc. There are two companies that sell good ones, and there are cheaper alternatives from

Amazon as well. For sensitive skin, I would recommend the one from Gus gear. Gusgear.com or Benik.com



If a belt is not an option, the "tubular elastic net" can be tried for babies/kids who need the tube/site covered. A small piece of netting is snipped off from a roll and placed over the stomach. Available on Amazon.



Grip lock-This is an additional sticker that helps secure the extension/tubing etc., to avoid it being tugged and pulled. It can also be used to secure NG tubes. Available on Amazon. (Tape can work fine as well.)



AMT feeding tube connector-This connects the bag tubing to the extension to avoid disconnection. Vitalitymedical.com



Connector protector-This covers the clamps to avoid opening and closing. Available on Etsy as: "Custom-made feeding tube."

Feeding tube briefcases-There are many different styles that the child or caregiver can wear. For babies, there are poles and other things to connect to the pump.



Tubesies-These are onesies with a special flap/pocket to access the tube. Tubesies.com

Helpful Feeding Tube Tips:

- A lot of parent-child bonding happens when a mother feeds her child. If this is being replaced by tube feeds, you can still bond in other ways.
- Ask other people with tube feeding experience if you have any trouble. You are most likely not the first person to encounter your particular problem.

- Get creative with your Google searches. There are lots of helpful tools and items available to help with tube feeding.
- Shabbos: Make sure to charge the pump at night so that it is charged during the day. Many Rabbonim permit necessary actions on Shabbos with a *shinai*. Follow your Rav's *psak*.
- If getting your feeding tube supplies becomes stressful, switch vendors.
- It is worth purchasing one extra tube in the beginning so that you have two spare tubes in addition to the one the child is wearing (one purchased and one from insurance). When you have one tube as a spare and use it, you are suddenly left with none until the replacement comes and you may end up in a real emergency situation. Aiming to always have two spare tubes (except for when you use the first spare and wait for that replacement) has literally helped us avoid real emergencies with tubes coming out.
- Coke, seltzer, diet ginger ale, or any carbonated soda is terrific for unclogging tubes and extensions. (G and J tubes usually require a clog zapper.)
- A hanging shoe rack (the type with pockets) is a great way to keep all the little odds and ends organized.
- A regular wire hanger works great for hanging up the feeding bag.
- If the extension gets clogged, it usually works better to syringe water through the back end (with the closure open).
- Never underestimate the power of a short little prayer when you are dealing with clogs and messes.

If you would like Perry's full guide on using feeding tubes, email neshamalemagazine@gmail.com and we will send it to you. This is especially helpful for parents to give new caregivers, camp counselors, etc.

Perry Binet, MS Ed, has been in the field of Special Education for over 15 years. She is currently the Director of Camp Migdal (a sleep-away camp for children with special needs), the Principal of The Hamaspik School (for children with Down Syndrome), and a mother of three boys, two of whom have a rare metabolic liver disease, Glycogen Storage Disease. She can be reached at perrybinet@gmail.com.



TUBE TALK

Perry Binet

Every day we learn something new,
Including a different vocabulary, too!
Pegs can be good therapy toys,
Or a way to eat, for some girls and boys.
When you think of gravity, it's related to space,
When we think of gravity, it's his feeding pace.
Though the A/C comes from a vent on the wall,
To us, a 'Vent' is a 'Get Rid of Air' call.
While shirts have buttons for clothing you wear,
Our son has a button on his stomach so bare.
Most people connect to their WiFi or 'Net,
When he connects, it's to his feeding set.
Some run to an outlet to shop for cheap things,
We run to an outlet to charge his pump when it rings.
To some, an extension plugs into a wire,
To us, it's a part of his feeding attire.
A pole is something kids like to slide down,
But his pole allows him to get around town.
Prime is a math concept for numbers (or whatever!),
For him, it's an action to remember forever.
At meals, most folks eat with a fork, spoon, and knife,
For his meals, though, syringes are part of his life.
Life is awesome and often strange,
When the meaning of the most common words seems to change.
Yet nothing can redefine the love so sweet,
Between parent and child, however they eat!

SWEET SPICES

Introducing “Sweet Spices,” our new column about seeing the hashgacha/providence in everyday encounters with our special children. The title is based on the following Torah medresh:

When Yosef’s brothers sold him into slavery, the Torah mentions that the caravan in which he traveled down to Mitzrayim carried sweet-smelling spices, as opposed to the foul-smelling cargo usually transported on that route. Rashi points out that this brought comfort and encouragement to Yosef, who understood that Hashem prepared these sweet spices to accompany him on his journey, and to teach him an important lesson: Although it was painful that he had been sold into slavery and sent down to Mitzrayim, it was not random. It was orchestrated by Hashem, down to the very last detail, and Yosef knew that he would not suffer an iota more than was destined for him.

As we journey through life with our special children, we need to remember that Hashem is the One planning this journey, with all of the bumps and jolts we may encounter. Let’s try to smell the sweet spices along the way, and be encouraged by the knowledge that nothing is random, and that we are on a journey to greatness!

A Chazakah of Hashgacha

Yehudis Wolpin

I am sure you have all felt clarity and Hashem’s guiding hand on your journey with your special needs child. I will share three incidents that happened recently, and I hope they will remind you of similar incidents that have happened to you and your child on your journey.

My 6 year old son, Naftali, is in Yaldeinu. Since they are a gluten free school, they serve all the snacks and lunch. Naftali goes to school with just his notebook in his briefcase every day. When my other children fill their knapsacks with snacks each morning, he wants snacks too, and puts some into his knapsack. Right before he leaves, I tell him: “Naftali, your teacher gives you snack. Let’s take it out, and when you come home you will get your snack.”

Recently my son needed shoes, so I made the arrangements for his Yaldeinu van to drop him off at the shoe store, where I would be waiting for him. Then he would go straight to his evening program after we bought his shoes. He was dropped off and I brought him into the store, but realized I had no food or drink on me. I always give him something to eat and drink right when he comes home, and especially now, when he was going straight to the next program.

We sat down in the store, and then it happened: “I want snack! I want drink!”

He started crying. I tried distracting him, but I knew it wouldn’t help for more than a minute. Uh Oh! Was this going to be a full-fledged melt down? He laid down on the floor and started kicking his feet. Just then I decided to

open his briefcase to check his notebook and see what he had learned in school that day. I gasped. Not only did I find his notebook, but there were two snack bags and a water bottle! Then it hit me—that morning I forgot to take out the snacks that he put into his briefcase, as I do every single morning. Although he never put a water bottle into his briefcase before, that day he did. Hashem takes care of everybody!



Another story happened a week before Yom Tov. I was shopping with my girls for clothing, and B”H, we found what we needed. I decided to take a peek at the boys clothing, as I can’t shop with my two special needs boys. I always buy the clothing without them, and bring it home for them to try it on. My boys are very picky; they won’t wear shirts with buttons or zippers, so it’s not that easy to find them things. I browsed through the racks and spotted a perfect pullover Shabbos top. There was only one left in a size 10; that would be perfect for my older son. I really would love it if my two special needs boys could be matching, though. Then Hashem showed me that He would help me on my journey by making the shopping easy for me. As I pushed away some shirts on the rack, I found one more of that exact shirt in the exact size I needed for my younger son! Thank you, Hashem!



I live in the center of Boro Park and there are always many boys playing in front of my house. I never appreciated the fact that I

את פתח לו

Leah Tawil, SLP

can send my older children outside to play and not have to worry about them. I can't do that with my special needs son Sruly, who is 7. Whenever he wants to go outside, I have to stand outside with him and watch him. And that's what happened two weeks ago. He came off his van and saw the boys outside. He stood there and just stared and watched the boys play. I wished he would have been able to play with the boys, but he had no idea what they were playing. For a moment I felt pity for him, as he just stared with wide eyes at the boys running around and having so much fun together.

But there is a Hashem in this world. Hashem does not forget about anybody, even little Sruly who just wants to play with a friend. All of a sudden Sruly turned to me and said: "Mommy, look! There is Chaim across the street. I want to play with him." Chaim is a special needs boy who lives across the street from us. I took Sruly's hand and we crossed the street together. As if on cue, Sruly closed his eyes and counted to ten, while Chaim ran to hide. Hashem took care of my Sruly and found a friend for him. There was no reason to worry all!



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.

Tuki Part II

"Tikki, Tokki! You're home from school!" Mama Tuki chirped as she peeked out of her nest. "Come, eat a little snack. Would you like some yummy worms?"

After Mama Tuki served them their snack, she went to take care of some laundry. Soon, Tikki wandered in and started pecking at the shirts. Mama decided to incorporate some speech and language into doing the laundry as she interacted with her youngster. "Tikki, whose shirt is this?" (**possessives**)

"My shirt!" Tikki squawked happily. Eyeing the next pair of pants, he screeched, "Tokki!"

"Yes, Tokki's pants," Mommy reinforced, also *expanding* on what Tikki had said. "Would you like to fold Tokki's pants?" She showed Tokki how to fold the pants. "**First** fold it, **then** put it in the basket. There you go!" Mommy chirped encouragingly. (**sequences**)

Soon enough, Tokki flew in to join the excitement. "Tokki, come, can you sort these? See, the *dark* ones go *here* and the *white* ones go *here*. Come, let's do it together." (**categorization, basic concepts 'dark,' 'white'**) Soon, Mama decided to change it bit. "Now, let's put all the *pants* in this pile, and all the *shirts* in this pile."

When they were done with the laundry, Mama sat down to read them a book. She picked out one of their well-worn favorites. They loved hearing "Are You My Mama?" again and again, ...and again! (**repetition-repetition!**) She

positioned them on her lap sideways, so that she could engage with them by seeing their faces, but in a way that they could also see the book.

"Tokki, you may turn the pages." (**participate, even without verbalizing**) As she 'read' the page, she simplified the words, **saying** less, **stressing** the important words. She read **slowly**, while **showing** and pointing. "...you are not a plane, or a boat, or a snort..." she read, as she turned the last page.

"...**You are my Mama!**" the children happily filled in, as they snuggled next to their Mama.

On that happy note - Kudos to us **mothers** out there (both human and winged), who constantly 'open the mouths' of our dear Neshamalas. I take this opportunity to wish you farewell, as this will be my last column in this series. Thank you for accompanying me on this wonderful journey through the day, and year, as we explored communication opportunities and techniques, helping us incorporate more language into the daily lives of our families.

It was Tweet knowing you!
Leah



WOW! MOMENTS

compiled by Fraydel Dickstein

Hashem is with us every moment of the day, whether we see it or not. Here are some beautiful stories that make us all stop and say "Wow!" – Thank You Hashem!

My delicious autistic 12 yr. old Shalom loves to visit a neighbor who finds his social calls difficult. I recently made a fresh pot of soup and sent Shalom down to this neighbor with a beautiful note and some soup. Tonight, Shalom asked me numerous times if he could visit, but I had to say no. Noticing that I had an apple pie in the oven, he turned to me and asked: "Can I bring pie?" I was amazed at Shalom's genius!



Dassi, my wheelchair-bound daughter, was going to be in 6th grade at Bais Faiga this year. Although the building has an elevator, it was broken. We spent a lot of time in the summer ensuring that it would be fixed in time for the start of school.

When I came to open school night, I noticed that the walls were bare; there were no signs decorating the halls anywhere. I was quite surprised and I asked my niece, who teaches there, why this was so. She told me that two days before school started, the principal had called all of the 5th and 6th grade teachers and told them that they would be switching rooms.

Since the elevator did not reach the regular sixth grade wing, they moved all of the 6th grade classrooms down to the ground floor, and moved the 5th grade classrooms upstairs. When I asked why *all* of the 6th graders had to move downstairs, not just Dassi's class, the principal replied: "It's worth switching all of the classes to prevent even one girl from saying: "Too bad we can't be together with our whole grade because of Dassi."



When my new brother-in-law of a few weeks came over tonight, he gave Yehuda a big hug. It meant so much to me. Thank You

Hashem for making this family member love our Yehuda; it makes it possible for us to stay a part of the family in a most positive way. All my husband's siblings-in-law love our son and are great with him. *Hodu LHashem Ki Tov!* Hashem orchestrated even this seemingly small, but so significant act, as a bonus for us.



Yossi is B"H verbal, but every once in a while, he gets obsessed with a word or a phrase, which he yells out over and over. This past Rosh Hashanah, throughout the Yom Tov, Yossi kept screaming in a very loud, excited voice: "Daven!" I felt this was Hashem's message, literally loud and clear, through my precious *neshamale's* voice, and boy, did I daven!



The following was told by an inclusion morah in a mainstream class:

One morning my class was walking to an assembly, and the hallway was crowded with all of the preschool classes heading in the same direction. Suddenly another *morah* turned to me and said: "I just counted, and we are missing two boys." I circled back toward our classroom to check, and a short way behind us I found Meir leading Yossi, a classmate with autism, gently by the hand. Without any criticism or arrogance, Meir said: "*Morah*, I know that sometimes Yossi falls behind, and I realized he wasn't in line anymore." Meir continued to patiently assist Yossi all the way, until both boys were seated for the program. Having a special sibling himself, Meir is a model of empathy toward the special children in our class!



With my daughter in the car, I picked up Chaim, my autistic thirteen year old, from his Sunday program. A relative, who is very close to Chaim, had a baby who was not doing well and was in the hospital. I heard my eleven year old daughter, who at times definitely expresses her annoyance with Chaim, talking to Chaim. She was telling Chaim, who is non-verbal: "Chaim, you must daven for Shanie's baby. Your *tefilos* are very special to Hashem. You are extra-*heilig* and Hashem will listen to your *tefilos*. Please, please daven!"

I was just amazed that she truly believes it!

This is a tough one! When we take our son, it's hard to control him, and possibly embarrassing to his siblings. When we leave him behind, we feel guilty and sad, and wonder if we could have taken him! Our son is on a very restricted diet, which usually makes it impossible to take him to *simchas*, so in a way, I am thankful that this difficult decision is out of our hands. It helps me to think that this is a big part of the *nisayon*, but I dare to hope it's temporary—that even special needs kids will grow up and mature!

Tips: 1) "Lev with Love" volunteers are lifesavers! 2) I just discovered the miraculous time-release melatonin, which keeps my son asleep longer. This enables me to have a babysitter at night when necessary.

May we be *zoche* to be fully part of, and enjoy all *simchas* really soon with *Moshiach! Hatzlacha!*

T.S.

Please do not rely on your own children to watch/care for your special child during a family *simcha*! Once, as a teenager, I took care of my older special sister at one of the first *simchas* in the family. At the end of the *simcha*, I burst into tears, as I was overwhelmed by having to take care of her and was unable to enjoy the *simcha* myself. Since then, my mother makes sure to find someone outside of the family to watch my sister.



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

We'd love to know how other families handle *simchas*, family events, etc. Do you take the special child along, and if so, how do you manage him? Are there other good ideas for childcare arrangements?

- Submitted by the F. Family

It really depends on how your child acts in social gatherings. My child has extreme social anxiety and throws tantrums, so why in the world would I take him? As the saying goes: "Your child won't remember the *simcha*, but you will never forget it!" There are many families out there that are ready to take our special needs child for a night. I call girls that work in his school, his *Bnos* counselors, camp counselors, etc. If you don't know whom to call, try calling your child's school and ask them for some names and numbers of the people who work with your child. Our job, as parents, is to reach out and ask for the help we need. On the other hand, if your child can handle being at a *simcha*, and it is not hard for you, then why not take him?

Yehudis Wolpin

Balancing our family and our special child at *simchas* is very challenging.

Now that our son is older and there are *yichud shailas*, going away for Shabbos is really difficult, so we have missed attending some occasions.

If I feel it's possible to attend, I will ask for help even when it is uncomfortable for me.

For his own aunt's wedding, we had a therapist bring our son. He was there for the pictures and then they left. (Unfortunately, he had to return at the end, as we had no one to watch him at home so late. It wasn't easy!)

When I made a *bris* this year, I asked his most high profile BCBA (Board Certified Behavior Analyst) to watch our son, as I knew she was the only one who could navigate it. She brought him at the end, when most of the guests were gone. He really enjoyed it for a bit, but then ran out to sit in the car.

Our son loves to be a part of the family, but it's just so overwhelming for him.

At times like this, I try to think about all the *brachas* that come from his *heilige neshama* and how lucky we are to call him our own!

E.D.

Baruch Hashem, we have been *zoche* to make three *chasunas* in the past two years. Our youngest, a non-verbal, low functioning 14.5 year old boy, was at all of the weddings, albeit with an aide. It was well worth the cost to hire someone to care for him so that we could be fully present for our other children. *Baruch Hashem*, he was able to be in pictures and dance with the *chasan*, but we did not have to spend the entire time watching over him. We also hired teens to watch him for as many *sheva brachas* as possible (during the week at home, and on Shabbos at the *seudah* with us). While they weren't professionals, it still allowed us greater participation in the *simcha*.

M.E. Weiner

It's 100% worthwhile to hire someone whom your child knows and likes to be his shadow at the *simcha* (or to stay home with him, if you prefer that). It will make all the difference. So spend a bit less on the décor or the flowers and hire the best person possible to take care of your child. You will not regret it!

N. M.

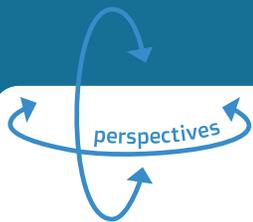
There is a woman in Lakewood who helps find babysitters for children with special needs (Malky Carlbach 848-480-3545). Hopefully there is a similar service in other communities. If not, maybe you could start making a list of appropriate people and help others who could use this information. It's a wonderful and much needed *chesed*.

C.T.

Question for the next issue:

My daughter is eight years old. She has special needs and attends public school. She's always so left out of things at home because she doesn't learn in Bais Yaakov with her sisters. I'd love to hear ideas from others about how to bring *Torah* and *Mitzvos* into her life.

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



Gitty Waxler

Day 1:

My sister Rivky recently gave birth and is having a difficult post-partum recovery. I offered to host her son so that she can focus on regaining her strength. I'm so excited to help out. I love my nephew Ari, and I think we'll have a great time together. He's four years old and oh, so cute! He'll play with our kids and enjoy! I feel good that my sister trusted me with her child. It's the first time that she's letting him go away.

Ari's father and mother show him a picture calendar of the days he will be at my home. They review it over and over again, so he knows that he is going for a short time, not forever. Even though they don't know how much of a sense of time he has, it does give him security on whatever level he understands.

As we travel to my home, I try to make arrangements to ensure that Ari will have childcare during the day when I'm at work. I make call after call, with no confirmations. I'm a pretty well-connected person in the special needs world; how do people without connections in the special needs world manage? By 8 PM, I realize that I've done all the hishtadlus I can. I finally (should've done this first!) turn to Hashem: He's Your child. I'm trying to help, but I need You to come through. I slowly relax, knowing that it's not in my control.

Ari arrives in our home towards evening. It's time to go to sleep. 7, 8, 9, 10 PM. He seems calm and relaxed but doesn't fall asleep. Hmm... so this is what Rivky talks about when she says he has trouble sleeping! Thankfully, at 10:30 I remember that melatonin sometimes helps him sleep. One melachew later, and guess what? By 11:15 he is sleeping. B"H!

Day 2:

When we awake at around 8 AM, Ari is happy and calm. He wants to sit and read books. How do I explain that I need to be at work at 9 AM? I try to give him his time, while simultaneously getting him dressed and ready for the day. B"H he is cooperative. We drive to my workplace and I find parking.

B"H, the childcare volunteer who agreed to watch him shows up. Wow, what a relief!

I check on him throughout the day. He looks happy and seems to be having a good time.

I finish work and we go home, but when we exit the car, instead of walking with me, Ari skips down the block. Interesting... I never saw him skip or run before. All of a sudden, I realize why—he's not wearing shoes! It's 30 degrees and the concrete is freezing. After my shock, I burst out laughing! Apparently, he took off his shoes in the car and left them there. I carry him the long block home.

Ari needs to de-stress. He chatters about various topics that don't seem to connect with each other, and I listen amicably, trying to engage in the world that belongs to him. He eats supper with the kids. He chatters straight through supper, without stop. The other kids are quiet. I realize that they, too, need a chance to talk about their day. I try to focus his attention on the food, but Ari refuses to eat anything. He takes a sip of soup after being given a red straw (his favorite color), and eats a tiny bite of chicken. He will only drink water and bottles. Contests, bribery, distraction, games—he isn't interested. His mouth is closed shut. So this is what my sister means when she says he doesn't eat. Well, I'm starting to understand!

After two hours of chattering, I'm starting to feel overwhelmed. I need a little space to breathe, to be. How did my sister last 4.5 years without a break? I feel myself caving in emotionally. I need him to go bed. We go straight to the bath. He spritzes water all over the bathroom (despite my reminders that the water must stay in the tub). "No! I don't want soap!" he cries, the tears collecting in his eyes. After some negotiation, he lets me put on a little soap. Before I can wash out the shampoo, he says: "I'm done!" and hops out of the bath! I try to dry him, but he runs to the toy he wants to play with.

When my 7:30 pm client calls for her appointment, I'm not ready. I had told her that my schedule isn't regular, so she called to confirm. I tell her: "Let's try for 8:00 PM." I feel so overwhelmed, I just want a quiet night. But there are life commitments, so I'll try.

Melatonin. Shema. Bottle. Bedtime. Ahhhh! The sweetness of melatonin once again. Thank You, Hashem, for this gift. Please Hashem, give every child tonight a night of sleep. Including ours! I leave the room with a sigh of relief.

I don't believe that I'll be able to give my client the attention she deserves, but I try. Strangely, there is something calming

about engaging in an interest outside this dear little boy. Though thoroughly exhausted, I enjoy the distraction of throwing myself into another sphere. It kind of keeps me balanced.

After my client, I return all my missed calls and deal with the other things that we call life. The girl who was supposed to watch Ari tomorrow will not be available, but then another girl called to see if I needed backup. Another hour, another miracle. Is this a bit of what the life of a special needs mother feels like?

Day 3:

we had a full night of sleep! What a relief!

I try to ensure a calm morning routine but when it's time to leave the house, Ari doesn't want to put on his coat. "I don't want to go. I want to stay home! The day is too long!" After some negotiation, he finally agrees to go if he can take his video along. At this point, it's whatever works. So on to work!

Ari is sadder today. He misses his Mommy and Abba. I hope I'm doing a good job as an aunt. I'm really worried that he barely eats. I don't want to send him home skinnier than he came.

I have a 5:30 meeting, outside of my regular work hours. Change of schedule for our little guy! I tell him about the change and he seems to react well. I take him to a volunteer who loves Floortime and always wanted to try it out on my nephew. I feel blessed that he will be in good hands. But then he refuses to leave the car. Thankfully, I am able to stay calm, even though the clock is ticking and I see I will probably be late for my meeting. After a few minutes, he agrees to go. What a brave boy!

We come home at 7. Ari is exhausted. He isn't used to so many people and so much stimulation. My mother stops by to visit. She tries to comprehend his issues as he sits and plays. "Do you really think he is on the spectrum?" "Do you think he'll ever be mainstreamed?"

I try explaining the diagnosis to my mother. Part of me feels that it's futile, since my mother is from a generation that sees "special needs" as a child with no hope and no future, but part of me wants to give her a chance. Because he looks really normal and is fully verbal, it's hard to see his challenges at first glance.

I tell my mother what to Google as part of her research trying to "get it." Most importantly, I try to explain that my sister needs support, validation, and encouragement from everybody in the family, since raising a challenging child is frankly, well, challenging!

After Ari's bath, he is ready for a bottle and bed. I make him his bottle. "Too cold!" he says. I pour it down the sink. I make him another one. "Too hot!" Another one. "It's spoiled!" I daven to Hashem that the next bottle I make should find grace in his eyes. Finally, he takes his bottle and goes to sleep. Thank you, Hashem!

I'm facing piles of laundry to fold. Lists of phone calls to return. But I don't want to talk to anybody. I don't want to see anybody. I need to de-stress too. I lock myself in the bathroom for a long time. Is this what's called coping?

Day 4, 5, 6, 7:

By now, Ari's honeymoon period ends. I have found him to be exceptionally sensitive to my emotional states, and as my initial excitement and energy wanes, his behaviors and difficulties increase. We have night after sleepless night. We have tantrum after tantrum.

I don't want him to watch videos while in my house, but after days and nights of sleeplessness, my strength is fading. I try giving him only Jewish videos. "I don't like these ones, these are too Jewish!" he says. It's 4 AM. Try negotiating with a 4 year old at 4 AM. I feel like he is the King of the house, and all must be done his way.

I am an adult with training, schooling, experience, understanding, and support; yet I am not managing. I have support around the clock—babysitting, morahs, and more—and I'm not coping. I love him so much, but one sleepless night at 5 AM, it comes to a point that I really feel myself losing it.

This brings me to a startling realization: I always thought that my sister wasn't doing "enough"—that if she would just be more structured, more firm, get Ari a different therapist, and so on, he would improve. Now I see how truly difficult it is to give every ounce of strength, physical and emotional, and not see the results you were hoping for.

My little taste of what it means to be a special needs mother taught me what every teacher, educator, therapist, and family member should know: never judge these special parents until you've walked a mile in their shoes.

Smart & Safe

Fraydel Dickstein

MEALTIMES & PESACH CLEANING

When Klal Yisrael left Mitzrayim, the pasuk says that they left “b’rchush gadol,” with tremendous wealth. Rabbi Daniel Kalisch explains that these words are describing not only Klal Yisrael’s financial state, but also their emotional state when they left Mitzrayim. They didn’t emerge as broken and beaten slaves, but rather as healthy, wealthy individuals. They didn’t just survive, they thrived.

When I heard the above *D’var Torah*, I was ecstatic, literally on a high. It was in middle of the summer, but I quickly opened a document that was titled “Smart and Safe #10,” as I knew I had to share this with all of our readers. These words resonated deeply with me as I feel they described my family’s journey with Yehuda. When he was younger, we lived in a state of constant crisis. You know the feeling when something is stretched so thin that you are sure it will break if someone so much as breathes on it? That was our family’s state – we always felt as if we were choking and only one breath away from snapping... I thank Hashem every day that our family emerged from a state of barely surviving to a place of thriving. We have come a long way, and are now in a place of feeling Hashem’s love so deeply, as if the *brachos* are pouring into our home through the windows and we need to grab containers to hold it all. We have come to a place of “b’rchush gadol” – of feeling so happy and highly privileged to have this special *neshama* in our home, with our children and us all in one piece. Ironically, this feeling of Hashem’s true love is often strongest when Yehuda is around.

There are still many days when we feel like we are just surviving. As I write this, what comes to mind is: “*Kol HaNeshama T’hallel Kah*” (every soul will praise you) which can be interpreted as: “*Al kol neshima v’neshima t’hallel Kah*”—for every breath, we thank Hashem. Survival itself is an unbelievable *chessed* from Hashem, worthy of us to sing *Dayenu*. When we also thrive, it’s *al achas kamah v’kamah* (how much more so)! We are overpouring with thanks to Hashem!

Mealtime Challenges & Solutions

This issue of *Neshamale* focuses on the topic of feeding. For most of us, this subject presents a challenge in one way or another. I will discuss the issue I grapple with most, as I know I am not the only one, although of course there are many readers for whom this particular challenge does not apply. It’s what I call the

“rice falls and kugel showers,” or perhaps “meal debris” is more accurate (though if it was only “meal debris” it would probably stay in the kitchen or dining room—yet these “snowfalls” tend to track everywhere!) Yehuda will not sit and eat nicely at home (although he sits at the table in school). He insists on running around the house, raining food as he goes. This is a work in progress, but I will touch on some practical solutions that have made this issue a whole lot more manageable.

Firstly, if you can use a Rifton meal chair, and have your child eat with a tray, it may be the biggest *chessed* for your child and family. Everyone will find it more pleasant if he doesn’t make such a mess and will eat his meals without sharing most of it with the floor (to my knowledge, the floor does not supply the child with any known nutrition).



Rifton Meal/Activity Chair

These chairs can often be obtained through insurance with a good letter from your OT and doctor. Safety concerns always needs to be stressed.



I personally would love a Rifton chair and planned to use it without shutting the tray, as Yehuda was too big to turn back the clock and start using a closed meal chair. I felt the sides would ground him and help him sit better. However, my insurance would only cover 50%, and I did not feel it was worth it. His incredible team in school put therabands on the two front legs of his chair. He can kick and tangle with it, which helps him ground.

TheraBands Resistance Bands Set, Set of 3, multicolored (\$14.15 on Amazon)



I designated him a special meal spot, against the wall and away from the table leg, so that he can tuck his chair in



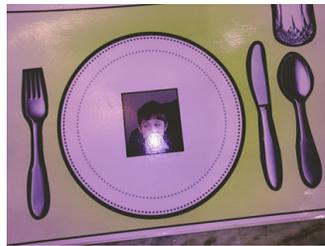
properly. The closer to the table his chair is, the less spillage there will be.

Putting a mat under the child's chair is another idea that makes clean-up easier.

Splat Mat High Chair Mat for Mealtime, Anti Slip and Waterproof Splash Mat
(\$28.11 in Walmart)



Yehuda uses a placemat in his classroom, as this helps him with a number of skills. His incredible teacher sent home beautiful placemats to enhance our Shabbos table, with pictures of each family member on them. This grounds Yehuda to his spot, and we always make a big deal about the beautiful placemats that Yehuda made for our family for Shabbos. Yehuda grows a little taller with each compliment sent his way. (I don't usually wash dishes on Shabbos, but I wash these placemats after every meal.)



Pesach Cleaning Ideas

Pesach will soon be here! Our question is—how are we going to deal with our children who, among other challenges, rain food all over our premises?

I spoke with a few mothers to hear how they manage. One mother said that a cleaning crew is the way to go. I second that. If you have a cleaning crew, then you can do most of it in one day. My biggest challenge is maintaining the twilight zone of having *chometz* in the house and also being *Pesachdik*. The cleaning crew helps with this problem, as you turn over later and have less of that challenging period of time with *chometz* and *Pesach*...

Another mother said she gets rid of all her *chometz* before she starts cleaning, as it would just be a waste otherwise. She buys *kitiniyos* and *Kosher L'Pesach* food to eat.

It does not sit so well with me to wait until the last minute. I can't risk being without help the week before *Pesach* and getting stuck... Here are some ideas I have come up with over the years:

I clean my bedroom and keep it locked. I feel comfortable cleaning the majority of the closets, as Yehuda doesn't touch most of them. Upon the advice of my *Rav*, I do the bare minimum. (I am embarrassed to say what that looks like, so I won't elaborate).

Another trick is I shop in advance for everything from sponges

and Shabbos shoes to bows and baking pans. I try to buy all the meat and chicken. I hide all the *Pesach* goods somewhere safe.

I turn over one locked fridge and freezer in advance. These things make a huge difference. Then, the actual cleaning, with a ton of cleaning help, goes really fast.

We don't change the dust ruffles, we just check that there is no *chametz*. For the most part we don't move furniture, but like I said, ask your Rabbi. My family *mishes*, so we buy all kinds of finished products—I always plan an extremely simple menu with tons of bought stuff so I don't feel pressured. Honestly, I often do make some nice food, but this takes the pressure off. One year I bought potato *blintzes* and then, on *bedikas chometz* night, I had some time, so I made my own. Guess which ones everyone liked better?

It helps to remember that appetites are smaller at the *Sedorim*.

The truth is that whichever way you do it, making *Pesach* is stressful and hard. I wish I knew how to make it not like that! I have learned how imperative it is to eat and sleep during this season, as otherwise I am sure to get sick. One thing I see is that when I am well fed and well rested, my ability to accomplish is many-fold.

One more thing, that may sound borderline insane, is that I try to keep up my exercise routine every day, even on the day of *bedikas chametz*. Anyone who sees me walking must either think that I snapped, or that I am just so super *geshikt!*

I can't wrap up this column without sharing a true story that happened one year. It was *Chol ha'Moed* and we were home in our *Pesachdik* house. I woke up in the morning to find a bag of flour scattered all over my kitchen floor. I can still picture the white dust everywhere. I know I didn't scream, I just went cold as I looked on in total horror. My husband called the *Rav*, who told us what to do. I remember vacuuming up the flour with my red Electrolux canister vacuum cleaner. Thankfully, we did not have to *kasher* the kitchen again. I have definitely learned a lot of lessons since, including not to keep flour in the house! I think that stories like these may be everyone's nightmare. I hope you take comfort in hearing that we survived and have since recovered from the trauma—though we have learned to be much more vigilant!

Dear Readers: You are all the biggest experts in getting to *Pesach* with your special children in tow. I am sure you have accumulated lists of great hacks. Here at *Neshamale*, we love to share with others. Even if your ideas seem very specific to you, chances are someone will springboard their own good idea off of it, or your tip might give someone *chizuk* for the day.

Please share your humorous (or not so humorous) *Pesach* stories with us as well!

Baby Album

C. K. T.

When my baby was born
I started an album.
I wanted a beautiful place
To record
The fulfillment of my dreams
And to remember
His all-important milestones:
His first days
His first smile
His first steps
His first day of school.

I lovingly picked out
The perfect infant photo
And pasted it on the very first page
Along with his birthweight and name.

But as time went by
My dreams remained unfulfilled
And my hopes unraveled into despair.
Where were the smiles
And the milestones
I had been so sure
Would be mine to treasure?

Instead of my baby
Growing and developing
I was the one
Who was forced to grow up:
To develop my *middos*
To mature in my *tefillos*
To take strides in my *bitachon*
To train myself to accept
With love and devotion
My special needs child
Who seemed so limited and flawed.

It's now years later
And sometimes I take out
That baby album
With the promising first page
And leaf through the blank pages
That follow it.

And in hindsight
I can say
That every single
Page in my boy's album
Is truly
Picture -perfect.



GLOSSARY OF HEBREW TERMS APPEARING IN NESHAMALE MAGAZINE

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

Arba kosos – The four cups of wine drunk during the Pesach seder
 B'nai Yisrael – The Children of Israel
 B'sha'ah tova – Lit: "In a good hour," blessing to an expectant mother
 Ba'al tashchis – Wastefulness
 Badeken – Ceremony of veiling the bride before she goes to the Chuppah
 Baruch Hashem – Praise G-d
 Bitachon – Trust (in G-d)
 Bnos – Girls youth group
 Bnos Yisroel – Jewish girls
 Bracha/brachos – Blessing/s
 Bubby – Grandmother (Y)
 Challah – Special bread for Shabbos and holidays
 Chasan – Groom
 Chassidim – Sects of Torah Jews who follow the teachings of a particular Rabbinic leader
 Chasuna – Wedding
 Chesed – Acts of kindness
 Chuppah – Wedding canopy
 Daven/davening – Pray, prayer (Y)
 Emunah – Faith
 Erev – Evening; usually used as the time period before Shabbos or a holiday
 HaKadosh Boruch Hu – The Holy One, Blessed Be He (G-d)
 Hashgacha Pratis – Divine Providence
 Hatzlacha – Success
 Heilig – Holy (Y)
 Hishtadlus – Effort
 Kabalas Panim – Wedding reception before

the Chuppah ceremony
 Kallah – Bride
 Kedusha – Holiness
 Kever, Kevarim – Grave/s
 Kinderlach – Children (Y)
 Klal Yisroel – the Jewish People
 Koach – Strength
 Licht bentching – Candle Lighting (Y)
 M'samaech – to cause to rejoice (ie: to make a bride and groom happy)
 Malachim – Angels
 Mashiach, Moshiach – the Messiah
 Mazel Tov – idiom: Congratulations!
 Menucha -- Rest
 Midos – Character traits
 Mishloach Manos – Gifts of food sent on Purim
 Mitzrayim – Egypt
 Mitzvah/mitzvos – Torah Commandment/s
 Neshamale – Precious little soul (Y)
 Nisayon/nis'yonos – Test/s
 Olam haBa – The World to Come, Afterlife
 Olam haZeh – This World
 Paroah – Pharaoh, the ancient King of Egypt
 Pesach – Passover
 Psak – adjudicated Jewish law
 Purim – Joyous Jewish holiday
 Rav/Rabbanim – Esteemed rabbi/s
 Rebbe – 1) Elementary grade Torah teacher; 2) Jewish spiritual guide
 Rebbetzin – Rabbi's wife (Y)
 Ribono shel Olam – Master of the Universe (G-d)

S'char – Reward
 Seder – Ritual Passover dinner service
 Sefira/Sefiras HaOmer – Seven week period between Pesach and Shavuos
 Shabbaton – Sabbath weekend retreat
 Shabbos Seudas – Sabbath meals
 Shailah/s – Question/s
 Shechina – the Divine Presence
 Sheim HaShem – the Name of G-d
 Sheva Brachos – Festive dinners held during the week after a wedding
 Shidduch – Marital match
 Shinoi – doing something differently (ie: for halachic reasons)
 Simchas Torah – Holiday of "Rejoicing with the Torah"
 Simcha/s – Joy; joyous occasion/s
 Tefilla / Tefillos – Prayer/s
 Tizku l'Mitzvos – idiom: May you merit to perform more Commandments
 V'ahavta l'rei'echa kamocho – Love your neighbor as yourself
 Yartzeit – Anniversary of someone's death (Y)
 Yeshuah/Yeshuos – Salvation/s
 Yichud – Prohibition of men and women being alone together
 Yom Kippur – the Day of Atonement, the holiest day of the Jewish year
 Ze'ro'a – Shankbone, one of the ritual objects on the Seder plate
 Zoche/zechus – Merit (verb)

In the incoming Summer issue we plan to print a section on the topic of "**The Bar Mitzvah: A Special Simcha for a Special Boy**". We are looking for your input to help cover this theme from all angles. Please submit your articles, stories, poems, thoughts, concerns and advice that may be of interest. Your anonymity will be protected if requested.

We always welcome, Wow! Stories and Sweet Spices (hashgacha) stories, as well as any questions you may have for a Rav, a doctor, or a social worker.

Deadline for submissions: **May 20th**
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Mail: 112 6th St.
 Lakewood, NJ 08701

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Tov*

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“ Those who sow in sadness
shall reap with joy ”
(Psalms 126)

