

נשמחלה

*Sharing Our Special Experiences: Chizuk & Inspiration*

# Neshamale

magazine

## JOURNEYS TO ACCEPTANCE

THE ROAD TO RAISING HIGH-  
FUNCTIONING TEENAGERS /4

NEW STORY SERIES!

**DETECTIVE SHANA,  
PRIVATE EYE /18**

תש"פ // SUMMER EDITION #3

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Dear Readers,

“How are you? How’s it going?” I think that became a loaded question during COVID-19! In the first weeks of lock-down, I answered: “Great! We’re actually enjoying it!” Avrumi did well for the first week or two. But after Pesach, things got much harder. He desperately needed routine, a social life, and more stimulation. When the question came, I bravely answered: “It’s tough, but we’re hanging in there!” And then came a particularly harrowing day, when one of his therapists called to check in. I admitted to her that we were hanging in there, but the rope was getting very, very frayed—I was afraid it might snap...

I’m sure you’ve all had those tough days too, and hopefully, some better ones as well. In these pages, you will get to hear some of our readers’ experiences and perspectives on this topic.

In truth, I pushed off writing this piece, again and again. In general, I like to be organized and not wait until the last minute. So why shouldn’t I write the editorial early on in the game? By the time the past issue came to your mailbox, COVID had already taken over our lives. Confident that COVID life would be a distant memory by the time the next issue came out, I decided to wait a bit, so things would sound current. At first, our worries were very practical – like making Pesach while having our children home. As the virus spread and we started hearing besuros ra’os, our worries grew, and our tefilos became much more desperate. Every time I looked at my to-do list and sat down to write the editorial, I got stuck trying to picture it being read at the end of June. Who knew which world we would be inhabiting by then? Would COVID be a distant memory? Or would it get worse? So, so many questions... and not so many answers.

The uncertainty was (and still is) one of the very challenging aspects of this already devastating situation. In today’s world, most of us are not accustomed to feeling so helpless, so uneducated. But some of our families have actually lived with the reality of the unknown for a long time. Some children with special needs fit neatly into a box with a label. Their family knows, more or less, what to expect and how to get there. It doesn’t mean it’s an easy journey, but they do have a GPS.

There are, however, other children, who seem to have come without any instructions, any titles, or any expectations based on others’ experiences. At first, the baby looks healthy and normal and the journey commences with a joyful, typical start. But slowly, the scenery starts to change.

Are we lost, the parents wonder, or maybe this is just a short detour? This wasn’t exactly what was expected. They call out for help, but no one really has answers. After rounds of testing and countless appointments, there is still no clarity, no diagnosis, and no reassurances that things will turn out fine. These children can be “high-functioning” enough to be mainstreamed, yet challenged enough to never truly fit in. The feeling of always being different and “not enough” is painful for the children themselves, and heartbreaking for their parents to watch. (I would like to acknowledge that there are also children who are not “high-functioning” at all, who also do not have a diagnosis, but that is a subject for a different time.)

This situation is not a nisayon that I was given, as my son has very clear disabilities and a diagnosis. In fact, I remember that when I called my family members to inform them of the diagnosis, I started by saying: “I have good news and bad news. The good news is that we have a diagnosis. The bad news is that we have a diagnosis.” As devastating as it is to receive a life-changing severe diagnosis, it is also a relief and a bracha to have the clarity, the information, and the resources that come along with it. I was, therefore, fascinated and moved to hear Devorah and Rochel’s stories. Two mothers who have invested their all, and then some, into raising their special neshamales, who are now teenagers. They share their stories with honesty and courage, and give us all something to think about.

For me, personally, the line: “the grass is always greener on the other side” came to mind as I heard their stories. I go to great lengths to do everything possible for my son to be as “high-functioning” as possible. It was startling to see that my very goal is their reality, and it’s not an easy one at all. I came to the realization that the destination I had subconsciously entered into Avrumi’s GPS was actually a mistake. “As high-functioning as possible” was NOT where we needed to end up. I decided to reprogram it to: “fulfill his potential, while bringing out the best in him and his family.” Which, when you think about it, is really every human being’s goal in life, regardless of ability or circumstances.

May we all be zoche to special help from Above in navigating our way through raising our special children. And though at times the road will feel bumpy, and it may seem as though we are lost, let us try, nonetheless, to enjoy the spectacular scenery that comes along when you have a special neshamale in the back seat!

*Chayala*

# Journeys to Acceptance

## *Two Mothers' Paths of Challenge & Growth*

### Raising Dovid

Devora Stein

#### Meet Dovid

A wave of sadness washed over me. Yet again, my son, Dovid, came to tell me how his classmates had bullied him. Dovid, now in high school, is an extremely high functioning, sweet special needs boy. He struggles to interact with his peers, as making friends has always been a challenge for him. Due to his social differences, he isn't interested in the same things as others his age. This has caused a lot of loneliness for Dovid over the years. He is great with younger kids, very personable with adults, but has a hard time relating to kids his age. He is different. They know it, and he knows it, too.

Learning is very difficult for him as well. It isn't his fault. He usually tries very hard, but paying attention is quite challenging for Dovid, especially when there are more exciting things to look at all around him. Dovid's various learning disabilities have caused him to fall well below grade level in certain subjects. Since Dovid finds it so challenging to stay focused enough to study, his grades, at times, reflect his difficulties. This, in turn, negatively impacts his self-esteem.

Dovid will say to me: "I am dumb" or "I am stupid," and I cringe when I hear those words. There is so much good about this special boy. I just wish the world would see it! Dovid needs to see it too. It is at those times that I need to remind him of what a kind, helpful person he is. I remind him that he is the first to jump up and help a teacher in school, or a guest in *shul*.

#### Stepping into School

In elementary school, it was too difficult for Dovid to stay in class, because he couldn't keep up with the learning and he felt he needed to leave his classroom.

Once in the hall, he would always eagerly put himself to work around the school building, wherever he saw that help was needed. He would help direct traffic at the dismissal line, give out milk in the breakfast line, or

stamp envelopes in the office. He would even voluntarily help the janitors.

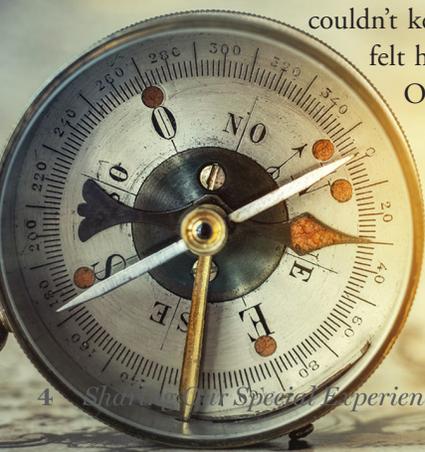
As an aside, I recently needed to buy a new mop, and Dovid asked if he could come shopping with me. Once we were in the store, it became apparent why. He beamed as he showed me the "best mop to get, because it is the kind they use" in his school. Mopping the kitchen floor is one of Dovid's weekly pre-Shabbos chores, and he wanted the right tools for the job. Ah, the things he was learning in school!

Honestly, it did frustrate me that, no matter what time of the school day I would show up, there was Dovid, in the hall and not in class. Is this what I was paying tuition for? Why was my child never in class? But maybe this is how he contributes to society, maybe this is how he learns best. It was a shift in perspective that I needed to make. It wasn't going to earn him good grades on a report card, but it was going to earn him good grades in *Shamayim*.

At the end of 8<sup>th</sup> grade, Dovid's school recognized his many contributions to the smooth running of the institution. He may not have excelled academically, but he excelled in his personality. He was always jumping up to help others with a smile, so they awarded him with a service award at graduation. He was absolutely beaming and bursting with pride, and so were we! He had kept the award a secret from us for over a week! We didn't find out about the award until we saw his name in the program at the graduation ceremony. My husband and I were absolutely floored and brought to tears, as we watched our son accept his award on stage, with the most radiant smile on his face.

#### A Bumpy Social Life

I often feel sad for Dovid. He is quite frequently the "last one picked and the first one picked on." Dovid quite regularly laments that the boys don't want him as their *chavrusa* in *shiur*, or don't want him on their sports teams. And when he is on their sports team, he often gets little-to-no playing time. I am in agony knowing that he is feeling such rejection. To try to remedy the situation, I sometimes



speak to the teachers or administrators to fix the *chavrusa* or sports situations. But whatever improvements happen don't seem to last for long. I know he may not be a strong ball player, but I also know that he would love to be given the chance to help his team.

There are times when I feel that having a special needs child is quite challenging. It is then that I try to imagine what it must be like for him to know that he is different, yet not be sure what he can do about it. Dovid would love to have friends his age. He would love to fit in. He would enjoy not being bullied anymore because of his weaknesses and differences. Unfortunately, boys commonly pick up on his immaturity and delays, and taunt him for it. Dovid would also like to be able to attend a full day of classes in his yeshiva like all the other boys. But academically, he's not ready for that. The services he needs are just not available there.

## School Issues: An Uphill Climb

My husband and I have gone to tremendous lengths for Dovid, trying to get him the best specialists, therapists, and doctors. We have spent thousands of dollars beyond insurance on appointments, medications, and testing, and now we are trying to find the best school for him, as well. Since we do not live on the East Coast, our choices are very limited. We have come to the disappointing realization that the most suitable school for Dovid may not even be a Jewish school. We are looking into a therapeutic school, which would be a better environment for him academically, socially and emotionally. Since it is a therapeutic setting where all of his classmates would also have special needs, they would naturally be more understanding of his challenges and not taunt him for it. The downsides to choosing this school are that it is well beyond our means financially, and there are no Judaic studies. In order to subsidize the tuition, we have hired attorneys to help us obtain the necessary funding through our local public school system. We are still in the middle of this long journey, which has been dragged out because of the restrictions in place due to Coronavirus.

I so badly want Dovid to succeed. I want my son to feel good about himself, but life is so challenging for him. Dovid also struggles with anxiety and an unstable mood at times. It is hard for him to find a place where he belongs. I hope that we can find that place for him. We are still on that journey, which seems endless at times. We keep thinking we have found a good fit, but then it doesn't seem to work out for him.

## Our Current Location

It is comforting to know that, at times, he shows his appreciation for our efforts. Let me share an example: When I was driving my son's carpool this year, my

phone was on the dashboard and Dovid was in the back of the minivan. As I was waiting in front of another boy's house, I received a text. The text was from my son in the back seat. It said: "I love you." I was so incredibly touched; it meant so much! So often, out of the clear blue, Dovid will come up to me and give me a big hug or ask to cuddle. He craves attention and love just like any other child. Dovid's heart of gold and his smile can get me through the toughest days.

It is my job, as his parent, to help him learn to recognize his strengths. He needs to see all that he is capable of. It is not enough to merely compliment him when something goes well. I need to show him how successful he can be. He may not become a mathematician when he grows up, but we are finding areas where he is incredibly talented. He loves to cook and work in the kitchen, and he often makes delicious salads for the family. He is exceptionally creative with his Lego assemblies. Maybe he will work in a kitchen or be some kind of engineer when he is older. His warm personality will help him go far; it isn't all about the academics.

People stop me all the time and tell me how sweet, friendly, and helpful Dovid is to them. He really is a gem. He will race to hold the door for a teacher or help someone with their packages. If he sees a guest in *shul*, he will show them where to find a *tallis* or *siddur*. And if the guest has a young child in tow, Dovid will take the child to the Candyman. It is important for me to remind myself, and him, that although it is terribly sad that he doesn't have friends his age, he is making such a *Kiddush Hashem* as he runs to help those around him.

## Lessons Learned Along the Way

I remind myself that I was given a special child to help me bring out my own potential. This journey has taught me tolerance, patience, and acceptance. At times, when Dovid's behavior or mood leaves much to be desired, I need a lot of those things. Having a special needs child has also helped me give guidance to other parents in similar situations. I can relate to the pain, frustration, and heartache, since I know what it is like to watch my child struggle to do the things that other kids his age do with relative ease.

Although life will likely turn out differently for Dovid than I may have imagined, it won't be inferior. His triumphs are all-the-more victorious, and his achievements are all-the-more glorious, as he reaches his goals. He has so much to be proud of, and I am so lucky to be his mother.

I love Dovid so much! I can now see past the differences to all the unique qualities that he possesses. It is my hope that he will set high goals for himself in life—academically, socially, and professionally. I want him to reach his goals and feel fulfilled with his accomplishments. Dovid is such a special person! He has taught me to stand up against adversity and make the best

out what life has given us. He has also learned not to fight back when others pick on him—he is better than that! Dovid has already demonstrated, in so many ways, how he has taken his strong desire to help others and put it to such good use. He

may not have been born in the fast lane, or given the latest model car, but I am sure am proud of how far he has gone!

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*Devora Stein is using a pen name. She can be contacted through Neshamale Magazine.*

# Raising Pessy

as told to Tzipora Friedlander

## Meet Pessy

At first, we didn't realize there was anything different about our little Pessy. Looking back, there were some pointers, but nothing to make us think she was 'special needs.' As a baby, she never put things in her mouth like all babies do. Rather than find that worrying, it fascinated me.

As she grew, and developed, we noticed she was very shy, but still, it didn't concern us too much. When she started nursery, her teachers started mentioning that perhaps she needs some extra help. It was when she was seven, starting first grade, that it hit us: she was not 'typical' and probably never would be. Her peers were starting school, ready and excited, while she lagged behind.

So began our journey. A journey fraught with challenges, a journey traveled in the dark. We grope around, trying to find a signpost, a trail, but there is none. We can't find anyone who has walked this path before us, whose footsteps we can follow. So we walk, stumbling our way through. Sometimes it seems we find a path: this therapy, that method, but it turns out to be a dead-end, leading us right back where we started. Sometimes we do find a path: a method, a specialist, and we find ourselves one step closer to our goal. One step closer to our vision of our precious daughter reaching her potential.

## Stepping into School

We kept Pessy in a mainstream setting throughout her school years. She was too high-functioning for any special-ed program we looked into. We didn't want her to learn from and copy behaviors of lower-functioning children. We felt that she should be in a mainstream setting so that she could learn from her peers.

Within the mainstream setting, Pessy needed a lot of therapy and help. She was pulled out of class and received therapy at home. At one point, she was in the resource room for two years, then we put her back into the regular classroom. One summer, we sent Pessy to a special-ed day camp in

Brooklyn and they did a ten-day ABA program with her, which was amazing. I was very nervous that she'd pick up behaviors from the other children there.

I tried everything under the sun. There's no method, therapy, or program that I heard of that I didn't try: floortime, counseling, everything! We were constantly trying different things, and looking into different programs. Some were great, some not, and some were great—until they stopped working. From it all, we found ABA to be the most effective. But it was a combined effort that got her to where she is now. The tutor helped her with her learning disabilities, a therapist worked on her social skills, the OT helped with her executive functioning... and with all of it together, we saw progress and she developed.

Being that Pessy doesn't have a clear diagnosis, there's no one perfect program for her. Children like her have very little available to help them, and they tend to fall through the cracks.

## A Bumpy Social Life

Socially, things were very hard. At

first, people don't realize that Pessy has special needs, until there's an incident, or until you try having a conversation with her. She's very sweet, she has a good sense of humor, and she can have fun. Parts of her are very normal.

One year she went to sleep-away camp and had an amazing time. She loved it so much that, the following summer, she wanted to go back for the full summer. That summer though, it was a disaster. She was bullied and was miserable. She never went to camp again.

Growing up, Pessy experienced rejection from her peers over and over again. She never fit in, she wasn't 'with it,' she didn't pick up on trends. She wouldn't pick up on the 'in' thing, be it stickers, napkins, or erasers. She was treated as an outcast, looked upon as different and strange, and she felt it. She realizes there's something different about her, but can't figure out what.

Pessy would try to get involved in friends' conversations, try to be part of things, but she wasn't successful. She would talk about



things that interested her, not picking up cues that her peers weren't interested in what she was saying. It's like she's wrapped up in her own world and doesn't know how to look beyond herself and see the other person's needs, feelings, and interests.

I remember when we sent Pessy on a trip overseas, and she stayed at my friend's home. My friend's daughter was determined to give her a good time, genuinely trying to be nice.

But Pessy was oblivious to the reality that this girl was working hard to entertain her. When they went to the grocery store, my daughter didn't think to offer help to *shlep* the groceries. She didn't think to try to make things easier or more pleasant for this girl. Like a young child, she saw herself as the "queen" and didn't have the sense to reciprocate to the girl who was trying to befriend her. Inevitably, that girl (as well as most other girls over the years) had enough and lost interest in the relationship.

## School Issues: An Uphill Climb

Throughout her school years, there were some nice girls who would talk to her and include her. But a lot of girls were mean and snobby. My daughter became very cautious and wary. She feels when she is being excluded, and every snide comment really hurts her.

In high school, things got even more intense. The social scene in high school is hard and complex for anyone, with cliques, intense pressure to 'fit in,' and politics. For Pessy, it was a disaster. While she was in high school, we moved to Lakewood. It wasn't realistic to switch her to school here, so at first, she traveled to Brooklyn for school. Then, things got so bad socially, that we had no choice but to take her out. Once again, we ran around looking into every program we could get our hands on. But we ran into the same problem as before: every program was for lower functioning girls; there was nothing catering to people like her.

Believe it or not, Pessy ended up staying home for a year and a half. As you can imagine, this was very challenging on many levels. The boredom was intense. She slept late, until 11 or 12 every day, as she had nothing to wake up for. For lack of any schedule, she came along with me on my errands. With Hashem's help, we got through that very difficult time.

## Our Current Location

Pessy is now 19 and attends an ABA program. She "works" in their preschool and also receives therapy. It's a nice arrangement. She has a job, so she feels good that she's working, and she's getting her therapy at the same time. It's not the typical arrangement, and I'm very grateful that we were able to make it work. Of course, it's not without its

hurdles. Her direct supervisor is a young woman close to her age and my daughter is jealous that she's her boss. It is like a mirror for her, as it highlights for her how "different" she is.

With all of our efforts and all of the progress, Pessy is still missing a lot socially. For example, I have a neighbor who lets her come for an hour a week to 'help.' She loves to go; she loves working with babies. Last week, when she was there, something happened in their home and an uncomfortable situation ensued. To anyone else, it would have been obvious that it was time to leave, but not to Pessy. Once they asked her to go, of course she left immediately. She always wants to do the right thing, she just doesn't know what that is on her own.

Unfortunately, she doesn't really have any social life right now. She goes walking with two girls her age in our neighborhood. But when she comes home she says, "I'm not going again, I was just walking next to them, I wasn't part of it." One on one works better, but then we need someone to be in the mood to come over and spend time with her.

## Lessons Learned Along the Way

Yes, it's been a journey of challenges, but it is also a journey of growth. Our journey has forced me to learn life's lessons, to move beyond my comfort zone—beyond what I believed I was capable of—and to stretch myself in ways I could never have imagined.

I've learned patience. I've learned the power of unconditional love. I've learned how to get along with people who are not 'my type.' I've learned to respect people's emotional needs. I've learned how to empathize, really empathize—to look at another and try to understand her side, her thoughts, her feelings. I've learned what it means to go the extra mile for those we love, to do whatever we can, with all our being.

I've learned about coping. Coping when things are not the way we want it to be. About accepting Hashem's plan and moving on. I've learned how to be creative in difficult times, to find solutions to problems that seem insurmountable. I've learned that my child's behavior is not a reflection of me. I've learned how to nurture her dreams, even when they seem impossible. I've learned to smile and be happy, despite the harsh reality.

... And it's a journey of hope. I hope for the day that Pessy will recognize the strengths that she does have and use them to be more of a contributing member of society. I hope that she will learn how to socialize enough to have friends and relationships. I hope for the day that my daughter will be able to get married and build a happy, thriving home. Until then, I will keep on doing my part, to guide and direct her on the path that is her life's journey.

# From The Doctors Desk

## | *Bifocal Lenses for Children with Down Syndrome: Looking at the Research*

Robert Lederman FCOVD (*Fellow, College of Optometrists in Vision Development*)

*Just a week after Yaakov, a 6 year-old boy with Down Syndrome, received his first bifocal glasses, his mother called my office excitedly to tell me that no one in school could believe the almost “miraculous” improvement in his ability to concentrate when looking in a book, and in his coloring and drawing, too. Yaakov had already been wearing glasses for two years, but getting much-needed bifocal lenses suddenly made the world up-close so much clearer. Suddenly, letters and lines looked clear.*

All the evidence points towards the fact that **at least 75%** of children with Down Syndrome have reduced accommodation. This means that from up close, things look blurred.

Kids don't want to look inside the book when the words aren't clear. And, though you're trying your best to help children reach their potential, it's really hard to keep looking in a book, color in the lines, or learn to read, when you're working so hard to see the lines, or the letters and the vowels, and just not managing.



After all, a blurred “tzereh” can look like this: which might be read as a “patach”.

A blurred “segol” like this: might be read as a kamatz.

A blurred looks quite like a

**Bifocals are Best:** All the studies to date (see below for links) show that giving bifocal lenses to children with Down Syndrome, who require them, helps them to see well, up close.

**The Surprise!** The big surprise is that the research (<https://www.sciencedirect.com/science/article/pii/S1091853114004406>) shows that children with Down Syndrome who have bifocal lenses are MORE compliant in wearing their glasses than those who get regular glasses. Many children with Down Syndrome are hypersensitive, and would only wear the glasses if they felt

that they could see better with them. Unfortunately for many, their potential of seeing clearly, even with glasses, is reduced. So often, they don't feel the glasses bring them much benefit. They don't feel that the glasses make a big difference when looking at large objects, and the words on the page remain small. With the bifocal lenses, things up-close are suddenly significantly clearer! Their ability to color, draw, and progress in reading can suddenly improve dramatically.

**Conclusion:** All the research points to the fact that children with Down Syndrome do better with bifocal lenses. Thus, they will be more able to cope with the up-close visual demands of their therapy/lesson! I prefer to use an evidenced-based approach and check every child regarding the need for bifocals. This check requires more advanced testing skills and can only be carried out without eye drops.

People with Down Syndrome have many challenges (communication, the ability to cooperate for long periods, etc.), and vision is certainly one of them. That's why choosing the right eye-care provider for your child is something that is so important. Board certified Developmental Optometrists are the specialists who understand the impact of physical development on the ability for vision to emerge as the dominant sense. They also understand the deep relationship between vision and overall cognitive development. In addition, they will take the time to look at vision beyond just seeing 20:20. Find your local developmental optometrist at [www.covd.org](http://www.covd.org)

People with Down Syndrome are not the only population who struggle to meet the visual demands of the classroom. Being able to navigate a page means that in addition to maintaining a clear picture for each eye, we need to be able to carry out the tiniest of eye movements (called saccades). If you hear of any child with fine-motor issues, remember that the finest of all the fine motor are the oculomotor (eye movements) that we make when reading. These eye movements are learned, and can therefore be developed. Under the supervision of a developmental optometrist, the

# את פתח לו

Leah Tawil, SLP

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

## Laundry and Language

Laundry. Like it says in Pirkei Avos: "לא עליך המלאכה לגמור" ולא אתה בן חורין להבטל ממנה. Well, maybe our sages didn't say this about laundry, but it certainly does apply. Laundry is definitely one of our essential services! How about if we *fold* some techniques into this seemingly mundane task, to occupy your "helper," and simultaneously incorporate some language and learning? Here are some ideas to try:

**Sequencing:** Use sequencing vocabulary, such as "first" and "then." For example: "First we wash, then we dry" or "First we fold, then we put away." (If you want to be really ambitious, you can even take or draw simple pictures of yourself doing the various steps and hang them on the wall to refer to during future laundry sessions.)

**Opposites:** First, show both: "This is dirty and this is clean." Then, introduce one of them, for example, the concept "dirty". Say, "This one is dirty, let's find another one that is dirty. Is this one dirty? No, this one is not dirty. Or, YES, this one is dirty!" Usually, introducing one opposite concept at a time is less confusing than trying to introduce both at the same time. It's also easier to track progress.

You can work your way through these words as you sort or fold: dirty/clean, wet/dry, hot/cold, white/dark/colors, big/small, empty/full, soft/rough, short/long.

**Possesives:** If you have a family picture or photo album nearby, you can use it to work on possessives, such as: "This is Moishy's." Don't worry if the possessive 's' doesn't make it in yet. Working on the concept should come first; you can add the grammatical structure later. Depending on your child's level, you can teach possessive pronouns like this, too (ie: his, hers, theirs).

**Matching Categories:** Try sorting by colors, by people, or by types of clothing (ie: pajamas, boys', girls'). For example, hold up a pair of pants and encourage your "helper" to find another pair of pants. You can also present him with a choice of two articles of clothing and show him one to match it to. Who knows? You may discover a great socks "pairer"!

So, get moving, because there's loads of language to be found in your laundry room!

Acknowledgements to Esti Sochaczewsky, MA CCC-SLP from Spark Therapy Services for the ideas included in this article.

ability of a child to accurately scan can be improved enormously. Furthermore, we need our eyes to work in tandem, and vision therapy trains the brain to be able to control these binocular movements, to a level of automaticity. And that's what we need, because there is so much processing that is required at the same time that the reader is organizing all these aspects of his/her visual system. About 20% of readers are not meeting the visual demands of reading in an efficient way. 4/5 people with a reading difficulty have a visual component to the problem. Developmental Optometrists use lenses, prisms, and colored overlays/lenses to help people achieve more. Optometric vision therapy takes care of those aspects of vision that lenses alone (prisms, bifocals, colored overlays/lenses) cannot. Everyone deserves a well-functioning visual system that does not interfere with their ability to reach their potential in life. In the majority of cases, in addition to the ideal glasses, it is optometric vision therapy that will bring someone to their maximal visual efficiency. And that can be life-changing.

Here is a link about vision in the Down's syndrome population. It is a wonderful paper and I highly recommend it.

<http://onlinelibrary.wiley.com/doi/10.1111/j.1755-3768.2010.01944.x/full>  
Contact [neshamalemagazine@gmail.com](mailto:neshamalemagazine@gmail.com) for a list of more links

Robert Lederman FCOVD is an acknowledged leader in the field of developmental optometry. People travel to Jerusalem from around the world to consult with him about their vision. Together with his team of Optometric Vision Therapists, he has successfully treated thousands of people who have not found solutions to their visual challenges elsewhere. His patient population includes children and adults with reading difficulties, those with AD(H)D, people on the Autistic spectrum and those with Down Syndrome. Robert Lederman has spent much of his professional career clarifying how the visual demands of reading vary from language to language. He has lectured over 200 times about vision over the last 25 years both in Israel and internationally to varied audiences including teachers, neurologists, ophthalmologists, occupational therapists and psychologists. For more information visit [www.ledermanvision.com](http://www.ledermanvision.com)

# SPECIAL PARENTS of SPECIAL CHILDREN:

Sara Lieberman

## Our Interviewees:

**Rochel**, mother of Malky (8), who is non-verbal, non-mobile, and fully dependent, with a diagnosis of spastic quadriplegia.

**Chana**, mother of Nachman (11), with a diagnosis of autism.

**Tova**, mother of Yaakov (16), who is the oldest in his family, with a diagnosis of autism.

### How are you managing through this corona era?

**Rachel:** *Boruch Hashem*, I'm managing better than what I anticipated, considering the situation.

In some ways, I miss "normalcy." I miss the quiet time I used to have when my kids, including my special needs child, were in school. I miss having a cleaning lady, as well as other help and therapy for my special needs daughter, that I used to have. I'm shocked and saddened about the news of people that I knew and cared about who passed away, and of so many close people who lost loved ones. However, I have seen *siyata d'shmaya* in various difficult situations, and I have found that a hard day or a hard moment is usually followed by an easier one. I hope with *siyata d'shmaya* to not just survive and pull through somehow, but to become a better person from going through these hard times.

**Chana:** There's a lot of *siyata d'shmaya* ...

**Tova:** In a way it's really nice, it's a slower pace of life. It was my family's first time making Pesach. We all worked together, calmly and pleasantly. One of my sons found jobs that he could do along with Yaakov, which was so nice. We had a magnificent Yom Tov at home. Everyone loved it, including Yaakov. After Pesach, we had to adjust to the at-home school experience, which was overwhelming in the beginning, but we are down to a routine by now. So it's been pleasantly functional in a very dysfunctional situation!

### What does a typical day with your special child at home look like?

**Rachel:** Although Malky's more bored than usual, she does enjoy being home with her family. I try to give her siblings space and not burden them. But they have really stepped up to the plate. They voluntarily go over to their sister to *shmuz*, play, help with feeding her, take over with some of her exercises, and take her out for walks.

Without the usual aides coming, taking care of all Malky's needs can be physically and emotionally challenging. Her mealtimes are very time consuming, due to severe oral motor difficulties. We give her the rest of her nutrition and hydration via her g-tube. Her therapy and physical exercises are very important, due to her condition, so I try to find ways and time to get some of them done, incorporated into her daily routine.

Socially, she can join in family activities; for example, sitting near me (or my older daughter) when we're baking, with a piece of dough placed in her hands. She listens in, with her younger sister, to her sister's Morah davening and teaching on the school hotline. When the weather is nice, we put her in the swing outside, or take her for a walk in her stroller or stander. In these ways, I hope she's continuing to be stimulated, despite missing out on school and her regular therapies.

**Chana:** Although we've had some challenging days, more often

it goes well. Nachman gets dressed, eats breakfast, and keeps occupied by taking pictures and videos on my camera. He goes out from 11:30 to 3:00. After supper, we go out for a drive or a bike ride. In between the outings, he finds ways to amuse himself, like jumping from bed to bed, and trying to do a flip in the middle. He bounces on the cushions of the couch on his knees. Sometimes he even does something educational, like reading alef bais cards, or spelling words out loud.

**Tova:** Even though Yaakov has a diagnosis of autism, for some reason, this kind of change doesn't bother him. He likes being home. He doesn't really miss school. He never enjoyed getting up early or working on schoolwork.

He plays pretty nicely with my two youngest kids, as he relates to their level of playing. He gets wild with them, but they play running, falling, and laughing so he and the baby are entertained. Some of the older kids are more bothered by him, because he's loud and he goes into their space and demands a lot of attention.

Before Corona, we had an ABA therapist (we call him Yaakov's counselor), who was coming every night for two and a half hours. They would do fun activities while working on behaviors. When corona started and we had to stop the counselor, it became really hard because he had no school and no evening activities. Once things eased up a bit, we got the counselor back, and it's really much better. Since they can't go out, they're doing house projects, like redoing the tiles in my basement. I feel like every stage with Yaakov, Hashem sends me His *malachim*. We are very grateful for this counselor; we could not have survived corona without him!

Yaakov has school online now. It's only two classes a day, but it's good for him. The Menucha organization set up a Sunday night learning program, and now the boys learn every night over the phone with a Rebbe. Yaakov loves it so much; he wouldn't miss it for anything! He also learns with a Rebbe three days a week on the phone, as part of a *Mishmar chaburah*. The fact that he is learning, has structure, and is occupied in the evenings is so good for him, and so helpful for me.

### Can you see a silver lining in this situation?

**Rachel:** At this time, so many people have extra time on their hands and are looking for ways to keep themselves gainfully occupied and feeling fulfilled. I am thankful that my children and I have a built-in *chesed* opportunity in caring for Malky.

**Chana:** Before corona, Nachman was always out of the house. He had school, and a therapy program until 8:30 at night. He even went away for many *Shabbosim*. He had so little home time. It's beautiful to see how he can be part of the family, specifically at the *Shabbos seudas*. Overall, he's part of the program; he goes to sleep and gets up more cooperatively because he's part of the routine. He has taken the baby out of her crib a couple of times, which has been helpful for me. He plays so nicely with the younger kids. My two-year old massages him and plays with him. They say such cute things to each other! I heard one of my kids saying: "Nachman, you're the cutest!" They all share the bikes.

It's a very wholesome feeling that he's home with everyone. As much as he wishes he could go to other people's houses, I think he does feel secure that he's here when everyone's home.

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*Having a special child  
and going through these  
unprecedented times share a  
common challenge—we need  
to live in the moment and  
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worrying about the future.*

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There are definitely difficult moments, but I do feel so much *siyata d'shmaya*. I look at Nachman as such a gift. He's so full of joy, and he doesn't complain. We're treating him normally, within the framework of the family, and he responds well to that. One day he came up to our room and said proudly: "Avi listened so nicely!" He was talking about his younger brother. It was so sweet to see him integrating into the family like that.

**Tova:** Yes, our family is spending so much quality time together. Instead of running out to friends and lessons, we have more big kids and little kids at home now, so it's a different dynamic. Another big plus is that Yaakov is spending a lot more time learning Torah. He attends a non-Jewish school and learns secular subjects, and we used to try to fit in learning and davening. Now his day revolves around his Torah learning and davening. We set up a family shul in the basement, and he davens with the family.

### What are some life saving tricks that help you cope?

**Rachel:** The best life saving trick that I can think of, which I wish I could do more of, is to constantly ask Hashem for help throughout the day. It really works! The next one would be taking care of myself by eating healthy food and getting enough sleep.

**Chana:** Inside combination locks, that's my thing! Also, when the weather is nice, the family outings are great for everyone.

**Tova:** Having a schedule and a similar routine every day, including an outing, makes the whole day go smoother. I take Yaakov with me to pick up the school meals. He gets out of the

house, and away from the other kids, and it breaks up his day. Of course, having the counselor come is a huge game-changer.

**What are some lessons you've learned or *chizuk* you'd like to share with parents who are in a similar situation?**

**Rachel:** Having a special child and going through these unprecedented times share a common challenge—we need to live in the moment and not get carried away with worrying about the future. While I tend to enjoy making plans, Hashem keeps showing me that He alone is in control, and I need to let go and leave things in His hands. I think everyone is getting this message loud and clear during these unpredictable times. Having gone through the experiences that I have with my daughter, this lesson is not a new one to me, but one that constantly needs work.

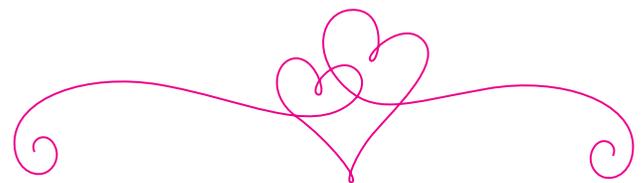
In these times, I believe we have a special *eis ratzon* to beg Hashem to send the *geulah shelayma*. We are in a unique position to really look forward to the *geulah* when our special children will hopefully “get us in” and we’ll have so much *nachas* seeing them completely cured, *Bim'hayra v'yamaynu, amen!*

**Chana:** As we see, life can take you on really interesting journeys that you wouldn't have been able to dream of yourself, for better or for worse. Hashem is in charge of this world and you have to take what life gives you and make the most of it. Who would ever have dreamed of this virus, running through the whole world, having the kids home and the schools closed, it's almost like science fiction! Just leave it in Hashem's hands and *DAVEN!* Make the best of it. Believe in yourself and believe in your child.

**Tova:** I am amazed by so many people who are reaching out to help others. The Rebbe who's doing a nightly *chaburah*—I'm sure he's equally as busy as everyone else is at home—but his doing this makes a huge difference to our entire family. I've learned about how incredible people are, and how much of a difference they can make in the lives of others.

My advice is: don't feel pressured to accomplish a certain amount or to be a certain way. I used to have a certain standard of organization that is impossible to uphold now. My cleaning lady isn't coming, the kids are all home, and I'm juggling being a teacher and a mother. As a teacher, I'm very into my kids doing their work, but now, we're just doing our best. Yaakov was always getting services all day, and now he's not, but he's fine. He's getting different experiences being home and being part of the family. Formal therapy is very necessary and important, but there can be a tremendous amount of growth, sometimes, in these unstructured moments, too.

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## Absence Makes the Heart Grow Larger

Yitti Berkovic

I am hiding in my bedroom, my head buried deep beneath the pillow. By the way the walls are rattling, it is clear the slumber party is fully underway. Even with my sound machine on its highest volume, I can hear the squeals, the laughter, and oy, did I say the squeals?

I pray I'll still have my hearing come morning.

My own headache notwithstanding, the pre-teen girls who've invaded my bungalow are giddy in the very best way, sharing side-splitting jokes completely incomprehensible to me, and screeching camp songs at a pitch so high, even the skunks outside have run for their lives.

If I picture the scene, I'll probably start having heart palpitations: *Popcorn kernels crushed into the carpet weft. Hot cocoa cups teetering perilously on the edge of windowsills. Puff paint streaks on everything but the T-shirts they're supposed to be decorating.* Help!

As I kiss my good night's sleep goodbye and bemoan the fact that I am going to be spending all of tomorrow cleaning marshmallow fluff out of the linens, I realize that I'm smiling. *Good for Tehilla. She deserves this party. I'm glad it worked out for her.* Because Tehilla and I both know something important: There is no way she could throw this party if Naftali were home.

Naftali, Tehilla's big brother, can't tolerate loud noises. He can't handle disruptions to his bedtime routine, and he hates messes more than a Hungarian housewife despises dust. Having Naftali in the house at the same time as a raucous party would be like inviting a ticking time bomb to the celebration: it would be a surefire recipe for disaster.

Tehilla knows this as well as anyone – she's experienced it. This past winter, Tehilla invited a friend to sleep over for Shabbos – as she often does. This friend – I'll call her Chavi – had never been to our house when Naftali was home, so she didn't really know what to expect from her friend's older brother with special needs.

Everything was going smoothly until Shabbos morning, when, in a fit of frustration about something I can't recall, Naftali threw open the door to Tehilla's bedroom and began pounding his fists on the door. The pandemonium lasted only a few seconds. As soon as we realized what was happening, my husband and I interceded, closing the girls' bedroom door and calming down Naftali. But the damage was done.

Chavi, yanked from her sleep by the loud and unexpected intrusion, was terrified. For the rest of Shabbos, she was on high alert for Naftali's next tantrum. She eyed him warily and anxiously, spending as much time as she could as far away from him as possible. No one was surprised when she called her parents before my husband made Havdalah, then made a beeline out the door even before the candle was blown out.

No one was surprised when the next time Tehilla invited her – just for a Sunday playdate – Chavi immediately declined, bluntly informing Tehilla she wouldn't come to our house when Naftali was home. Ouch.

To her credit, Tehilla took it in stride. "She just isn't used to kids with special needs," she explained to me with a shrug. "I don't blame her." *Wow. Good attitude for a 9-year-old.*

I, on the other hand, took it personally. I want kids to feel comfortable in my home. And I want my children to feel comfortable having friends over. I don't want Naftali to be the bogeyman who scares their friends away.

The reality is that Naftali's behavior is unpredictable. Even under ordinary circumstances, his tantrums are inevitable, and because he is big and loud and struggles to keep his emotions in check, his outbursts can be scary and upsetting to the unprepared.

So Tehilla can only throw this party while Naftali is away at sleepaway camp, and right now, when my ears feel like they're on fire, I'm glad Naftali is away at camp, safely protected from his sister's less-than-melodious caterwauling. But my relief also leaves me feeling conflicted – even pained. It doesn't feel good to be happy that one of my children is not under my roof.

Yes, camp is an amazing, nurturing, fun-filled environment, but Naftali makes it abundantly clear that he prefers to be home, where he gets to call the shots, where he can dictate what's for supper and how he will spend his downtime, and where his parents' consistent presence ground his often confusing world.

Home is where he is most comfortable, and every summer, we push him further out of his comfort zone. It's good for him –

everyone in my family knows that – and I tell myself that every day. Especially when I see how pale his cheeks are when we wave goodbye to him on his first day. Yes, it's good for him, but it's painful to admit that it's also good for us.

Here's the funny thing—I don't think you have to be a mother of a special-needs child to understand these conflicted feelings. I know because my son Tzvi is in camp now, too.

He wouldn't have spoiled Tehilla's slumber party, but he would have moaned and groaned about the girls disturbing his peace, and he would've rolled his eyes enough to give himself vertigo. He and Tehilla would have fought about some aspect of the party – I'm sure of it – because fighting with each other is their favorite pastime. So I can't help but think that Tzvi's time away in camp is healthy for the two of them.

I remember last summer, when Tzvi showed up on visiting day with an endless stream of stories— and, lo and behold, Tehilla actually showed interest! As they engaged in dialogue that didn't involve insults or put-downs, my husband and I laughed in bewilderment: Who are these foreign creatures? And how long can they maintain this détente?

We all know the old adage, "Absence makes the heart grow fonder," but I think it's especially true during summer camp season. In our case, absence makes the heart grow LARGER – we don't forget all the things that drive us crazy about the kids off at camp, but we realize our love is so much bigger than the things that drive us crazy – like the fear of the next tantrum or the constant sibling quibbling.

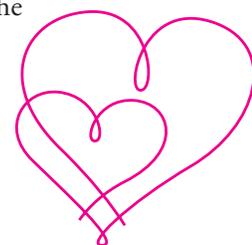
I always get a little choked up when, after a few weeks have passed, my other kids start to ask: "How many days left to camp?" "When is Naftali/Tzvi coming home?" "I miss him—it's so weird not having him around!"

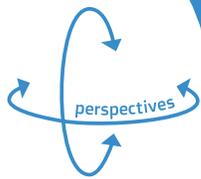
Yes, we love our children with every fiber of our beings. And I know our kids love each other too. But, too often, our time together involves focusing on the itty-bitty things that get under our skin, instead of all the wonderful qualities we love so much.

So, at least for me, being able to send my children to camp is its own brand of blessing, not only for the temporary peace it brings to my household, but for the little bit of insight it grants me and my children: Yup. We love each other after all.

*But, too often, our time together involves focusing on the itty-bitty things that get under our skin, instead of all the wonderful qualities we love so much.*

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





From the perspective of:

# *A Sibling*

T.M.

## Why Is He More Special Than Me?

When I'm by a chasuna,  
They all notice him, dance only with him.  
I wonder why they don't see me there,  
maybe I became invisible, disappeared into thin air.

When davening in shul,  
They all notice how he davens so fervently.  
I wonder why they don't see me there,  
maybe I became invisible, disappeared into thin air.

When we go visiting relatives,  
They all slap his back, they talk to him.  
I wonder why they don't see me there,  
maybe I became invisible, disappeared into thin air.

Sometimes when we go out as a family,  
strangers notice only him.  
I wonder why they don't see me there,  
maybe I became invisible, disappeared into thin air.

When he does the simplest tasks  
I see that special sparkle in my parents' eyes.  
I know I can do the same thing, only better.  
I wonder why they don't ever get that excited  
when I do things.

Why is he more special than me?  
Why is it me they never see?  
Can't they hear my silent plea?  
Being the brother of a special sibling is not so easy!



compiled by Fraydel Dickstein

Being in lockdown is challenging for everyone, but with a special needs child, the challenge can feel stupendous. There are now so many opportunities for "Wow moments," and they bring joy and smiles to all those lucky enough to encounter them...

It was the first Shabbos right after Pesach, and we were enjoying delicious (chometz) cookies. Everyone had their share and begged for more. My son really wanted another one, bargained for it, and got it. My special needs son, Chaim, walked by and gestured for it. His brother gave him his own cookie with great joy. I looked at him in disbelief, shocked that he would give away the cookie that he had wanted so much. He said to me: "What do you think I want more, a diamond or a cookie?" He may have given Chaim a cookie, but I felt like I was gifted with a sparkling diamond!

We were walking through our soon-to-be new home. I asked Hindy, age 5, what her favorite thing was about our new house. I thought she would say her new room or something like that. She surprised me by answering: "That Yehuda is coming with us!" I said: "Why is that your best thing?" She said: "'Cuz he is special needs and so yummy!" (Yehuda is 11 and adorable). I was left with my mouth hanging open.

Here are two stories about neighbors who showed such sensitivity and caring:

One of our neighbors put in landscaping with new sod. We overheard the landscaper say that it wouldn't grow well if it was walked on. I made a comment to my neighbor about my son going on it. Her immediate response: "He is always invited!"

My neighbor put up a pool, but without a gate, and Rikki was very attracted to it. A different neighbor (not the owners of the pool) put up a gate, although it was not their obligation. She told me that she can see what a challenge the pool is for us, and it was the least they could do. Sometimes people show so much caring and sensitivity they make me cry!

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

Shalva Sauer, SLP

# Food for Thought

Part 2 in a series

*Moishy was getting feeding therapy in school once a week, and making great progress in his ability to chew more difficult textures. Now school is closed. The family has no Internet access, and phone sessions are not practical. Moishy has regressed over the past few weeks, and his mother is very concerned.*

*Tova was learning to drink from a cup when everything shut down. Her early intervention therapists are now providing therapy via videoconferencing. She has two sessions of PT, two sessions of OT, and two sessions of speech therapy every week. It's too hard for Tova's parents to be with her during another session, so her feeding therapy has fallen by the wayside.*

These past two months have been a very challenging time for parents in many, many ways. I would like to address feeding therapy during a period when such therapy is very difficult or nonexistent. If a child is able to access his therapy via Zoom, the parent must be there throughout the session. On the one hand, this can be a great opportunity for parents to learn techniques. But for many parents, this is proving impossible. What can you do to help your child when traditional therapy is just not happening? Here are some “bite sized” ideas to help your child maintain the skills he has learned thus far, and maybe even make some progress while at home. These recommendations may not work for you. It may be too overwhelming to even think of implementing a single one – and that is OK. Feel free to turn the page. But if you can, choose something that seems doable and try it. I would love to hear your feedback!

One suggestion is what I call the “Five Minute Focus.” Choose a skill which is high priority or that your child has worked on in the past and you would like to maintain. When you have a quiet moment, focus on your child for **five minutes** only. Do this **no more than twice a week**. For example, if your child is learning to chew and the feeding therapist has been modeling chewing for him, sit for five minutes with a snack and do the therapy activity with him. At mealtime, stick to easy, safe foods and drinks and don't stress about advancing his skills. The trick here is to keep it short, sweet, and apart from mealtimes. If you do this, it won't seem so overwhelming the next time. You will not believe how much can be achieved in such a tiny segment of time!

Another idea is to eat with your children. Many mothers are busy serving their children at mealtime and end up eating later. But if you can, sitting down and eating at the same time as your children can really take the atmosphere to a different level and promote better eating habits and skills. (The ideal, of course, is for both parents to be at the table, but this is not always possible.) If you are not accustomed to eating with your children, it will be a process, but it is worth your effort. Some tips to make this happen: Put all the food, drinks, and utensils on the table prior to the meal so you don't need to jump up constantly. You can choose one or two foods to eat with your children if you are not

ready to eat the entire meal with them. Just eating together with their parents can be a huge help to many children.

When everyone is home all day, children tend to wander into the kitchen and request or take snacks frequently. When kids are constantly asking for food, it can make any mother go mad! And it will also wreak havoc with small appetites. Scheduling meals and snacks for everyone in the family is another way to keep your child on the right track. Try to plan for snacks and meals to be at least 2.5 to 3 hours apart from each other and offer drinks of water in between. Keep in mind that a bottle of milk would be considered a meal or snack. Here is an example of a family meal/snack schedule:

8:00 Breakfast	3:30 Afternoon snack
10:30 Morning snack	6:00 Dinner
1:00 Lunch	

If your child is afraid to try new foods, a few minutes of play with a new food can be very helpful. There is a significant hand-to-mouth connection, and touching/feeling a new food is one of the first steps to being able to taste it. An older sibling can do the food play, if that is easier. You can put the food on the child's high chair tray, the table, or even the kitchen floor and allow free play and exploration. If your child is able to use cookie cutters or a plastic knife, that can be fun. Some children enjoy putting things in and out of containers or cups.

Speaking to parents over the past couple of weeks, I can only express my admiration for all of you. You are working so hard to keep everything together—you are true heroes! I wish you all continued *hatzlacha*, and I hope some of these ideas will help you during this very trying time.

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

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



## My Special Brother

Bayla Koplowitz, age 10



I have a special brother, since I was in first grade,  
Yes, he is very special, 'cuz that's how he was made.

And when I first saw him it made me very glad,  
That he was a little different than the other babies we have had.

If he failed to do something, again he'd try it all,  
From going on his hand and knees, to standing straight and tall.

And I want you all to know, that every single day,  
He's always very happy with whatever comes his way.

He barely ever cries, and he never makes a fuss,  
He's always laughing to himself while playing with his bus.

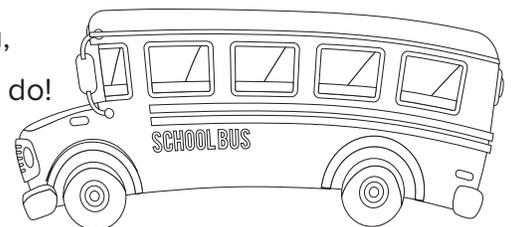
Each morning, when I leave for school, he smiles and waves goodbye,

And then when I come home I get a big hug and a "Hi!"

Even though he is still young, just four years old, not more,  
I learn many important lessons from him, that I know for sure.

Always be happy and keep trying to do your best,  
Even if it's hard, don't give up – Hashem will do the rest.

So, Avraham Yeshaya, I love you,  
And I'm so proud of everything you do!



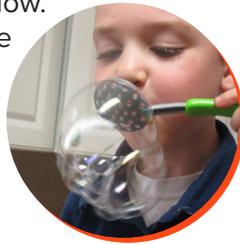
# FEEDING NOODLE

By Elisheva Dickstein

## Activity Time!

### Blow Some Bubbles!

Who doesn't love bubbles? There's something magical in those iridescent shapes flying through the air that captures everyone's attention. The problem in our home was that the containers of bubbles spilled all too often, resulting in disappointed kids, left without bubbles to blow. We decided to try a homemade recipe, but the first try wasn't successful. We experimented with a few recipes, until we hit upon a great one that is easy, cheap, and makes nice, strong bubbles that don't pop too easily.



### Ingredients

- 3 cups water
- ½ cup dishwashing soap (Palmolive works best)
- 2 tablespoons corn syrup

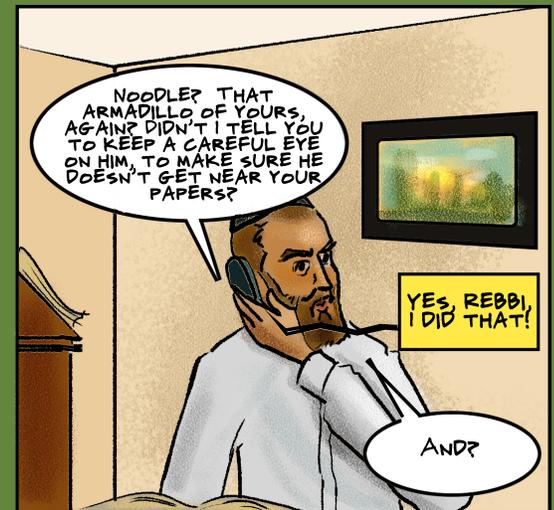
### Directions

Pour all ingredients into a container. (Suggestion: Use a container that has a good cover. A disposable 2 lb. container works well for this.) Mix very gently with a spoon. You can use immediately, but the solution works even better after it sits overnight.

(You can easily double or halve this recipe based on how much you want.)

Now for the bubble blowing! You can use the wands that came with the (spilled!) store-bought bubbles, but we had more fun coming up with more creative ideas. Anything that has holes can work—try a funnel, for instance. You can dip the narrow side into the bubble solution and blow through the wide side. Our favorite was a small spatula with holes in the spoon; it produced lots of tiny bubbles coming out and sticking together—it looked like a huge cluster of grapes!

Now you can blow away and let your special sibling have a blast popping all of those bubbles! Enjoy!





## THE CASE OF THE MISSING NECKLACE

R.B. Fishelis

The soup was orange.

“No thank you,” I said, pushing my bowl away from me. “I don’t eat orange soup.”

Leah gave me a quick glare. “What?” I asked, picking up my bowl and bringing it back to the counter next to the stove, where Leah was pulling out a pan. “It’s gross!”

“Don’t say that!” she hissed, keeping a careful eye on the table, where Gavriel was pouring almost the whole saltshaker into his soup. “Now Liza will –”

“I don’t want my soup,” Liza announced, right on cue. “It’s orange.”

“ – copy you,” Leah finished. She gave me another glare.

“Um, just kidding,” I said loudly, looking sideways at Leah. “I love orange soup.” I hastily brought it back to the table. “Mmm...Delicious!”

Liza looked at me with wide eyes.

“Look,” I said, taking the salt shaker from an annoyed Gavriel and dousing my soup to disguise the taste. “Amazing.” I ate a spoonful, trying not to wince.

Liza happily dipped in her spoon, too. “Yum,” she agreed. “It’s great, right Shana?”

“Right,” I said painfully. I took another – ough – spoonful.

“You’re such a copycat,” Henna said disdainfully. “You always copy Shana.”

“Not true!” Liza said, stung.

“Yes true,” Henna said loftily.

“Nu-uh! –”

“Leah,” Mommy came into the kitchen, a worried look on her face. “Did you see my necklace? The teardrop one?”

“The one Abba got you for *Succos*?”

Leah asked, straining to remember. “I don’t think so. Why?”

“Oooh, Mommy, you’re so pretty,” Liza said admiringly.

“Thank you,” Mommy smiled, then turned to Leah. “It’s gone missing. I don’t know where it went.”

“I didn’t see it,” Leah said, shutting the oven door.

“Me neither,” said Henna primly.

“Not me,” I said, trying surreptitiously to make my way to the sink, where I could spill out the soup.

“Not me,” Liza echoed me.

Gavriel stole back the salt shaker. “I didn’t see it either.”

“Well, if anyone sees it, please let me know,” Mommy said, taking her purse from the counter. “I hope none of Mordy’s therapists walked off with it...it’s very precious to me. Okay everyone, Abba and I will be back late, so everyone should listen very nicely to Leah. *Very nicely*,” Mommy repeated, looking at Gavriel and me meaningfully. “Okay Leah, Mordy is sleeping, and if everyone is quiet, he should hopefully stay that way, so you’ll have it easy.”

“I hope everyone stays quiet,” Leah said darkly. “Cuz if he wakes up...I can’t deal with his reflux.”

“So hopefully everyone *will* stay quiet.”

“Why’s everyone looking at me?” Gavriel complained.

I hope it doesn’t sound like we don’t love Mordy to pieces, ‘cuz we do. Mordy, my two-year old brother, has Down Syndrome. It’s not as big of a deal as people think. He just needs a lot of therapy and help to learn how to

do things. He also has really bad reflux and throws up a lot.

“Goodbye, everyone.” Mommy kissed us all and went to the front door. “Oh, and if all of you can just please keep an eye out for my necklace, that would be great. Good night!” The front door closed.

Immediately, I slipped out of the kitchen, dropping my bowl in the sink.

“Shana! Get back here!” Leah howled, but I dashed up to my room and firmly shut the door.

I dropped onto my bed and pulled out my notebook, carefully printing “The Case of Mommy’s Missing Necklace” on the first available page.

**Suspects:** Leah, Gavriel, Henna, Liza.

I inspected it for a minute, then added **Mordy**. Listen, I know he’s two and doesn’t even walk or talk yet, but you never know.

**Clues:** None yet. Was found missing tonight. No known date of disappearance.

Hmm. This was going to be one tough mystery. But that was okay. This mysterious case was perfect for...I dug under my bed frantically and finally found what I needed, trapped under an old shoe and a crumpled math notebook... Detective Shana, Private Eye!

I fixed the bushy mustache under my nose. Leah had told me the dentist prizes were useless, but I *knew* that this one would serve a purpose!

Stealthily, I crept out of my room, keeping close to the shadows, which was a little hard, because there were no shadows.

“What are you doing?” someone asked from the floor.

I jumped. “Gavriel! What are you *doing*?”

He was wriggling on the floor, next to the baseboard. He was also holding an empty jar. “Looking for bugs,” he said, like it was obvious. “I’m having a contest with Ari.” He looked up. “What are *you* doing? And why do you have a fake mustache on?”

“I,” I said importantly, “am looking for the thief.”

Gavriel looked blank. "The thief?"

"Of the necklace?" I said. He still looked blank. I sighed. "Mommy's necklace? The one that went missing?"

"Oh," he said, uninterested.

"And speaking of..." I whipped out my notebook. "Where were you at the time of the crime?"

"Um, the same place you were?" Gavriel said, staring at the floor. "The kitchen. Hey, there's an ant!"

He dove for the jar. "Got it!"

"So, did you?" I asked, scribbling in my notebook.

"Steal it?" Gavriel spun the cap back on the jar. "Ew. No. What would I do with a necklace?"

"Sell it illegally?" I suggested.

Gavriel thought for a minute. "No. Hey, I think there's a spider!" He hurtled down the hall, leaving me with my notebook and mysterious thoughts.

#### Next Suspect: Leah

I found her in the kitchen, cleaning up from supper, but ran away before she noticed me. If she saw me, that would mean I would have to help. I would ask her later.

Henna and Liza were playing dress up in the playroom. I moved them onto the couch, then flipped open my notebook. "Okay gentlemen – and ladies, I guess," I said, looking closely at them. "Mommy's necklace has gone missing. Do any of you have anything to say about it?"

"I want a necklace," announced Liza.

"If we find this one," I said, "then maybe you can get your own. But first things first. The necklace."

"But *Henna* has a necklace!" Liza pouted.

I spun sharply to face Henna. "You do? Where is it?"

Henna shrank into the couch. "It-it's mine," she said weakly, her eyes getting wet.

"We'll see about that," I said coldly. "Bring it to me." I folded my arms sternly as Henna ran off, the first guilty tears trailing down her cheeks.

I smiled at Liza. "Well done, Liza." This could be my big break, I fantasized, finding the necklace a mere hour after it was reported missing. You have great detective skills, Shana, I thought proudly, mentally patting myself on the back.

Liza smiled back. "Can I have a necklace now?"

A sobbing Henna came back in, followed by an angry Leah. "Shoshana Welch, what do you think you're doing? Why is Henna running through the house crying?"

"I'm looking for Mommy's necklace," I said, smoothing my mustache loftily. "And I think I've found it. Henna took it. *She* is the thief!"

Henna cried louder.

"And she's crying out of guilt, I suppose," Leah said sarcastically.

"Exactly!" I said. "Give me the necklace, Henna."

Henna handing me the necklace, her hand trembling. It was a junky dollar store *tchatchke* she had probably got as a *kriah* prize.

"Great job, *detective*," Leah said sarcastically. "Next time, don't arrest someone till you're sure. And *definitely* don't make her cry."

I made a face. "Okay, I *get* it. I'm sorry, Henna."

Henna sniffled and grabbed her necklace back. "You're mean," she accused, and went to Liza. "Let's finish playing, Liza."

"But I want a necklace!" Liza complained.

Leah gave me one last scathing look before leaving the room.

I flopped back down on my bed. Oh boy! That was a sticky mistake! Grimacing, I pulled off my mustache and threw it. It hit the wall and stuck to it. Looks like I'm not as great of a detective as I thought, I reflected gloomily.

Okay, I get it. I made a little mistake, accusing Henna. But really, if she wouldn't have been such a *baby* and cried like that, it wouldn't have been such a big deal and Leah wouldn't have gotten so mad.

I sighed. I needed a new direction for this case. Sighing again, I fell onto my pillow. Maybe I should try bugging –

Something crinkled. I sat up. There was a paper on my pillow which I guess I didn't notice earlier.

*Shana, please put in a load of your room's laundry.*

*Thank you, Mommy*

What a way to make a great day greater! Grumbling, I got up and began lugging the laundry basket out of my bedroom and into the laundry room.

Why is it that when something annoying happens, it attracts more annoying things?

I yanked open the washing machine's door and got ready to dump in the load when – something inside the machine – glittered?

Bemused, I stuck my hand into the machine and felt around a little. My hand closed over something cold and round, and I pulled it out. The thing twinkled and I gave a gasp: "I found it! Leah, I found the necklace!"

"Shh!" Leah hissed, running up the stairs, a book in her hands. "You'll wake up Mordy!"

"I found the necklace!" I whispered. "Look!"

I held up the necklace. It twinkled in the fluorescent light.

"Where was it?" Leah asked, fingering the dainty teardrop shape.

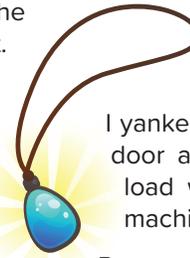
I shrugged. "The washing machine."

"Why there?" Leah wondered. We stared at it.

"I don't know," I said finally, then ran to my room for the hairy brown mustache that was stuck to the wall. "But this sounds like a job for Detective Shana, Private Eye!"

Grinning, I slapped the mustache on.

Leah gave me a weird look. "Just don't make anyone cry this time. And Shana," she added as she turned to leave. "For some reason, there's paint stuck to your mustache."





# Sibs Spot Interview: Menachem Stern, Brooklyn, NY.

**Hi Menachem! Can you tell me a little about yourself?**

I live in Brooklyn, NY. I just turned 10 a few days ago and I'm in 4th grade... but I don't go to school these days, of course. I have a special needs brother named Baruch. I love typing and doing puzzles and making things out of beads. That's what I was doing five seconds ago, and yesterday, and the day before that. I just made a flower!

**Wow! Could you send us a picture of it?**



**Oh nice! Thanks for sending it!**

I'm also learning with my father, and I learn the *Daf Yomi shiur on Kol haLashon*. My *maggid shiur* is Rav Moshe Meir Weiss. Also, I'm part of a statewide comedy contest.

**Sounds like you keep busy. So what can you tell us about your special needs sibling?**

Baruch is 20 years old and he loves to play. He's usually very happy—I think you could say always! He has his own language, and when you want to communicate with him, you have to learn his language. I want to write up a dictionary of his words to help every time he gets a new helper (who takes him off the bus and plays with him). I tested him on all the school subjects, and he knows math, science, reading comprehension, etc. For example, I asked him: "What's smaller, a molecule or atom?" And he said: "Atom." He knows all his colors, too. So he knows stuff. Also, I understand him VERY well—times 8!

**That's so good that you understand him so well! How do you feel about having a special sibling?**  
I feel special!

**Are there times when it's difficult?**

There are times when we don't understand what he's saying and he gets very frustrated and upset. And he sometimes tantrums about it.

**So what do you do?**

Well, I can help him calm down by saying the magic words or magic sentences. Like: "Do you want Ashley to come over?" She's his teacher and she came over to set up the Chromebook for his schooling. Or I could say: "Baruucchhhhh!" That makes him happy again!

**You're such an amazing brother! Baruch is so lucky to have you! How much do you feel that your life is affected by having a special needs sibling?**

VERY, very much.

**How so?**

Well, we always get the best parking spots—because we can park in the handicapped spots! But there's really so much more, it's hard to describe.

**Are there any interesting stories you can share?**

Yes. Baruch's speech therapist said that I should be his speech therapist, and I could make \$90 an hour! Also, when he used to go to the grocery store, he's so friendly that all the cashiers know him by name. But now (because of Corona) we can't go to the store.

**So, what is it like in quarantine with your brother?**

Well, it's nice that we have so much time to spend together. I love playing with him, and I treat him like a regular brother. I really enjoy being with him, and I understand him really, really well. Baruch's teacher sends him homework, and I help him do it. I also have a lot of homework, so we keep busy.

**Menachem, it was so great talking to you! Thank you for telling us about yourself and your brother.**

*Menachem Stern is using a pen name. He can be reached through Neshamale Magazine for questions, comments & pen-pal requests.*

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

# What Would You Do?

Do you have something precious that your special sib likes to take or touch? Tell us about how you deal with it.

Chani, 11:  
My brother loves my room and all my things. I lock the door and try to ignore it. My mother buys me more things if he ruins my things...

Akiva: I hide anything that I don't want her to take.

Shevy, 8: My brother loves chewing on squishy things. I had a big strawberry filled with orbees (water beads) that I got for a present and he loved it! Once he even popped it, and I was very upset. A different time I got a smaller green orbee ball. He popped that one too! I took the orbees out of it and put them in a container. Then, when I wasn't looking he spilled the container out, too! Oh boy, what a mess!

Yehuda: I try and ignore it.

Yaakov, 9: I got a little fake hamster. It was very squishy and gooey. My brother loved it so much. He always bit it and ripped it. Then one day, I just gave it to him!

Malky, 11 : I don't know if this is considered precious, but something that gets pulled a lot is actually my hair! I used to get very upset when my brother pulled my hair, but then I realized that he's usually trying to tell me something. One day, I was looking for my shoes for a long time and couldn't find them. Later, my brother was pulling my hair and I got very annoyed. But then I looked down and saw that he was holding my shoes! Now, it is still annoying when my brother pulls my hair, but I know that usually it means he wants to tell me something. This is the way he "talks."

Avigdor 13: He touches my seforim and I just tell him to go away.

Question for next issue:

**How is your life better because you have a special sibling?**

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

# To Cry or To Rejoice?

Rabbi Ezra Klein

I believe it's important for us to examine a fundamental question: Is having a special child essentially a bad thing that happened to us, and we just have to realize that even bad things are really blessings since everything is for the best? Or, is our child really something good, notwithstanding his or her challenges? When we find out we have a special child, should we cry or rejoice?

These are really two separate questions. The first question, if it's essentially a tragedy or a blessing, is intellectual. The second, if we should cry or rejoice, is emotional.

Let's tackle the intellectual one first. Most people whom I've encountered, who never had a child with Down syndrome, are convinced it's a tragedy. They react as if someone just contracted a life-threatening illness. I believe that's a mistake.

If a child was born "normal," and then later developed Down syndrome, I could understand why people might consider it a tragedy. But that's not what happens. The extra chromosome that causes Down syndrome is a part of the child from the moment of conception. Hashem gave you a child with Down. Nothing "happened" to your child.

But what about you? Something surely happened to you.

This was your gift from Hashem. You may be disappointed that you didn't win "First Prize." Those who win Silver in the Olympics are probably disappointed that they didn't win the Gold, but they surely rejoice knowing that they won a valuable prize. They "won." You also "won." But you're even better off than the Silver winner. Because, perhaps for you, this *was* First Prize. You may not have been in the running for a "normal" child at this point in your life at all. If you hadn't had this child, you wouldn't have had any. It was a choice between this and nothing, not between this and a "normal" child. If that's the case, it's definitely better to have a special child than no child at all (although some people may prefer no child, I feel that anyone who has not raised a special child is not qualified to give such an opinion). At any rate, Hashem definitely considers it better.

R' Shlomo Zalman Auerbach, *zt"l*, *parkened* that, generally speaking, children with Down syndrome are obligated to keep all the *mitzvos*, because they are capable of doing so. This is a child who will live a life of Torah and *mitzvos*, with a *neshama* endowed with just as much *kedusha* as anyone else's. A *Yid* just like you and me. Is that not valuable enough?

Imagine someone who worked his entire life developing a *chesed* project. He built it into an international organization, with a beautiful building. All the records, contacts, and information needed to run the program are in that building, and there are no digital backups. There are also *sifrei Torah*, *chumashim* and *siddurim* in the building. One Shabbos, a fire breaks out. No one's life is in danger, but the whole project will go up in smoke, literally, if you don't put out the fire. The *sefarim* would be destroyed, and all the *tzedakah* money would be lost since there is no property insurance. The *halacha* is clear. One cannot put out the fire. [There may be permitted ways to extinguish the fire with the help of a non-Jew, but we are not discussing practical Halacha here.] However, if there is a child with Down syndrome in a shack, we can and must put out the fire on Shabbos to save the child. To Hashem, that child is more valuable than anything else in this world. More valuable than money, *chesed* projects, *sefarim*, even Shabbos. *Hakadosh Baruch Hu* gives you this treasure for a gift, and you call it a tragedy?

Ultimately, for us personally, having our special daughter was even better than having a typical child, as I explained in my first article, "Why Me?" (Neshamale Vol 1) But we are discussing now how this child can be recognized as a blessing, even without taking into account that everything from Hashem is ultimately for our good.

Now, we're ready for the emotional question. "When one has a child with Down Syndrome (or other special challenges) is it appropriate to cry or rejoice?"

The proper answer, in my opinion, is: both. Parents are usually very disappointed that they did not receive what they were hoping for. Understandably so. Children are not usually born with Down Syndrome. No one thinks it's going to happen to them. Parents are also beset with fears, prejudices, feelings of inadequacy, and concern about others' reactions. They are afraid of the future. Many questions race through their minds and they don't have clear answers yet. Until this point in their lives, they might have looked askance at Down children. Perhaps they avoided them out of fear. Now they're going to have one?! They usually don't feel up to the job of taking care of a child who is going to need a lot of therapy to build up muscle tone, speech, and general capabilities. These children often have more health-related issues than other children. Parents also realize that, even if they eventually come to peace with this

child, many other people will not. So it's definitely appropriate to cry and express hurt. They might recognize that Hashem loves them; it's just harder to feel it right now.

Rejoicing is also surely appropriate. As we mentioned, we just received the most precious gift from Hashem, a child. Even if we are disappointed that we didn't receive what we wanted or expected, we can still rejoice over what we *did* receive. This can be likened to someone who earns a million dollars from a business deal, when he expected to earn two million. Although disappointed that he missed out on the extra million, he is still very happy with the million! Although we may be disappointed about what we didn't receive, we can still be happy about what we did receive.

A friend of mine related a conversation he had with R' Shlomo Zalman Auerbach, *zt"l*, in which the *rav* told him the best piece of advice I ever heard on this topic. His sister had just given birth to a child with Down syndrome and the family was devastated. He called R' Shlomo Zalman to ask his advice: "My sister just had a baby with Down syndrome. *Mah osim?* What should we do?"

"*Mah osim?*" replied R' Shlomo Zalman incredulously, as if he couldn't comprehend the question. "Raise him, take care of him, love him, and teach him *Torah* and *mitzvos*."

We focus too much on the child's "condition." We forget that he is a real child who is ours to love and raise, who also happens to have a certain condition.

One of the genetics doctors at the hospital mentioned something that made us much happier: "Your child has your genetic makeup: she will look like you, she will have your personality, and even her intellectual capability is greatly determined by her parents." Many people focus so much on the syndrome that they view this child as some sort of alien being that was somehow born from us. This is not true at all. She is our child, who will be part of our unique family, with a personality and capabilities which will be uniquely her own. Generalizations such as, "Down children are always loving," or "Down syndrome children are stubborn," are unhelpful and inaccurate. They may have certain tendencies, but each one should be treated as an individual. They will not necessarily follow anyone's "plan" for their personality development.

People who do not have children with special needs usually don't comprehend the appropriateness of rejoicing when a special child is born. Many of the reactions and phone calls I received after Nechama was born sounded more like they were trying to be *menachem avel*, rather than wishing me *mazel tov*.

After our Nechama was born, I told someone that I get a *mazel tov*, since we had a girl. His reaction was *pareve*, at best. I found out later he was confused. Since I looked genuinely happy, he was sure that I either didn't know yet about my daughter's diagnosis, or I had no idea what Down syndrome was.

About a week after our daughter was born, the phone rang in our home. It was my oldest daughter's friend from a different city. She said "*Mazel tov!*" cheerfully to me and asked for my daughter. When I got off the phone I felt like crying. This was the first genuinely happy *mazel tov* I had received—and it felt so good!

Truthfully, for almost everyone with a special child, these questions are moot. As soon as our daughter came from the hospital and we held her in our home, we all fell in love with her. The joyful feeling of loving your own child is, without a doubt, one of the most pleasurable feelings a human can experience. It is completely natural and we don't need a logical 'reason' to experience it. This feeling of love will give us continuous joy throughout our lives. Although we may experience serious frustrations and anxieties with our child due to his or her condition, we will also certainly experience much love, and therefore much joy. The more we give our child, the more we love her, and the more joy she brings us.

We made a *Kiddush* in honor of Nechama's birth the Shabbos after she was born. At the *Kiddush* one of my older daughter's teachers called her over and said: "You know, you and your siblings are going to have to learn to love your sister." Without hesitation, my daughter looked her in the eye and said: "We love her already!"

Some readers may think that these ideas are the thoughts of naïve father who doesn't really know what it takes to raise a child with special needs. So I must mention that our Nechama is now a teenager and, *Baruch Hashem*, everything I wrote is truer today than it was back then. She is an integral part of our family, we love raising her, and we wouldn't give her up for the world.

The important thing to remember is that, ultimately, it is up to us what we focus on. We could dwell incessantly on our frustrated dreams and the difficulties we might encounter. Or we could think of all the positive things this child can bring into our lives and focus on how much we enjoy just loving her. Why would anyone dwell on negative, depressing thoughts, when they can fill their minds with happy, uplifting thoughts instead?

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

**We forget that he is a real child who is ours to love and raise, who also happens to have a certain condition.**

Q

## IN SESSION

Dear Shira,

My child with special needs is the middle child of seven. He is a delightful and happy child, yet he also has some very challenging behaviors. His siblings are caring and accepting for the most part, but at times, they get annoyed and hurt, physically or emotionally. For example: My six-year old comes home with a project she made in school. Her special sib grabs it off the table and breaks it. She looks quite upset. How should I react? My first reaction is to be upset along with her, to validate how upsetting and frustrating it is to have a sibling who always ruins things.

However, on second thought, I feel that it may make the problem bigger by acknowledging it. In a way, this is normal life for my kids and I don't want them to "know" that they are growing up in a very difficult situation. If I stay calm and matter of fact about these things, the house stays calmer and things "look" better. But am I just locking the bad feelings inside of them and asking for trouble? I hope you have some clear guidance for me!

Confused mom

A

Dear Mom,

Thank you for your question regarding a very common occurrence in many families with typical and atypical developing children. Every child has to feel that they have a valid and respected place in the family. When a child's 'valuable' belonging is ruined, it is crucial for the parent to validate the child's feelings. The mother can model appropriate behavior by staying calm, but it is essential that the child be aware that the parent shares in his/her pain.

If this is a fairly common occurrence, proactive planning should be done. For example, problem solve as to where the valuables can be stored so they won't get ruined—the valuables shouldn't be left lying around waiting for destruction to happen. Perhaps a special safety box with an extra strong lock can be bought to protect their valuables. This will help the child feel that the parents are respecting his/her needs, which is very important.

Children have very attuned sensitivities. Even if the special needs situation has never been explained to them explicitly, they are certainly aware of the unique atmosphere in their home. The parent may be working hard to maintain that everything is 'normal,' but the child is very attuned to body language and non-verbal messages. A child will feel more secure if the parent explains in appropriate developmental language what the special needs are and how it is being addressed. The parent will be providing the child with the necessary information and the child will not have to guess or have gaps in his knowledge.

I would like to add an extra dimension to this question. Our children are brought up with examples of great people—our *Avos* and *Imahos*—and learn about how selfless they were. *Avrohom Avinu* had a bris at 99 years old, yet was still running around to do *hachnosas orchim*. *Rachel Imaynu* completely sacrificed everything for her sister, so that Leah wouldn't be embarrassed. Perhaps your child is thinking: "I am such a terrible person—I am so selfish that I get upset at my sibling with special needs! What is wrong with my *midos*? Why don't I behave and feel like our great ancestors did?"

Children need to feel secure and validated, not guilty. Let them know that it's okay to feel the way they do, that their needs are important too. This will ultimately enable them to feel more loving and accepting of their sibling with special needs.

Wishing you much nachas from all of your children, and continued strength and *hatzlacha*!

Shira Speiser, LCSW

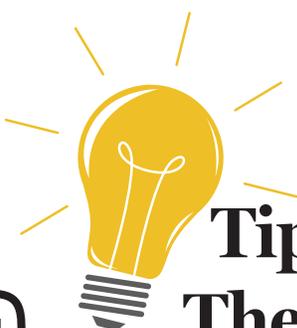
*Shira Speiser is a social worker in Lakewood, New Jersey and has helped children and families for many years. You can contact her with your own individual concerns and needs at: (732) 367-1503 or shira732@live.com*

What saved our sanity is a weekly sectional pill box (like you see in nursing homes). I fill each day's morning and afternoon doses once a week and then medicine time takes seconds. And there's no guess work if we've (*Chas v'Shalom*) forgotten.

--E.H., Lakewood

My son and I both take several medications—some three times a day. My son is almost 15 and self-administers his meds in school. To remind him of his afternoon dose, he has an alarm on his watch. He snoozes the alarm until he has actually taken the pill. His alarm helps me as well. My afternoon reminder is on my phone, so when I hear his watch alarm on Shabbos or Yom Tov, I am reminded to take my meds too (It stops ringing on its own after a minute). My son and I both keep our meds in pill boxes for the week, with the times of day that they are taken labeled on them. My husband and I spend a while each Motzei Shabbos filling our pill boxes for the upcoming week and then checking them over for accuracy.

--D.S., Chicago



## Tips From The Experts

*hey! that's us!*

**What are your tips and tricks on the topic of medication? Keeping track of dosages, getting it down without getting worn down...**

1. I like using the 10 ml bd slip tip syringes. For meds that need dissolving or dilution—I pull the syringe apart, cap it, then add the med & water. Put the plunger back and shake well. Bonus for mini gt buttons- it locks straight into the button with no extension needed (the 60 ml irrigation syringes with blue tip fits there as well—makes it so much easier for flushes).



2. For oral meds—even toddlers can take small pills. Place it on the back of the tongue and give the child a drink. Especially helpful when meds can't be crushed or taste horrible; swallowing it whole can avoid a big fight. My toddler figured out a trick to put her pill into a sports cap cover and then “drinking” it from there (inspired by a special cup that you put a pill in the side of, but which didn't work in our case).



--Chany, Brooklyn

*A cute tidbit from our toddler: She got almost weekly blood draws, but B”H this was recently changed to monthly draws. On our last doctor visit, no labs were done. As we got home, with a very horrified expression, she said: “Uh oh! No blood test!” Not the typical worries of a toddler, that her doctor ‘forgot’ an essential part of her care.*

Big pills can be crushed up and “hidden” in a spoon of ice cream. The coldness and sweetness masks the flavor pretty well.

--S.T., Los Angeles

The best tip I can share is to always use plugs on top of bottles of liquid meds. It makes things so much neater and easier. Just ask the pharmacy to include it with the medicine.

If you are lucky enough to have a medicine that does not need to be refrigerated, I suggest keeping it in the bathroom next to your child's toothbrush. I find it very easy to remember to administer medicine at the bathroom sink, in the morning when we wash *negel vasser* and at night when we brush teeth. I keep the syringe there, too, and rinse it quickly in the sink.

If you need to keep the medicine refrigerated, keep the bottle with the syringe inside a ziplock bag so things stay neat.

--Chaya, Lakewood

Question for the next issue:

**Any ideas for how to deal with my child's hurtful behaviors like pulling hair, biting and pushing the toddler down? I hope so because it's really out of hand in this house, especially during lock-down...** submitted by Eli T., Lakewood

**Let us know how the experts do it!**

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

# Smart & Safe

Fraydel Dickstein

Cleaning Supplies & Summer Safety

I write this from a place of disbelief as I am simply amazed that I am still sane and (believe it or not) happy at this time! In my wildest dreams, if you had told me about these circumstances, I would have been sure that we could not do this. In this super challenging time it is essential that we live smart and safe, both indoors and out.

Yesterday was one of “those” days, when due to the rain Yehuda was home all day. With not much structure and simply not enough supervision, it was a recipe for trouble. Yehuda went upstairs by himself and I was a bit concerned about it but I hoped it would be fine. When I came up to check on him, he was ice skating on his hand-made Palmolive soap rink. By now I know that dish soaps are usually not toxic enough to warrant an ER visit, but when Yehuda ingests non-edible, possibly toxic things, it stirs up my anxiety.

By the time I came back downstairs, he was sitting calmly on the couch holding an empty Mr. Clean spritz bottle. I ran to my cleaning lady and asked her how much liquid had been in it. She said very little and pointed out that he had spilled most of it. Again, I knew it's not good but it still does not warrant an ER visit. I did spend much time checking my poison control web app.

I must stop this story to share with you this incredible resource that has saved me many poison control calls and is just so helpful. <https://triage.webpoisoncontrol.org/#/exclusio> is a free tool that you could use to evaluate if you need to go to the ER due to the poison ingested. If you don't have this link just put into your browser “web poison control app” and you will hopefully get to this page. The program asks you to supply information based on exactly what happened and then it tells you if you need to get medical attention or not. I also use it to know which items are safer to buy based on the information it shares. I am so grateful for this tool as it saved me so much heartache, not to mention frantic calls to the doctor and poison control.

I personally am on a mission to not have these toxins available in my home at all. My biggest dream is simply not to have anything around that could be dangerous for Yehuda to eat. I have not been able to do this across the board but I have been able to replace some products. For example, I found nail polish remover wipes that are safe.

## Karma Naturals Nail Polish Remover Wipes

(\$9.99 package in Walmart)

This was super exciting for me as I had already thrown out the nail polish remover and a few such substances.



Seventh Generation and Branch Basics are two companies that have child-friendly products.

Seventh Generation once responded to my email inquiry that it is safe to drink a whole bottle of their detergent even though it would cause a stomach ache and they didn't think it's humanly possible to do. I have not been successful in getting rid of Mr. Clean and laundry detergent for a number of reasons. I recently e-mailed a new company, Branch Basics, who sounded like they could help me have a calmer house by not worrying about this and here is their reply:

*Frieda, Thank you for your question and concern for your son. No, we would not suggest that our product, or any cleaning product for that matter, would be safe to drink. I would make sure that all cleaners would be out of his reach.*

This is actually helpful in making me realize that maybe they are right and there is no simple solution. If anyone does know of a total solution please let us know.... I think it's one of the secret worries many of us have.

I keep the toxic cleaners in my bedroom or high up in a closet locked with the Keeblok doorknob (*see Smart & Safe Issues #1 and 2 for more info about locks*). I have been told that ingesting bleach is really dangerous. Something like Mr. Clean is better. I wish they made all of the bottles with child safety locks; it would save us lots of stressful moments. I do think our children would be better off if they didn't ingest things that say harmful for humans and pets.

To end this story, I will tell you that I watched Yehuda closely even though I knew what he drank was most likely well under a toxic amount. When he coughed, I got nervous. When he got upset, I got more nervous. I woke up at 6 am and sat by his bed to make sure he would wake up... Yehuda woke up chirpy as ever, Boruch Hashem!

Let's hit a more cheerful note and talk about ...Summer! The first thing I think about is the great beautiful outside which many of our children love, and even thrive in. Especially this year, when there may not be any camp, the outdoors will play a big part in entertaining our special children. We do need to prepare for the challenges that come along with it, though.

To give a personal example, my family recently had a barbecue outside in an ungated yard. It wasn't a complete disaster as I had anticipated it to be, but it was super difficult. Constantly watching and checking where Yehuda is, is not my favorite thing. Let me tell you that for him, he hates it- he wants to be trusted and do what he wants. Therefore, outdoor gates are essential. Our gate has literally given us life.

These life-saving gates are very costly, though. I just spent some time researching if it would be cheaper to go with a handyman versus a fencing company. In my situation it was not, but perhaps it's an idea to keep in mind. Some families cannot install outdoor gates for multiple reasons. If you do have the capabilities, here are a few tips to keep in mind while planning:

**A. Choosing what kind of gate:** It's important to make sure that the gate is not climbable. There are a few options for this.

**Vinyl gate** - Super durable and should not be climbable. Personally, I would make sure there is no lattice, or high poles on top to make it more difficult to climb. The price is \$19-\$35 per linear foot including installation.



**Chain link with evergreens** - I was told that its not climbable due to the evergreens. I do wonder if some of our brilliant children would be able to figure it out. The price is \$10 to \$20 per linear foot including installation.



**Pool grade fence** - This is supposed to be impossible to climb. The price is \$15 to \$25 per linear foot including installation.



**B. Choosing the right lock:** The lock is very important and in some cases more important than the gate itself. I personally did not want the plunge lock as I believe Yehuda will figure

it out so I chose the self-closing hinge lock which has a key. I plan to add a sliding combination lock.

**Combination Bolt gate Lock (OWACH AL-971) Combi Bolt Latch, Sliding Barrel Bolt Lock, Stainless Steel Sliding Bolt** (\$19.99 on Amazon)



Another option is a **simple latch lock** that you can put a **master combination lock** into to secure it.

I really feel that gates keep the peace WHILE giving us peace of mind!



As I think summer, I cant help but remember the days when we were struggling with Yehuda running the hose until the water pump inside the house would overheat (we have a well) and shut down leaving us with no water. We were sure there was no way for us to deal with this behavior. One day I decided that it was out of control and googled for a solution until eventually I found a hose lock.

**B&K Flow Lock Brass Hose Bibb Lock** (\$15.54 in Walmart)



When I put it on and looked at it, it gave me an incredible feeling of Hashem being with me. I thought to myself, "If there are hose locks, Hashem will help us find the right things to make our lives work for us, to allow us to enjoy our special tzaddik".

When we moved into our next house, I actually thought of something even simpler and I unscrewed the "flower" on top of the outdoor hose with a screwdriver. In my mind this symbolizes how our journey of acceptance and calm help us find super simple solutions that just make things so much smarter and safer. Thank you Hashem!

Another biggie during the summer is the adult sized or big boy sized swimmers (swimming diapers).

I will never forget one summer spent taking Yehuda to the pool and having to change his Underjam numerous times as they would fill up with water. Swimmers did not work for him as they only come in smaller sizes. I tried and tried to find larger swimmers to no avail. When Yehuda went to camp SCHI his counselor told me he had swimmers. I had her send me the package and now I have the answer to my problem!

**Swimmates Disposable Diapers** (The price varies, depending on size and amounts. It's approximately \$15 for 20 diapers.)



Here is wishing you a safe, happy, healthy summer. Once again please send in your questions, solutions, tips and ideas. Feel free to contact me as I would love to help you in any way I can. I can't wait to meet you all with the coming of Mashiach really soon!

# Illuminations

*Rabbi Avrohom Yaakov Pam zatzal was an American Gadol who lived from 1913-2001. He was Rosh Yeshiva of Torah Vodaath in NY and Nasi of Shuvu in Eretz Yisroel. His wise council was sought out by thousands of his students and yidden from all walks of life. The following are excerpts from the chapter **Rav Pam's Special Friend** in the biography about Rav Pam.*

In the winter of 1989, a son was born to Rabbi and Mrs. Baruch Rabinowitz of Ditmas Park, Brooklyn. The child, to be named Nota Shlomo, was born with Down Syndrome.

Though Rabbi Rabinowitz was close to Rav Pam, he did not immediately inform him of Nota Shlomo's birth. Shabbos morning, the father was given an *aliyah* at the Torah reading in Torah Vodaath and, as is customary, a "*Mi Shebeirach*" was recited for mother and child. Rav Pam, whose seat was in the center of the *beis midrash* only a few steps from the *bimah*, wished "*Mazel Tov*" to Rabbi Rabinowitz, who in turn, informed Rav Pam that the baby had been diagnosed with Down Syndrome. Rav Pam's eyes welled up with tears. Rabbi Rabinowitz tried to comfort the *Rosh Yeshivah* by saying that though he and his wife were broken when they first received the report, they had already made peace with the situation.

"I'm not crying for you," Rav Pam responded. "I'm crying because *Chazal* state that *Mashiach* will come and heal all who are infirm. Now, there is one more reason why *Mashiach* has to come."

Rav Pam was Nota Shlomo's *sandak*, and at the *seudah* following the *bris*, he addressed the assemblage. He prefaced his message by saying: "Yesterday, on the Tenth of Teves, we relived the *Churban*. Today, we shall endeavor to say words of *nechamah*." Rav Pam then quoted a verse in which the prophet Yoel describes the spiritual levels that will be attained with the coming of *Mashiach*: *And it will be after this, I will pour out My spirit upon all flesh, and your sons and daughters shall prophesy; your elders shall dream dreams, your young men shall see visions. (Yoel, 3:1)*

*Malbim* sees this verse as referring to three levels of prophecy. At the End of Days, the Jewish people will receive a flow of prophetic inspiration from Above, and the level that each Jew attains will be in inverse proportion to the level of his exposure to the spiritual decadence before the exile ended. For, prior to

the exile's end, the world will sink to astonishingly low levels of sin and immorality. The elders, who lived most of their lives in the sinful, pre-Messianic period, will attain the lowest of the three levels of prophesy, that of dreams. By contrast, children, who will enter the days of *Mashiach* young and relatively unscathed spiritually, will attain the highest of the three levels.

Rav Pam concluded: "We see tangibly that we are not far from this glorious period. Thus, every child who is born in these times has a great possibility of benefiting from this tremendous spiritual flow that will descend from Above, and which will enrich Jewish children with awesome powers and abilities, the likes of which cannot be fathomed. "I would like to bless the little boy, Nota Shlomo, who as I have heard carries the name of a *gaon* and *tzaddik*: May the name he has been given impact upon his soul and may he merit to receive the spiritual blessings of which the prophet foretells. May he utilize these spiritual blessings to develop beyond the plane of nature; may he become an *ish kadosh* and be a source of *nachas* to his family and a blessing for *Klal Yisrael*."

In the years that followed, Rav Pam developed a deep attachment to Nota Shlomo Rabinowitz. When the child was past the age of four, his father began taking him to *shul* on Shabbos. Nota Shlomo did not disturb the *davening*; instead, he would circle the perimeter of the Torah Vodaath *beis midrash* with quick steps, again and again. Someone suggested that this was not in keeping with *k'vod ha'tefillah*. Rav Pam disagreed. "Perhaps this is his way of *davening*," he said, for he perceived that Nota Shlomo possessed a lofty *neshamah*. "If it's not really disturbing, we should not stop him."

Sometimes, during *davening*, Nota Shlomo would place himself to the right of the *aron kodesh* with a *Tehillim* in hand and shake to and fro, lift both hands upward and make sounds as if he were *davening*. Rav Pam mentioned this in a *shmuess* and commented that one cannot know what such a child accomplished with his "*tefillah*." Similarly, when Nota Shlomo hurried to open the *aron kodesh* prior to the Torah reading, Rav Pam remarked that certainly it was of great significance for the *minyán* that he was the one performing this honor, though what Heavenly ramifications this has is beyond us.

For most Down Syndrome children, singing and dancing have special meaning. For Nota Shlomo, *Simchas Torah* was a highlight of the year. When Nota Shlomo was almost eight years old, his grandparents bought him a child's *sefer Torah* to hold on *Simchas Torah*. Throughout the night and day in *shul*, he held the *Torah* tightly to his chest, displaying an attachment

that was cause for wonder. Only with great encouragement did he relinquish the *sefer Torah* from time to time and dance.

On the morning of *Simchas Torah*, when the *Torah* reading commenced in the *beis midrash* of Torah Vodaath, Nota Shlomo approached the *gabbai* at the *bimah* and offered him his *sefer Torah* to use for the *Torah* reading. The *gabbai* politely refused the offer, but Nota Shlomo continued to ask that his *sefer Torah* be used. And though his father instructed him to return to his seat, the child returned to the *bimah* a number of times to again make his request.

Finally, Rabbi Rabinowitz told his son quietly but firmly that the *gabbai* would not use his *sefer Torah*, and that he should return to his seat and sit quietly.

Rav Pam, who was sitting in his regular seat, only a few feet away from the *bimah*, overheard this. He motioned for Nota Shlomo to come over to him. Rav Pam spoke to the child in a whisper for less than a minute and succeeded in calming him. Nota Shlomo happily returned to his seat. When *Mussaf* began, Nota Shlomo became increasingly anxious, asking his father every few minutes how much time was left until *davening* would be over.

As soon as *davening* ended, Nota Shlomo said, “*Abba*, now my turn.” He then took his *sefer Torah* to the *bimah*, put it down and said, “Rav Pam said that now it’s my turn.”

Rabbi Rabinowitz approached Rav Pam, who explained, “I told Nota Shlomo that right now we are using the big *sefer Torah*, but after *davening* we would do more *leining* from his *sefer Torah* and that we will call up people to the *Torah*.”

And so, after most of the congregants had left, Nota Shlomo’s *sefer Torah* was opened on the *bimah* in Mesivta Torah Vodaath and, with some fifteen people crowded around the *bimah*, three people were called up by name for their “*aliyos*.” After each man pretended to recite the blessing over the *Torah*, Nota Shlomo, standing on a chair, proudly “read” from his *sefer Torah*. When the third “*aliyah*” was completed, two men were honored with “*hagbah*” and “*gelilah*.” Then, the *sefer Torah* was given to Nota Shlomo and an enthusiastic *rikud* ensued.

The last years of Rav Pam’s life, when walking was very difficult for him, a *minyán* would gather in his house for all the *tefillos* of *Shabbos* and *Yom Tov*. Rabbi Rabinowitz would bring Nota

Shlomo for *Minchah* on *Shabbos* afternoon and Rav Pam would always seat the boy to his immediate left. If someone else was already occupying the seat when the Rabinowitzes walked in, Rav Pam would have Nota Shlomo stand next to him. Rav Pam would greet Nota Shlomo with a hug and the child would always ask: “How’s Rav Pam?”

One *Shabbos* afternoon, when Nota Shlomo entered the Pam residence, he ran straight for Rav Pam, grabbed hold of his legs and hugged him. And Rav Pam responded in kind, holding the child close to him. Someone attempted to move the child away, for instructions had been given that, to prevent any passing of germs, no one was to shake Rav Pam’s hand. But Rav Pam told the person: “For him [Nota Shlomo], it’s O.K.”

Nota Shlomo let go, took a step back and noticed how visibly ill Rav Pam appeared. (He had been discharged from the hospital only a few days earlier.) “Why Rav Pam so weak?” he wanted to know. “Why am I so weak?” Rav Pam responded softly, a slight smile on his lips. “What do I know? Ask the *Ribono shel Olam*.”

Nota Shlomo looked upwards and said: “Hashem, why Rav Pam so weak? Make him all better. Give him *refuah sheleimah!*”

Rav Pam took hold of the boy and said with emotion, “Nota Shlomo, may Hashem answer your *tefilos* and grant us both a *refuah sheleimah*, so that we can together go to greet *Mashiach tzidkeinu, bimheirah v’yameinu, Amen*.”

On the morning of Rav Pam’s funeral, by which time the Rabinowitz family had heard the tragic news, Rabbi Rabinowitz arrived home from *Shachris* to find Nota Shlomo sitting on the porch. The boy said: “Rav Pam sick, Rav Pam hospital, Rav Pam died. Now Rav Pam happy.” He then marched into the house, grabbed a *Chumash* and said: “Me learn *Chumash* for Rav Pam.” Each day of *shivah* he sat for a while learning *Chumash*, and to this day, when he remembers, he learns *Chumash* for Rav Pam’s memory.

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# On the Lighter Side...

## A Day in My Locked-down Life

Moishy's Mommy

As I write this while sitting at my dining room table, Moishy hangs onto one of my arms. He cheerfully chews on a nipple from a baby bottle (No wonder they are always missing when we need them). My two-year old is playing Hungry Hippos on the other side of the table, and I am officially the other person in the game, gobbling little red balls. I wonder why he is winning... On the couch, my daughter sits reading a magazine. She asks if we can try the fancy baking recipe that is featured. I know it will wreck my kitchen and come out looking nothing like the picture. But we don't say no to *anything* if it keeps kids busy these days.

Yes, we are home, under lock-down. Home sweet home. Quality family time. All the lovely euphemisms.

In theory, I totally agree. It is indeed nice and homey and calm to just *be*, without running, driving, shopping, and working on the day's agenda.

BUT...

It's also *challenging* and *trying* and *stressful* too. Mostly because of a delicious, mischievous, BORED little boy named Moishy. No, he cannot "Zoom" or take a class on the phone. No, he cannot play games or read books. No, he does not nap or like to watch videos. "What does Moishy do all day?" people ask me. I usually give them an evasive reply, but I will be honest with you. This is what he does: he looks for things to chew: bottle nipples, rubber gloves, pacifiers. Once his mouth is settled, his hands need some action. Pulling things off the kitchen counters (ie: a can full of pickle juice that's now all over him and the floor, a bag of bread opened with slices strewn across the kitchen, a marker uncapped and now decorating his face), rummaging through his sibling's belongings, books, and school papers, and throwing all of the toothbrushes and bathroom paraphernalia into the sink is a good hourly activity. (I make sure to clean it up so he can do it again.) Please don't ask me why I don't lock the doors to the rooms that should be off-limits. (Because doing so includes *all* the doors, and we are under lock-down in the house, remember?)

The truth is that the above entertaining activities are relatively healthy and safe. It's when it involves his younger siblings that things turn a bit problematic. His two-year old brother has so many bald spots, we ought to just give him his *upsherin* already. And hugging his baby brother in a tight, albeit loving, choking maneuver or giving him a gentle push down the stairs are decidedly not acceptable activities. So I will stop doing all of the superfluous things that distract me, such as laundry, redialing the hotline that hung up on my son's *rebbe*

again, and making sandwiches for lunch, and just be a full-time security guard around here. Eating and wearing clean clothes are overrated anyway.

Before you accuse me of being a completely dysfunctional and inattentive mother, let me clarify that this child is not bored because he is totally neglected. In fact, I spoon-feed him 3-4 meals a day, change him (the number of times depends on his level of messy trouble-making), and try to play with him too. I hold him and cuddle with him on the couch. We sing songs and look at picture books. We sit on the floor and play with toys. For about two minutes at a time. His attention span is that short, and he does not want Mommy to be the *Morah* or the therapist.

He came home from the last day of school with a thick folder: reams of instructions, activities, and fill-in sheets to record his progress (aka: Mommy's homework). I was excited to have the ideas. Until I saw what they were. I don't own a pop-up tunnel, a ball pit, pop tubes, peg boards, or a body sock. At the risk of sounding genuinely deprived, we don't even have soap crayons or corn starch to make goop. So most of the activities were not even possible to try. We did do the egg-shell art activity which involved cracking egg shells and gluing them onto a paper, during which Moishy gave me strange looks. Why was I encouraging the very act that usually elicits my displeasure, when he breaks gooey eggs on the floor? I'm not sure what kind of lesson that particular project taught him.

Not to worry though. Moishy has been keeping his muscles well exercised. He has his own brand of therapy. PT includes never keeping on socks or shoes and tackling his brothers. OT involves great sensory experiences like smearing the bathroom with toothpaste (our expensive Kosher for Pesach tube, of course) and chewing his baby brother's pacifiers. He even passed the difficult challenge of untaping some of the taped-up-for-Pesach cabinets! What more interesting and motivating ideas could his wonderful staff come up with had he been in school?

The i-pad that was sent home for him to work on communication has been adopted by his siblings, so at least *they* are kept busy. And as you now know why, so am I.

*Postscript: My eldest daughter is reading over my shoulder as I write. She says to me, "Ma, people are going to think that you made this up or exaggerated it, but it's totally true – all of these things happened just this morning!" I told her that the people who read Neshamale won't think that at all; in fact, their stories may even be more colorful than ours!*

*So to all of you, I say: try writing a humor column. It's great therapy!*



# Lets Get Educated

## PROMPT Therapy

Leah Tawil, MS, CCC-SLP

PROMPT (Prompts for Restructuring Oral Muscular Phonetic Targets), is a therapy program that targets speech production disorders by developing motor skills in the context of language used for interaction.

**Background:** Deborah Hayden developed PROMPT in the late 1970's, and the program has evolved since then. The method uses tactual-kinesthetic-proprioceptive input to the oral-motor structures, for children with severe motor impairment who do not respond to traditional therapy (which utilizes strictly auditory and visual prompts).

**Target Recipients:** PROMPT can be used with all speech production disorders, from the age of approximately 6 months. Typical clients have motor speech disorders, articulation problems, or are non-verbal children. However, PROMPT therapy can be used with a wide range of clients with communication disorders. These include: aphasia, apraxia/dyspraxia, dysarthria, pervasive development disorders, cerebral palsy, acquired brain injuries, and autism spectrum disorders. In order to determine if a child would be an appropriate candidate for PROMPT therapy, start by getting an evaluation by a PROMPT-certified Speech Language Pathologist (SLP).

**What is it?** PROMPT uses an all-inclusive approach, by determining where the motor breakdown occurs and incorporating the PROMPT Conceptual Framework, which consists of skills in social, cognitive, and physical domains. A client's ability to communicate can be impacted by a delay or disorder in any of these three areas.

During treatment one can expect several things to take place:

1. The PROMPT clinician targets words that: a) strengthen a specific motor pattern, b) are meaningful to the client, and c) are used in a realistic social interaction.

**For example:** *If a client clenches or restricts the jaw, the SLP will choose words containing sounds that require an open mouth posture, such as 'ah', like: 'on', 'mama', 'pop', or 'all gone'.*

2. The clinician will use a motivating activity/game in which the word will be repeated.

3. The clinician will then use his/her hands to support the movements of the oral structures (jaw, lips, tongue, etc.) as the client practices these words.

**In action:** *Yehudis, certified PROMPT SLP, asks Rochie, a 5-years-old with apraxia, what sound popcorn makes. Rochie says, "op." Yehudis says "let's do that together." She supports Rochie's jaw and puts pressure on her lips, while she says "pop." Rochie successfully says "pop" together with the clinician. "Good job! Let's do that again," Yehudis says.*

**How does it work?** PROMPT Therapy is guided by the PROMPT Conceptual Framework, consisting of three parts, each one playing a crucial role in speech therapy:

**The Social-Emotional domain** includes skills that relate to interaction with others.

*These might include: initiation and maintenance of conversation, eye contact, trust, and various communicative functions such as: protesting ("No"), requesting ("More"), questioning ("Why?")*

**The Cognitive-Linguistic domain** includes skills that relate to understanding and using language.

*These might include: understanding what someone says, following directions, using words to express oneself, seeing/feeling/hearing things in the environment, and being able to discriminate what's important in what is seen, heard, and felt in the environment*

**The Physical-Sensory domain** includes skeletal structure (jaw, lips, tongue, palate, and larynx), muscular skills (gross and fine motor), and sensation (using sight, sound, taste, and touch for learning).

*These skills improve intelligibility (how well the client is able to be understood) of sounds, words, and phrases.*

**Case Study:** *Noam began traditional speech therapy at the age of 12 months. He received a diagnosis of CAS (Childhood Apraxia of Speech) when he was 2.5 years old. Although he had great, experienced therapists, progress was very slow. When the therapists had exhausted all their resources, they advised Noam's parents to*

*continued on page 34*

# *My Couch, Leiby, & Me*

## Leiby's Mommy

When the first flecks appeared in the dustpan from a random daily living room sweep-up, I promptly called pest control. They came, closed a hole they purportedly found, charged a few hundred dollars, and left. But I continued to find flecks. They came faster than I could sweep them. They seemed to come from nowhere and everywhere and everything was full of it. I called another pest hunter, and another, but those flecks didn't stop. Until Vinny, an honest fella, looked at me a little funnily, and said: "Ma'am, we get this all the time. It's not mice, it's yaw couch." My couch! That can't be. No way. Not my dear cherished couch! My couch is flawless and can do no such thing. Not the perfect couch my husband of a few weeks and I had lovingly purchased one fine day! So, we continued calling the pest troopers until the first spots on the couch became visible and I could no longer hide from reality. My beautiful, faultless, comfy couch was perfect no more. What a horror.



I was on a roll. I called the furniture place, and of course, it was not their liability. I called a repair guy, but he couldn't help. I called family members and friends to cry. Nothing doing. Nothing helped. Guests and friends would look at the couch and kindly suggest it's time to part, but no, no, no! I will keep this couch forever because I love, love, love, this couch! I couldn't and wouldn't and would never, ever do that to my dear beloved couch that I had so lovingly selected. My relationship with my couch is real, tangible, and inseparable. But how I hated those shavings all over my floor! How I loathed those gray spots on my couch! My couch is not merely a resting place. Precious family memories are absorbed in its cushions, now bare and stripped, but full of love. I crave the connection every time I sit, lounge, recline, sprawl, relax, sing, read, or snooze.

I like to draw a parallel between my couch and Leiby.

Leiby came first and we loved him because he was ours. We loved him right away, with his small ears and flat nose—he was so cute! We loved how he cried with that ferociousness. We loved how he hated to cuddle and how he communicated that. We loved how he fixated at lights and avoided eye contact. We loved how he hated guests and we loved how he hated loud noises and touch and we loved how he obsessed with little things. We loved his meltdowns and we loved his crabbiness. We loved him because he was first and we didn't draw any comparisons—we just loved him because he was ours. When a visiting family member commented, we

ignored it. And even when his differences stared at me in my face, I knew he would always be mine, my pride and joy and nachas. Even if he is some strange creature to some family members, to me he is precious and pure.

Even when my other children wonder: "Who is Leiby?" "Why is he ours?" "Why doesn't he love, play, pretend, like my friend's brother?"—he is still mine, forever.

To the world he may not be perfect, but to me, I love him just the way he is. Because he is my love, love, love. He is my treasure and I see it and feel it. He is mine.

### Postscript:

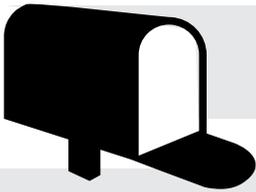
We called for bulk pick-up. When the truck arrived, the men got out, all ready to lug my couch to its eternal rest. Puzzled, they looked around for a couch they could not see. They drove off, the steam of the exhaust filling the space where the couch should have been. No, the couch did not suddenly become invisible. It was still there, in its trusty place in my living room, with my family sitting on it, with me, crying. Emotionally attached to a piece of furniture? Sounds crazy, yes. But to our family, the couch is so much more. And there it will remain, in our living room, a bare, ugly thing that symbolizes the beauty of our family, the preciousness of it all; perfectly imperfect, but cherished and loved.

# *My Baby*

Chany

Tiny, feisty baby,  
 Hooked up  
 To monitors, tubes, leads.  
 IVs in her hands and legs,  
 Tubes down her nose,  
 To breathe for her,  
 Give her nutrition,  
 Keep her alive.  
 Then—surgery.  
 Two permanent holes  
 In my perfect child,  
 Cut into her neck & stomach,  
 To breathe safely,  
 Give her food,  
 Help her grow.  
 More surgeries, more MRIs,  
 Lots of precautions  
 And special care.  
 Finally, homecoming.  
 Equipment galore,  
 A revolving door,  
 Nurses day & night,  
 No privacy.  
 Non-stop appointments,  
 More hospitalization,  
 Exasperation.

But...  
 Ein Od Milvado.  
 We believe in miracles.  
 Despite the pain  
 For her, for us.  
 We will get there  
 One day,  
 Ascend the mountain,  
 Throw off the shackles  
 Of sickness,  
 Of sorrow,  
 Of tubes & monitors  
 & deafening beeps.  
 Happily  
 We will rejoice  
 In our miracle.



# INBOX

After two weeks of homeschooling the children, I was desperate for some “me” time. Not in the kitchen, not near the laundry, not signing any of the papers about how long a child did their schoolwork!

Neshamale Magazine was a *matana min hashamayim!* (gift from Heaven) I laughed so hard reading about Avremle killing those poor Yerushalmi chickens... And cried from the beautiful magazine... I sure hope Mashiach is coming soon, and I'll get to meet all you amazing moms in the front row...Til then stay sane!

I really enjoyed reading about Mari and her amazing family. Just had to let you know that I am so excited about the Mari undershirt! My son is still squeezing into size 24 months onesies and we had been wondering what we would do next. Thank you, Shevy! It is so inspiring to see how people take their challenges and turn them into opportunities to help others!  
L. Steinberg

I read your magazine a couple of months ago when a friend forwarded it to me. I was so impressed by the quality of the articles, and enjoyed reading it again and again. As a mom of a special needs child who is also very medically involved,

it was such *chizuk* to read about others and how they grew and learned from their challenges. May you have much *hatzlacha!*

Sincerely,  
Raizy

I wanted to thank you for the beautiful magazine and specifically for one paragraph that changed my family's life. We recently moved to a new neighborhood, and I was uncomfortable asking my new neighbors for help with my son. I kept pushing it off, although my family was clearly suffering (sorry to use that word but it is the truth) by not having the needed respite. When I read the last paragraph in the article by Shoshana Lob, the respite coordinator in Detroit, it gave me the confidence to do what I needed to do and not feel bad. To quote: “Please! Don't hesitate allowing others to assist you... You are gifting them with the amazing opportunity...to fulfill their obligation to care for the children Hashem gave to all of us.” Thank you, Shoshana, and thank you, Neshamale!  
Esther K.  
Lakewood

Thank you so, so much for your beautiful magazine! I printed out two copies before

Pesach for the family to read on Pesach; I knew they would all enjoy it. One nice part about us all being home for Yom Tov was having time to *shmooze* about the magazine. We all agreed that the best article by far was “The Perks.” We really had a laugh, because it was so true and we really related to it.

One thing I learned from “Corona,” besides that Hashem runs the world and we have zero control (which I learned long ago, when we started with my daughter's whole saga), is that Hashem is also the best therapist.

I was pretty worried in the beginning about what I was going to do. My daughter went from 16 hours (!) of therapy a week, to two half-hour video therapies! Therapy is crucial in her situation—but guess what? Hashem knew what He was doing and took this into account. Obviously, it's not the therapy that helps, because Hashem, Who can do anything, is helping her even without 16 hours of therapy. Thank you again for your beautiful magazine.

Anonymous  
Lakewood

### Corrections:

There was a letter in the last issue regarding a Seizure Support Group in Lakewood. The second phone number was mistaken. The correct number is: (732) 833-3755.

*continued from page 31*

*seek out a PROMPT-certified therapist. He started PROMPT therapy when he was 4 years old, at which time he had around five sounds and was learning some signs to make communication easier. His family was able to receive a grant through Small Steps in Speech (a non-profit organization), and received PROMPT therapy once a week for 6 months. Right away, Noam began responding to treatment by making sounds that his family had never heard before. After the grant ran out, the family decided to continue PROMPT and their son continued to make steady progress, producing more sounds, then syllables, then words. By the age of 6, Noam began speaking out loud*

*in sentences. Noam is now 7, and his family recently discovered that strangers have understood him and responded to him appropriately on a number of occasions! Although he still has a long road ahead of him, his family no longer worries that he will not be able to speak – because he already does!*

*The information used in this article was obtained from the PROMPT website, <https://promptinstitute.com>. Please visit the website for more information.*

## GLOSSARY OF HEBREW TERMS APPEARING IN NESHAMALE MAGAZINE

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

- Abba—Father  
 Aibeshter—God (Y) (lit: The One Above)  
 Alef Bais—Hebrew alphabet  
 Aliyos—Calling up to the Torah  
 Aron Kodesh—the Holy Ark  
 Avos—Patriarchs (Abraham, Isaac, Jacob)  
 Avrohom Avinu—Abraham, our Father  
 Beis Midrash /Battei Midrash—Synagogue  
 Besuros Ra'os—Evil tidings  
 Bim'hayra V'yamaynu, Amen—May it be speedily, in our days, Amen.  
 Bimah—Platform  
 Boruch Hashem—Thank God (lit: Bless God)  
 Bracha—Blessing  
 Bris—Circumcision  
 Chaburah—Learning group  
 Chas v'Shalom—God Forbid (lit: Mercy & Peace)  
 Chasuna—Wedding  
 Chavrusa—Torah study partner (Aramaic)  
 Chazal—Sages (acronym: Our Sages, may their memory be a blessing)  
 Chesed—Acts of kindness  
 Chometz—Leaven  
 Chumash /Chumashim—the Five Books of Moses/pl  
 Churban—Destruction (usually used in reference to the destruction of Jerusalem's Holy Temple or to the Holocaust)  
 Daf Yomi Shiur—Daily class to learn a folio page of Talmud  
 Daven/Davening—Pray/Prayer (Y)  
 Ein Od Milvado—There is no one but Him (God)  
 Eis Ratzon—Propitious time  
 Gabbai—Sexton  
 Gaon—Genius  
 Gelilah—Wrapping the Torah scroll after it is read  
 Geulah—Redemption  
 Geulah Shelayma—the ultimate Redemption  
 Hachnosas Orchim—Hospitality to guests  
 Hagbah—Raising the Torah after it is read  
 HaKadosh Baruch Hu—The Holy One, Blessed be He  
 Halacha—Jewish Law  
 Hatzlacha—Success  
 Imahos—The Matriarchs (Sarah, Rivka, Rachel, Leah)  
 Ish Kadosh—Holy man  
 K'vod Ha'tefillah—Respectful attitude to prayer service  
 Kavana—Intent, usually in reference to concentration during prayer  
 Kedusha—Holiness  
 Kiddush Hashem—Sanctification of God  
 Kol HaLashon—Jewish radio station  
 Leining—Reading from the Torah (Y)  
 Maggid Shiur—Teacher of Torah class  
 Malachim—Angels  
 Malbim—Commentator on Torah (1800s)  
 Mashiach Tzidkeinu—The Righteous Messiah  
 Matana Min HaShamayim—Gift from Heaven  
 Mazel Tov—Congratulations  
 Mi Shebeirach—Blessing given at Torah reading (lit: "May He Who blesses...")  
 Midos—Character traits  
 Minchah—Afternoon prayer service  
 Minyan—Prayer quorum of 10  
 Mishmar—Lit: Guarding (Late Thursday night "protective" Torah learning session)  
 Mitzvos—Torah Commandments  
 Morah—Teacher  
 Mussaf—Shabbos and Holiday "Additional" Prayer Service  
 Nachas—Pride & Joy (usually from children)(Y)  
 Nechamah—Comfort  
 Negel Vasser—Ritual hand washing upon arising (lit: Nail Water)(Y)  
 Neshamah/Neshamale—Soul/Little Soul  
 Nisayon--Test  
 Olam Haba—The World to Come, Afterlife  
 Paskened—Adjudicated (according to Jewish Law)  
 Pesach—Passover  
 Pirkei Avos—Ethics (lit: Chapters) of the Fathers (section from Talmud traditionally read on Shabboses between Passover and Shavous)  
 Rachel Imaynu—Matriarch Rachel ("Mama Rachel")  
 Rebbe—Elementary Torah teacher  
 Refuah Sheleimah—Speedy Recovery  
 Ribono Shel Olam—Master of the World (God)  
 Rikud--Dance  
 Rosh Yeshivah—Dean of Yeshivah  
 Sandak—Person with the honor of holding the baby at a briss  
 Sefer Torah /Sifrei Torah—Torah Scroll/(pl)  
 Seudah—Festive Meal  
 Shabbos Seudas—Sabbath Meals  
 Shachris—Morning Prayer Service  
 Shamayim—Heaven  
 Shechina—Divine Presence  
 Shema—Foremost Jewish Prayer  
 Shiur—Torah Class  
 Shivah—7 Day mourning period  
 Shmuess /Shmuz—Informal discussion (Y)  
 Shul—Synagogue (Y)  
 Siddur/Siddurim—Jewish Prayer Book/(pl)  
 Simchah—Joy, Joyous occasion  
 Simchas Torah—Holiday of "Rejoicing with the Torah"  
 Siyata D'shmaya—Help from Heaven (Aramaic)  
 Sovel—to suffer, bear it  
 Succos—Holiday of Tabernacles  
 Tallis—Prayer Shawl  
 Tefillos—Prayers  
 Tehillim—Psalms  
 Tzaddik—Righteous person  
 Tzedakah—Charity  
 Upsherin—3 yr old boy's first haircut ceremony  
 Yeshiva(h)—School of Jewish study  
 Yid /Yidden—Jew/(pl) (Y)  
 Yom Tov—Holiday  
 Zoche—Worthy, meritorious

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*You can't stop the waves  
but you can learn to surf.*