נשמהלה

Neshamale magazine

Sharing Our Special Experiences: Chizuk & Inspiration

BIRTHDAY REFLECTIONS /18

TOP TEN TIPS ON SLEEP /33

A SMOOTH RIDE TO YOUR VACATION DESTINATION /26

ISSUE #21 // SUMMER EDITION תשפ"ה

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

With much appreciation to our contributors:
Yitty Berkovic
Toby Brief
Batya Dancykier
Ezra Greher
Milaine Grossbard
Chaya Suri Grunwald
Vicky Horowitz
Rabbi Boruch Rabinowitz
Shira Speiser LCSW
Gitty Weiss

Sponsored Anonymously

לע״נ

הבחור שמואל ז״ל
בן ר' חיים נח הלוי נ״י

Neshamale Magazine welcomes your contribution of articles, poems, personal experiences or any material that may inspire our readers. We will respect your request for anonymity. We reserve the right to edit all submissions for clarity, space and sensitivity.

We also request your comments, suggestions and donations. Please contact us if you are interested in the opportunity of sponsoring the next issue.

CONTACT INFORMATION
E-mail: **neshamalemagazine@gmail.com**
Mail: **112 6th St. Lakewood, NJ 08701**
Text: **848-299-2908** Phone: **732-436-9916**
To subscribe for free e-version:
neshamalemagazine@gmail.com
To subscribe for printed magazine, view the current issue and explore archives:
https://www.ramapost.com/neshamale

Table of Contents:

Connecting

Inspiring

Educating

Sharing

Exploring

In the upcoming issue we plan to focus on

Identity

Who am I? Who is my special child/sibling/student? Where does their abilities and disabilities, labels and diagnosis, fit in? How does it affect who they are and how they are viewed? Perhaps your answers to these questions are evolving as you live life alongside a special Neshamale… Please share with us!

We always welcome photos, Wow! Stories, Memorable Mishaps stories, Sweet Spices stories, as well as any questions you may have for a Rav, doctor or social worker.

Deadline for submissions: **Sept. 17**
Email: **neshamalemagazine@gmail.com**
Mail: **112 6th St. Lakewood, NJ 08701**

Dear Readers,

What's the significance of a birthday?

As *Yidden*, we celebrate the dates of events that affected our destiny, such as *Yomim Tovim*. As individuals, we celebrate the dates that have personal significance to us — and what is more significant than being born? It's when Hashem said: "I need you here. I have a mission for you to accomplish, and I trust that you will pull through."

To paraphrase a popular birthday card slogan: "Happy Birthday! The day you were born is the day G-d decided that the world couldn't continue to exist without you in it." Let's appreciate that idea – our children, as limited as they may be, were an absolutely necessary addition to this world. The world couldn't continue to exist without them! Just that thought alone should give us reason to celebrate!

I must tell you how much fun it was preparing this issue! I just loved thinking about, reading about, and talking about birthdays! It is such a fun, light, and happy topic, as opposed to some of the more serious topics we often cover.

Over the years, I have gotten some negative feedback regarding the positive vibe that our magazine conveys. One reader wrote*: Although you undoubtedly mean to be encouraging, I find the tone demeaning and dismissive. I find the words of chizuk infuriating. This child has ruined my life and I don't want you to make a party out of my suffering.*

While I understand where this person is coming from, and I feel for her, I don't agree with her. Being positive doesn't mean all is perfect. Being happy doesn't mean it's a party. We can try to feel joy in the pain and be optimistic, despite a current crushing reality. As *Rebbetzin* Chaya Sara Kramer replied indignantly when questioned how she was always so happy despite her not having the children she so badly wanted: "What? Should I be both barren *and* sad?"

She was able to say this because she recognized that happiness is a choice, not an outcome of life's circumstances. Choosing happiness is a life-long process of working on *emunah, hakaras hatov* and being *samayach b'chelko*. But the first step is to make that choice: "I want to be happy." And, more specifically in our situation: "I want to be happy with my special child, the child that Hashem gave me, the child as he is today. Although I may wish he were different, and hope things improve, today I will be happy with my child as he is."

That's the first step – celebrating our children for who they are! And what could be a better day to do that than on their birthdays? A child's birthday is the perfect time for us to stop for a moment and realize how special this child is, what makes him unique, and what there is to appreciate.

While we do try to keep *Neshamale* upbeat, we would never want to invalidate the reality of the burdens that we carry. Our goal is not to whitewash or deny their weight, but rather to express the value of our mission and give us the ability to carry our "package" with pride and purpose.

To balance the levity of our birthday focus, we have more serious pieces in the main feature section. It's fascinating how the experience of raising a child with special needs has changed in the past fifty years. Three devoted family members shared with us their stories of living with a special family member – in an era without much support, infrastructure, respite, or respect. Although the read may be heavy, it's an opportunity to recognize how much better we have it today and to be grateful for so much of what we take for granted. As a friend recently remarked to me: "In 2025, it's doable to raise a child with special needs." Isn't that another reason to celebrate?

So how to do we do it? Each family celebrates with their own unique traditions, which you can get a peek at in the article "How Do We Celebrate?". In a more spiritual sense, there are some celebration ideas brought down in *sefarim,* such as taking on a new *mitzvah*, giving *tzedakah*, and saying extra *Tehillim*. I've heard that every year of life has a corresponding *perek* of *Tehillim*, the *perek* whose number matches the year you are entering (ie: for a 30 year old – *perek lamed alef*, 31). When I *daven* for my children, I sometimes say the *perek* of *Tehillim* that corresponds to their age as a *zechus* for them. Perhaps a birthday is a good time to start saying the appropriate *perek* for our special children.

There is another custom for the person whose birthday it is to give *brachos* to others. Their *mazel* shines strong on their special day, and we can take advantage of it! Hashem orchestrated that I should be writing this on my very own birthday(!), so I want to end with a heartfelt *bracha* to all of our readers: Hashem should *bentch* you with the ability and the strength to celebrate your special children, not only on their birthdays, but every day of the year. May you be *zoche* to see what there is to celebrate, and to do so in good health. May we share in *simchos* until the speedy coming of *Mashiach,* when our celebration will finally be whole and complete!

Chayala

Chizuk Boost #13

Rabbi Baruch Rabinowitz

Eileh Ha'Devarim

Hashem communicates with us in different ways. The *Avos* and *Moshe Rabbeinu* merited personal revelation. *Klal Yisroel* was *zoche* at *Har Sinai* to hear Hashem speak to us directly. At other times, Hashem spoke to us through a *bas kol* or the *urim v'tumim* or He gave an indirect message through *neviim*. These are all versions of *dibur* - the words of the *Ribono shel Olam.*

Today, when we are no longer *zoche* to *urim v'tumim* and *neviim*, Hashem communicates with us through a different type of *dibur. Devarim* - the events of our lives - serve the same function as *dibur,* which is why the two words share the same *shoresh*. Hashem speaks to us through events, through actions. Our paths are guided by the *Ribono shel Olam* through those events and through the *nisyonos* He presents to us.

תורתך ודברך ישים על לבו*(Your Torah and Your words He will place in His heart).* Just as we said *naaseh v'nishma* for the Torah and accepted *kol haTorah kulo* before we understood, so too, we must say *naaseh v'nishma* on all the *devarim* of life. We might not be able to comprehend why we have been selected for whatever happens to us; it might even appear to be harsh - *lashon davar*, not the gentleness of *lashon amira*. But our job is to accept. Perhaps one day we will perceive and understand. Or perhaps not.

The *pasuk* in Tehillim says: הקל הנותן נקמות לי וידבר עמים תחתו. *Va'yadber* is, once again, the same *shoresh* as *devarim*. *Va'yadber* says Rashi, means *va'yinaheig*. Hashem who gives challenges to us, He is guiding us. The *dibur* guides us; the *devarim* of life guide us. Through *dibur* and *devarim*, וידבר עמים תחתו– *HaKadosh Baruch Hu* gives us the messages to lead ourselves, and empowers us to lead our families.

Sefer Devarim is also called *Sefer Tochacha*, an indication of the dominant content in this *Chumash*. *Tochacha* are words of warning, admonishment, and of possible *onesh,* as represented by the extreme of the *klalos* of *parshas Ki Savo*. The real purpose of *tochacha,* however, is to show us the proper way to live, communally and personally. *Tochacha* means Hashem showing us direction, step by step, through His *devarim.*

The *shoresh* of the word *tochacha* may be the word *koach*. When I am given *tochacha*, overtly or with a deeper message of direction, that *tochacha* gives me *koach*. It gives me parameters; it empowers me and focuses me. I am being directed toward a goal, led by *HaKadosh Baruch Hu,* in the mission of my personal life. Even if I am weary, I am fortunate that I know my *tafkid*, and I will be able to dig deep within myself to find the *koach* to work toward that *tafkid*. *Ha'nosein l'ya'eif koach* – despite my being tired, Hashem can give me the energy to keep going, to keep climbing and growing.

The *tochacha* of *Chodesh Av* is particularly intense and powerful. There is so much challenge and hardship in this month, yet it is called Av, because only a Father loves and cares enough to give such *tochacha* to His child. In our own lives, with our unique *nisyonos*, only a Father loves and cares enough to challenge us in raising children. He invites us to lift ourselves up to become the parents that He wants us to be, that He knows we can be. To give incessantly, to give *l'sheim Shamayim*, to give without ulterior motives.

I once took a group of *talmidim* to see an elderly distinguished *isha Yerushalmis*, Rebbitzen Chaya Shainbergerer *a"h*. The *sefer* of *tochacha*, she told us, begins with "*Eileh ha'devarim*" because the word *devarim* is related to the word *devorim* – bees. Although bees sting and a sting hurts, bees are also the source of honey. The *devarim* of life might sting; they might be difficult and challenging. But their source is the *Ribono shel Olam.* There is a sweetness accompanying the challenge *HaKadosh Baruch Hu* gives me, uniquely designed for me and my family. There is a sweetness to fulfilling my *tafkid*, to fulfilling the *ratzon* Hashem.

This Chizuk Boost is excerpted and adapted from one of Rabbi Baruch Rabinowitz's weekly 10 minute Chizuk shiurim for parents of children with special needs. There are now over 250 recordings, which can be accessed on Kol HaLashon (718-906-6400, press 1, 4, 97, 2). They can also be accessed at yedei.org

IN SESSION

Q

Several people have said that they didn't want to see pictures of my premature baby while she was in the NICU because it made them queasy. It was very hurtful to me, especially as a postpartum mother! Now that she's out of the NICU, but still on tubes and wires (O2 and feeding), how am I supposed to approach these people when I meet them in public places? Or do I go out of my way not to see them?

Leah F.

A Dear Leah (but really to every reader of *Neshamale Magazine*),

Your letter made me feel very sad, but full of compassion for you. Having a preemie, while you yourself are postpartum, takes a huge physical toll. I hope that you will do the essential self-care to aid your complete recovery.

In a previous edition, I addressed a concern similar to yours, but feel it is important to restate it. Many years ago, I attended a lecture in a theater style hall, with each row of seats slightly higher than the row below. The instructor was at ground level with a huge white screen that was probably two stories high. Can you picture this? This huge screen was totally white, until she added a red laser dot. She asked everyone what they saw. Approximately, 99% of the participants responded that they each saw a red dot.

She then introduced her topic: you guessed it, people with special needs. She wanted us to recognize that we are focusing on the red dot, which was miniscule, in proportion to the giant white screen. Indeed, we should have said that there is an extremely large white screen, with a tiny red laser dot in the middle.

Let's refocus and put this into perspective. What the people you write about are doing, is focusing on the 'red dot'—the tubes and the wires—and not noticing the 'white screen' of your child's entirety. How should you deal with this? Firstly, you do not have to hide—absolutely NOT! In previous generations, babies with special needs frequently died at birth and/or were hidden. Fortunately, we have a new perspective and everyone can be accepted. Yes, there might be differences, but every baby has beauty and something unique!

Allow me to digress, but understand that this is very relevant. For many years, I have tried to help women who suffered pregnancy losses: unsuccessful IVF, miscarriage, perinatal loss, and stillbirth. These are ALL losses, and need support and validation.

For this discussion, the focus will be on a woman who had a loss further on in her pregnancy, when she was 'showing.' Frequently, when such a pregnancy loss happens, other people are unaware of the woman's loss. When she returns to work and/or is back in public, her co-workers or friends, who haven't seen her for a while, will typically come over to wish her *"Mazel Tov."*

This is a potentially awkward and painful situation for the woman who experienced the loss. She needs to be prepared, as this scenario is very possible and probable. Proactively, she and I practiced—yes, practiced a script that she prepared beforehand. Initially, it's very difficult to say the words/script. However, the more she practiced, the smoother it became, until it flowed naturally.

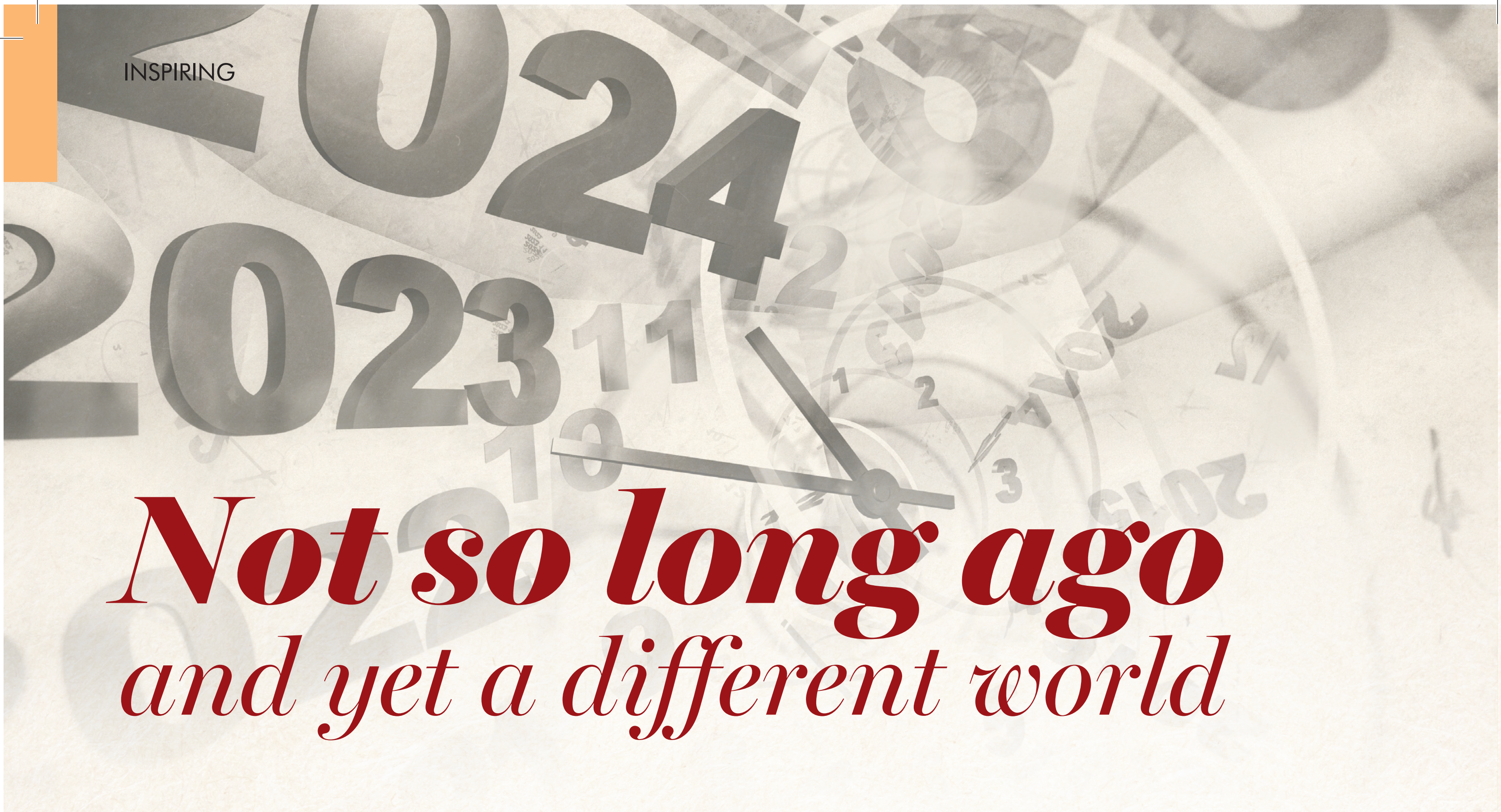
Yes, this is relevant to you. *Boruch Hashem*, you have a baby; however, comments about your baby's appearance will perhaps be said, that will be painful to you. Write up a script and practice. Choose words that are meaningful to you, but maintain your respect and integrity. You can be in control! Practice in front of a mirror, and with people with whom you are comfortable sharing these words.

Let's acknowledge and embrace your strength and courage as you embark on this journey. Don't be drawn into the prejudices and shortsightedness of others. I feel like saying to them: "Shame on you!"

Wishing you continued *nachas,* and may Hashem give you continued strength as you raise your child.

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



Not so long ago
and yet a different world

Raising Joshua

A father's story of navigating the special needs educational system and beyond

Ezra (Elliot) Greher

My son Joshua was born nearly 46 years ago with a congenital disability: Down Syndrome. He survived, despite a still-evident congenital heart defect, and severe respiratory infections during the first seven years of his life. He has needed eyeglasses during all waking hours since he was three, used shoe orthotics for the last thirty years, requires a CPAP machine during sleep for most of the last 25 years, and for the last three years often uses hearing aids. But his health is generally good.

Since moving from Maryland to New Jersey about 19 months ago, our current medical challenge has been to find the most competent medical services within a reasonable distance from our home. We are succeeding slowly, but have yet to find a "local" expert in adult Down Syndrome equivalent to the clinic at the Kennedy Krieger Institute in Baltimore.

Joshua's educational experience in Maryland was very mixed. He entered the public school system when he was only three weeks old – probably their youngest student. In those days, there were no Early Intervention therapists showing up at your door; he received his therapies in public school. My wife, who didn't drive, had to take public transportation with baby Joshua every day. When he was a few years old, we moved him to a private school to try and give him the best education possible. It was a Catholic school, and he was actually their first male student (it was originally a female-only school, that opened up to males just when we applied). It was there that he learned to read and write.

When Joshua was eight, he transitioned back into public school. Public schools in our wealthy Maryland county were very regimented. IEP's were lengthy and useless. Some years were more productive than others. His education was very important to us, but we also gave him opportunities in other areas. When Joshua was very young, we noticed that he had an exceptional understanding of rhythm and loved anything related to music. We decided to give him music lessons, a move that brought so much joy and satisfaction to his life. His first love was the drums, and it is still his favorite instrument. He also plays guitar and keyboard. Whenever we attend a wedding, Joshua gravitates to the bandstand, where he watches the drummers for hours on end.

Fortunately, we found Joshua a paying job a few months after he left school. He worked in several Federal government mail rooms. He was not a Federal employee, but a mail clerk working for a contractor. This experience lasted nearly 23 years (with a two year Covid hiatus). He earned above minimum wage for his 16 hour, 4 day/week job. The only problem was getting him to and from work. We used taxis and driver services like Uber. This worked, but we were often anxious about his pickup at the job. His employer helped greatly to assure that Joshua met his driver every afternoon.

In New Jersey, Joshua received state funding from its Division of Developmental Disabilities after an eight month application period. We hired a consulting service to facilitate and speed his application process. It was a wise move, as he quickly received funding at a generous level. We are busy finding programs to fill his day, and looking for personal aides (direct support professionals) to be with him in the afternoons/evenings. New Jersey pays for *frum* day-hab programs six days a week, and Joshua enjoys going into the community for horseback riding, guitar instruction, a *frum* bowling league, and *frum* club activities. We plan trips to concerts, restaurants, shopping malls, and sporting events. Playing golf is a favorite of his. We have an excellent State-provided support coordinator/case worker, and we hired a support broker to find additional service providers and activities.

When our grandchildren (and great-grandchildren!) come to visit, Joshua is a loving uncle who relates very well to all children. Our home is now just 150 feet from the *shul's* front door, a great improvement from Maryland's three-quarter mile walk. The religious life in Lakewood, New Jersey is wondrous and often overwhelming. Our son and we, his aging parents, have traded a mostly secular environment in Maryland for a mostly religious environment in Lakewood. We look forward to many more healthy, productive years together with our Joshua.

Raising Tzvi Yehuda

Forty years ago, raising a child with special needs was a very lonely journey

Vicky Horowitz

I was a post-World War II baby, born to parents who came to America right before the war. In fact, my parents named me Victoria because we won the war!

Although we lived in a part of the country that had very little in terms of *Yiddishkeit*, my parents did everything they could to keep the *mitzvos*. They ordered kosher meat and kept Shabbos and the Holidays.

My husband, Avrohom Horowitz, attended Rabbi Jacob Joseph School in Manhattan. He had wonderful *rebbeim*, who, together with his *frum,* learned parents, brought him up to love Torah and *mitzvos*. Little did I know, at the time of our marriage, how fortunate I was to marry such a righteous, learned man. Neither of us imagined the challenges we would face with the birth of our first child, Tzvi Yehudah.

My husband and I grew up in an era when special needs children were rarely seen in the general community. For the most part, they were hidden. Thus, neither of us was prepared to raise the autistic child we were given by HaShem. The great blessing that we were granted, however, was that we both loved Tzvi Yehudah unconditionally. We were determined to keep him home as long as we could, and to do everything that we could to help him.

Although Tzvi Yehudah was born ten days late, he appeared normal at birth. He was well-formed, and had a beautiful smile. His physical development was on time.

However, his speech was delayed. The doctors blamed me, claiming that I didn't expose him to other children enough. As time went on, other issues came up. Instead of playing nicely with his toys, Tzvi Yehudah threw them down the stairs of our second-floor apartment. He was also very restrictive as to which foods he would eat. I constantly worried about his nutrition.

Due to the fact that, at that time, there was no clear diagnosis for Tzvi Yehudah, doctors and educators tended to blame my husband and I for our son's developmental delays. Thus, instead of feeling supported, we felt guilty. We became more and more depressed when, as each month passed, our precious child fell more and more behind other children his age. It was scary to see the sister who was born two years after him surpass Tzvi Yehudah in verbal and other cognitive skills.

Within just a few years, our family was blessed with three adorable, neurotypical daughters. As they grew, they became involved in teaching their older brother various skills, such as better use of language, doing puzzles, and playing match-up games. They learned to forgive his foibles, even if it meant copying over math homework that Tzvi Yehudah had scribbled on. I bless them every day for their patience and kindness.

It was hard to find a school for Tzvi Yehudah. The many frum, special needs schools that exist today had not been founded yet. The best years of Tzvi Yehudah's childhood were spent in HIDEC (Hebrew Institute for Deaf and Exceptional Children). He went there for preschool and when he was eight and nine years old. Those were times of progress and growth. Afterward, our son spent his school years in public school, where his disabilities were not really understood.

Some of our son's behaviors in his younger years were quite unique. For example, on our way to go shopping, Tzvi Yehudah would run into a number of the stores along the way, and turn off the lights. I tried to explain to the startled storekeepers what had happened. When we arrived at the supermarket, Tzvi Yehudah busied himself with taking cans off of the shelves, and lining them up in the middle of the aisles. We soon learned that one of us had to stay home with our dear son, while the other parent went shopping.

Life with Tzvi Yehudah was beyond hectic. Sometimes, he would put beans in his ears, and need to be brought to the hospital emergency room. He also kept us up late at night because he had fallen asleep on the long bus ride home from school. Another major problem was his love of walking. Unfortunately, he had no interest in limiting his itinerary; he walked, and walked, and walked. My poor husband got lots of exercise!

When Tzvi Yehudah turned ten, he began vomiting almost nonstop. He lost so much weight that he had to be hospitalized. The first few months were spent in hospitals in New York. When they could not help him, he was transferred to Kennedy Krieger Institute in Baltimore. By that time, Tzvi Yehudah was also suffering from food refusal. He spent a total of nineteen months in hospitals. When he returned home, he was still on a feeding tube. He required a night nurse to administer feedings. During the day, he ate and drank a little bit on his own. The vomiting continued for many years but slowly his eating improved and at least his weight stayed normal.

I hope to write more in the future about my son's years growing up, and his years as a young adult. For now, I will sum up my feelings of thanks to everyone who has helped us on this long, lonely journey. To the family members, neighbors, friends, teachers, and therapists, may you all be blessed. Thank you also to the *Hatzalah* members and the *Shomrim* volunteers who helped find our son so many times when he went missing. We could never have managed without you. And most of all, thank you, dear Tzvi Yehudah, for being the beloved *neshamale* that you are. You inspire us every day with your love of life, your indomitable spirit, and your will to keep trying to learn.

Growing Up With Shlomo

A sister's memories of growing up with her autistic brother in the 80's

J.G.

My brother Shlomo was born in January, 1972. He was an unusually quiet and content baby who barely cried. At the proper developmental age, he said the words "Ma-ma" and "Da-da," but then never spoke again. My parents took him to many specialists, but no one could figure out what was wrong with him. At five years old, he was finally diagnosed as severely autistic, with a high level of mental retardation.

My parents were referred to the Behavior Research Institute for Shlomo's treatment, a school comparable to the infamous Willowbrook State School. When they realized what kind of abuse was going on there with their 5-year-old child, they immediately took him out, and my father sued the school. As a young child I didn't understand the details of what was transpiring, but I felt the tension in my home.

Shlomo was often up all day and all night, and my parents needed to take shifts to stay with him. He was also constantly ripping and breaking things, probably in frustration at not being able to speak. I was very young during this time, so my memory of it is limited to small flashbacks.

We lived next to one of the best public school systems in the country. Shlomo was placed there in a "special" class, comprised of all the special needs children together, with one teacher in charge of them all. This clearly was not ideal, but it was the only thing available locally.

When I was nine and Shlomo was 13, my father found a school in Japan for autistic children and shipped him off for a year. My father was so impressed with this school that he helped bring it to America. It was called the Boston Higashi School. As it gained popularity, other *frum* children joined the school, and my *Bubby* came from Florida to be the kosher cook. There was a huge yearly performance that I remember clearly, in which kids were riding unicycles; I thought it was pretty cool. Baruch Hashem Shlomo did well there, and his skill level and behavior improved.

As a child, I felt stumped by the whole thing. My parents had to figure things out from scratch, and I had to figure out how to be helpful and not get too resentful. I remember going out on long walks when things got too overwhelming for me at home. I felt at a loss because there were no support groups for siblings of special needs individuals—that's why I was so excited to find *Neshamale Magazine!*

I always said I would never work in special education because I had enough of it growing up, but I ended up taking a job in a *Hamaspik* Group Home two years ago, and loved it! In addition, I've now become an ABA therapist in an ASD preschool, and I'm seriously considering going back to school for my masters in ABA Therapy. Now, I'm grateful that I grew up in a home like mine, because it gave me experience to go into the field, and most importantly, it taught me to be kind to ALL types of people.

It's amazing how things have changed over the years. Now, both the Board of Education and health insurance companies cover services for the developmentally delayed; I hope Hashem will allow this to continue without any major changes. May all the families with special needs individuals be blessed with the strength they need to handle their challenges, and receive the tools and support necessary to feel that they are not alone!

perspectives

The Volunteers' Perspective

Chaya Suri Grunwald

Dear Shimon,

I was privileged to meet you a few years ago, and it's been a journey of connection, love, and joy. The journey is still ongoing; a journey that shows me the deep, immense bond that giving creates. This journey teaches me how giving makes one grow within themselves. It brings such fulfillment into my life, and teaches me far more *emunah* and *bitachon* than I thought was attainable.

I used to feel deeply saddened by your plight. I admit that I questioned Hashem—I didn't think it was fair that a nonverbal autistic child who is so helpless and misunderstood should also have medical challenges. It hurt me when this vibrant, energetic child became listless and pale. I couldn't bear to watch how uncomfortable you were, begging for someone to ease your pain. Although we tried, there was nothing anyone could do.

And your saga continues.

While walking home, I would turn to Hashem and say: "Hashem, enough! Stop it already! How much can one child suffer? Why are you doing this? I can't watch Shimon like this; I love him too much!"

I repeated this *tefilla* for weeks, until one day I realized how wrong my perspective was. I suddenly realized that Hashem is the *Ba'al Harachamim*. He loves and cares about Shimon way more than I do.

Ba'al Harachamim means that Hashem is the ultimate of *rachmanus*, His compassion transcends by far the compassion of everyone in the world put together. Therefore, there is no doubt that He is pained by Shimon's plight, far more than anyone else.

And He definitely has the ability to stop Shimon's suffering in an instant. So why doesn't He? Surely, *k'viyachol,* He can't bear His child's pain.

But Hashem in His mercy and tremendous love for His children is willing to look away from His own pain of seeing one of His children suffering, because He knows that this is for the good. He knows that for Shimon, going through this is a *tovah*, and the *tovah* is so great that our Father in Heaven is willing to be pained, *k'viyachol*, so that this good can occur for Shimon.

Our Beloved Father is willing to feel tremendous pain so that Shimon can ultimately benefit.

So now, when I take you out, Shimon, I'm at peace. At peace because I see Hashem's love. At peace because I know that there is Someone up there Who loves you far more than I can ever imagine. And that He is doing this all for your benefit.

As I walk you home now, I am enveloped in a cloud of *ahavas Hashem*, and that makes my connection to you—my love for you and my joy that you are in my life—far stronger.

It is a journey that is very worthwhile.

A Gift Passed Along...

UTILIZING OUR EXPERIENCES & ABILITIES TO BENEFIT OTHERS

Chayala Tawil

Interview with Malka , Co-founder and Director of Abilities

Can you share what prompted you to start your organization, Abilities?
We started with two girls who saw a need and said to each other: "Maybe we can fill this!"

It bothered us that children with severe handicaps such as CP and traumatic brain injury were consistently lumped together with special-needs children—in schools, camps, and programs. Additionally, many of these children have complex medical needs (ie: trach/vent), and special-needs programs are not equipped or prepared to take responsibility for these children.

That's where Abilities comes in. We provide services and support to families of wheelchair-bound children ages 2-29 across the U.S. and beyond. Our motto is: "Not a Disability, Just a Different Ability." We believe that every child, regardless of his level of functioning, is a shining, capable star.

What are the services and supports that you provide?
There are three main categories: Services, Support, and *Shabbaton.*

Our services currently include events, crisis support/hospital shifts, and divisions for wheelchair-bound teens and young women. We run bi-annual *Chol haMoed* trips for our families, and will soon launch a Mothers Night Out to allow mothers to relax, connect, and support themselves and each other. We have crisis support/hospital shifts and we have three hospital shift chats—in Brooklyn, Monsey, and Lakewood. We try to pair volunteers to take shifts when a handicapped child is in the hospital. We also send beautiful care packages with games and treats for the siblings, who are struggling with parents away from home.

We have two separate divisions, one for girls who are totally "regular"—go to typical schools and live regular lives, while dealing with the challenge of being wheelchair-bound. OurPlace is for girls ages 9-15, and EMPOWERED is our division for young women, ages 16-29. These girls receive daily humor/*chizuk* quotes via email or text, special care packages, and live events. We also have a separate division on our *Shabbaton* for our EMPOWERED and OurPlace girls, who tell us that this is the most fun Shabbos of their year!

Raising a severely handicapped or medically fragile child is a tedious, sometimes lonely journey, so we try to make their story just a bit sweeter. We're here to show our families that they're not alone. We send out a daily email of two quotes of humor or encouragement. We produce *Stars*, our bi-monthly magazine, exclusively for Abilities families, with humor, inspiration, and practical information for our families to enjoy. We also send out beautiful, supportive care packages throughout the year and before the *Yomim Tovim.*

The highlight of the year is our much-anticipated bi-annual *Shabbaton.* It is truly in a league of its own. The entire hotel is filled exclusively with wheelchair-bound children, many with medical conditions that no other organization will accept. Every child comes along with a staff who knows them. The *Shabbaton* is for girls ages 5-29 and boys ages 5-13; we then divide into different groups by age. It is a very uplifting weekend and gives the participants something special to hold onto long after it is over.

What are some of the unique aspects of running a Shabbaton for this population?
We are proud to be the only organization to readily accept and take responsibility for trach/vent children. Obviously, such an undertaking is a tremendous responsibility, and we always have multiple trained nurses and close access to Hatzalah.

Our program is uniquely one-of-a-kind, with each activity thought out and planned to cater to our children's unique abilities. Our goal is to create activities that each child can do as independently as possible, while still producing a beautiful finished product. For example, if you want to paint with a handicapped child, there are two options: either the volunteer does most of the work and the project looks nice, or the child does it on his own and the project looks like it was made by someone…well, disabled. On an Abilities *Shabbaton*, an art activity might look something like this: each child gets a canvas and a blown-up balloon. The volunteer helps the child dip the balloon into paint, and then 'paint' the canvas by pressing the balloon on it to create unique modern art. This way, the child does the activity almost completely independently, and the end result is a gorgeous painting!

Of course, on Shabbos we aren't doing crafts, but our program is jam-packed and exciting. Favorite activities include a life-size matching game, sensory activities, parachute, and relay races. Most of the children don't eat by mouth, but the *seudos* are still magical events, with singing, *shmoozing*, and connecting. The highlight of every *Shabbaton* is our Shabbos afternoon talent show, which sums up our belief in a beautiful, tangible way—that every child has something special, and is worthy of applause!

Seeing the glowing faces of our children, hearing feedback from the families… it's more than enough to give us the motivation to continue.

What are some of the challenges that your organization faces?

Fundraising, hands down. Our programs are provided at absolutely no cost to parents (they have enough expenses!), and some are quite costly. Each *Shabbaton* costs $20,000-$25,000, including transportation, accommodations, food, and programming. We are constantly fundraising, and with Hashem's help—and the support of our amazing donors!–we keep pushing through. Although worthwhile, it's definitely a constant challenge.

What keeps you going?

Seeing the glowing faces of our children, hearing feedback from the families… it's more than enough to give us the motivation to continue. We feel so privileged to support our families every single day.

Do you have any future plans?

When we see a need, we strive to fill it. B"H we've been *zoche* to fill many of our dreams already. Our goal is to be able to reach every family, and we are always trying to spread the word and help more children. If you know a family that can benefit, PLEASE have them reach out to us!

Do you have any nice stories to share?

There are so many… A ten-year-old boy for whom our *Shabbaton* was his first Shabbos away from home IN HIS LIFE! I remember him being so confused by the concert, as he had never seen such a thing before (Imagine, a boy with special-needs who had never been to a concert—and we were able to give him that, B"H).

My favorite story is about one of our incredible volunteers, who helped launch OurPlace and EMPOWERED. She recently got sick and ended up temporarily wheelchair-bound—and discovered that she had practically started a program for herself! Now EMPOWERED is giving her support and *chizuk* on her own journey.

Can you share a message with our readers?

I'll share the words that one of our EMPOWERED girls penned:

If you're a caretaker, teacher, mentor, friend, sibling, or parent of a special child, try to really make a point of internalizing this message: That different is not bad or less. Communicate this through actions and with words, because what you believe carries over, even if you think they may not understand. They may not be able to express it or understand in the way that you can, but they definitely understand and pick up on it.

So remember: Different; not less. A special child has a unique mission who brings so much light into this world, and it is your privilege to take care of him. You don't have *to; you* get *to. It's all about how you switch the script. It's all about how you think about it. It's all about your attitude.*

Love,
A CP Warrior

To contact Abilities, call/text 848-326-8337 or email office@abilitiesstars.org.

Sensory Bin

- Water Sensory Bins -

Chayala Tawil

My son Avrumi really gets the credit for this column, as he is the original creator of the water sensory bin in our home. Years ago, he started playing with water and toys in the sink, often for long periods of time. As long as he wasn't flooding the floors, I never stopped him as it was a harmless activity that he enjoyed, and one of the only things that kept him self-occupied for more than two minutes. I remember one Yom Kippur, when he was around five years old, he stood by the sink for a good few hours, immersed in the experience. I guess he hadn't learned about the *issur* of *rechitzah* in school!

In truth, a water sensory bin is so simple, it's almost embarrassing to print it here. But I am sharing it because it provided so much fun and entertainment. And there's no excuse not to try it—you've got the supplies. If you have running water and some kind of receptacle, you're good to go!

The official definition of a water sensory bin involves providing a container filled with water and incorporating various materials or objects to enhance the sensory experience. This can be set up indoors or outdoors, allowing your child to explore and engage with water in a safe, contained environment.

My favorite basic water bin is a long, flat container (like the type that you would store under a bed) filled with room temperature water. Add in items such as cups, bowls, funnels, and various-sized containers. Pouring and scooping water is surprisingly addictive, even hypnotizing. If you want to dress it up, add in some food coloring, bubbles, waterproof lights, or scented soap.

Water Sensory Bins can also be great for imaginative play. Try one of these ideas, or create your own with a theme that appeals to your child's preferred activity:

Soup Bin Add in a bowl or small play pot, spoons, measuring spoons, small ladle, and play "making soup."

Bath Bin Create a bathtub in the bin by adding in a doll, rubber ducks, sponges, and even some soap.

Fish Tank Bin Tint the water blue with some food coloring. Add in fake fish, shells, and rocks. You can also use a fish net to catch the fish.

Break the Ice Freeze small toys/objects in ice cubes and then dump them into the water bin.

Bubble Bonanza Fill the bin with bubbly water by pouring in dish soap before adding the water. Add in wands, straws, and sieves for creating different sized bubbles.

Car Wash Bin Boys will love this one! Fill bin with soapy water and add in toy cars, sponges, toothbrushes or small scrub brushes, and a spray bottle for washing and rinsing cars.

I'd like to add a similar activity that we did recently in my home. I think it was only because I was thinking about the water bin article that this idea was born. We had a large empty Rita's ices container and a red scooper sitting on my counter, about to go into the garbage. I filled it with water and added some food coloring. I took a few more empty containers and filled them with other colored water. I set up a small table on my porch with the water bins, scoopers, and plastic cups. I told my children that they could play "Rita's"!

They took turns being the servers and buyers. They were really excited about it! Just then, a surprise shower began raining on them. I quickly brought the whole thing inside, put a large towel on the floor, and let them continue playing. Despite three buckets of water being scooped into cups by little hands, nothing got wet other than the table and the towel.

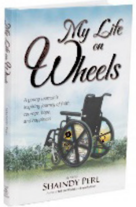
I saw that it's really possible to play with water bins inside the home. Of course, on a nice day it's even better outdoors. But sometimes allowing our children to play and make a little mess prevents boredom, which can often lead to bigger, more aggravating messes! Try it and let me know if you agree!

Supportive Reading Material

Teen Books

Book List and Details by Toby Brief | Comments by Chayala Tawil

10 My Life on Wheels



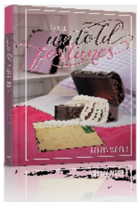
Author: Shaindy Perl
Publisher: Israel Bookshop Publications
192 pages, Ages 14+

Breindy is a smart intelligent woman who is just like all of us. Yes, she has CP; no, she doesn't let it stop her from living life.

Publisher's Summary: A young woman's inspiring journey of faith, courage, hope, and happiness.
Breindy H. is a severely disabled young woman, who must rely on others for her every need. Yet her mind is sharp, intelligent and witty. In this book, she describes the challenges of "life on wheels," her surprising social life, the personal growth of herself and others around her. For a boost, a smile, an understanding of life—read this book.

My Personal Take: Having been lucky enough to be personally acquainted with Briendy, I can vouch for every word in the above description. Her life is an inspiration – and a testament to the tremendous heights that even one who is disabled can reach when the willpower is strong enough.

11 Untold Fortunes



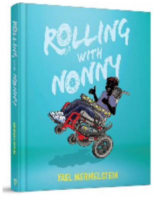
Author: Penina Weiser
Publisher: Menucha Publishers
184 pages, Ages 12-15

What happens when a teenager with the 'perfect' life is gifted with a baby sister with Down Syndrome?

Publisher's Summary: Fourteen-year-old Aviva Weinstein has the perfect life—an amazing best friend, adorable siblings, and a dazzling pink-and-white trimmed bedroom. But when a family member's medical condition turns her life upside down, Aviva is determined to keep it a secret, burying the truth under layers of deception and despair.

Untold Fortunes is a heartwarming and suspenseful story about overcoming fear of the unknown and discovering life's treasures in the most unlikely places

12 Rolling With Nonny



Author: Yael Mermelstein
Publisher: Menucha Publishers
176 pages, Ages 9-13

Beneath the surface, beyond the wheelchair, is just another awesome kid!

Publisher's Summary: There's a new kid in town. Yochanan Bear, better known as Nonny, is a spunky eleven-year-old who's smart, funny, and friendly…Oh, and he has cerebral palsy. With his cool motorized wheelchair and his overeager helper, Gavriel Farber, at his side, he can do pretty much anything he sets his mind to. Even if it sometimes involves coping with a flat tire or putting a bully in his place. Whether Nonny is joining a marathon, trying out at a singing competition, or

Supportive Reading Material, continued on page 31

WOW! MOMENTS

compiled by Fraydel Dickstein

It was a difficult week. Yehuda had been getting into lots of stuff, and everyone was at their wit's end. My kids really had it. I cried, I felt broken in some ways. I begged Hashem to help us.

The next day, Yehuda's therapist Kalev dropped off these simple doorknob locks that I had been waiting for. I looked at them and said this is not what I meant, I needed the metal Kee-block locks that use keys. He told me that these would work for Yehuda. I could not believe it! I put them on some important doors, and it was a relief to not have to look for a key before we opened the bathroom and bedroom doors.

Hashem, did you hear me and send me a little light to say: "Fraydel I am here for you, I am with you in this"? I do know that we are all better people because of the challenges of our special children, but sometimes we need those little glimmers to remember that we can do this.

* * *

It was twilight of the second day of Shavous. I was sitting in my dining room with the window open, keeping an eye on Yehuda scootering outside. I turned to my daughter and asked if Yehuda had made any major messes or caused any catastrophes. Had there been any bathroom mishaps? We both realized that there hadn't been. My husband also commented on how calm this Shavous had been. Yehuda scootered and scootered, and hung out at one of our neighbors (Shout out to the Millers—true *tzadikim!*). When he wasn't there, he was watching videos.

I thought about it, and could not help but feel Hashem's incredible love for me. I know that I have cried and begged quite a bit lately, to the only One who can change Yehuda's behavior. I had really beseeched Him to make it easier, as the challenges were sometimes feeling overwhelming! I don't know that we have hit a new high, but for today I am reveling in Hashem's embrace, feeling how close He is to me, and how He really listens. I know that even when I don't feel it, He is really at my side!

* * *

In a quarterly meeting with a PPP rep, I was told the following by Crystal V:

"I have many clients, in and around Lakewood. I myself am a parent of two young adults with autism.

The homes I go to in Lakewood are filled with so much light and Godliness. The respect the families display, the love, care, and warmth, is unusual. Most of my home visits end with me, in tears, in my car.

As a parent myself, I dislike when people say this to me, but clearly God knows to whom to give these children. No population takes care of special needs kids like my Jewish families. The devotion, the endless dedication, and the deep connection between parents and children moves me to tears."

Neshamale Mommies, behind closed doors, you are holding up the world with your endless *chesed*. No one will ever appreciate the magnitude of your sacrifices, but every so often, someone else gets a tiny glimpse, and you are responsible for a tremendous *Kiddush Hashem*.

Just Laugh!

When Yossi put on his new Floafers, he exclaimed:

"Wow! I am wearing my new shofars!"

How Do We *Celebrate?*

Our son with severe Cerebral Palsy loves his family more than anything! Many years ago, on a big birthday, I decided to make a video of all his favorite people wishing him a Happy Birthday! We got siblings, aunts, uncles, cousins, and even favorite friends and neighbors to contribute good wishes and *brachos*. It was a lot of fun and our son really enjoyed the gift. The nice thing about it is that he can look back on it and enjoy the gift over and over again. I hope to do it again on a future birthday, and the technology is even easier now.

Happy Birthday! C. W. Baltimore

Yaakov's birthday is in the summertime, and now that he attends sleepaway camp, we celebrate his birthday there. I send/Instacart supplies and ingredients to the camp, and the counselors do a fabulous job of making it so exciting and wonderful for him! I think birthdays in a child's safe space, whether at home, camp, school, etc., are the best places for them to enjoy their special day! Batya Greenstein

For my daughter's third birthday (during COVID) we invited all the therapists to a Zoom party. We dropped off an invitation along with a party hat, a whistle, and a cupcake to each house, and we all celebrated together!

Esther Hazan

Both of my special boys want to just skip over their birthdays and don't want to hear about it! If we even mention the word birthday, they start crying. They hate being in the spotlight of a party! I once traveled to my son's school on his birthday, only to see him cry through the entire classroom party... what a lesson it was for me!

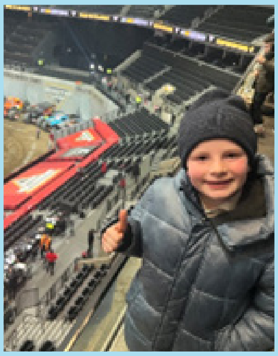
If they don't like or even want to hear about their birthdays, then we go with what they want. So now I have it easy! No *pekelech* ever! No birthday presents ever! As it turns out, the biggest present we can give our children is honoring their personalities and preferences. Yehudis Wolpin

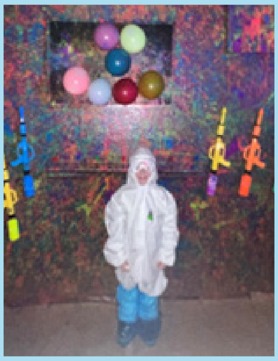
I use Gitty's birthday as an opportunity to give gifts to her many devoted teachers, therapists, respite workers, and neighborhood volunteers. I write a nice note with each gift, and we present it to them in honor of Gitty's special day. Nechama L.

We've celebrated with birthday trips for the last four years, and it has been very memorable! With diet and rationed food a big part of my child's lifestyle, parties simply didn't work for us. They didn't work for anyone else in the family either, as we would have at least one child that couldn't enjoy the party food.

Instead, we celebrate each child's birthday with a trip of their choice. The entire family enjoys the trip, while appreciating the birthday girl/boy. The kids remember their special birthday trips and have the best memories!

The kids have an ongoing discussion about which trips to choose. One kid loves art, so we went to The Splatter Room and enjoyed paint fights and fun. One loves cars, so we went to Monster Jam, an epic car show that was mesmerizing! The other kids get their trips too. It's so much fun, and a great reason to celebrate together as a family as we celebrate each child. Perry Binet





We celebrate birthdays in our house by taking that child out to dinner, just the birthday child with her parents. When we take Tzippy, our special needs daughter, we go someplace we know she can handle, or to a place that won't care about her behavior. In the past, Glatt Bite was her favorite. This year, when she turned 16, she decided that she was "big now," so we took her to Tomahawk. We prepped her beforehand about the expected behavior there, and B"H it all worked out. The look on her face when dessert came out was priceless! Adina

Leah does not get to have a Siddur party, Chumash play, siyums, etc., so we regard her birthday as the milestone of the year. We discuss and prepare for it six months in advance, and then reminisce about it for six months after! Leah is fully involved in the planning stages. In the past I've had a volunteer take her, or I have taken her myself, to Party City to choose paper goods. Using her iPad, she chooses the menu, special dessert, drinks, what she wants to put in her *pekalach*, etc. She then packs the *pekalach* herself!

I ask a therapist or volunteer to take her to Target or Five Below to buy birthday presents for all her siblings (none over $10). My other children go to buy her birthday presents, usually from Dollar Tree—with cards, and of course balloons.

Leah loves baking, so she will usually bake a cake with her therapists. They have tons of fun wrapping the presents and writing the cards.

We use PunchBowl (an online graphics program) to create a fun, cool invitation to send to all her therapists and volunteers. We have the most amazing friends and volunteers, who really make an effort to come to her birthday party. They bring presents, cakes, etc. for Leah to enjoy!

Leah really looks forward to her parties, and so do my other children! (No worries—we make a big deal out of her siblings' birthdays, too!)

Now we have to start preparing for her really big birthday... her Bas Mitzvah!

Y.R.

For all of my children's birthdays, we have a special family supper (usually pizza or a barbeque). We sing birthday songs and give a small gift, like a toy that they would enjoy. I do the exact same thing for my daughter who has special needs—why should she have it any differently? Gila D.

Yanky is not the type to appreciate a party or presents, so each year I buy a present for Yanky's sister, instead. She puts up with him all year, and I have him give her the gift. She now looks forward to his birthday all year, and this helps promote positive feelings between them . S.W.

It's My Party and I'll Smile If I Want To

Batya Dancykier

There is a lot of excitement, anticipation, and enthusiasm when it comes to birthday parties. These are BIG feelings. For children with special needs, this hyped-up reality surrounding their birthdays can be overwhelming. As parents, we set out to celebrate our children, but sometimes it ends up like the cliché: It's my party and I'll cry if I want to.

How can we effectively plan birthday parties for children with special needs to make them feel celebrated?

Here are some things to pay attention to when planning your child's birthday celebration:

Tune in to Their Preferences:

Take time to think: Is this your child's favorite outfit, or his most uncomfortable one? What are the child's favorite foods vs his worst foods? Are there images or decor that might overwhelm or scare him? Are there calming or enthralling color schemes you can use? Is your preferred location a comfortable one? Now take all the likes and incorporate THOSE into the party!

Keep Your Child at the Center:

When it is a child's birthday celebration, he should be at the center of all the attention. Choose games that put him there. For example, place a child with special needs in the middle of a parachute while everyone spins it around. Perhaps have him put on a show for everyone, if that is within his ability. Keep the spotlight on the birthday child.

Mind the Guest List:

Consider the comfort level of your child when it comes to the number of people present. Either minimize the invite list or have people come in shifts, so the amount of people present won't be overwhelming. Unfamiliar faces added to the mix can make things worse, so make sure to invite people your child is familiar with. This will ease anxiety and help your child feel more comfortable.

Watch the Volume:

Noise level is a big factor. There is a degree of uncertainty at a party because it is not a routine occurrence. Furthermore, a birthday party is a heightened sensory experience. Adding music to the mix might push it over the top—loud, booming music can be a recipe for disaster. Play a selection of calming music or songs that your child loves.

Make Food Inclusive:

Whatever specialty diet your child is on, keep the food uniform, so everyone is eating the same thing. Everyone is on a special diet for your child's party!

Preview the Plan:

Lastly, and perhaps most importantly, whatever you plan, give your child a heads-up. Have a conversation going over the details. The more information, the more security when the time comes for the celebration.

This may all sound like a lot of preparation for something that should be easy-breezy, a child's birthday party. Attending to all of the above adds an extra layer of care and attention to detail. The benefit will be seeing your child beaming from ear to ear as he experiences what it feels like to be truly celebrated for who he is, with all his likes and dislikes, and with consideration for all his special needs.

Happy Birthday

Happy Birthday, Chloe

Milaine Grossbard

This is how I imagine it…

26 years ago today, Hashem, the Ruler of the universe, sat high over all that He had created and chose a very special *neshama* to do a very important task. He told this soul: "I will send you to Earth. I will give you a body that is not like the others. I will give you sickness and disability. I will bring you close to death, but then show you a sliver of Myself. Dear Soul, I will give you opportunities within your disability to teach your family, friends, and community what is important. You will lead them on a journey they never thought would be theirs. You will teach them to be aware. To be humble. To be grateful. To be sensitive. Mostly you will teach them that I make no mistakes."

Hashem told me: "My dear Milaine, I am sending you on a journey. You have never seen this destination up close. You will not be packed and prepared as with other trips you have taken. You will have to use your mind and your belief to travel on this expedition. You will work harder than you ever have, and you will never be the same. I know you can do it."

26 years ago today, I was blessed to give birth to my third child, Chloe. The pregnancy and birth were typical. As I held this new life in my arms I foresaw her future, the future that I thought was important. I saw school, friends, playdates, ballet lessons, seminary, college, marriage. These were my dreams and, so I thought, they would be Chloe's reality.

But this was not the case. Chloe was diagnosed with Cerebral Palsy at age 12 months. Her reality has been therapies, foot braces, wheelchairs, doctors, hospitals, seizures, and special education. This was not my dream for my child. At the beginning, it felt like a nightmare. Poor Chloe, how sad that she will never… (fill in the blank).

I did not start off strong. I did not start off prepared. I had never thought much about special needs and had never spent time with anyone with special needs. I had to search the internet for "Cerebral Palsy." I had never heard of a seizure. I had never pushed a wheelchair. I was on foreign ground and had not packed correctly for this destination. No map. No guide. Just a little baby in my arms.

Thus began my journey to make Chloe's life full, happy, and healthy.

I have traveled a road less traveled. I definitely pack better these days and I can read my map with a bit more ease. I don't know how long this journey will last, and I don't know where it will take me. We met so many wonderful people along the way who gave us help, kindness, and reality checks; people whom we would never have met otherwise. I have seen kindness in ways you should never ever need.

I do know that every day is gift. Every day is a lesson, and every day I am grateful to Hashem for giving Chloe to me. I wouldn't trade her for anyone else.

Happy 26th Birthday Chloe.

Happy Birthday, Dovi

Gitty Weiss

In my home, we don't usually do major birthday parties. Instead, I bake or buy a cake, according to the birthday child's choice, which we serve as dessert on Shabbos, along with some other goodies. After presenting the cake while singing birthday tunes, everyone at the table has a chance to say why they are happy that the birthday child is in their family. It can be anything from: "He is so nice to me," to: "She always saves me nosh," and it's sweet to hear some positive things from siblings who don't always get along!

The year that Dovi turned four was a turning point. Until then, he was very much at the baby stage of not doing much, just a very cute, smiley boy who was easy to love. Once he got older, he turned into a real mischief-maker who made endless messes of everything, and who needed constant supervision. Pulling hair became his new pastime.

I remember sitting at the Shabbos table, and realizing, with a sinking feeling, that I was not looking forward to his birthday dessert. I couldn't imagine my young children being able to relate to his behaviors positively, and worried that it would turn into a very negative round-table discussion. I decided to myself that I would just serve the cake and not ask them to say anything. To my chagrin, one of the kids piped up: "We have to say something nice about Dovi!" I held my breath.

The first one spoke up: "Dovi always makes me laugh. He is so happy, even though he can't talk or walk." Wow! I was so relieved that at least one of my kids found something nice to say. But it continued on. The next one volunteered: "When I'm sad, Dovi always makes me happy." And on it went: "I love to play with him!" "He is so cute!" My tension melted away as I listened to their compliments. I was in awe of my kids, who were able to look away from his many challenging behaviors (for the moment!), and zero in on something positive to say. It was really heartwarming!

Since then, I never worry when Dovi's birthday approaches. Although some of his behaviors have gotten a lot more challenging since he was a little four year old, I now know that my children will come through. Though they may complain and wish away many of the complications and difficulties that having a special sibling entails, once a year they have what it takes, to look past the challenges and find that spark of goodness inside of him.

Happy Birthday, Moishe

C.L.

I have a very precious 3 year old son Moishe with CP. He is extremely delayed and he cannot sit, stand, talk, or eat yet. When he turned three, with *daas Torah*, it was decided that we should not give him an *upsherin* or make him *payos* yet. Moishe's third birthday was an emotional day for me.

As mothers, we dream about this special day of cutting their hair, wrapping them up in a *tallis* and taking them to *cheder* for the first time. With tears in our eyes, we watch them read *alef bais* and lick the honey as we whisper the words of *veharev na*. But our *tzaddik* was not ready for that yet, and it was hard.

On his birthday, a very dear friend sent me this beautiful, validating poem:

Dear Mommy,
You're not putting a scissor to your son's beautiful brown curls,
But if you look closely, they are studded with diamonds and pearls.
You're not standing in the store, choosing colors, patterns, and thread,
But you are standing in Hashem's presence, choosing His path instead.
You're not making *pekelach*, inviting all the neighborhood kids,
But you're amassing the *pekelach* that count, those *vus m'nemt shpeiter mit*.
Mommy, for all those things you are not, there's just one big YOU ARE,
In this bumpy journey of life, you emerge as a rising star.
Although there's no scissors or *kappel,* no *pekelach* or grand celebration,
There is one devoted mother who deserves a standing ovation!

Happy Birthday, Princess!

A Diary of Birthday Letters to my Precious Daughter

L.M.

Eight years ago, we were blessed with a beautiful gift, wrapped in unique, rare edition giftwrap. Our medical journey, aka roller coaster ride, began.

Fast forward a year, and on Princess's first birthday, we found ourselves spending the day in the ED, awaiting a PICU bed.

That night, sometime way past midnight, with a couple of nurses and doctors in the room, I zoned out and wrote this letter to my baby:

Dear Princess,
As I sit at your bedside, looking at your beautiful face,
watching the doctors and nurses around you,
I recall that moment you were born,
Life-changing.
Today, my little girl, you are one year old.
Ironically, we're spending your birthday in the hospital.
How fitting,
To celebrate in the same place where so many babies enter this world!

As you were poked and prodded today, while hooking you up to IV,
I recalled that first IV placed immediately after birth.
I recalled your extensive NICU stay with all its ups and downs.
I remember how you showed us, with your strong cry at birth,
How feisty you are.
My little fighter,
Even though your voice was taken from you,
You work so hard to let us know what it is you need.
But just so you know, my little girl,
Your silent cry breaks my heart.
Watching you helpless and in pain is gut-wrenching.
But you, my darling, soldier on.
With a smile constantly adorning your face,
You show the world that pain is not a hindrance.
You proved the doctors and experts wrong again and again.
And they can't believe their eyes when they see you eat!
My little neshamale, you suffer so much every day,
I wish I could take your pain and discomfort away,
Make you feel all better,
Find a cure for your disease.
Make you healthy and well and not technologically dependent,
Have no need for poisonous drugs,
Throw off the shackles of your illness
And just be a regular baby.

How I yearn to just hold my little baby tight,
No "strings" attached.
No strangers roaming my home, invading my privacy, supposedly here to "help."
No worries about what your vitals are,
No need to constantly be on the run to another appointment
And yet another hospital stay.
No monitors beeping, interrupting sleep yet again every night.

But my dearest,
This year has taught me so much,
You taught me to always be happy, despite it all,
The situation taught me to tough it out and just shoulder on.
Your siblings taught me acceptance.
Look how much they all love you.
You are the light of their lives.
They don't even notice your differences.
They just see beyond it all-into the yumminess that is you.

I have learned so much.
My, how we've all grown!
To appreciate life,
Appreciate every warm breath we take through our mouth or nose.
Appreciate every gland that works as it is supposed to.

I am so lucky to be chosen by Hashem to be your mommy.
It is such a zechus for me to house such a precious darling neshamale
With such an amazing personality.
I am so so blessed!
Thank You Hashem.
But at the same time, for your quality of life,
אבל ממך ואליך
Hashem, please!
Renew the health of our little girl.
Please give us the proper kochos to continue on this journey,
And help us get to get to that place b'm'heiru.

My dear Princess, I will sign off here.
I need some strength for our day ahead tomorrow. Today was beyond exhausting. You are, B'H, sleeping peacefully now. Hopefully the meds kicked in and you're fighting off that nasty bug that, for the first time in your 12 months of life, took your smile, took your joy of life. I am hoping and praying that tomorrow you will feel better and bounce back like you always do.

Sleep well my darling,
Happy Birthday!
❤️ Mommy

And so we started a sort of "tradition" for the next couple of years. Princess spent her birthdays in the PICU, at appointments, or "just" home and sick (holding our breath, hoping for no admission). And since we are, B"H, Jewish, we get to have two birthdays each year. So, if one was spent in the hospital, Princess compensated on the other date, traveling to/from long appointment days.

🎉🎈 Happy 2nd Birthday, Princess! 🎈🎉

You are now officially in the terrible twos, where antics are expected and entertaining. But you, my little trouble maker, are taking things to a different level! Those fevers have gotta stop, and for a change it would be nice to not be congested, don't ya think? Speaking of levels, please keep within the proper therapeutic trough guidelines and stop driving your doctors (and me, never mind) nuts with all those fluctuations...
Wasn't it cute to visit the NICU today and show off to some of the doctors and nurses how big you are already? They couldn't believe it's been two years, but gotta tell you, they've been two looooong years. Hopefully, next year we won't have to celebrate your birthday in a clinic or any medical facility as you've been doing so far...
Oh, and did you see the look on the NICU nutritionists face when she heard you're fully PO and long-since graduated tube feeds? That was priceless! We gotta cash in on that and keep it as a reminder that when thing get tough, you can beat the odds! You're a little fighter and you will win the war against those over-reactive cells and the over-friendly bacterias you love hosting.
Oops, I hear you beeping in the background. Bu-bye!
❤️ Mommy

P.S. Hebrew Birthday Party #2 was Minnie Mouse themed, and celebrated with many doctors and nurses while overlooking the East River. An added element of entertainment was its perfect view of the heliport and ferries, nine flights below.

Dearest Princess,

It's a few weeks past your 3rd birthday, B"H, but I don't have to remind you how you spent it and how you've kept me busy. So here's my letter to you, a bit delayed. (When you get older I want you to share the source of the minhag to spend your birthday sick or in the hospital!)

It's been three years of various treatments, about 16 PICU admissions, a dozen or so ED visits, plenty of emergencies and uncomfortable ambulance rides. Too many to count of pokes and blood draws (I tried counting your blood draws on the hospital portal, but stopped at about number 180), IV lines/infusions, infections, antibiotics courses, and fever days. At least 16 MRI's and 20 rounds of anesthesia (that I remember off-hand), 15 surgeries/procedures, 1 CT scan, 3 swallow studies, 1 sleep study, a gazillion chest X-rays, cultures, and nasal swabs. Over 150 doctor appointments , too many insurance fights, about 170 "nurses" through our door, and roughly about a thousand therapy sessions.

Three years of many, many humbling learning experiences, sleepless beeping nights, and a very unpredictable life. Three years of meeting the most wonderful doctors and people caring for you, and the start of some beautiful friendships with other moms of medically complex kiddos.

Three years of many more to come, B'Ezras Hashem, of being mommy to the most awesome little girl who has taught us all so much, with your spunky personality, joy of life, and pain/discomfort tolerance. The comments and expressions we hear from you are priceless and keep us laughing all day! You really are the life of the party, and give us plenty of reasons to celebrate.

Three years of miracles and joy, and BE"H we hope to see the yeshuah soon, but until then, keep going. Keep making us laugh and creating a Kiddush Hashem wherever you go. Keep showing the world that a diagnosis and medical 'appendages' don't mean anything. Keep smiling through the endless pokes and hospitalizations like the brave little girl you are. Just keep being independent you-a toddler who is one of a kind! Keep giving your bear hugs and wet kisses, melting everyone's heart just by flashing your yummy smile 😊.

Love, Mommy ❤️

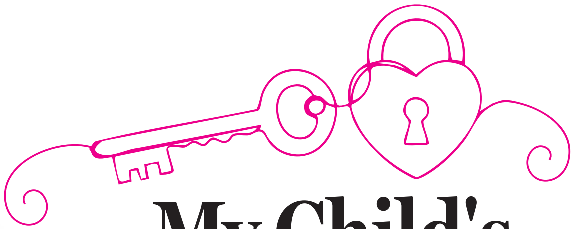
Happy Birthday #4! Princess Dear,

This was another year of accumulating new diagnoses, and B"H ditching some other complications. Another year of Mommy searching the globe for a super-specialized surgeon and playing insurance agent. Another year of lots of hugs and snuggles while we bonded all year on your long days home ("home-schooled", aka stuck to Mommy's hips), sleep-disturbed nights, and hospital stays.

Another year of having your medical team scratch their heads, while having them wrapped around your finger! Another year of you enduring tremendous pain and discomfort, complicated surgery, and annoying treatment side-effects, yet, with your sunny personality shining through. Another year of counting our blessings, and cracking up at the comments coming out of your mouth!

It's been a long year, full of ups and downs and twists on the roller coaster ride, yet it flew by so fast! We hope to hear good news in your upcoming surgeries, which will hopefully be a turning point in your/our life, leaving some challenging things (trach life) behind, BE"H.

❤️ Love always, 💕 Mommy 💕



My Child's *Keeper*

Yitti Berkovic

We aren't really big on birthdays around the Berkovic house.

We celebrate with the typical trappings – a cake, a present, a card or some balloons. Usually I remember it's my child's birthday the night before, and then I'm stuck making a mad dash to CVS and buying whatever they have in stock.

As the kids get older, it's fun to make little tweaks to the birthday routine. Nowadays, the big kids choose sushi instead of birthday cake. They ask for cold hard cash over presents, and they would rather celebrate with their friends than with their boring old parents.

But then there are Naftali's birthdays.

Naftali's birthdays have a way of staying frozen in time.

Even as he gets older and bigger, his preferences stay the same. He still likes a vanilla ice cream cake (G-d forbid it have even a trace of chocolate on it!), he still likes presents that have something to do with fire trucks (my toy closet looks like a fire station gift shop), and he still loves letting go of the helium balloons (a split-second after we hand them to him) so he can watch them soar into the sky.

He never wants a crowd at his parties, so it's always just us, and he never lets us sing "Happy Birthday" because he's way too sensory to stomach the sound of our offkey singing. He likes predictability and sameness, and that makes planning his birthday celebration super easy for his last-minute and creatively challenged mother.

Except this year.

This year, as Naftali's birthday inches closer, I'm feeling strangely *stuck.*

Maybe it's because it's a milestone birthday – more for me than for him – and I might be a little knee-deep in denial.

Naftali is turning 18.

My oldest, my once teeny-tiny preemie, my little guy who forced me to grow up when I was still a child myself, will now be a legal adult.

It's not a milestone because of *shemoneh esrei l'chuppah* – I made my peace long ago that it's not within Naftali's *tafkid* to marry.

It's a milestone because in New York State, when a child with special needs turns 18, his or her parents must apply for legal guardianship if they want to continue making legal and medical decisions on their child's behalf.

In honor of Naftali's big birthday, I need to fill out stacks of paperwork, find a notary to attest to my signature, and sign on the dotted line for the right to do *what I have always tried to do:* protect the special *neshama* Hashem has entrusted in my care.

So, if I usually procrastinate before my children's birthdays, I am now procrastinating *on steroids*. I don't want to look at the calendar, because as the day ticks nearer, I know I'm going to have to do something that is making me very emotional.

I am on a group chat with a lot of fellow "special moms" (if we may say so ourselves), and those mothers who have already crossed the guardianship bridge assure me it's really no big deal.

Just sign the papers and don't think about it, they coax, *it's just part of him growing up.*

I get it.

I know how to keep a stiff upper lip.

But what if I'm not ready to admit he's all grown up?

What if it's hard to accept that he has moved from a child with special needs to a *man with special needs?*

When he was little, the gaps between him and his neurotypical peers never seemed as a wide.

Even when he acted up, when he struggled and challenged, he was still so *cute.* I could hold him and hug him and soothe him in a way that made me feel like he was any other child who needed his mother.

Then suddenly he wasn't so cute anymore.

He was big and he was loud, and if I tried to lift him off the ground or to hold him, I'd throw out my back. Before I knew it, he was wearing adult-sized clothing and shaving every week.

Now, he is taller than I am and weighs much more than I do, so when he's scared or hurt or unhappy, I can't hold him and rock him like I once did.

The gaps between him and his neurotypical peers grow wider and wider. He still needs me to care for him like he is a child, but he is becoming a man.

A man who needs a guardian.

As his 18th birthday looms, I hired someone to help me with the guardianship paperwork, because every time I looked at the forms, the words just swam before my eyes.

The woman on the other line was kind and understanding, but she has done this process a million times, and she wasted no time in ripping off the Band-Aid.

"You and your husband won't be able to take care of him forever, you know, so it's important that you also choose a backup guardian."

I struggled to process what she was saying.

A backup?

Someone other than his parents?

Who else would love him and understand him and enable him to maintain his routines and his rhythms – the way we did?

Who else would stay up with him at night when his body refuses to let him sleep, and who else would make sure there was no chocolate on his birthday cake and that there was a new fire truck waiting for him to enjoy?

She heard me faltering and assured me: "You don't have to choose a backup guardian right now. When your other kids are old enough, they can be chosen as backup guardians."

> *Who else would stay up with him at night when his body refuses to let him sleep, and who else would make sure there was no chocolate on his birthday cake and that there was a new fire truck waiting for him to enjoy?*

I hung up the phone, fighting back my tears. She said it with so much confidence, but life is hard to predict. Would his siblings grow up to love him and care for him when we no longer can? Will their spouses welcome him into their homes when we no longer have the strength or the capacity to have him in our home?

These were terrifying questions, and they unearthed in me something that feels akin to grief. My friends who have daughters Naftali's age are filling out seminary applications, but here I am, making my way through guardianship forms. Instead of my child flying the coop, I'm trying to make sure he can stay safely in my coop for as long as possible.

There is grief in knowing that I can't take care of him forever, that life is fast and fleeting, that so many of the things we pretend are in our control have a way of slipping right through our fingers.

So I'm dreading his birthday, not because anything really changes that day, but because it feels like everything is beginning to change.

I know—this step is normal and natural and expected, and I'm going to do it like I've done a lot of hard things since Naftali was born: with faith that Hashem has a plan for us all and that I can only do my *hishtadlus* in the here and now.

But I'm going to hold on to these papers for a few more days, because this time, my pre-birthday procrastination isn't due to laziness or a lack of creativity.

This time, my procrastination is my heart's way of asking for a little more time before doing something that hurts.

This article was originally published in The Voice of Lakewood

SNIPPETS

Graduating 186 days in the NICU!

TEEN SIB SPEAKS

By: Miri

Hi, my name is Mimi and I'm 14 years old. I have an 11 year old brother with special needs. I love my brother Dovid dearly, but sometimes wish he could be a normal, regular boy. It's hard for me, especially when he's being stubborn and challenging. I'm sure all of you reading this can relate to me in some way or another. It happens many times that I get frustrated when my brother is acting out and people tell me: "Don't worry, I understand!" I feel like screaming, "NO, you don't!" Unless you actually experience it, there is no way you can understand. So I am writing to you here because I know you can actually understand.

One Shabbos, I went to pick up Dovid from a neighbor. He was riding his bike home and went ahead of me. When he reached the spot where we were supposed to cross the street, he didn't stop and wait for me to catch up. Rather, he continued riding down the street to another neighbor. Dovid rode down their driveway and ran into their backyard. I chased after him and found the yard filled with lots of neighbors schmoozing together. As they all watched, I tried to cajole Dovid to come home. When that didn't work, I started threatening him, even though I know he reacts negatively when I do that. In the end, I had no choice but to practically shlep him out and force him home. When I finally got inside, I was totally wiped out. This wasn't the first time such a thing happened, and it won't be the last.

In difficult situations, I try to keep in mind that Dovid has a special neshama. He also has feelings, and it's not his fault that he was born like this. There is nothing I can do to change the situation, but I can change the way I deal with it. A trick I have is to think about the nice middos and talents that Dovid has. Dovid is an amazing piano player and I really enjoy his music. I try to compliment him on his playing, which makes him feel really good. He is always giving out compliments, which is something I try to learn from him. Another one of his talents is mimicking people in a funny way, which brings lots of healthy laughter to our home. When I think about his positive qualities, it's easier for me to appreciate Dovid, and his actions don't bother me as much.

Your special siblings might not have the same issues as mine, but they surely have at least one thing in common – their holy neshama. So next time your sibling does something you find embarrassing or annoying, try to remind yourself that he didn't choose to be born like this. It is not in your hands to change his actions; you can only control the way that you respond. Try to focus on some of his positive qualities, think of a funny story that happened with him, or a moment of sibling pride that you've had. I hope that will give you the strength to pull through. Hatzlacha!

A Smooth Ride To Your Vacation Destination

From those who have been down that road before

N.M.

Summer implies vacation, and vacations includes traveling. Although it may be overwhelming to envision a vacation with your special needs child, with some necessary modifications, your family can still enjoy traveling together! Just as your child may need accommodations to get through day-to-day life at home and in school, there are things you can do to help your child when traveling. Planning ahead is key to a successful outcome. Read carefully through these ideas for a smooth ride:

Medication

Make sure to travel with extra medication. Most insurance companies will allow you to refill prescriptions seven days before the actual refill date. Call your pharmacy to find out your insurance provider's policy, if a refill is due during your trip. Using a national pharmacy chain (such as Rite Aid) makes it easier to refill at your destination. Prescriptions can also be transferred from pharmacy to pharmacy if necessary. If you will need meds compounded when you're out of town, make arrangements to temporarily transfer the prescription to a compounding pharmacy before you leave.

Ask medical suppliers to deliver early, or to deliver to your vacation destination. Always pack extra medical supplies! Don't forget medical insurance cards and anything else that may be needed in case of emergency.

Insurance

Call your insurance company before the trip, to find out what their policy covers when you are not in-state. In case the need for medical help arises, you will want to know in advance if you should go straight to an urgent care center or the emergency room. Ask your insurance company to put a note in your file as to where and when you will be away.

If your child is medically fragile or medically complex, consider Traveler's Insurance. This can help if your child gets sick and/or you need to cancel expensive tickets, etc. The peace of mind this will give you is worth the cost.

Flying Arrangements

Check TSA guidelines to find out how to pack mediations, medical equipment, etc. so you won't be denied on the spot. For example, will you need a doctor's note to bring along bottles of Pediasure? Check which car seats are allowed on the plane, as not all car seats are FAA approved.

When you get to the gate, arrange with airline personnel to be first to board the plane and get settled. As you walk onto the plane, greet the staff and mention that your child has special needs, and inform them what accommodations you will need.

Car Travel Arrangements

Pack plenty of fidget toys and comfort items. It's good to have familiar toys, but it's also nice to have some new, exciting toys. A plug-in cooler for the car can be a life-saver. Fill with drinks, protein snacks (such as string cheese and yogurt pouches), and prepared bottles. It's a lot easier than measuring out formula while on the road! Keep a roll of paper towels near you at all times.

For young children who suffer from reflux or other issues when buckled into a car seat, look into the idea of a car bed. Call your insurance company to find out if your medical equipment is available in travel mode. This can prevent scenarios like a feeding pump that beeps throughout the trip because of bumps on the road!

It may not be conventional, but it can be a lot easier to have one parent drive while the other is in the back seat caring for the child. It sure beats spending your trip twisting and turning around to hand out things every five seconds!

Hotel Arrangements

In this world of Internet information, there is still no replacement for talking to a human being. Call the hotel in advance and ask questions. You may want to request a room on the main floor near the elevator to minimize walking distances. Specify if you need wheelchair accessible bathrooms, doorways, etc. Do not assume that all rooms will be wheelchair accessible, especially in older, touristy locations. You should also request a non-smoking room for those with breathing sensitivities such as asthma. If you need a crib, inquire if one will be available. Bring along a crib tent or an enclosed bed, as needed.

Safety

Many parents' biggest fear is of their child wandering off in a public setting. To avoid this scenario, consider using a stroller, even if your child is able to walk. If a stroller is too babyish, consider a wagon or bike, which are more contained. Some amusement parks, zoos, and large outdoor attractions offer colorful, exciting looking "vehicles" for children to ride around in.

Dress your child in brightly-colored clothing such as a red or yellow t-shirt/dress. This will make it easier for you to spot him in a crowd. Snap a picture of him each morning before starting out on any outings. If he does get lost, this picture will help others find him faster. Before enjoying any large attraction, learn where the Lost and Found center is located.

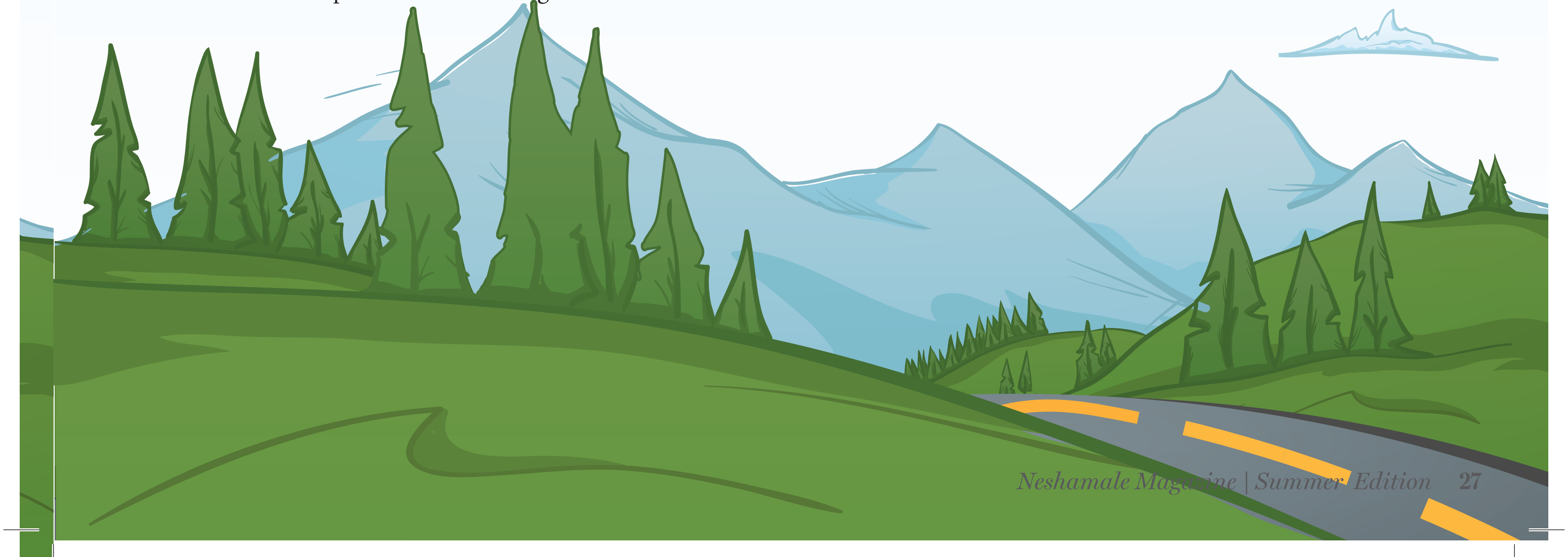
Attach your contact information somewhere on the child, where he will not be able to remove it. Depending on the child, it can be a bracelet, a paper in his pocket, or a label on the back of his shirt. Do not display the child's name in public, as that can be a different type of safety hazard.

Plan it Right

When planning your trip, keep to your child's normal routine as much as possible, including bedtimes, bathroom times, familiar foods, comfortable clothing, etc.

Determine whether the activities you are planning are realistically doable and enjoyable for your child. Remember that being in a new place is overwhelming in and of itself; too much overstimulation will probably backfire. Staying up late to watch the fireworks may sound nice, but is it worthwhile if it will totally wreck the next day's schedule?

Anticipate meltdowns and be prepared to take frequent breaks. Always have small snacks handy. Use head phones/iPods to block out noise in loud environments. Lastly, accept that there may be activities that don't work out. It's upsetting when you have purchased expensive tickets to a venue and you can't even get your child through the door, or when you can't get your child to wear a life jacket for a boat ride. Remember that it's not the activities that constitute a vacation – it's the attitude. Expect at least ten things to not go as planned, and just count them as they come!



Smart & Safe

Fraydel Dickstein

AAC PART II
(Augmentative & Alternative Communication)

Klal Yisroel is filled with thousands of *Gemachs*, but I think my Keeblok doorknob *Gmach* is pretty unique. These doorknobs have enabled many families to have respite on Shabbos. The lock has been borrowed from me numerous times, and each time I am so happy to help families have a functional Shabbos. As anyone who has been there knows, you cannot put a price tag on this – it can be literally life-saving.

Major A100 KEE-BLOK for Knobs *($54.71 on Amazon)*

The Kee-blok does such a great job and it's temporary. We used to use it every time we went to my in-laws or elsewhere for Shabbos. Unfortunately, I have not been successful in finding one that works on a hotel door knob.

When I recently lent the lock to someone for a Shabbos, it reminded me of why I thought of writing the *Smart and Safe* column. In the early years with our special needs son, I often felt so trapped, like there was just no possible way for us to have a normal life. Then we began learning so many tricks along the way.

Much of what I've learned has appeared in previous *Smart and Safe* columns. I've written about doors, locks, bathrooms, laundry rooms, bedrooms, kitchen, window safety, and more. There are also lots of practical strategies for many of the common challenges we encounter. Please feel free to email me at sngifts1@gmail.com for other ideas in these areas; if we haven't covered it, I would love to explore it with you.

I recently had an eye-opening moment when I asked Yehuda's counselor to pick up some of the metal door knob covers, and he showed up at my house with cheap, simple plastic ones. I laughed and said that was not what I wanted, but he insisted that I try them. I put them on a bunch of doors, and they really have been working.

Safety 1st Parent Grip Door Knob Covers, White, 3 Pack, Toddler *($4.77 at Walmart)*

One more summer tip that I cannot resist sharing, before I continue discussing AAC (Augmentative and Alternative Communication), is that if you are having water issues, like your child uses the hose all day and you don't want to drown your yard or support the local water company, you can almost always shut off the water source from the inside of your house. There should be a knob or lever in a utility room, closet, or basement that can turn off the external water sources. You need to find out where this is in your house! It has been a life saver for us.

AAC - Part II:

In the last column we covered some of the "smarts" of iPad use. Now let's talk about keeping it "safe." Giving an expensive piece of technology to our children for them to handle can feel risky.

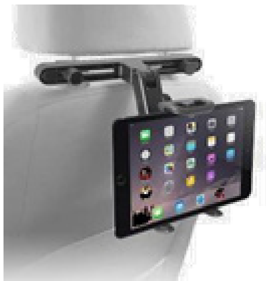
The first step is to block all apps and accessories, other than those you want your child to have access to. The next step, if we want the device to last, is to protect it properly. The ProCase Kids Case for iPad is hands-down my favorite. It's cheap, easy to use, and has saved the iPad many times over from breaking.

ProCase Kids Case for iPad, Shockproof Lightweight Case with Convertible Handle Stand *($15.99 on Amazon)*

Another issue is keeping the iPad accessible. The above case has a great handle that is easy to carry around. I have also seen some kids hang it around their neck and carry it with them wherever they go.

HDE Shoulder Strap for Shockproof iPad Case - Adjustable *($10.99 on Amazon)*

A practical tip is that you can attach keychains to the clips of this shoulder strap and have constant access to anything small that you want to have handy. For example, a friend shared that she keeps the key to unlock her son's seatbelt lock clipped onto his iPad, so they won't lose it while traveling.



Talking of traveling, it can be incredibly helpful to have an i-Pad mount in the car.

Macally Adjustable Car Seat Head Rest Mount and Holder *($19.99 on Amazon)*

Another point to keep in mind is the idea of having more than one iPad. One reason for this would be to keep them in different locations, such as school, home, the car, a respite program, etc. Depending on how your child is transported from these various locations, you may be comfortable using one iPad that accompanies them throughout the day, or you may want multiple pieces so they won't get lost in transit. If you do you have multiple iPads, it's important to update all of them when you make basic changes, to avoid confusion.

Another consideration is keeping AAC and entertainment separate. Some people have both their AAC app, and videos, music, games, etc. on the same iPad. This is convenient, but can lead a child to use the iPad primarily for entertainment. By having two separate pieces, you are making a clear differentiation as to the purpose of each one. I would suggest using two different-colored cases.

There are simple cheap options to use in specific situations instead of an iPad. For example, at one point in Yehuda's classroom, they used Answer Buzzers, buttons that spoke about Yehuda's environment (ie: there was a button on his classroom door that said: "Open door"). These buttons can be customized and you may find them useful around the house.

Learning Resources Recordable Answer Buzzers - Set of 4 *($22.21 on Amazon)*

I would like to wrap up this topic by sharing some very powerful lessons I have learned from our communication journey, which somewhat portray the collective lessons Yehuda has taught me. I thought Yehuda's use of the iPad would allow him to be an almost normal child, as I viewed his lack of speech as his primary disability. Yehuda cannot utter a single word, which is very atypical. Most of his peers can say some words, albeit not necessarily functionally.

The iPad enhanced Yehuda's life tremendously. I will never forget him having a tantrum, and me pulling out the iPad and hitting the word "angry," and how he instantly calmed down. Yehuda is not self-motivated to use the iPad, and it is still, in some ways, useless to him. He cannot initiate anything abstract on it, only very concrete things, such as food and places. All of these are things he would rather point to, and he honestly does not always care where he goes. He really doesn't seem to have such strong preferences. Is it that all his years of being locked in silence did not allow his communication to develop, or is communication beyond the concrete not motivating to him? I believe the answer is a little of both.

Nevertheless, the iPad has enhanced Yehuda's life greatly, and it increases his quality of life by 50%. This is huge, and is worth all our efforts. We have learned that it is worth our efforts to obtain even small improvements for Yehuda. *"Prutah u'prutah mitzterefes l'cheshbon gadol"* (One penny at a time equals a large sum). We try to do little things to improve Yehuda's life, and we are so grateful for all the improvements, and all the good that Hashem showers upon us!

Yehuda's AAC journey has humbled me and taught me that my job is to try, but that all success is completely from Hashem. May we be *zoche* very soon to the day when we will hear the sweet voices of all our *neshamos* who were not yet granted the ability to speak.

Tips From The Experts

hey! that's us!

What can be done for a child who constantly wakes up in the middle of the night, tossing and turning the whole night? Some days he starts his day at 4:30 in the morning—and some nights he is up from 1-5am having a blast while his poor parents want to sleep! While most nights are better than this, we were wondering if anyone has any solutions as to getting a good night's sleep on those bad nights.

C.B.E.

Children with special needs will often be awake at night, despite our best attempts otherwise. Creating a safe environment is important, as they are more in danger of getting hurt when there is less supervision. Here are three ideas to implement:

1. Install child-proof windows and doors. Install alarms to alert you when windows or doors are open.

2. Block the bedroom door. Depending on the age of the child, this can be done with a baby gate or a secured half-door. Alternatively, use a special needs bed. This is designed to keep children secured and comfortable all night. Perhaps you want to allow books or toys in the enclosed area to keep the child occupied.

3. Eliminate opportunities for climbing. This may mean opting for low bookcases and dressers. Anchor all furniture to the wall. Lock up all dangerous chemicals, cleaning supplies, etc. A.S.

If your son is awake at night on a constant basis, an enclosed bed is mandatory. Either you can get it through insurance, or take a regular bunk bed and enclose it yourself. This topic was written about extensively in past issues of Neshamale. I personally allow my son to have some fidget toys, cardboard books, and his favorite blankets, etc. in this bed with him. This way he has something to do when he is awake at night and does not need to be entertained. G.W.

We went through a period like this with our daughter. We wound up putting her in her own room and installing a second doorknob higher up on the door so that she couldn't get out on her own. We also then removed ANYTHING that she could use to get into trouble with. She was left with clothing and some toys that were deemed safe. We also put a camera in the room so that we could keep an eye on her without opening the door. We found that since she couldn't get out, very often she went back to sleep after playing for a bit. Adina

Sleep is a very common area of challenge to super-special people. In our house we took the following steps: First, we gave my son his own room! Then we got a Courtney bed, which is an at-home version of a Soma bed. When our clever child learned how to outsmart it, we put an outside style door on his room. It has a huge window so we always know what he is up to. It locks from our side, so he is safe, and it's pretty soundproof as well, so the thundering sounds from his music and dancing are less distracting. Unfortunately, any medication we threw at the problem did not get him to sleep. I wish I had energy like that! Chaya Friedman

I got my daughter the Dream Pad. It's is a sound pillow that uses gentle vibrations to deliver calming audio and music, promoting relaxation and better sleep. While it's not a cure, it does help her sleep better.

Esther Hazzan

Use a sleep coach. You may think there's nothing to be done, but there really is help out there. Look for one who has experience with the special needs population. You can contact me through Neshamale for further recommendation.

Chava T.

My son used to sound very similar to this. It felt like he never slept, and even when he was sleeping, he'd sit up and rock back and forth. I took him off of dairy for a different reason, and we saw huge changes in him in general. He suddenly had almost no congestion. When he got sick, he got better much faster. His sleeping patterns also changed drastically. I think it is because of lower congestion levels which is helping him breath better. It could also be because of the digestion changes. I have no idea which is the true reason but I would say it is definitely worth a try to see if it helps. He now sleeps through the night from 7:45-6am (unless he is sick). I call it my *Tevadige neis*! R.K.

Certainly, it is a relief to know we are not alone in this challenge, although I wouldn't wish it on anyone.

One night last year, when I was up for many hours with my daughter (who was 13 at the time), I made a mental list of other Jewish mothers who were probably up then, as well:

Mothers of hostages

Hostages who are mothers

Mothers of soldiers in Gaza

Mothers with children in the hospital

Mothers who don't know where their children are hanging out all night

Mothers of older singles

I thanked Hashem that I was in my own home, with my family healthy and safe. This too, would pass.

Sometimes I take my daughter out in the middle of the night for a walk, hoping to tire her out.

Sometimes I wonder if I am meant to stay up all night saying Tehillim or Tikkun Chatzos.

I have noticed that most of the time, after we have been up most of the night with our daughter, we have extra energy and kochos the next day! Chanie Landesman

The first step to dealing with sleep problems, as with any non-normative behavior, is to rule out physical causes. A visit to your child's pediatrician will help diagnose or rule out any of the following issues that could be affecting your child's sleep:

Thyroid dysfunction

Iron or vitamin B-12 deficiency

Blood sugar issues

Sleep apnea

Side effects from medications your child takes

If the pediatrician gives you the all-clear, then you can continue to address the issue as a behavioral one.

A Mommy and a Nurse

Question for the next issue:

My six year old son is extremely hyperactive, one of many aspects of the rare syndrome that Hashem created him with. He can barely sit still ever; he is always running, climbing walls (literally!), bumping into other people, etc. It also impacts his learning as even though he has some level of intelligence, he is not able to focus enough in class to learn well.

He is not able to swallow pills so typical ADHD meds would not be possible. Are there any alternative ideas that others have done to help in this area? Thank you!

C. K.

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

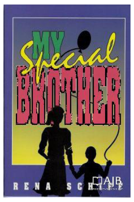
Supportive Reading Material, continued from page 13

catching a thief, there are plenty of laughs to go around in this fantastic book by award-winning author Yael Mermelstein.

My Personal Take: I just bought this hot-off-the-press book for my kids, and of course read it myself, too! Yael does a great job of portraying Nonny as a fun-loving, normal boy who happens to have some handicaps. A fun and light read.

12

My Special Brother



Author: Rena Schiff

Publisher: CIS Publishers (out of print, used books available for purchase)

250 pages, Ages 9-17

The sister of a new baby with Down syndrome explores her initial and subsequent thoughts and experiences as she learns to embrace her new status.

Publisher's Summary: Rochelle Weinfeld was bubbling with excitement. Her mother was in the hospital having just given birth to a baby boy, and the Weinfeld household was abuzz with activity in preparation for the new arrival. But when her father came home, it became apparent that something was seriously amiss. After the shalom zachar, he called the children together and gently broke the news. There was something wrong with the baby. It seemed that he had Down Syndrome; he was different – a "special" child.

Memorable MISHAPS

Compiled by Fraydel Dickstein

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

Doughnut Disaster!

The Chanukah party was starting in ten minutes. We had donut dough rising beautifully on the counter. We planned to toss them into oil and fry them fresh during the party.

Suddenly, I heard screams erupting from the kitchen. I came in to find three chewed-up balls of dough, thrown back into all the other dough!

I had forgotten Yehuda loves raw dough! All I could think was: *"Hashem give me the strength to love this man and just laugh and laugh at everything he does; he is for sure the cutest man out there!"*

(I once Googled "raw dough" and read a whole write-up about what to do if your dog eats it, as it was deemed very unsafe. But I know from years of experience that raw dough must be safe for humans, as Yehuda seems to metabolize it just fine. I take no responsibility, however, so please don't try it!)

Camera Kaparah

It was a busy Friday afternoon, and I was trying to get ready for Shabbos. I noticed from the corner of my eye that Ezzy was playing with my camera. Truthfully, I was happy that he found something to keep himself busy with. Shabbos came and went. On Sunday, I picked up my camera to look at some pictures. When I turned it on, it said: *Memory Card Blank.* I thought I was imagining it, and tried again. I was getting frantic, but I could not retrieve any pictures. These were gorgeous family pictures covering the whole previous year. I was devastated and, when I think about it, I am still pained. Does each lost picture count as a *kaparah*?

Tzviki's *To'a'me'ha*

It was Erev Shabbos; my house was immaculate, I was feeling on top of the world. The oven timer beeped; I went to remove my perfectly browned potato kugel, and put it on the counter to cool. Soon after I heard squeals of delight emanating from the kitchen. I walked in to find Tzviki, my six year old son who has Down syndrome, happily eating the potato kugel that he had overturned on the floor. He told me it was yummy and generously offered me some. (My littles could not resist helping me clean up by eating some of the globs of fresh kugel on my (previously clean!) floor).

Sensory Soups

Did you even know that if you open up enough cups of noodle soup, pour them out, and jump in it, that it makes a really joyful sensory experience? The crunch it creates is evidently something that Dovy finds thoroughly enjoyable. Why can't he stick to jumping on trampolines?

If you think that's messy, my friend Zahava's daughter likes to smear peanut butter on her linen! The sensory experience is unparalleled. And the mess? 100% impossible to clean!

Orange Puddles

I have always loved design, and color is really my thing. That must be why my eight year old Chaim took the entire case of orange juice I had bought for Pesach and made as many orange juice puddles as he could. Yes, I do I love color. Mopping and cleaning? Not so much! But I am sure that Chaim had my best interests in mind!

Lollypops Down the Drain

The cries were earth shattering, so I ran – perhaps someone had hurt themselves? I found three year old Sury holding an empty bag of lollypops. These were the lollies that we had gone specially to the store to buy for her long-awaited turn to be "Shabbos Mommy." I knew what happened without her telling me. Asher, my autistic nine year old, had gotten into it and probably flushed them all down the toilet. My dilemma: What do I do first: comfort Sury, or call the plumber?

Orzo Fiasco

I don't usually serve orzo more than once a year, as it makes an unparalleled mess. It's stickier than rice, smaller than macaroni and gets everywhere! But I served it on *Motzei Shabbos* at our *siyum*/Chanukah party. By the time my son had eaten his fill, the house was covered in orzo! The banisters, doorknobs, floors, etc. were all gooey and globby. I was hosting a massive party the next night—how would we do it? Hashem sent my cleaning lady (who never comes at that time), at 8:30 the next morning to work her magic.

Barging into the Barber

We were on our yearly vacation in Baltimore, and our family stopped at the pizza shop for supper. Yehuda needed to visit every shop in the area other than the one we wanted to go to. As he made his rounds, there was a barber shop with many scary looking men inside, and sure enough, Yehuda barged right in. Aside from my heart rate increasing, there was no other damage done! Thank you, Hashem!

STRESS BUSTER TIPS

THINK POSITIVE!

I sometimes look at my other children who, *Chasdei Hashem*, are growing up to be wholesome adults, and I marvel; this is not something I ever thought would happen. I can't help but think that perhaps there is no ayin hara on these children. Although we should never be jealous of anyone, it is human nature to be jealous. Yet, due to the many embarrassing scenes Yehuda instigates, maybe others are just happy to see our other children doing well. And maybe they even send up a prayer on our family's behalf.

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

Top 10 Tips on sleep!

N.M.

Getting our children to sleep and to stay asleep is quite a tiring job, pun intended! Here are ten tips to get you started:

1. Try to have your child get a lot of exercise during the day, so he's physically tired by bedtime.

2. Having your child get plenty of sunlight during the day will assist in melatonin production.

3. Avoiding naps (for your child!) during the day will make him sufficiently tired at bedtime.

4. Have him avoid eating and drinking close to bedtime to avoid extra bathroom trips, messy diapers and stomach aches.

5. Establish and adhere to a relaxing, soothing bedtime routine to help your child relax and prepare for sleep.

6. Take into account your child's sensory needs when choosing sleepwear. Some children need loose fitting garments to be comfortable, and some need deep touch pressure to settle down. I have heard of children being put to sleep in a full protection UV swim suit – whatever works! To stop diaper escapologists/diggers, put a sleeper on backwards.

7. Keep the room a cool, comfortable temperature.

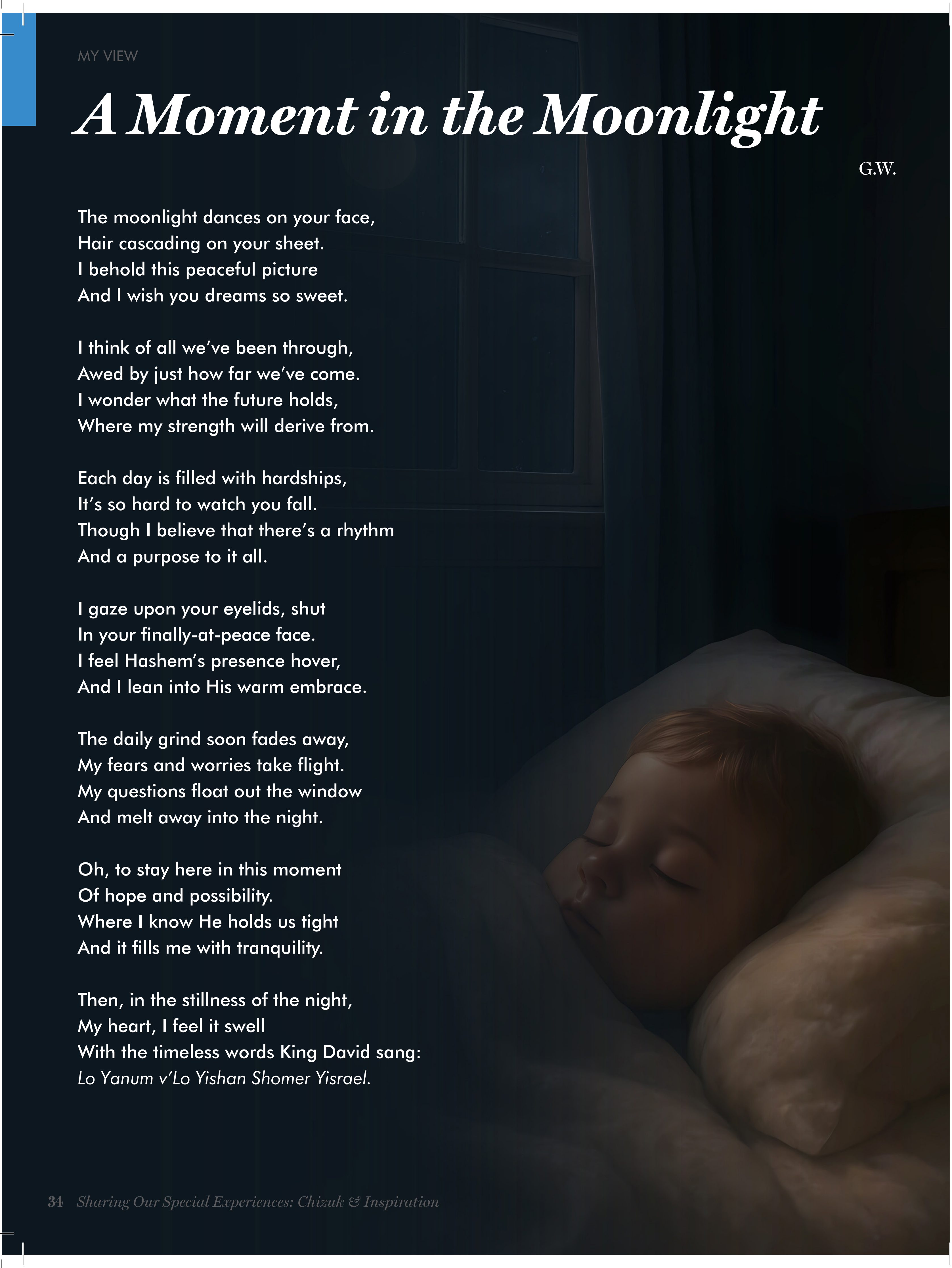
8. If your child is the type who needs extra sensory input, try a long body pillow; squeezing it can be reassuring. Another idea is to wrap a quilt cover over the bed and tuck it tightly under both sides of the mattress. This keeps things snug and tight. For a smaller child who moves around a lot, a sleep sack can keep him warm and secure.

9. Try a SLD light box. It helps regulate the circadian rhythms which leads to improved sleep patterns and a generally happier mood.

10. If necessary, try melatonin or other sleep aids, as discussed with your doctor.

A Moment in the Moonlight

G.W.



The moonlight dances on your face,
Hair cascading on your sheet.
I behold this peaceful picture
And I wish you dreams so sweet.

I think of all we've been through,
Awed by just how far we've come.
I wonder what the future holds,
Where my strength will derive from.

Each day is filled with hardships,
It's so hard to watch you fall.
Though I believe that there's a rhythm
And a purpose to it all.

I gaze upon your eyelids, shut
In your finally-at-peace face.
I feel Hashem's presence hover,
And I lean into His warm embrace.

The daily grind soon fades away,
My fears and worries take flight.
My questions float out the window
And melt away into the night.

Oh, to stay here in this moment
Of hope and possibility.
Where I know He holds us tight
And it fills me with tranquility.

Then, in the stillness of the night,
My heart, I feel it swell
With the timeless words King David sang:
Lo Yanum v'Lo Yishan Shomer Yisrael.

GLOSSARY OF HEBREW TERMS APPEARING IN NESHAMALE MAGAZINE

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

Ahavas Hashem – Love of G-d
Avos – The Jewish Forefathers
B'Ezras Hashem – With the help of G-d
Bim'hayra – Soon
Ba'al HaRachamim – Master of Compassion (G-d)
Bas Kol – Heavenly voice
Bentch – Bless (or to say the Grace after Meals)
Bitachon – Trust (in G-d)
Brachos – Blessings
Chasdei Hashem – G-d's kindness
Chodesh Av – Hebrew month of Av
Chumash – Five Books of Moses, Pentateuch
Daas Torah – Advice of Torah Sages
Devarim – Words
Dibur – Speech
Emunah – Faith (in G-d)
Emunah P'shuta – Simple Faith
Frum – Religious (Y)
G'mach – Free loan organization ($ and items)
Ha'Nosein l'Ya'yef Koach – He Who gives strength to the weary
HaKadosh Baruch Hu – The Holy One, Blessed is He (G-d)
Hakaras haTov – Gratitude
Har Sinai – Mount Sinai
Hatzlacha – Success
Hishtadlus – Effort
Isha Yerushalmis – Jerusalemite woman
Issur of Rechitza – Prohibition of Murder
K'vi'ya'chol – As if
Kaparah – Attonement
Kappel (Yarmulke) – Jewish skullcap (Y)
Kever – Gravesite
Kiddush Hashem – Sanctification of G-d
Klal Yisroel – The Jewish People
Klalos – Curses
Ko'ach – Strength
Kochos – Strengths
Kol haTorah – The entirety of the Torah
L'Sheim Shamayim – For the sake of Heaven
Mashiach – Messiah
Mazel – Good fortune
Mesivta – Yeshiva high school
Middos – Character traits
Minhag – Custom
Naaseh v'Nishma – "We will do, and (then) we will understand"
Neshamos – Souls
Nevi'im – Prophets
Nisyonos – Tests
Pekelach – Goodie bags (Y)
Perek – Chapter
Peyos – Sidelocks
Rachmanus – Compassion
Ratzon Hashem – The Will of G-d
Ribono shel Olam – Master of the Universe (G-d)
Samayach b'Chelko – Happy with his lot
Sefarim – Jewish books
Sefer Tochacha – The Book of Rebuke
Seudos – Meals, generally festive
Shabbaton – Shabbat weekend program
Shemoneh Esrei l'Chuppah – Suitable for marriage at 18 years old
Shlepp – Drag (Y)
Shoresh – Root
Simchos – Joyous events
Siyum – Completion ceremony
Tafkid – Purpose
Tallis – Ritual prayer shawl
Talmidim – Students
Tefilla – Prayer
Tehillim - Psalms
To'a'me'ha - Lit: The taste of it, refers to tasting the Shabbos food on erev Shabbos
To'cha'cha – Rebuke
Tovah – A favor
Tzadik – Righteous person
Tzadik Gamur – Completely righteous person
Upsherin – 3 year old boy's first haircut (Y)
Urim v'Tumim – Prophetic stones on the High Priest's breastplate
Yartzheit – Anniversary of someone's death (Y)
Yeshuah – Salvation
Yidden – Jews (Y)
Yomim Tovim – Jewish Holidays
Zoche – Meritorious

"The best thing about memories is making them"