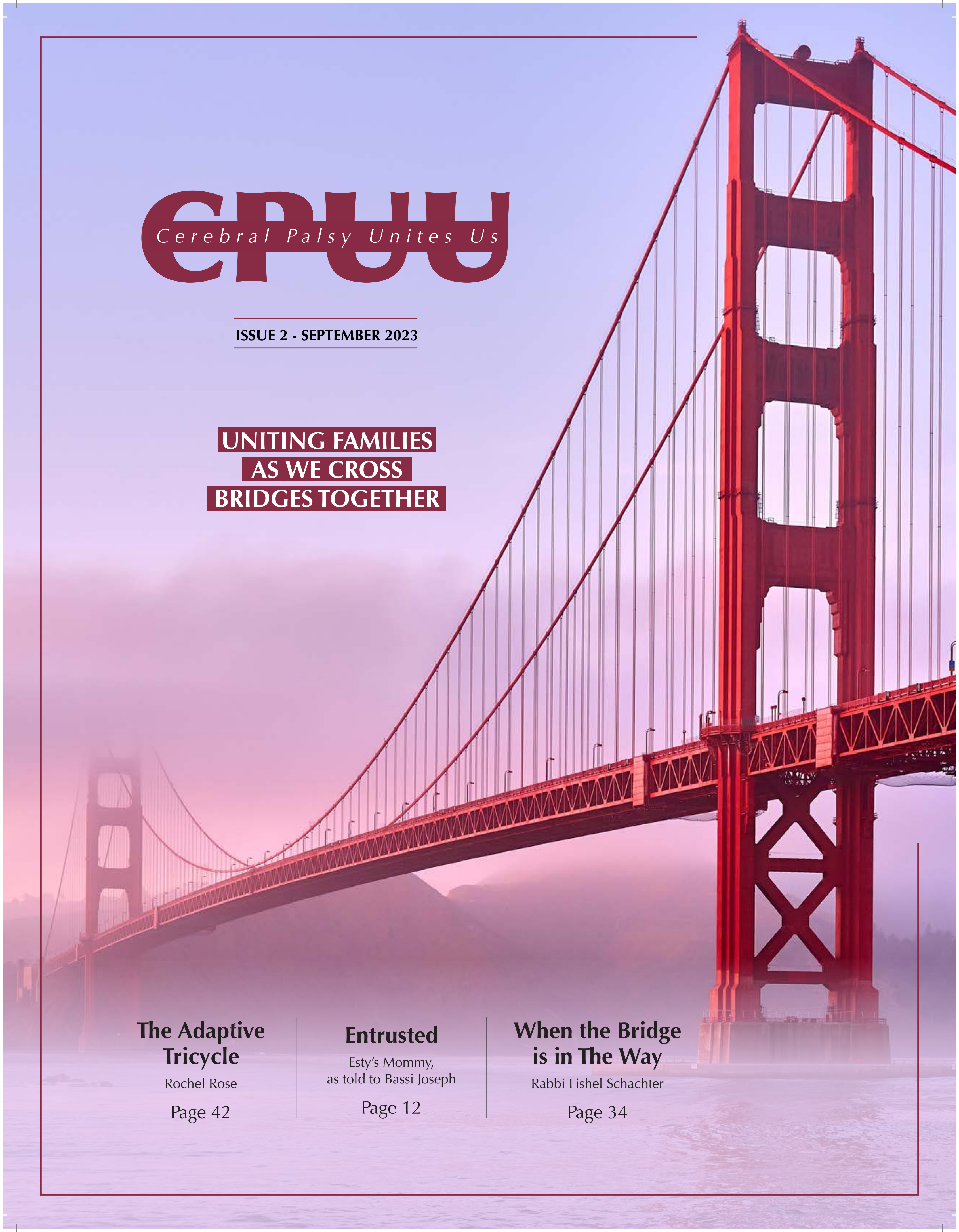

CPUU

Cerebral Palsy Unites Us

ISSUE 2 - SEPTEMBER 2023

UNITING FAMILIES AS WE CROSS BRIDGES TOGETHER

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Note: This magazine contains Divrei Torah.

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Editorial

Dear CPUU Families & Friends,

Welcome to the second issue of the magazine!

Now during the auspicious days of Chodesh Elul, amidst the hustle of a new school year, shopping, and Yom Tov preparations we are also preoccupied with collecting many zechusim, to bring us into the Yimei Hadin in a higher state.

The thought of collecting zechusim reminds me of a beautiful vort I heard from HaRav Rosenblum Z'tl, the Rosh Yeshiva of Yeshiva Sharei Yosher. When Bnei Yisroel were in the midbar and traveled from one camp to another, it was the responsibility of the Leviim to move the components of the Mishkan and its keilim. The beams and curtains were loaded onto wagons. The keilim were carried by the Leviim utilizing long poles, called Badim, attached to the sides of the keilim. The aron, however, was different. When Bnei Yisroel were about to cross the Yarden River into Eretz Yisrael, the aron miraculously lifted itself, taking along the Leviim holding the badim, drifted across the river, and rested on the opposite side of the bank.

This is astonishing! If the aron had such great kedusha and therefore had the ability to lift the Yidden across the Yarden, why was it necessary for the Leviim to carry the aron?

The Rosh Yeshiva's answer was a huge eye-opener for me. I believe his answer can shift our perspective and transform our interactions with the Heilige Neshamalach around us.

Yes, the aron could lift itself and the Leviim with it, and no, it wasn't necessary for the Leviim to carry it. The reason why the aron had badim at all, was to give Leviim the great zechus of 'carrying' the aron.

Similarly, I thought this may be the case with our special Neshamalach.

Our Kinderlach are pure and heilig, children שלא טעמו טעם חטא. Likely, they are Nashamos that came to this world, as a כפרה and תיקון for the חטאים of the generation. These elevated souls can hold up the entire world because of the zechusim they draw down from above for our benefit.

At the same time, we see that Hashem created them with many needs, many more than one family alone can even fill.

Our children bring numerous individuals, agencies, and organizations together to collaborate and bring out their best. Medical professionals, therapists, teachers, paraprofessionals, com-hab workers, respite and after-school programs, volunteers, friends, and neighbors come together to care for and support our children and their families. Even passersby will stop and help shlep a wheelchair upstairs or into or out of vehicles. This way we all have a chance to connect and be touched by their greatness.

May we soon be zoche to the time when we will clearly see the beautiful gifts we were granted, the precious treasures that are part of our families and communities; we see ourselves as the givers when in reality it is they who are giving us the amazing zechus of supporting them.

The responsibility is awesome, but I think this shift in perspective can ease the pressure significantly. We will find it easier to 'carry our aron' and appreciate the opportunity to perform such a lofty task!

May Hashem grant every family member and caregiver a new year filled with happiness and nachas. May we be zoche to a year of redemption in every way.

Wishing you all כתיבה וחתימה טובה

The Publishers

Inbox

I'm Speechless!!! This magazine is unreal........... so professional. May you continue to have Hatzlacha in your Avodas Hakodesh!!
Goldy Silberman

I didn't really read the whole magazine, yet I am truly amazed by it! It's amazing! Can we do a feature/ interview about it for Sisters Corner?
Hatzlacha!

I was forwarded a copy of your gorgeous magazine. Kol Hakavod!
Is this magazine going to be an ongoing publication? Can I forward it to our families that have children with CP?
Thank you for all your work in Avodas Hakodesh.
Chana Barrett
Gesher Cleveland | Agudath Israel of Ohio

Thank you for your magazine. I really appreciate reading this magazine.
M. M.

I just came across an email of your magazine, through Yitzchok's Toy Box. It was so impressive, wow! I'm really inspired and super impressed that you created such a magazine. Your magazine, devoted to CP, is very relevant to me.
We have a delicious 8-year-old son with CP. We live in Baltimore.
How can I subscribe?
Thank you!
M.B.

Hi,
I just opened the magazine!
It's absolutely beautiful.
Lots of people will benefit from this and it's amazingly put together.
Thank you so much!

Thank you for the beautiful magazine. It was very insightful. Looking forward to many more editions.
Chavy Frier

Hi, I just gave my copy of the magazine to my PCP. Can you please send me another copy?

I just wanted to let you know what a fantastic job you did with the magazine! I didn't have time to finish looking through it but printed out a few copies to give to students and clients. The love, dedication and time that went into this project is evident on every page.
Hatzlacha!
Morah Shaindy Nathan M.S.Ed.
Special Needs Consultant and Family Trainer

Wow! What a gorgeous magazine! Hatzlacha on this new endeavor. I'll try to send new pictures of our prince. I'm not a writer but if you need help with anything regarding the magazine, you can reach out.
Can you do a write up on different activity chairs/ strollers for children with CP?
Chanie Lipschutz

Who we are:

Ezreinu provides guidance to parents of children with developmental delays. We are passionate about providing you with help, so you can make the best decisions for your family. From assisting with school placement, finding a respite program, or connecting you with a parent support group, we're here to help you, and to help your child thrive.

What we do:

Ezreinu can provide you with information to many different programs including, but not limited to:

- ABA therapy
- OPWDD traditional & Self-Direction
- HCBS (children's waiver) services and agencies.
- HHA, Nursing agencies, CDPAP.
- BOE info, and agencies that provide p3, paras, seitts
- After-school, Sunday, Shabbos programs
- Reading and Kriah specialists,
- Asd Evaluators, Psychiatrists, psychologist, and lcsw's.
- Early Intervention
- Special Ed schools, Yeshivos, & Misivtah's.
- Informative magazines, Hotlines, support groups.
- Camps, daycamps, camp after camp.
- Info on highly-qualified OT's, PT's, speech therapist, Aqua therapy, Music therapy, Cranial Therapy, Mnri, animal therapy
- Dayhab adult programs
- Residential group homes
- Vision therapists, Optometrists, CVI experts
- Developmental Pediatricians
- Dentists who deal well with Special needs.
- SSI, guardianship, Funds.
- Diagnosis matching
- Child care availability (call for details).

- Info on all Medical supplies gemachs & Bikur Cholim Organizations
- Info regarding transportation to and from hospitals
- Shabbos accommodations near hospitals
- Liaisons & chaplains in many hospitals

- All birth related organizations, specifically the ones geared to parents of developmentally delayed:
- Care management
- Practical day to day advice
- FSS reimbursements
- Extracurricular activities

Ezreinu can also help you with:

If your child has been diagnosed with a condition or genetic issue, you might feel like no one understands what your family is dealing with. Our devoted staff will try their best to connect you to another family who has a child with a similar diagnosis.
We also have child care availability. (Call for details)

Our purpose:

At Ezreinu, what drives us is the desire to help as many parents of children with developmental delays as possible. We do this by providing them with accurate information, as well as necessary support and guidance. Additionally, we help them find resources in their area, and provide them with care for their children in times of need.

SCAN ME

EZREINU
GUIDING • ASSISTING • CONNECTING

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A Wife on Wheels

Nechumelle Jacobs
Facilitated by Chana Romand

Meet Nechumelle Jacobs, a woman of great courage, determination, warmth, and wit. Read her unbelievable story in her own inimitable style and good humor.

My name is Nechumelle Jacobs; I have Quadriplegic Spastic Cerebral Palsy, so I am wheelchair-bound and can use only my right hand. I'm so lucky that my speech or cognitive ability is not affected. I hope my story will inspire anyone affected by CP, friends, families, and particularly the CP population.

I grew up and still live in Stamford Hill, London, where I had a wonderful childhood. How could I possibly say that? I am disabled, after all. My childhood was beautiful because of my parents, family, and friends. My parents had confidence in my potential and fought for me to attend a mainstream Bais Yakov. My classmates embraced me, including me in everything, even wheelchair races! I was one of them; we played together, laughed together, got into escapades together, and somewhere in between, did some studying.

At one point, the school administration thought it would be better for me to change to a different classroom on the ground floor of the building, and that would be more suitable for me; my classmates protested and lobbied for me. Eventually, the entire class moved down to a ground-floor classroom! My friends saw beyond my external disabilities, and I had many friends; we had loads of fun! They would laughingly declare, "WE are disabled," and the bemused workers at the gate of an amusement park let ALL of us in with priority passes!

I stayed with my classmates straight through high school until our seminary year. I desperately wanted to attend seminary but knew joining my friends out of town was impossible. I was devastated! I really wanted to attend the same seminary as my sisters had.

Instead, I settled for a local chassidishe seminary; it was pretty different from my Bais Yakov high school. In the end that didn’t even matter because I had a wonderful experience and made great friends. Since most Chassidishe girls stayed close to home after marriage, I had a warm circle of friends who supported me during the lonely years that followed seminary.

My friends were getting married, and I was positive I could get married, too, despite my disability, but I was still concerned about finding a compatible shidduch. I davened hard to be zoche to meet the right one, especially when I traveled with my friends to Kivrei Tzadikim in Poland. My tefillos were answered! Hashem granted me the most beautiful gift, six years of marriage, to my extraordinary husband. He was niftar two years ago, but his influence and memories are still part of my life. I felt privileged to have been married to him.

> **I had a wonderful childhood. How could I possibly say that? I am disabled, after all. My childhood was beautiful because of my parents, family, and friends.**

My husband had his own health challenges, but that did not stop us from building a solid and healthy marriage. Wondering how that happened? I did not ‘arrive’ because I got married; I got married because I arrived! I worked on myself to the degree that I could get married and nourish a relationship. I had very high expectations of a marriage partner; I didn’t want to marry someone who would take care of me; I wanted to marry someone who cared.

So, you want to know how my shidduch came about? Miraculously, like everything else in my life.

Once, I heard about a girl with diabetes who was worried about her shidduchim. Her father watched her as she worked on assembling a jigsaw puzzle and asked, “Why do you start with the corner piece?” Her insightful answer was, “After using all the corners, fewer options are left.” He encouraged her, saying, “Your shidduch, too, will be easier to find because you have fewer options!” This story resonated with me and gave me courage and confidence.

I crossed paths with my husband’s parents many years earlier while on vacation in Holland. They had kept an eye on me but wondered if I would agree to marry their son!

Years later, I volunteered at Schonfeld Square, an assisted living complex where my future husband lived. I was thirty years old at the time, and our shidduch was the brainchild of the social manager there! I wanted someone who cared, and my husband cared; oh, how he cared! He was older than me, had exceptional midos, and a great sense of humor; looking up to and admiring him was easy. He was the first person who understood me; I didn’t have to pretend; I could be myself. Every person has a shidduch that is perfect for them, and my husband was perfect for me!

Everyone had an opinion about our shidduch:

‘You won’t have a normal chasunah’.

‘You’re right; I won’t have a regular chasunah, but I *will* have a normal chasunah!’

Another comment:

‘But you never even went on a date!’

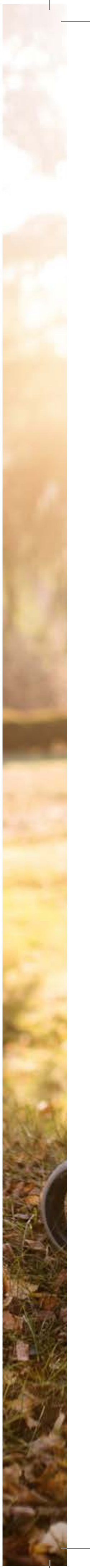
‘That’s true, but in our everyday life, we won’t be going out often anyway; we’re not planning on going out together; we’re planning on living a life together.”

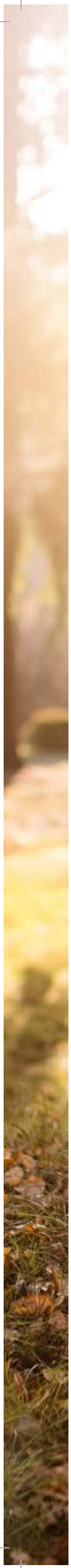
My husband did not always need to use a wheelchair but rode in one when he came to my badeken. He didn’t want me to be the only one in a wheelchair. This was typical of his caring and understanding nature, and it characterized our marriage. I had a beautiful bridal wheelchair that my friend’s mother decorated to match my gown. Someone posted on WhatsApp during our wedding: “The chasunah is on wheels!”

All the pain of my single years was eased when I got married. My husband was my faithful life partner; we supported and understood each other well, and his humor helped us stay positive.

Once, we were riding in a van, and the driver kept up a constant chatter, which annoyed me. Suddenly, my husband yelled, ‘Ouch!’ I thought I pushed my chair over his foot. Reassuring me I didn’t, he whispered, “I’m ok; I was just trying to change the topic of conversation!”

It is known that every marriage has its challenges, and I went into marriage knowing ours would have more than its fair share.





I moved into Schonfeld Square, the assisted living complex where my husband lived. At first, we had two apartments, one for daytime and one for night, because our medical devices and equipment took up so much space. After a year and a half of shuttling between the two areas, we could finally move into one much larger, single apartment. The apartment was outfitted with a call bell, like the bell attached to hospital beds, and we could call for any assistance we may have needed throughout the day. And we needed help with everything! Because all our physical and housekeeping needs were handled, we could focus on our life together and build our marriage. My physiotherapist once told me, "Even with your limited mobility, you could cook a meal for your husband, but it would take you all day, and then he wouldn't have a wife." I never once prepared a meal for my husband during the six years we were married, but we were there for each other.

> I strive to live by my husband's legacy, keeping a positive attitude and sharing our fortitude and bitachon with others.

They say Rome wasn't built in a day, which was accurate about our marriage; we both worked hard together. I told my husband's doctor that he was so good to us. Our shadchan commented, "If someone annoys one of you, they annoy both of you!" Our marriage was not easy, but it was good.

During the Covid-19 pandemic, I was frustrated because I kept getting infections. One day, I complained to my husband, "It's not fair; I always go along with you to your appointments, but you don't accompany me to my medical appointments." "After Covid," he promised, "I will go with you."

After Covid, he was gone. My husband was niftar on 25 Teves 5781. It's been two years, and I still feel very connected to him and feel his presence all the time: Just as he promised, especially during important medical appointments. Soon after his petirah, I had an appointment with a specialist at the hospital my husband frequented. No one could accompany me that day, and I had to go alone, which was difficult and frustrating. When I finally arrived at the hospital, I was tired and irritable, and feeling very low,

"Nechumelle," I thought, "you are all alone." The glass doors swung open just then, and my late husband's doctor walked toward me with a delighted smile. "This is a surprise, Nechumelle! What are you doing here?" I felt my husband was right there with me, encouraging me! I think he is constantly pulling strings up there to help me down here. Getting to the right doctors just when I need them, and often hard-to-come-by appointments are suddenly and immediately available for me (other people wait for months).

Recently, I was admitted to the emergency room, and the hospital staff needed a hoist to lift me onto a stretcher. Usually, there is a very long wait for one, as very few are available at the hospital. This time there was a hoist available; it was waiting for me!

I strive to live by my husband's legacy, keeping a positive attitude and sharing our fortitude and bitachon with others. He didn't want us to benefit from our disabilities, and he didn't want me to take a fee for public speaking engagements. I still don't. I also share my story in my book, 'Finding My Balance.' One of the common symptoms of CP is compromised physical balance, which also affects trying to live a balanced life. Only with Hashem's guidance and the lessons I've learned can I continue to try and 'find my balance.' I also started sending daily emails to spread chizuk and inspiration. Anyone is welcome to contact me at nechumellejacobs@gmail.com to receive emails or for information about my book.

Nechumelle is a prolific and talented writer. Her poetry is lovely and expressive and could only have been written by someone with such a powerful personality and deep, passionate Emunah. In addition to sharing her inspirational life, she shared two of her recent poems.

LACKLUSTER

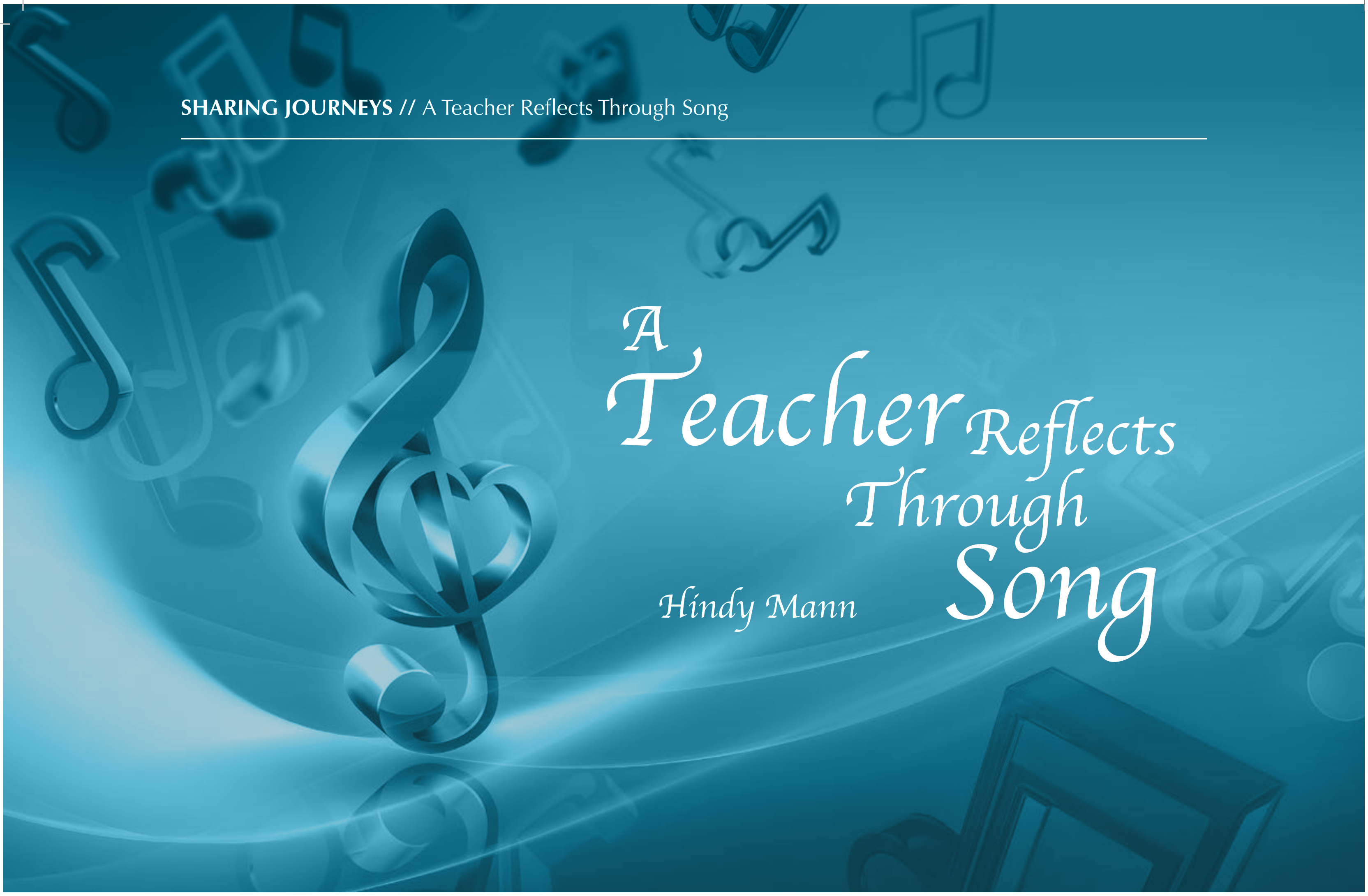
Today's poem misses the mark
Like the lights, dim and dark
Even though inspiration is low
And my writing juices don't flow
From life's troubles, I try to detach
This poem is truly not up to scratch
But despite these rollercoaster rides
Tranquility, therapeutic poetry provides
Just like we need oxygen to survive
Rhythmic writing helps me thrive
I felt lackluster at this poem's start
But now the grey clouds in me depart

©Nechumelle Jacobs – 26 Iyar 5783 – Wednesday, 17 May 2023

MISS UNDERSTOOD

Before marriage, most people didn't 'get' me
Thinking I was different due to my daunting CP
But after meeting Yisroel, my soulmate became
As I was his Mrs. Miss Understood, I'd not be again
On the rollercoaster of life, we shared the ride
By osmosis, he became my teacher and guide
His manner behooved me to mature and rise
Enabling me to cast off my natural disguise
Now I am misunderstood in the word's most total sense
This increases my longing for his counsel to be intense
But I still am guided by his empathy and perception
This indeed magnifies for me our continual connection
When feelings of bewilderment with others, I discern
It brings to the forefront Yisroel's uncanny concern
Adding to the reasons why to marry him, I made the choice
For it was his comprehension and insight that gave me a voice

©Nechumelle Jacobs



A Teacher Reflects Through Song

Hindy Mann

Yisroel has Cerebral Palsy and is nonverbal, yet he is full of life and personality and loves to learn. Yisroel uses an eye gaze device known as a Tobii to communicate. The Tobii is limited in how much one can express with it. Words and phrases are pre-programmed into it for the user to communicate.

I was privileged to be Yisroel's para at SCHI school in Lakewood, NJ, for five years. We spent a lot of our time together working with the Tobii. He learned to use the keyboard and can now type complete sentences to tell what he wants or needs or just to schmooze!

When I began working with him, Yisroel already knew the sounds of the alphabet. He learned the letters and their sounds in school using many visual and tactile aids. For example, his teacher would direct him to move his hands over a model of the letter to feel and become familiar with its shape or find the letter buried in the sand. After mastering letters and their sounds, Yisroel learned to blend combinations. Once he grasped these skills, his ability to communicate skyrocketed. The next step was to teach him to recognize words. I wrote words, drew corresponding pictures on a dry-erase board, and asked him to touch the word I called out. Eventually, I erased the images, and Yisroel learned to identify the words without the picture cues. Pretty soon, he was reading!

At that point, his sense of humor became evident in his typing. I recognized his intelligence and wit when he abbreviated words, for example, typing OJ instead of orange juice! We even created a book with all the amusing things he expressed while I was teaching him.

I worked with Yisroel from when he was eight until his bar mitzvah, and we developed a strong bond. After my third year with him, I got married, and he was concerned that I wouldn't be his teacher the following year. Soon after our wedding, I took my husband to meet him.

'Tell my husband how many times I told you I'm not leaving.' I prompted. With a twinkle in his eyes, he typed '100'. I reminded Yisroel that we discussed it was OK to feel two emotions at the same time. We can be both happy and sad that I was married. Yisroel liked that idea very much.

I wrote some lyrics to a song when Yisroel was younger and thought I would present it to him at the end of our time together, but I continued as his para for a few more years. I completed the song in time for his bar mitzvah. We figured out the Gematria of his full name equaled the same Gematria of the phrase אני עובד ד' בשמחה תמיד, and included those words in the lyrics.

Yisroel had a 'Corona bar mitzvah,' and it was beautiful. One room in the school was decorated for the event, and delicious food was set out. There was even a big, beautiful cake with Yisroel's picture. Yisroel delivered a speech using his Tobii device, a short Dvar Torah, and personal thanks to his family and teachers. We also compiled a booklet of letters from friends and acquaintances wishing him Mazal Tov. At the end of the party, we all watched a slideshow, a compilation of pictures of Yisroel from when he was a baby until his bar mitzvah day, using the song I composed for the soundtrack. I heard the melody for the song at a choir performance many years ago. My husband has a good singing voice and recorded the song in the school's music studio. The whole presentation was beautiful and very moving. The song tells us that every child wants his voice heard; even though someone else's voice may sound different, we should listen. Every person has something to offer, and we must take the time to listen fully, and then we will be open to being inspired by others.

Yisroel's Song

Every child is special, unique in their own way
But there are those who live their life with hidden powers each day
I never uttered a single word exploding in my brain you see
But if you just stop to listen, I talk through my Tobii

I want to be accepted like anyone on the street
Not with disabilities, unsteady on my feet
Some think I'm hard of hearing, but that's not so
I can do almost anything, how I wish they would know

Imagine a floating speech bubble announcing my words
My words and feelings would then be heard
I get closer to Hashem, happiness I see
I am a servant of Hashem- Yisroel Doivy
Ani oved Hashem besimcha tamid

The effort Yisroel Doivy invests just cannot compare
He is determined to reach the goal, he will never despair
When he learns and davens we truly see him shine
As he puts energy into his ruchnius, that's how he uses his time

With endless patience he will try again
He doesn't give up on whatever he does, his focus is on Hashem
We must accept all neshamos, open our hearts and minds.
For you never know a person's value- and what inside you will find!

Entrusted

Esty's Mommy
as told to Bassi Joseph

Everything was so blissfully normal.

We entered the hospital's Labor and Delivery ward on that cool summer night, subconsciously expecting things to continue in the taken-for-granted normal fashion. There was no reason to think otherwise, was there?

If only we knew.

The hours passed uneventfully, my husband dozing off in his chair, while I tried to do the same with no success. I stayed up until the next checkup, around 3:00 AM.

The midwife checked the heartbeat monitor and a sudden frown appeared on her face. "Hmm...", she muttered with concern, "Something doesn't seem right to me..."

We sat up in alarm and the midwife increased the volume on the monitor so we could hear.

We heard heartbeats. Rhythmic heartbeats echo in the silence.

And then... not so rhythmic. Slower, slower, struggling heartbeats... As if the beats were fighting an invisible force, trying to keep up...

Cold fear was an uninvited guest, wrapping its icy fingers around us. It sent the first resounding blow to our rosy illusion of the birth of our child.

"Something is wrong!" the midwife announced. "We'll have to do the delivery right now."

Nothing prepared us for what was coming.

First came a cry from the midwife. "Emergency!" she yelled. "Cord Prolapse! We need an operating room! Call the doctor!"

For some incomprehensible reason, her cries did not speed up the tired nurses who were moving at a snail's pace.

"Call the doctor!" she hollered, again and again. "It's an emergency!!!"

The next few precious minutes passed with no sign of a response from the hospital staff.

"Did you call the doctor?! I TOLD YOU TO CALL THE DOCTOR!!!" the midwife bellowed.

I was scared and confused, and I judged by the expression of hysteria on the midwife's face that something very serious was happening. Meanwhile, my husband was informed that they were taking me to the OR for an emergency C-section.

As it turned out, the doctor was in the middle of performing a different C-section. Twenty long minutes were wasted until an available table in the OR and a doctor were provided. Following the same pattern of negligence, the OR wasn't properly equipped, and the doctor had to yell for everything he needed to perform the C-section.

The minutes were ticking by, and as per Hashem's Master plan, these minutes sealed the fate of our child.

At 4:10 AM, our baby girl was born. She made her entrance into the world without a single wail, her skin an eerie shade of purple. The long minutes of lacking oxygen had left its mark on our precious daughter.

She was put on a respirator right away, and then was transferred by ambulance to a different hospital with a better NICU.

"Your baby is in critical condition!" the hospital staff informed us. "We don't have too much hope for her survival. Be prepared for the worst..."

The words reverberated around my ears as if slashing a knife into my heart. I was feeling awfully dizzy, and my head was spinning terribly with dark thoughts.

Hashem, save our baby. Show us that You are the Ultimate Leader, not these pessimistic doctors...

Upon arriving at the new hospital, the baby suffered seizures and was given medication right away. They placed a Cooling cap on her.

The hospital staff next informed us that for the next three days, we wouldn't know any more details about her survival and diagnosis.

The shock. The pain. It all happened so suddenly. Only a couple of hours before, we had walked into the hospital full of hope and expecting only the best. Now we were completely and totally shattered.

> Cold fear was an uninvited guest, wrapping its icy fingers around us. It sent the first resounding blow to our rosy illusion of the birth of our child.

My husband went to see the baby. It was an unfortunate sight, the damage clearly visible by the way she moved her tiny hands. She was such a pure little baby, yet so many clouds of uncertainty and fear hovered over her...

He left the NICU brokenhearted and made his way to the Ribnitzer Rebbe's zatzal Tzion to find solace in the holy words of the Sefer Tehillim.

My mother too, went to see the baby, and reported that she saw an adorable baby with dark hair." She even took a few sips from a bottle!" she claimed. But after a few days, a feeding tube was placed in her nose.

Three days and one MRI later, the results of all the tests were laid before us in detailed medical terminology, carrying within them the weight of Esty's future.

Cerebral palsy. Damage to the center part of the brain. Severe handicaps are predicted.

"You'd be best off placing her in a home!" a doctor with a heart of stone said to us.

What?! Our Esty... in a home?! No way!!!

After three weeks, Esty was transferred to Blythedale Rehabilitation Center. Our poor baby didn't stop crying, her every cry piercing my motherly heart. Why are you crying like this, my princess? Are you in pain? Perhaps it's your lofty soul protesting to be thrown down into this world of falsehoods...

To eventually bring her home, I had to be taught in detail to manage the NG tube, and we had to arrange homecare nursing. That was a story in and of itself.

Following three more painstakingly long weeks, Esty finally came home. Her siblings met her for the first time, and we were plunged into a stormy sea, trying desperately to stay afloat. Esty cried 20 hours a day and kept on vomiting. We ran around in circles from doctor to doctor, arranging every therapy and vitamin available, arranging, and rearranging visiting nurses, and trying to get help from agencies, but all to no avail.

When Esti's NG tube was replaced with a feeding tube in her stomach, at 7 months, her beautiful face was finally clear, and her special light shone forth. She was adorable!

Through Hashem's immense kindness, we reached the Kapayim organization, and spoke to the most wonderful messenger, Yitty Mendelowitz תחי׳. She connected us to all kinds of government services and help. May Hashem bless her with all the brachos We are forever grateful to her.

Since Esty was out of the house for many hours during the day for therapy and appointments, we switched the day nurse to a night nurse to be with her and give us some desperately needed sleep.

We were blessed to see the most beautiful side of Klal Yisroel. Many girls and women gave their time and effort so graciously and volunteered to take Esty out for walks, giving us a break to recharge our batteries. They even occasionally took Esty for Shabbosim.

Time and time again we would be privileged to witness a lovely scene as the selfless volunteers "fought" over the privilege of taking out our Esty...

Who would've believed...

Esty is now Baruch Hashem turning six and is a gorgeous, happy little girl. Our Esty, the baby who was given a low chance of survival at birth, now lights up our home with her radiant smile...

She isn't verbal but understands when you talk to her. She'll listen, and respond with smiles, with waving her hands, and sometimes even with a hum of "m...m...m..." that expresses her love and appreciation for her dear family and friends. On the weekdays, she uses a communication device that enables her to express herself.

Esty's siblings totally adore her! They are all aware of the fact that Esty is a special heileige neshama and that we were chosen by Hashem as the best people to raise her. When we take her out on Shabbos, everyone helps to get her ready and pushes her in her special stroller.

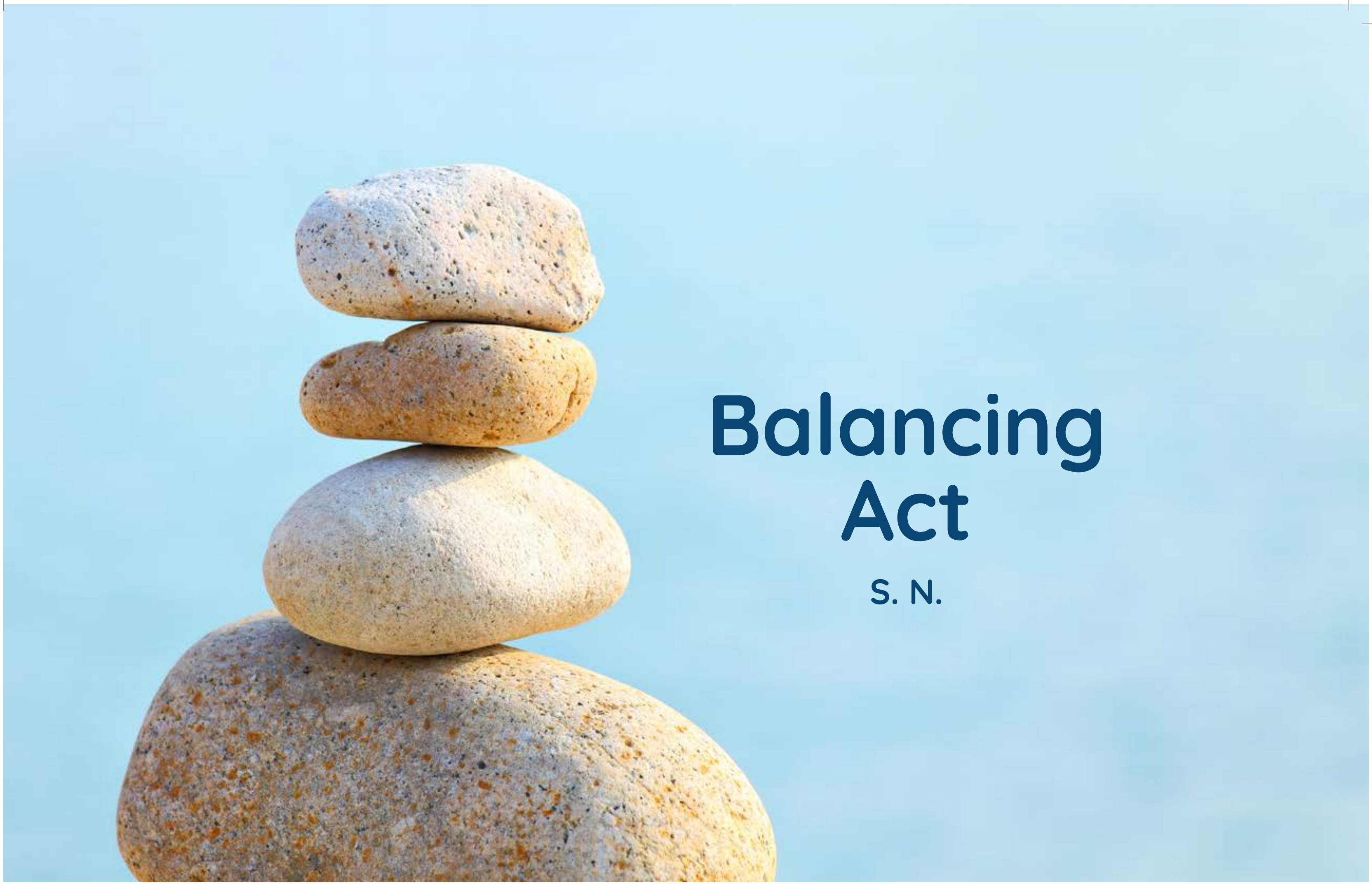
The HAMASPIK outings are special highlights for our children, rewarding them for the effort they put in to help us out with Esty. But most of all, the realization that nothing should be taken for granted is what truly makes our children so grateful. How can we ever thank Hashem for granting us so many healthy children, who naturally learn and grow and talk and laugh and eat all on their own?

While others choose to focus on that half-full cup, we view it as a cup filled half with water and half with oxygen. We always try to look at the positive in life.

Thank You, thank You, Hashem, the Father of our dear Esty, the Father of us all, of so many special families with special children.

You planned this journey for us, but You never left us alone. You walk alongside us, illuminating the way, and providing for our every need.

And one day, the big day when we'll all arrive at our destination and bask in Hashem's glory., we'll be at the front of the line... with our special Esty leading the way! ●



Balancing Act

S. N.

Cerebral Palsy comes with a lot of challenges; a common one is compromised balance.

SN shares a lesson she learned in balancing her attitude while losing her balance on stage.

Do you know how super careful someone with CP has to be throughout the day?

Last year our school held an exhibit, and each class took part in the presentation. My class was chosen to perform on stage in front of the whole school. We were so excited!

On exhibit day, my classroom was noisy and hectic as we all got ready and dressed in our costumes. Eventually, we all quieted down and made our way onto the stage.

I was so focused on my part that I made one wrong move and was flat on my face in the middle of the stage! There were shouts of 'What happened?', 'Is anyone hurt?', 'Call Hatzolah!' The whole performance came to a standstill!

A lot of blood was coming from a big hole in my chin. My teacher held a gauze to my chin to stop the bleeding, but it didn't help, and I needed medical care. The doctor could not stitch the cut then, so she bandaged it well and told me to come back later.

I returned to school, but my chin hurt so much that I couldn't perform my part. Later when the doctor reexamined the cut, I got scared when she said I might need surgery. Thankfully I didn't and just got a lot of stitches.

I started my day thinking about the play and was so excited to perform. Then I was scared I would need surgery. My day ended with stitches on my chin covered in a big bandage.

This experience taught me I don't have to worry or be scared. Hashem watches over us, even when we are not careful, and He knows what will happen every minute of our day. We do not have to ever be worried! ●

> "Falling down is an accident.
> Staying down is a choice."

STAND UNDER MY UMBRELLA

Malky Haimoff

Cerebral Palsy is an umbrella term for neurological disorders affecting movement, posture, etc. It is usually recognized as a life-long physical disability resulting from an injury to the developing brain.

The way CP affects the body differs for each person, ranging from mild to profound delay. For example, one child may have mild leg tightness or weakness in one hand, making tasks like riding a bicycle or writing with a pencil challenging. Another child may have profound muscle weakness and severe spasticity (abnormal muscle tightness), causing the inability to control movement or produce speech.

The multitude of presentations that come along with CP often lead people to refer to CP as an 'umbrella diagnosis', thus each experience with CP can be completely different than the other.

Of course, CP affects more than the child with the diagnosis. It is managed by the child's parents, who must wade through the sea of information about treatments, therapies, and equipment they hope will enable their child to overcome his or her challenges. There are many, many options, and trying everything at every stage of a child's development is impossible. Parents should not feel they didn't do enough for their child if they discover a new therapy that is out of reach due to expense, location, or time. There is no exact recipe for our children's success. Showering them with love and encouragement, along with healthy amounts of experimenting with different activities can go much further than exhausting them with constant therapies and not letting them experience their childhood.

> **There are many, many options, and trying everything at every stage of a child's development is impossible.**

As a parent of a teenager with CP who has had success from some treatments and no results from others, even regression at times; I wish I had the perfect advice for parents of newly diagnosed babies or younger children hoping to achieve the maximum amount of mobility for their children. I don't. Every child is different.

But here are some things that I have found helpful over the years in trying to manage life with CP:

ROUTINE

One of the most important things is to manage everyday tasks in a way that makes them less disruptive. Establishing a routine helps. Although it may take longer to get our children ready for school, following a consistent routine helps the tasks get done more efficiently. The same with bathing or traveling. Thinking through every step in advance and proceeding with intention will help things along without allowing the inevitable glitch to turn into a complete collapse. Inevitably, those days will happen, and having a sense of humor often prevents a complete collapse and minimizes possible trauma.

Remember, routine looks different for everyone. Each child's ability is different, and each family functions differently. It is important to remember that what works for one family may prove disastrous for another. For example, having a home health aide every evening to support the CP child may be essential for one family; others will find it an intrusion of family time, space, and privacy.

ADVICE ON ADLs

Even if your child has a mild or more severe presentation, it is usually helpful to seek the advice of an occupational or physical therapist to review your child's positioning during her ADLs (Activities of Daily Living — e.g., dressing, brushing teeth, eating meals, showering, etc.) Sometimes a minor adjustment in movement or position can greatly improve function. For example, I have been doing stand-pivot transfers with my daughter Michal for years. As she grew, it became more challenging for me to do them repeatedly every day. She had to be transferred from her wheelchair to the toilet, back to the wheelchair, to the toilet, to her chair, to her bed, etc. Recently I sustained a knee injury and needed physical therapy. The therapist and I reviewed the various movements that were causing pain following my injury, and she pointed out that if I turn my knees outward instead of inward when standing up from a low stool, the pain disappears! Keeping my knees slightly crouched and pushing my hips outward as I transferred my daughter also greatly lessened my back pain. Little changes like that have decreased the wear and tear on my body as I care for my daughter.

Small tips from my daughter's OT on how my daughter holds her shirt to make it much easier for her to dress herself. Placing my daughter's homework sheets on a slant board makes her handwriting more legible and gives her the endurance to write for longer periods of time. These small adjustments have given her more independence throughout her day.

SOCIAL PROGRAMS

Thankfully there are a lot of special programs for our special needs children. Not all programs are appropriate for every child, but giving your child a community of peers is helpful, even if he attends a mainstream school and you don't think it necessary. Whether it is Chai Lifeline, Camp Simcha Special or their legendary holiday parties, Camp HASC or Ohel's Camp Kaylie, the Tantzers exciting shows, Kids of Courage ski trips, Friendship Circle events, Dancing With Dreams ballet classes, and so many more options, our children can enjoy many exciting opportunities.

Participating in these special programs can be the social outlet many children need, despite your thoughts about the rest of the population at the event. Even if some of the children in the program may have less functionality, your child can still benefit from the extra attention from the dedicated counselors and the company of other children. It is important to investigate the program or event and consider how it would meet your child's needs before choosing to have them participate in the program.

> **In addition to the time you will reclaim, you will find that your attention is focused on your child's accomplishments and not other people's children**

I used to worry that a mixed population at an event would hurt my daughter's feelings and affect her self-worth. She is a smart and humorous girl. Would attending an event with non-verbal or Down syndrome children make her feel like she is being seen as having the same abilities as them? I learned which programs seemed to put all the children in one room (an inclusive event), perhaps not suitable for my daughter, and which focused on developing relationships with appropriate peers or doting counselors she still keeps in touch with years later.

When my daughter was younger, she didn't care who else was at the event, even as she started to notice the difference in abilities. The counselors made her feel like a million dollars and made the event all about her. I am glad I put aside my concerns and let her enjoy the benefits she was taking away from participating in those programs.

GET OFF SOCIAL MEDIA

There are many resources online and some of the best parent support groups are online. It is good to designate time to go online to check into them and see what new topics these resources cover. I have found the best therapies, doctors, and vacation destinations online from other parent tips. But limiting your time online and putting the phone down once you have checked in is important. You do not need to catch the latest kids' fashion styles or even comment on your nephew's wife's new curtains that she posted on Instagram.

In addition to the time you will reclaim, you will find that your attention is focused on your child's accomplishments and not other people's children. It is great that your friend's daughter successfully rode her new adaptive bike, but don't let that diminish your son's breakthrough in speech therapy by mastering the elusive "r" sound in his own name! While social media has its place as a wonderful resource of helpful information, keep your time on it focused and limited.

There's a lot more where this came from. While I don't have answers, I hope to share more ideas in future issues. ●

בס"ד

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REAL QUESTIONS
REAL ANSWERS

Shoshana Levin, OTR/L

Q Sometimes, my daughter is unaware if I touch her hand when she's not looking. I also see that she drops objects when not looking at the object or her hand. Are the two connected? What is the cause of this problem, and is there anything I can do to help her gain better use of her hands?

A Thank you for your question! Most likely, the two are connected. What you're describing sounds like decreased tactile sensation, which can affect prehension (grip on objects) and motor accuracy. To properly understand the complexities of the sensory systems of someone with CP, we should first analyze our own.

When a child is born, it is inundated with sights, sounds, objects to touch, smells, etc. A baby is cradled, recognizes the smell of its mother, and differentiates the sounds of familiar and unfamiliar voices. As time passes, the brain learns to make sense of the world via the five external senses of sight, sound, touch, smell, and taste.

Additionally, two more senses are crucial in a child's early development: the vestibular and proprioceptive systems. The vestibular system originates in the inner ear and is responsible for the feeling of knowing where one is in space. Imagine being spun on a swivel chair with your eyes closed. You know you are moving even though you can't see.

The proprioceptive system gives our muscles and joints information about where they are in relation to each other. When one hand moves, the other instinctively recognizes its location and moves accordingly, depending on the task.

As a child grows and develops, these systems become more complex and nuanced with time and experience. When a baby can engage with its environment via movement and is provided with rich sensory experiences, the brain learns to adapt, and neural pathways develop. A young baby can hold a rattle, but as he develops his proprioceptive, visual, and tactile systems, he expands his skills and can then reach for and hold a large Lego piece. The motor and sensory systems are constantly working in tandem to accomplish tasks. Every person has their own unique sensory profile and way of experiencing the world.

When a child lacks early-life sensory-rich experiences; their sensory cortex does not develop as a typical child's would. Possible early hospitalizations, difficulty with movement, etc., may have impacted a child's ability to explore its environment in early life. Depending on the individual's unique sensory profile, a child with sensory processing or modulation difficulties may present as hyporesponsive, hyperresponsive, or sensory seeking. Additionally, some children may present as under or over-responsive in response to various stimuli, whether sound, smell, tactile, etc. A child may, for example, avoid low-frequency sounds, demonstrating auditory over responsiveness, yet may not be aware of light tactile input, displaying tactile under responsiveness.

Individuals with cerebral palsy will likely have sensory processing difficulties for two reasons. Firstly, 45% of children with CP present with white matter lesions, which can impact some sensory centers in the brain, specifically the cortical and thalamic regions. Secondly, neuromuscular deficits impact movement and the body's ability to learn about the sensory world via experience. This can help to understand the root of some behaviors and treat underlying sensory concerns.

It is, therefore, important that your child's occupational therapist establish a sensory profile with the information provided by you and by observing the child.

Fortunately, therapists have a variety of interventions and activities available which can help your child to deal with and work on sensory processing difficulties. The area you mention relates to tactile (light touch) and proprioceptive input. These two systems often work together to determine how much muscle force is required for functional tasks. For example, when picking up a spoon, they make a split-second decision to determine how heavy it might be, touch it, hold it in their hand, and adjust their muscle force. When a child drops a spoon after picking it up, this indicates that their ability to assess the force required is impaired or they don't have the required muscle strength to maintain their grip. Deep pressure input via massage is one intervention that brings awareness to the receptors about where they are in space. Vibratory input is also effective as it quickly brings information and awareness to the body. Over time, it can help a child to feel where their joints are in relation to one another and can assist them to complete their activities of daily living more easily.

I hope this helps!
Shoshana Levin, OTR/L ●

Do you have a question for Shoshana?
Email: cpuumagazine@gmail.com or
Call: 347-920-0771

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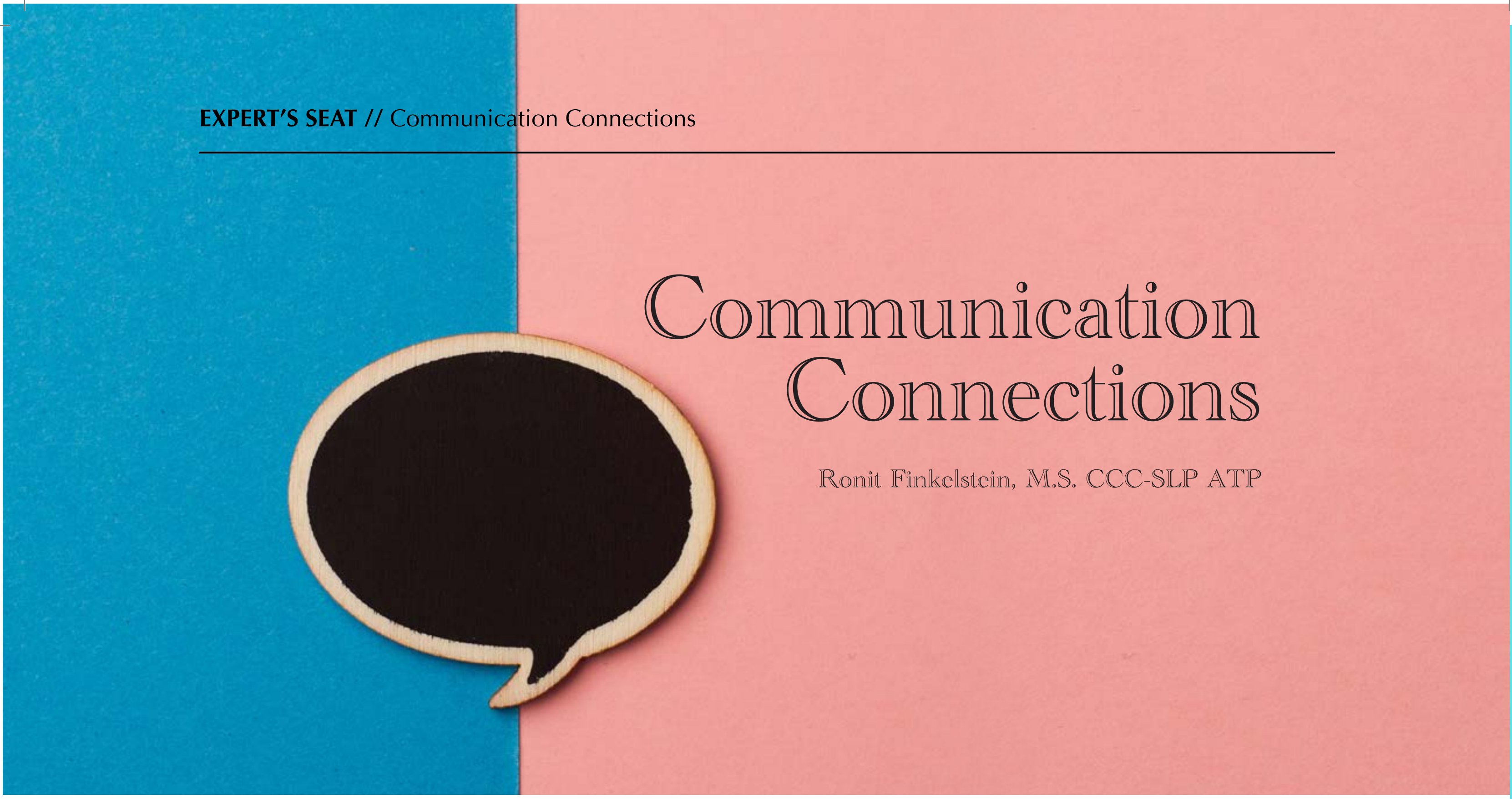

Communication Connections

Ronit Finkelstein, M.S. CCC-SLP ATP

Can you still picture the sibling pounding on the bathroom door or leaving your dentist with a "Novocain mouth"? We left off talking about how frustrating it can be for someone with so much they want to say, but no one understands them. Similarly, what if a person knew that what they wanted to say was not actually what was verbalized (think of a mother trying to get her child's attention who calls every name in the family except for the child she wants)? Finally, picture yourself in a foreign country trying to order something to eat when you don't speak the language. You might consider the following scenario to help you decide which of these would be the most frustrating.

You have just purchased a new communication device, and the manufacturer has entered you in their raffle. To your delight, you win the grand prize, which allows you and a person of your choice to eat at the most expensive restaurant in the city with no limit on what you can order. On the big night, you spend time choosing the right outfit, making sure all your accessories match, and salivating over the thought of all the foods you are about to order and enjoy.

You enter the restaurant, and the maître d' comes running over, stating how excited they are to have you as their guest. You are told that you can order anything and everything that interests you free of charge.

Sitting at the table, you look at the people around you to understand what to order. You see creamy soups, dainty hors d'oeuvres, juicy steaks, and mouthwatering desserts. You take out your communication device, which a well-meaning person programmed for you, and get ready to order all your heart desires; however, the only things programmed are French fries, sweet potatoes, and couscous. The waitress asks you if you are sure that is all you want. Inside your head, you are screaming, NO! I want steak, chocolate mousse, and tiramisu, I have no way to ask for it.

Should all options have been programmed into the device? This question highlights a debate I often come across. Some people feel that 'less is more' which translates to providing an individual with larger buttons or icons, thereby limiting the number of words available so that it is easier for them to find the words they regularly use to make requests. There are some arguments to support that view. However, as we can see from the example of the above vignette, the individual becomes very restricted in communicating. The opposite point of view is to provide smaller icons. Allowing for a large vocabulary base. Some people argue that this makes each symbol harder to find. That may be true, but as we saw in the above scenario, having more words would have transformed the evening into a special, memorable one rather than an exercise in frustration.

Even with more options on a page, there is still the possibility that the right words are not at the right time. Therefore, it is critical to ensure that both the number of words and the type of words are programmed to facilitate communication across all settings. But you'll have to wait until next time for that discussion.

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Proper Alignment

Shaindy Silber, PT, DPT

Why physical therapists are obsessed with alignment and why you should be, too.

Let's start with a little exercise together. Drop your head all the way down until your chin almost touches your chest. This is how so many of our children without head control sit. Now try to swallow. Pretty difficult. Now try to tilt your head all the way back with your chin tipped upward. This is how so many of our CP children lean against their headrests. Try to swallow again, this is not much better. We can clearly feel how we need our heads in proper alignment to be able to swallow correctly for safe feeding and to create effective vocalizations. Postural alignment refers to how our head, shoulders, trunk, hips, knees, and ankles all line up with each other in an optimal manner. The alignment of our muscles and bones decreases strain on bones and soft tissue. It is crucial in setting up our bodies for efficient movement patterns. Ideal alignment helps to prevent muscle tightening, joint contractures, or lengthening of muscles and subsequent weakness, all of which can lead to further complications.

Individuals with cerebral palsy frequently have a combination of muscle imbalances, weakness, and spasticity, which can create a predisposition to poor postural alignment if not properly managed preemptively. Let's imagine for a moment a rubber band holding together five or six pens. Let's replace those pens with 12 jumbo markers and leave them there for three days. When we remove the rubber band, it's all stretched out and won't 'hold together' those same original five pens anymore. Now let's think of the muscles in the back of the neck, which are supposed to contract like those rubber bands to hold your head up. If we let our heads hang down for several days, can we envision how those muscles will get overstretched and weak? How can we expect those 'rubber bands' to hold up our heads now again? On the flip side, if a muscle is in the shortened position for a very long time, it will tighten up, and we won't be able to straighten that limb as it is supposed to. Poor alignment can exacerbate muscle imbalances, leading to further tightening or lengthening of muscles. It can result in later discomfort, pain, and difficulty with movement and quality of life. This, in turn, can make dressing or bathing difficult as the child grows. It can also lead to secondary deformities, such as scoliosis, hip dislocations, severely pronated feet, or feet fixed in a tiptoe position. Even if a child is in a wheelchair, where it may not be feasible for him to achieve independent standing and walking, being in a stander or engaging in a tummy time program to facilitate change in position can be very important. This will ensure the maintenance of a joint range of motion and increase the ease of daily living skills for a caregiver. Activities like dressing, cleaning, and bathing will become less taxing if the child's limbs are easier to move. Proper alignments can even assist with body functions such as respiration, circulation, and bathroom needs.

Additionally, changes to one joint will not occur in a vacuum and will affect the alignment of other joints. For example, try to raise your arm in front of you overhead when your head is dropped down. You can't go very high. Your arm can go straight up once you straighten your head back up! We can clearly see how functional reaching would be affected in this scenario. Our kids are amazing and determined. When the range is affected, they will find another strategy or compensatory movement pattern to utilize, and over time inappropriate and inefficient motor patterns will be learned. These can be difficult to change and may lead to further imbalance, tightening, and discomfort over time.

> **Ideal alignment helps to prevent muscle tightening, joint contractures, or lengthening of muscles and subsequent weakness**

What is the solution? How do we manage imbalances and help to prevent further tightening? Better yet, how do we improve range and length when tightness exists?

Physical therapy is usually recommended for people with cerebral palsy to help manage posture and alignment. A physical therapist can collaborate with the family, caregivers, and the individual to customize an exercise regimen to strengthen weak muscles, improve flexibility and range of motion, and reduce spasticity. Physical therapists can also teach strategies for maintaining good posture throughout the day with equipment as needed. Devices such as braces or orthotics may be recommended to help support proper alignment in the legs or trunk. This will help stabilize the joints, prevent muscle imbalances as the child grows, and provide external support in a weight-bearing position in which the child may not be able to weight-bear without bracing. Let's look at the example of a child who can maintain a midline or symmetrical alignment when they are on their back. When they sit up, the demands on their musculoskeletal system are too great for them. This can cause their trunk to flex toward one side, or they may be unable to hold their head up. Over time sitting like this will cause further asymmetrical tightening or lengthening and, thereby, further weakness, which will become exacerbated as gravity takes its toll. We must determine how to maintain neutral alignment and head control in every position. That may be accomplished with the use of a TLSO (trunk brace), a head pod (ask your PT about this), or adaptive seating equipment that provides increased support (there is a vast array of seating available, from just a little bit of extra support to maximal accessories on the chair that can be added until optimal alignment is attained).

While not all obsessions are healthy, our obsession with alignment is one we won't give up any time soon! We are determined to maintain as optimal alignment as we can! This will prevent muscle tightening or lengthening, provide long-term comfort, make dressing and bathing easier, and set our children up for optimal movement patterns to impact the future progression of motor skills. Physical therapy, assistive devices, orthotics, positioning aids, chairs, standers, and appropriate supportive walkers can all be utilized with appropriate guidance to help maintain muscle balance and maximize comfort and motor development. Even if your child is older and you feel alignment issues may be too late to tackle, reach out to your orthopedist, physiatrist, or treating PT or OT so your team can work together. Always remember that you are making the best decisions with the knowledge you have when you make them. There are so many things to juggle and decisions and choices to make and prioritize. Whatever choices were made and continue to be made for your child, your family, and you are the right ones. This information is meant to empower you with knowledge and tools and give you information to 'stow away' to broach to your team of providers and caregivers at the right time. ●

Shaindy Silber, PT, DPT, is a licensed Physical Therapist in New York State and has been specializing in the pediatric population for over 15 years. She uses hands-on facilitation skills in conjunction with electrical stimulation, taping and/or aquatic programs in her practice and works closely with families and caregivers to maximize carryover and enhance outcomes.

Questions or comments on this article, or do you have a particular request for future publications? Email CPUUmagazine@gmail.com, and they will be forwarded.

EXERCISE IS THE BEST PREVENTIVE MEDICINE

Edward A. Hurvitz, MD

Exercise is important for everybody and is an important part of a healthy lifestyle. Exercise helps keep us functional, improves endurance, decreases body fat, and strengthens our muscles. It is also a positive activity that can be enjoyed in a group. These benefits are significant for people with disabilities such as cerebral palsy. In one form or another, exercise is the most important part of the overall care of individuals with cerebral palsy, from birth through adulthood.

Children with cerebral palsy have difficulty controlling movement, weakness, coordination, and tight muscles and joints. As they grow, the tightness worsens due to the bones outgrowing the muscles, and they develop contractures (tightness of the joints). Physical therapy is the cornerstone treatment for these problems, along with other treatments such as medications and surgeries. However, one of the most important things a family and care team can do is help the child develop a lifelong exercise pattern. These exercises help prevent tightness and contractures from worsening and contribute to early functional loss, pain, fatigue, and other medical problems in adulthood. Adults with cerebral palsy face particular challenges related to having a high risk of chronic disease. Studies have shown that adults with cerebral palsy are at increased risk of heart disease, lung disease, high blood pressure, and kidney disease. They are also at higher risk of fractures, and having a fracture puts them at an even higher risk of these diseases. Adults with cerebral palsy frequently complain of fatigue and pain. Those who can walk will start losing the ability to walk early in adulthood. Those affected on both sides of the body will start to notice a loss of walking function in their 30s, and if one side of the body is affected, they will notice this in their 50s. It is suspected that a significant factor in these problems are poor fitness levels, including low aerobic fitness, poor strength and flexibility, and poor coordination.

So where to start? While exercise is important, the first step is to sit less. Studies show that people with cerebral palsy sit more than people who do not have cerebral palsy—that is, they have higher amounts of sedentary behavior. The more difficulty the person has with movement, the less active and sedentary they are. For those who can stand by themselves, it is important to work on standing more, walking more, and just sitting less. For those who need help, standing devices can be used to encourage regular standing. Standing is good for the bones, muscles, and heart health.

Now that we have discussed standing, it's time to move! There have been many studies regarding exercise in children and adults with cerebral palsy, and they all draw the same conclusion: exercise is beneficial. It should be a part of daily life. There was a time when people thought exercise was bad for people with cerebral palsy. They thought that it would make tight, spastic muscles even tighter. Studies have shown that this is incorrect and that a stronger muscle is a less tight muscle. It was also thought that people with cerebral palsy would not benefit from regular exercise, but studies have shown that exercise increases strength and aerobic fitness in cerebral palsy. In addition, while anyone involved in sports and exercise is subject to injury, it has been shown that people with cerebral palsy are not really at increased risk for injury. The important thing is to be careful and use the right equipment. Unfortunately, there has been a lack of information about the best and safest exercise methods for people with disabilities. The good news is that this body of knowledge is growing. One great resource for this is the National Center for Health and Physical Activity for Disability (www.NCHPAD.org).

How should a child with cerebral palsy approach exercise? Children benefit most from movement, and play is the best stimulus for movement. Although PT and exercise programs at home are important, play is the most motivating. Adaptive sports opportunities are growing for children with disabilities. There are organized adaptive sports programs for children in many communities and often in university settings. Adaptive soccer, “Miracle League” baseball, and wheelchair basketball leagues are popular examples. Many individual sports, such as skiing and swimming, have also been adapted for individuals with CP. There are no limits: Kayaks can be adapted, there is even adapted tree climbing, and cycling is very popular. There are several models of three and four-wheel cycles that children power with their feet or arms. The important thing to remember is that any activity is better than no activity, and weight-bearing is healthy. Anything that gets a child moving and, if possible, on their feet is beneficial. General recommendations for children include 60 minutes a day of physical activity, and the same guideline is used for children with disabilities. For children whose CP has greater effects on their mobility, 60 minutes of standing in a standing device may be difficult to achieve, but any time in a stander is better than none at all. For children who are wheelchair users, activities involving the arms can build arm strength, burn calories, and contribute to heart health. Some online programs encourage sitting exercise, which has been shown to be beneficial. Interactive movement-based video games have been researched for use with children with disabilities and have been shown to produce good results.

For adolescents and adults, regular exercise should be part of their lifestyle. Their exercise routine should have the same goals as people without cerebral palsy; to increase aerobic fitness, muscle strength, flexibility, and coordination. Flexibility takes on a special importance for most individuals with cerebral palsy, as their spastic muscles tighten more as they age. A good daily stretching program can be helpful. Many people with cerebral palsy have chronic back pain. They generally have tight hamstring muscles, and stretching these muscles regularly can be helpful.

An article published in 2016 outlined the first exercise guidelines for people with cerebral palsy. (Verschuren, Peterson, Balemans and Hurvitz: Exercise and Physical Activity Recommendations for People with Cerebral Palsy. Developmental Medicine and Child Neurology 2016, 58:798-808). The general guideline for aerobic exercise is to participate in physical activity 2-3 times a week with enough intensity to raise the heart rate; sessions should be at least 20 minutes. Anyone embarking on a new exercise program should start with a period of familiarization, in which they exercise at an even lower intensity for a few weeks to get used to it. Next, they build the intensity to raise the heart rate for 20 minutes. Aerobic exercise can be as simple as walking outside or on a treadmill at whatever speed the person can tolerate and gradually building up to a speed that increases heart rate. Other exercises like swimming, biking, or whatever the person enjoys work well. Adaptive sports are available for adults, too, up to the Paralympics! Even individuals with cerebral palsy who use wheelchairs can find a form of exercise. The NuStep device was designed and built for people with disabilities. Research has demonstrated that wheelchair users can use this device and benefit from exercise.

> **IN ONE FORM OR ANOTHER, EXERCISE IS THE MOST IMPORTANT PART OF THE OVERALL CARE OF INDIVIDUALS WITH CEREBRAL PALSY, FROM BIRTH THROUGH ADULTHOOD**

In addition, individuals with cerebral palsy should perform exercises that increase strength. This can include sit-to-stand exercises, step-ups, using weight machines, or free weights, depending on the person’s ability. To start, the person should do a set of 6-15 repetitions, starting with six and working up to 15, and then rest for 30 seconds. He should then try a second set to complete 3-4 sets each, including 6-15 repetitions of the exercise.

In summary, people with cerebral palsy should develop life-long habits of less sitting and more movement, including exercise. They are at risk of chronic disease and functional loss, and exercise is the best preventive medicine. There are many options for safe and enjoyable exercise. Adaptive sports opportunities are available in many communities for all ages, increasing social opportunities. Exercise is good for the body, mind, and soul. Let’s all start moving more! ●

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Shmully


Gitty

Mordechai

Rivky

Yitzchok

Esty

Ava

Moishy

Sender

Hodaya

Miri

Bracha

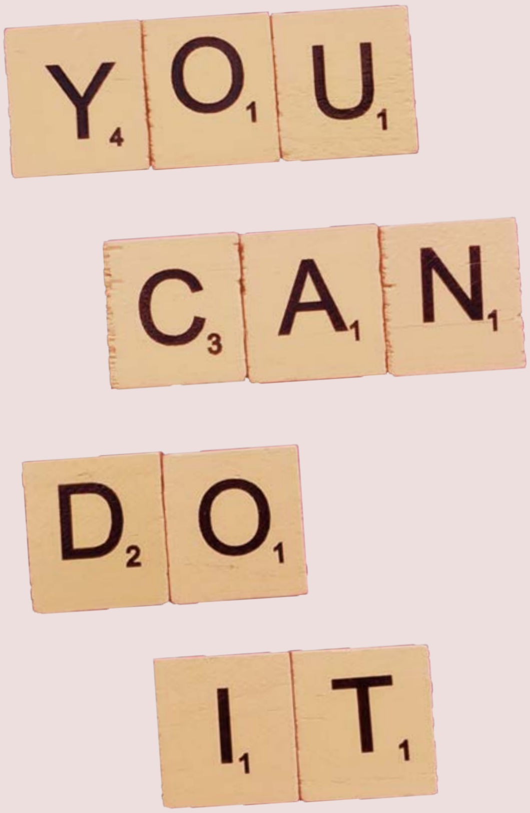
27/08/2023

Tovya

Yossi

CHIZUK BOOST

RABBI HERSHKOWITZ



Parents tirelessly spend days and nights helping their disabled child acquire and achieve various physical and mental advancements. It takes the joint effort of many therapists and volunteers working together toward the same goal to improve motor skills, speech communication, and behavioral markers. After many trials, progress is slowly made and noticed. The achievements are celebrated joyfully, accompanied by satisfaction and success. The sounds "you did it" and "wow, we're so proud of you" are heard when milestones of physical motor skills are attained and accomplished.

Certain activities and accomplishments, however, are not celebrated to that degree. That is because they aren't noticeable to the human eye; we can't measure the significance of these achievements. A human being cannot grasp the great joy that is going on in shamayim when a non-verbal child tries to answer "Amen." We cannot begin to fathom the great effort that the parent puts into her child so that they can point and identify one letter of the "aleph beis."

When a child with limited physical abilities performs a Mitzvah, such as putting on tefillin with the help of others; the amount of effort and determination the parents have endured to reach this major milestone is unbelievable. Parents often must help their child daily with the step-by-step process of putting on his tefillin. We can only try to imagine a tiny drop of the Nachas that Hashem is having as he observes the parents' devotion each day. The effort might not be so noticeable because the child is performing the mitzvah in a seemingly indifferent way. However, the celebration in shamayim is at its highest point each time the parent or caregiver helps the child perform the mitzvah.

There is a well-known story with the Rosh Yeshivah of Telz, Cleveland, Rabbi Mordechai Gifter Zt" l, who was standing in line at a check-in counter at Cleveland International Airport en route to New York. One of his close students had sent nine Cleveland-New York airline tickets along with his wedding invitations. Rabbi Mordechai Gifter and eight students boarded the aircraft and settled into their seats, already seeing themselves wishing mazal tov to the baalei simcha.

But Hashem had other plans. "Attention all passengers, this is your captain speaking. Due to severe snowstorms in New York, JFK Airport, we are being re-routed to Washington, DC." Rabbi Gifter and his eight talmidim spent the long afternoon hours in the Washington airport, while miles away, the wedding of their talmid and friend was celebrated without them.

When the time came to daven Maariv the group looked for a quiet corner where they could daven undisturbed. An airport employee stared at them, seemingly never having seen an Orthodox Jew, and allowed them to use a small storage room. The employee, who was part of the custodial staff, stood silently at the door, watching them intently, a dazed expression on his face. When they had finished and started leaving the room, they were astonished to hear him ask, "Why don't you say Kaddish?" "We need a minyan, that is, ten adult males to say Kaddish," one of the boys explained. "There are nine of us." To their astonishment, the employee responded, "I am a Jew. I will join your group to complete the minyan. Please," he begged, "let me say the Kaddish."

Haltingly, he began reciting Kaddish, stumbling over the unfamiliar Aramaic words. Realizing that his knowledge of the text was virtually non-existent, the group patiently helped him along, word by word, until he had pronounced each word carefully. After saying Kaddish, the man took a deep breath and told them, "I wasn't raised as a practicing Jew and barely knew anything about Judaism. Last night my father came to me in a dream and said, 'You are my only son; you must say Kaddish for my Neshama with a minyan." "How can I say Kaddish?' I cried out, "I barely know how to read the words, and how will I find a minyan?" "I will arrange it for you," he reassured me, and I woke up. "Now here you are, exactly nine of you," continued the worker, his voice full of wonder. "Heaven-sent! Literally! So that I can say Kaddish!"

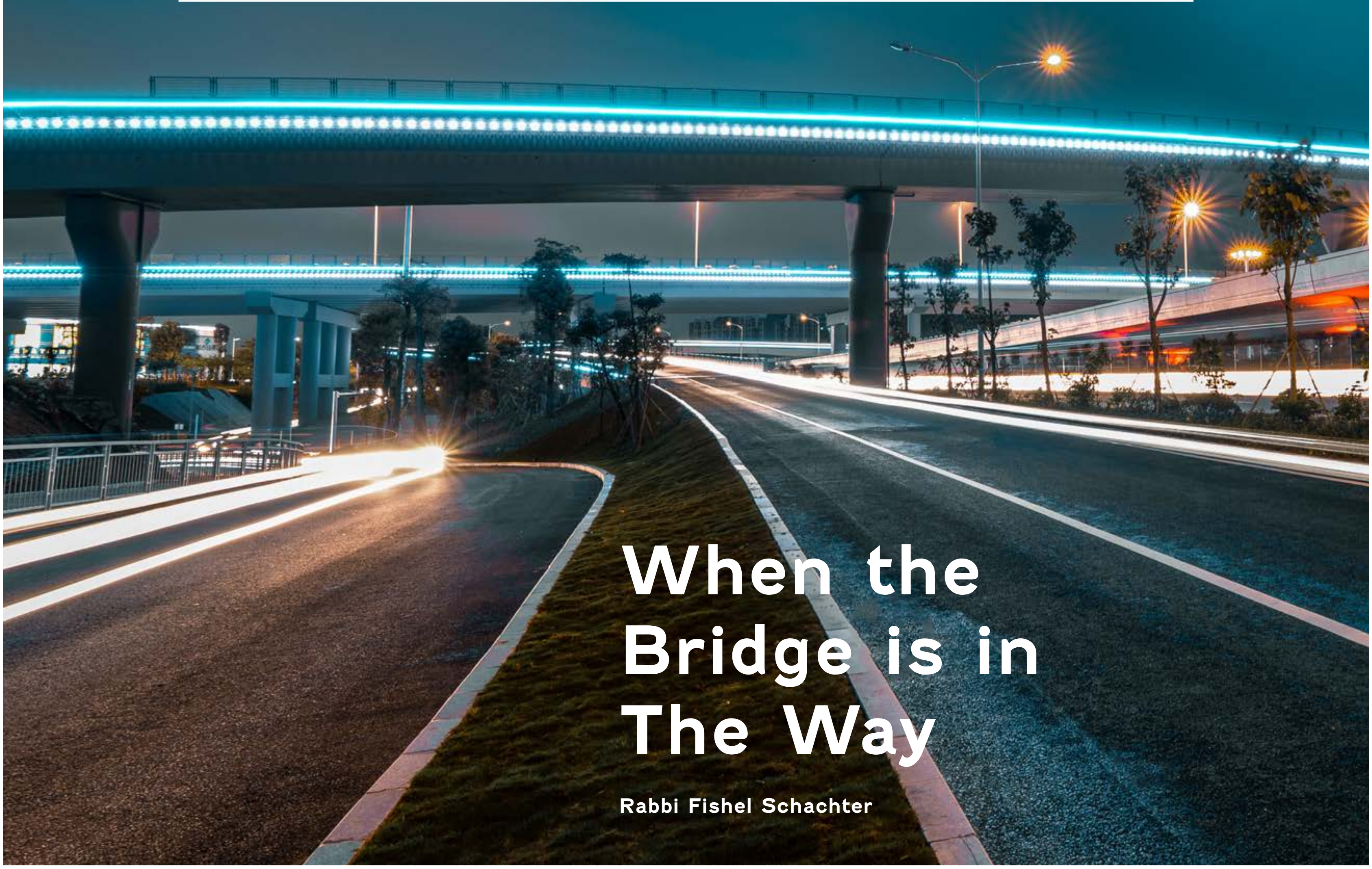
Rabbi Gifter then told him that they were not even planning on traveling to Washington, that their flight was diverted due to bad weather in JFK. "See how Hashem runs the world!" Rabbi Gifter marveled. "See how He orchestrated our meeting together! Nine tickets to travel to a wedding, a raging snowstorm in New York, the airplane's rerouting to Washington National Airport, and missing the wedding. All this so that you can say Kaddish for your father!"

A human being cannot grasp the great joy that is going on in shamayim when a non-verbal child tries to answer "Amen." We cannot begin to fathom the great effort that the parent puts into her child so that they can point and identify one letter of the "aleph beis."

Many years ago, I heard this story from Reb Tzvi Meir Silberberg shlita. His insight into the story and how important it was for Hashem that this airport employee, so far removed from his Jewish heritage, should recite Kaddish. Hashem orchestrated a global event. Hundreds of flights were delayed or canceled. Thousands of people were left stranded in various cities and airports. The huge economic impact because of delays, transfers, and canceled meetings. Hashem did this all so that one kaddish could be said by this son, who did not even understand what he was saying nor the significance of his fumbled words.

Similarly, all the seemingly endless effort put into these precious children so that they can perform any Mitzvah. Even when they have no obligation. It is not in vain. This effort serves a great purpose: Hashem gathering all His Malachim and proudly celebrating his children's dedication to Him despite such great difficulties.

May we be zoche to celebrate and grasp the greatness of our efforts! ●



When the Bridge is in The Way

Rabbi Fishel Schachter

Occasionally, you hear about a tractor-trailer that gets wedged in under an overpass on the FDR Drive, causing massive traffic backups. It usually happens during rush hour when almost every car seems wedged into place on the FDR anyway. Why does it happen? It's simple arithmetic. The truck is 11 feet high, but the height under the overpass is only 10 feet.

They say they once asked a driver who got wedged in, "What were you thinking? A large yellow warning sign is posted on the side beam of the overpass that warns it's only 10 feet high. On your truck's dashboard, there is a clear reminder that your truck is 11 feet high. Of course, you were going to get stuck! What were you thinking?

"I saw the signs," answered the truck driver. "But I didn't see any police, so I thought I could sneak through."

Do you know how the authorities dislodge trucks stuck in the overpass? Imagine needing a crane to lift some of the bridge's floor beams. But there is a far cheaper and more practical solution. They let the air out of the truck's tires. The truck sinks just enough to yank it out.

The Yesod Ha'Avodah of Slonim once told his chasidim that there is a small door between Gehinom and Gan Eden.

"Is it locked?" they asked.

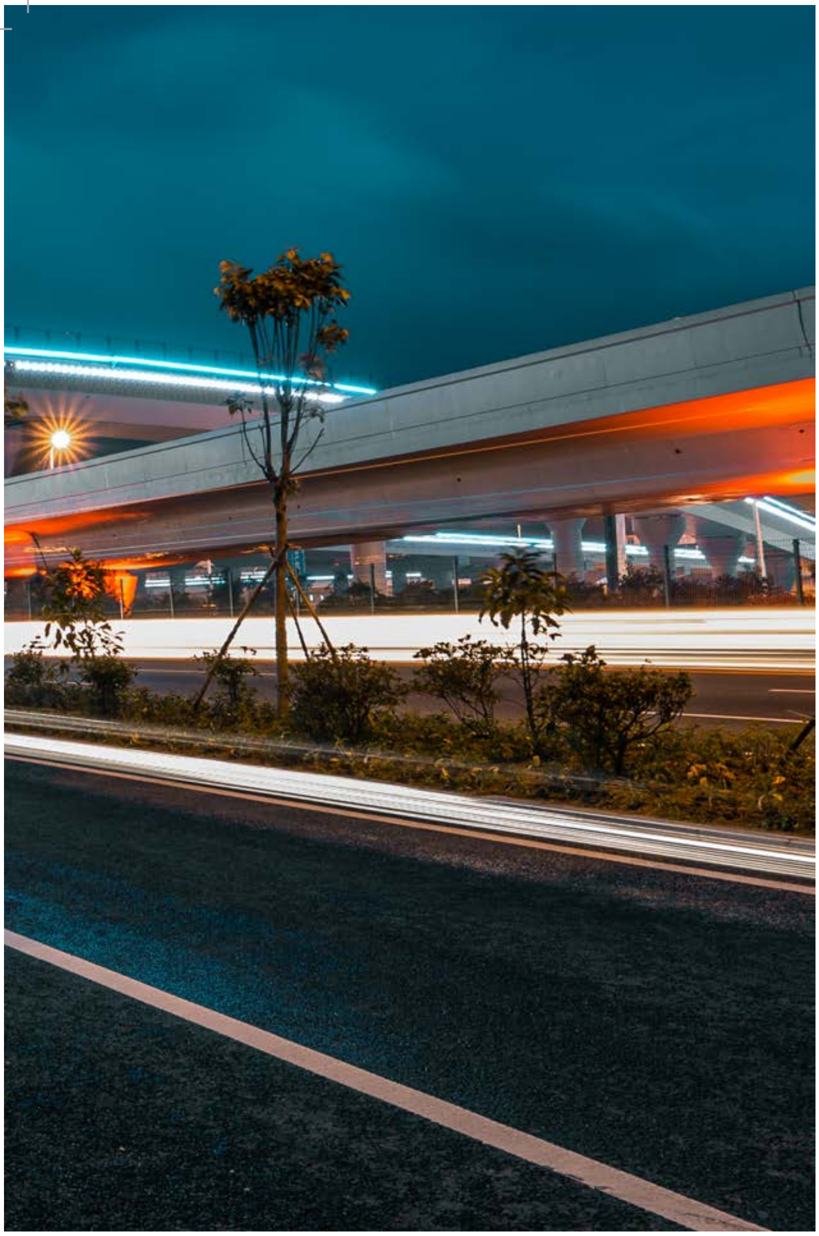
"Absolutely not! It's wide open."

So why don't all the residents in Gehinom just leave?

Because it's a very low door, and you must bend down low to get through it. But if you weren't willing to bend down in this world and bend your will to Hashem's, then you didn't learn to deflate your tires, so to speak. So now, in the next world, you can't bend down to fit through that door, either.

Once we learn to let go and accept our situation because it's the will of Hashem, then we can start making it through the narrow space we thought we were wedged into, and we start seeing the Yad Hashem. We will find Hashem opening the doors high and wide, helping us along the way, and carrying us. Then, we start reaching so much higher and better than we ever imagined.

Many years ago, I had a lively, leibedig bunch of boys



as students. I couldn't let go of the reigns for a moment. A certain organization was running a huge chizuk event for children in a different state, and they asked me to come and tell a story.

(When you address adults, you speak, and you throw in a story. To kids, you tell a story and throw in a speech. Basically, you do the same thing for both. It's just packaged differently.)

"Sorry," I said. "Your affair and its timing won't work out. I am in class then."

Well, saying that was a mistake on my part.

"Really! You're in class then? I have an idea."

"No, you don't understand. I really can't take off class."

"No, no, let me finish. If you can't leave the class for the event, we can bring the event to the class!"

"You can do what? It's really not a big room."

Now this was before the Skype days. So, it took me a while to catch on, but essentially, he suggested setting up a camera in my classroom. I would tell the story to my real live class with a satellite truck parked outside in front of the Yeshiva building. He was sure he could get a sponsor, and I was sure I would faint.

"No, no, it won't work," I insisted.

"Why not? All the people at the event would listen in. Furthermore, they can also see how a class ought to behave wonderfully. For that alone, the whole thing will be worth it."

Every fiber of my being was screaming for a way out of this.

"What if my students don't behave then?"

"Rabbi Schachter, in your class, there are loose moments? I don't believe it."

"Put in the camera tomorrow, and then you will believe it!"

"I am not taking no for an answer."

I tried a different angle. "My menahel would never allow it."

"Ok, if he says no, it's no. But I insist that you ask him."

So, I went into my menahel's office to convince him to say no.

My menahel had his reservations as well. He suggested asking the students themselves. They were thrilled, but I was still looking for a way out.

The event organizer didn't let up, and we eventually acquiesced. Somehow it became clear that this was meant to be, and the final preparations for the simulcast were being implemented.

Included in those preparations was my staunch warning to my students to perform their roles correctly.

"You will sit with smiling faces, your hands folded on the desk, and when the camera zooms in on you, you will look very interested, right?"

"Rebbe," asked a student in a very temimusdig way, "Will you tell us when we can stop acting?"

I wasn't sure what to do with that question.

The big day came, and once again, I literally pleaded with them to stay quiet and let this thing come and go. I promised them all the trips in the world if they behaved and that whoever acted up would lose his recess for at least ten years, or something to that effect.

After the cameras were set up, my menahel put his head through the door and summoned me.

"You know," he said, "I am particularly concerned about Baruch." (Not his real name)

The menahel had good reason to be concerned about Baruch. Baruch was impulsive, had temper issues, and was extremely sensitive. With Baruch around, the chance of a major storm was always in the forecast. In other words, anything could trigger an outburst.

The menahel called Baruch and politely suggested he could send him on an errand during the speech. Baruch chapt the matzav, and his eyes instantly swelled up in tears. He promised to behave, and the errand idea was taken off the table. Baruch returned to his seat, and we hoped for the best.

Now every rebbe and teacher knows that one of the major successes, or lack thereof, in the classroom, depends on his ability to seat the students strategically in the right place. Some kids need to be in the front, while others need a little more space in the back. But maybe even more important than that is deciding who should or shouldn't sit next to whom.

From day one, I knew Baruch should not sit beside Chaim (not his real name). Chaim had a special talent for entertaining himself by wiggling the tip of his tzitizis on his neighbor's ear and to quickly retreating, leaving no footprints. The kid who got his ear tickled would either laugh or accuse the wrong boy, and then it was yom tov.

Chaim had this ongoing mischievous gleam in his eye. Although he had kept his promise not to pull pranks with his tzitzis anymore, he was very innovative and kept coming up with fresh ideas.

> **What, when, where, how, and why are irrelevant to me here. I believe that you saw to it to put me here. I trust you, and please help me calm my nerves and guide me. I will do my best for my part.**

Now, you know how sometimes the camera and lighting people can be a little assertive and take over the chasuna? The camera person setting up in the classroom had his own ideas of who should sit next to whom based on how tall or short the kid was. Coordinating personalities was not a factor for him. So as hashgacha would have it, I realized too late that Chaim and Baruch were fellow row-mates.

The kids behaved beautifully for the first 20 minutes. But my assignment was to stretch this for 40 minutes. The last 10 minutes were designated for the mussar haskel to set the stage for the next speaker.

Getting kids to listen to the mussar after a story is always a tall order. I knew this was going to be a challenge when out of the corner of my eye, I noticed that Chaim had had enough. He pulled out an orange from his school bag and began to peel it.

I must have given them a list of a thousand things not to do. But I never set any restrictions on eating oranges. I should remember this for next time. When Chaim finished eating his orange I noticed a super bored look on his face that made me very nervous. I knew that Chaim didn't stay bored for long. He started playing with the orange peel until he perfected the art of squirting whatever moisture was in it on his classmates.

It wasn't long before a beeline squirt hit its target: Baruch's face. Baruch spun around, prepared to respond. I couldn't say anything because this was a live broadcast, and I was in the middle of a shiur. Maybe I could weave it into my storyline or concluding bracha, something like, "And may Hashem help that we should never be squirted on and be zocheh to the Geulah sheleima." But by then, it would be too late.

Just as Chaim was about to explode and the camera was facing the back of the room, I made eye contact with both Baruch and Chaim. With my eyes, I basically said as follows. Baruch and Chaim! At this moment, I can't tell you or order you to stop. But I need you to help me.

It was a humbling moment.

I don't know what they read in my eyes, but they nodded, and I knew the crisis was over.

Even though it meant going against his nature, Baruch pushed his feelings of revenge aside to do the will of his rebbe until the broadcast ended. Sitting quietly, he performed his best with great difficulty.

I can't begin to describe what a great year that turned into. Baruch and Chaim really matured and shteiged away. I had endless patience with them because I knew I owed them. I knew their respective personalities and what it had taken for them to hold off.

I keep thinking of Baruch's story when I hit rough waters. It gives me hope that the most frustrating times can lead to the most precious.

The Bal Shem Tov explains that the greatest avodah of a yid, as well as his best hope for a yeshuah lies in the words ממצוקותיהם יצילם.

There is no prouder moment in Shamayim than when a person says, "Rebono Shel Olam! I don't have to understand my matzav. I must believe that you put me here. You created me as I am.

"What, when, where, how, and why is irrelevant here. I believe that you saw to it to put me here. I trust you, and please help me calm my nerves and guide me. I will do my best for my part."

ממצוקותיהם --by recognizing that their pressures and difficulties are from Hashem.

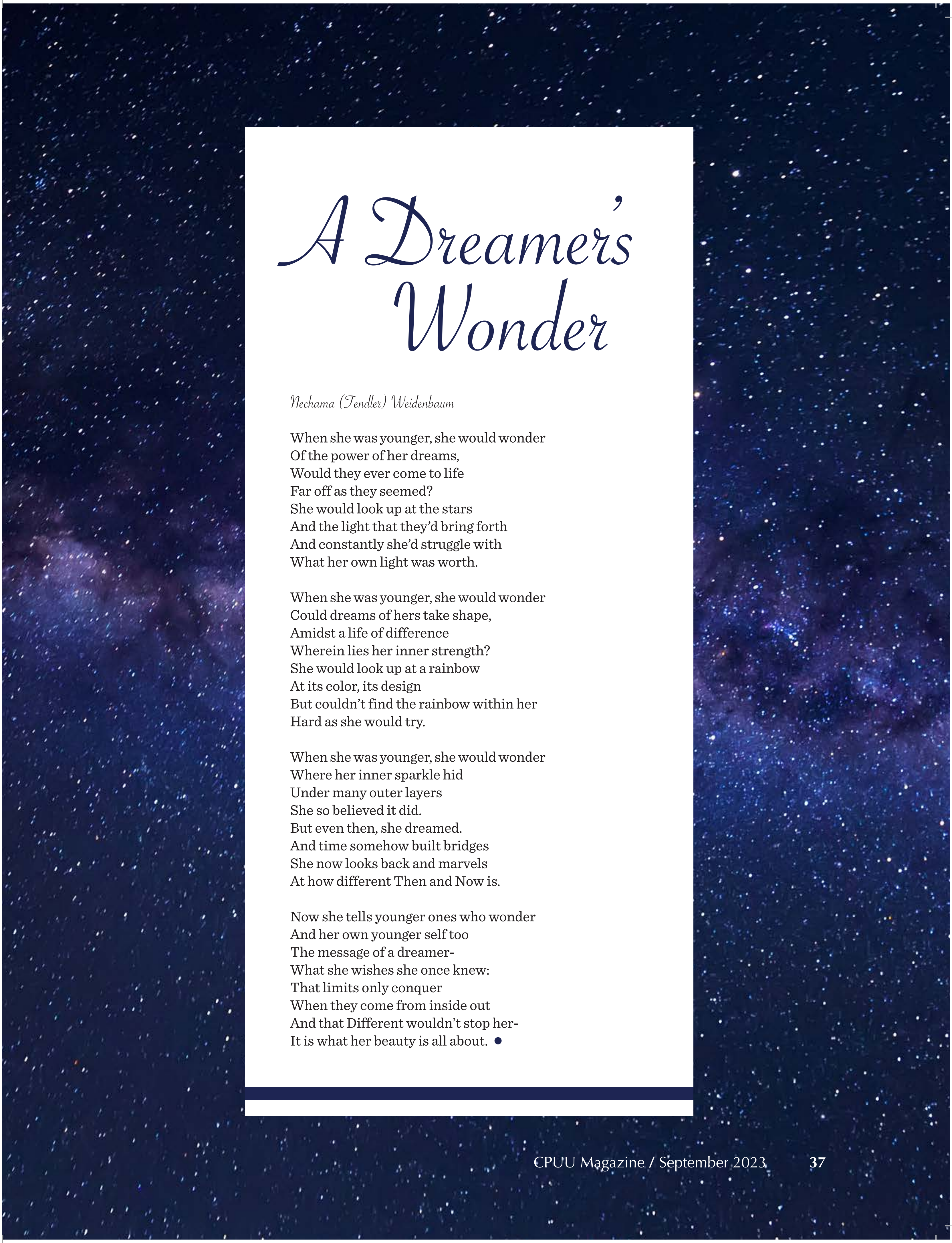
יצילם that alone will save them.

Every Malach in the universe above plotzes with jealousy when Hashem says, "Look at my children. I know exactly what they are going through, and they still believe I put them there."

There are times on life's highway when we wish all blocks would be lifted and all roads opened wide. When the path remains tight, we try to squeeze through but get wedged in.

But if we look (easier said than done) for the moment, we can take a graceful bow, then Hashem can show us that the bridge isn't in the way.

If only we could emulate Baruch. ●



A Dreamer's Wonder

Nechama (Tendler) Weidenbaum

When she was younger, she would wonder
Of the power of her dreams,
Would they ever come to life
Far off as they seemed?
She would look up at the stars
And the light that they'd bring forth
And constantly she'd struggle with
What her own light was worth.

When she was younger, she would wonder
Could dreams of hers take shape,
Amidst a life of difference
Wherein lies her inner strength?
She would look up at a rainbow
At its color, its design
But couldn't find the rainbow within her
Hard as she would try.

When she was younger, she would wonder
Where her inner sparkle hid
Under many outer layers
She so believed it did.
But even then, she dreamed.
And time somehow built bridges
She now looks back and marvels
At how different Then and Now is.

Now she tells younger ones who wonder
And her own younger self too
The message of a dreamer-
What she wishes she once knew:
That limits only conquer
When they come from inside out
And that Different wouldn't stop her-
It is what her beauty is all about. ●

Your Take

7 Word Responses

In the previous issue of CPUU, we asked readers to describe, in seven words, what life with CP has taught them.

Her shining smile makes my heart sing.
-Anonymous

|||||||

Rivky brought genuine joy into our home!
-Rivky's Family

|||||||

I definitely gain more than I give.
-T.Y.

|||||||

Leave it to Hashem; it'll be OK.
-Nechumelle Jacobs

|||||||

When roads get bumpy, enjoy the adventure.
-Anonymous

How to dance in the wet rain.
-Blimie T.

|||||||

There's more to people than you think.
-Ruchma Beily Lipschitz

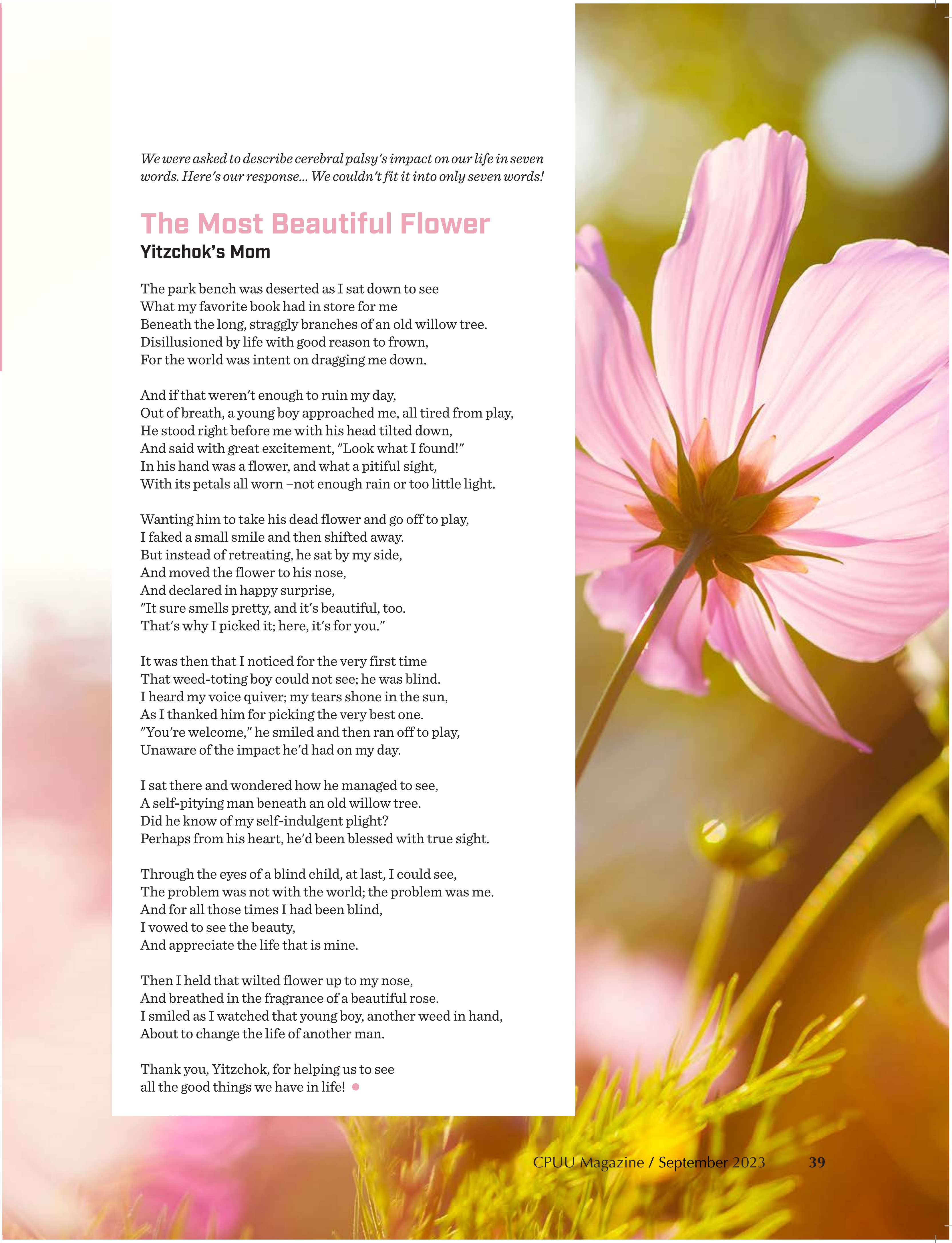
|||||||

Happiness isn't by chance but by choice.
-G. S.

Next issue's Your Take was suggested by one of our readers who was so grateful to find out about the option of more therapy available after school hours.

Share a piece of advice or tip(s) that you would've wanted to know earlier.

Send in your answers to:
cpuumagazine@gmail.com or
call us: 347-920-0771. ●



We were asked to describe cerebral palsy's impact on our life in seven words. Here's our response... We couldn't fit it into only seven words!

The Most Beautiful Flower

Yitzchok's Mom

The park bench was deserted as I sat down to see
What my favorite book had in store for me
Beneath the long, straggly branches of an old willow tree.
Disillusioned by life with good reason to frown,
For the world was intent on dragging me down.

And if that weren't enough to ruin my day,
Out of breath, a young boy approached me, all tired from play,
He stood right before me with his head tilted down,
And said with great excitement, "Look what I found!"
In his hand was a flower, and what a pitiful sight,
With its petals all worn –not enough rain or too little light.

Wanting him to take his dead flower and go off to play,
I faked a small smile and then shifted away.
But instead of retreating, he sat by my side,
And moved the flower to his nose,
And declared in happy surprise,
"It sure smells pretty, and it's beautiful, too.
That's why I picked it; here, it's for you."

It was then that I noticed for the very first time
That weed-toting boy could not see; he was blind.
I heard my voice quiver; my tears shone in the sun,
As I thanked him for picking the very best one.
"You're welcome," he smiled and then ran off to play,
Unaware of the impact he'd had on my day.

I sat there and wondered how he managed to see,
A self-pitying man beneath an old willow tree.
Did he know of my self-indulgent plight?
Perhaps from his heart, he'd been blessed with true sight.

Through the eyes of a blind child, at last, I could see,
The problem was not with the world; the problem was me.
And for all those times I had been blind,
I vowed to see the beauty,
And appreciate the life that is mine.

Then I held that wilted flower up to my nose,
And breathed in the fragrance of a beautiful rose.
I smiled as I watched that young boy, another weed in hand,
About to change the life of another man.

Thank you, Yitzchok, for helping us to see
all the good things we have in life! ●

CP PERKS

Looking at the brighter side

Yoni's Mom

I wheel my special needs child down the block, and I know you're watching and thinking, "She has other kids at home too. How does she manage?"

Honestly, my life is quite normal. Hectic? Yes. Normal? We have our own type of normal. We have gotten so used to days filled with therapies, appointments, and hospitalizations that it seems normal. Riding the waves of CP has taught us many lessons and earned us many privileges. I've collected stories, anecdotes, and tips, and I'd love to share some of them.

It doesn't matter what others think, say, or don't say

I once gave a woman a lift home from a radiology laboratory. Before getting into the car, she looked at my son, Yoni, and asked, "Does he have polio"?

Another time was a carpool day, and as I pulled into the parking lot of my son's yeshiva, a boy knocked on my window. I thought he might want a ride and rolled down the window, only to hear him ask, "Why do you have a handicap tag?"

Sometimes, people don't realize what they say is thoughtless or insensitive. When Yoni was a baby, he wore an eyepatch for lazy eyes. Other than the patch, he looked like any other adorable baby. A common comment I would hear then was, "How lucky, an eyepatch can solve the problem; some people have it much worse".

Don't EVER forget your wheelchair at home.

When Yoni was six, I took him and my infant to the doctor. When I unbuckled the two car seats, I realized that I left Yoni's wheelchair at home. With two children who couldn't walk and the doctor waiting, my only option was to carry them both. It was quite a sight!

Another time we learned this important lesson was when we went to the airport on a Chol Hamoed outing. The children were looking forward to the trip and were excited to watch the airplanes and ride the air-train. We unloaded the car at the airport, unbuckled the car seats, and no wheelchair! Ultimately, we had to watch the airplanes take off and land while standing in the parking lot. We still laugh about that almost-failed Chol Hamoed trip today.

It's not all lessons and inconveniences. CP comes along with some really awesome privileges.

At amusement parks or bounce places, Yoni gets free admission, and we all get to cut ahead of the lines!

Our favorite toys are 60ml syringes! They are fun bath toys and are great for water fights. In fact, on Chanukah, we use them to fill donuts. Our favorite gadget is Yoni's wheelchair, with the Tesla symbol printed on the front!

Yoni has a positive effect on his siblings.

We use more medical terms and technical words in our home than most families. It's cute to hear a two-year-old say, "That's Yoni's medicine and Yoni's processors (hearing aids)."

When my daughter's seventh-grade teacher asked for the definition of 'prone,' most girls said, "prone to disease." My daughter answered, "To lie on your stomach." That certainly made the PTs proud!

Having Yoni as part of our family teaches us to be grateful for everything in our bodies that work properly. I find that my children are more accepting of others that are different and of life in general.

More important than all the lessons, I want to note the many special people in Yoni's life. All the doctors, nurses, therapists, and camp counselors (thank you, camp HASC!), teachers and more do so much for us. They give much of their time, energy, and expertise to ease the bumpy ride. Thank you! Thank you! Thank you! So, when you see me wheeling my Yoni, know that hectic or not, I wouldn't have my life any other way!

Hashem has chosen us as his parents and family. We were chosen to grow from this experience, and we thank Him for the privilege. ●

> "Look at the bright side, then make it brighter."

The Adaptive Tricycle

Rochel Rose

When kids get home after a long day at school, they first want to play outside. For kids lucky enough to have a two or three-wheeler, this can mean hours of riding around the block or neighborhood. Some days, it's a solitary activity, a time to be alone with their thoughts. On others, it's a chance to socialize with other kids as they pedal alongside them, shouting and laughing. Children of all abilities enjoy the emotional and physical benefits that cycling offers. But for those with cerebral palsy, these are increased exponentially.

In the therapeutic setting, children or young adults with disabilities work towards improving their range of motion, gait, and functional strength. But therapy once or twice a week is not enough to achieve these goals. Motor learning and skill building are a result of hours of practice.

Riding a tricycle for fun allows children to build on and achieve the skills introduced in formal therapy. In children with cerebral palsy, studies show that the generalization of these skills leads to further functional mobility. Steering exercises, uphill pedaling, stopping and starting, backing up, and safety awareness can be incorporated into practice sessions for further challenges.

The use of the adaptive tricycle can improve balance, coordination, and strength in children with disabilities and improve their overall health. Additionally, an adaptive tricycle can be medically necessary for those who do not have the physical ability to walk independently or sit for long hours in a wheelchair.

WHERE TO BUY

Amtryke, Freedom Concepts and Rifton tricycles are the easiest to find, either through their websites or through durable medical equipment suppliers. Their products are available with customizable safety features such as headrests, backs, and harnesses for trunk support, seats, leg braces, and footrests.

The following information from these companies' websites can help start your search. Before going ahead with a purchase, speak to a physical or occupational therapist who can guide you to the product best suited for your specific needs.

Amtryke
www.amtrykestore.org
Prices range from $900-$1600. Their early intervention foot trike goes for $519.

Amtryke offers foot trikes, hand trikes, and a hand-foot combination tricycle. Foot trikes have standard foot pedals, while hand trikes have hand pedaling for those with poor lower body strength. Hand trikes are available with optional leg rests and foot platforms. The hand and foot trikes have both hand and foot pedals which stimulate reciprocal movement and make it easy for children with generalized weakness to self-propel. Amtryke also makes recumbent tricycles. All tricycles have removable seating for easy transport.

Freedom Concepts
www.freedomconcepts.com
Prices are in the $3,500 range.

Freedom Concepts offers upright and semi-recumbent options as well as handcycles and tandems. Their upright tricycle comes as models for young children to teens and teens to adults. The semi-recumbent trikes are for riders with stronger lower body abilities. Handcycles come in upright, semi, and fully recumbent styles with an adjustable steering column and optional foot propulsion. The tandem tricycle allows a parent or friend to propel the bike from the back.

Rifton Bicycles
www.rifton.com
Prices range from $2,500-$3000.

Rifton Bicycles is the most well-known manufacturer of adaptive cycles and the one insurance is most likely to cover. Their trikes come in small, medium, and large. Seat heights and depths can be easily adjusted without tools. Variable pedal resistance accommodates a child's needs and abilities. User-friendly laterals and handlebars swing out for easy accessibility. Backrests flip down, and rear wheels and front end can be removed, allowing the trike to collapse and stowed in a minivan. A stationary stand allows the trike to be used indoors.

HOW TO PAY

Paying for adaptive tricycles can be very complicated.

Some insurance companies may cover the cost of adaptive trikes, but it is a long process. Speak to them before you get started to avoid any confusion or complications. Be prepared to have a medical professional (a doctor or physical/occupational therapist, or even better, both) submit a justification letter. The letter should include a prescription and diagnosis code and a description of the diagnosis and the resulting impairments. It should detail how the device meets patients' needs and improves their capacity for normal activity. It should list the short and long-term benefits from a medical perspective, not a social one. And it should add that the patient has tested the device and found it helpful.

Adapt Community Network (www.adaptcommunitynetwork.org) is a non-profit agency in NY. Their

family reimbursement program provides financial support to cover the cost of goods, such as adaptive equipment, not obtainable through other funding services. Their telephone number is 877-827-2666.

National AMBUCS (www.ambucs.org) is a non-profit charitable organization owned by Amtryke. They have chapters nationwide that fundraise to help their members receive Amtryke tricycles. They may also have access to outdated, refurbished, or recycled trikes. The chapters closest to Brooklyn are in Mastic Beach, Long Island. (631-767-4354) and Toms River, Ocean County, NJ (732-674-7115). There is a national wish list for those who don't live near a chapter. AMBUCS has a fundraising effort to ensure that everyone on the national list gets a trike, but it can take up to two years. Including your child's picture and being willing to participate in fundraising efforts may decrease wait times.

Wheelchairs 4 Kids (wheelchairs4kids.org) is a non-profit organization dedicated to improving the lives of children with physical disabilities. They are here to give physically disabled children a better quality of life. When Medicaid or insurance denies coverage for any medical equipment Wheelchairs 4 Kids is there to help. By using funds from communities, sponsors and donors, Wheelchairs 4 Kids provides medical equipment, adaptive tricycles, home and vehicle modifications and wheelchairs for those in need. They work hand in hand with Rifton ensuring a smooth and easy process. They can be contacted at (727) 946 0963.

The Great Bike Giveaway (www.greatbikegiveaway.com) is an annual contest created by The Friendship Circle of Michigan usually runs March-April. Keep this in mind for 2024, as the 2023 giveaway is already over. The giveaway provides a fundraising platform to help you raise money for an adaptive bike. It offers discounted pricing and the potential for matching donations. You can win by receiving the most votes, random drawing, or raising enough funds.

The Freedom Program of US Variety delivers life-changing equipment and services for mobility, independence, and social inclusion. Their NY chapter (www.varietyny.org) services children across New York, New Jersey, and Connecticut. You can apply for a grant through their website.

Although they are hard to find and not always a good deal; occasionally, a used cycle can be found through eBay or Facebook Marketplace. ●

Rifton
Tricycle features

visit us @ www.rifton.com

Variable pedal resistance
The adjustable brake can provide drag, or lock the wheels for safe transfer.

Backrest angle
Position the backrest vertically or at a 7½° or 15° recline.

Carbon fiber drive belt
The drive belt will not rust or stretch, and will last at least five times longer than a bicycle chain.

Seat depth
The seat depth adjusts easily with a knob underneath.

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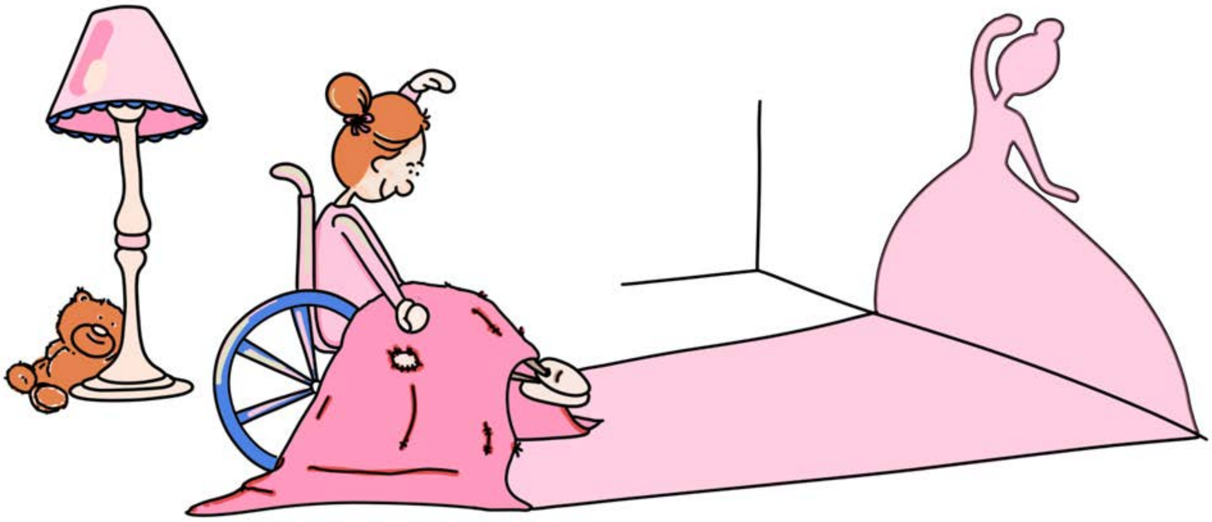
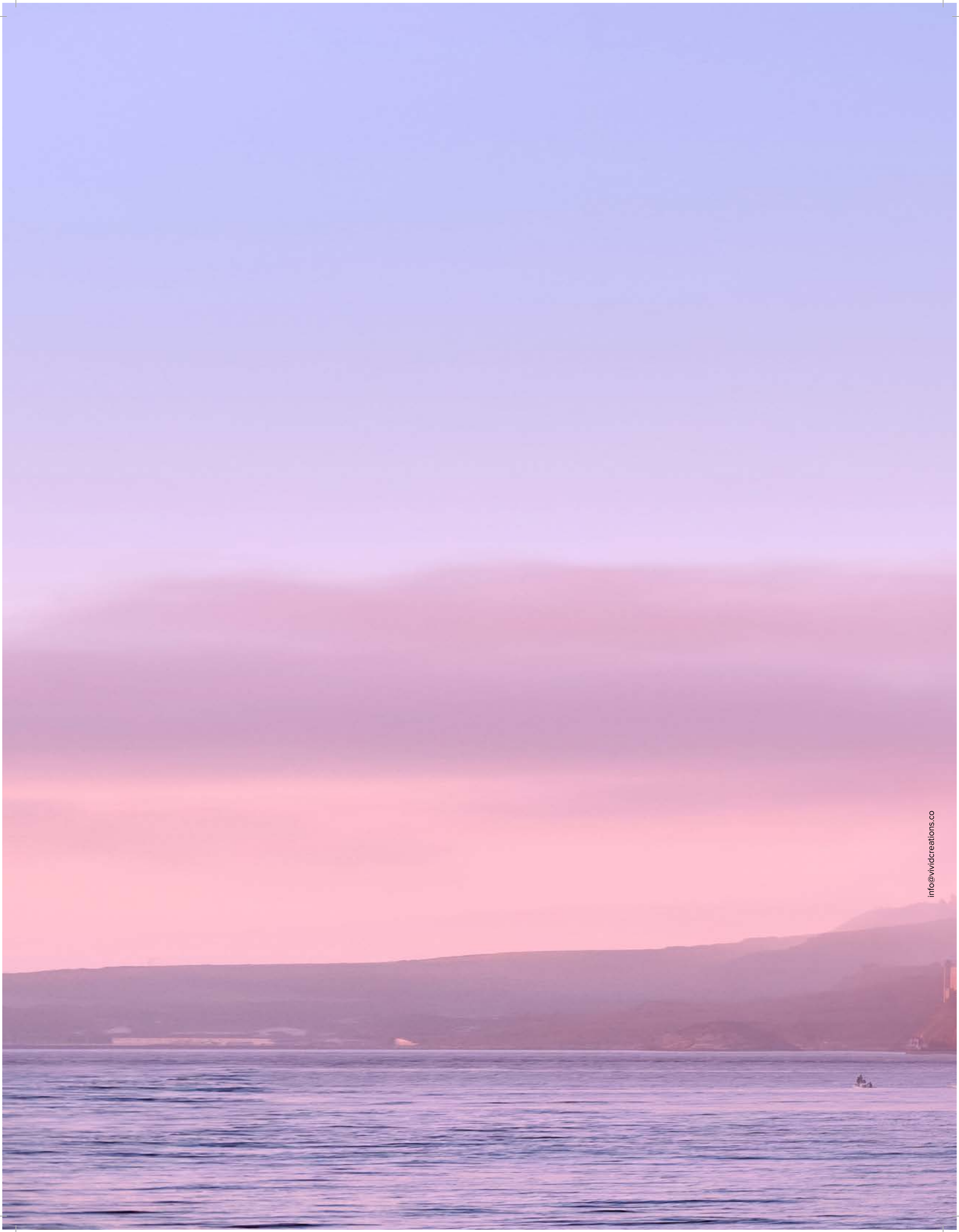


"How others see you isn't important,
How you see yourself means everything"



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