Our daughter had a year left to live. We had to do something wonderful with the time she had left.

When Havi was diagnosed with fatal Tay-Sachs disease, we decided to celebrate her with a lifetime’s worth of birthdays.

By Myra Sack  Updated June 8, 2022, 10:34 a.m.
Havi was beautiful. Perfect, actually, according to our midwife and nurse in the delivery room of Brigham and Women’s Hospital, where she was born at 12:27 p.m. on September 4, 2018. Clear skin, big eyes, strong neck. Six pounds, 9 ounces; 18¾-inches long. Matt and I couldn’t take our eyes off of her.

In the first year of Havi’s life, we said yes to everything. We traveled everywhere with her in the car and on airplane trips across the country, introducing her to as many family and friends as we could, no matter where they lived. We took her to work meetings. Perhaps we operated as other first-time parents do, our pride and love for our daughter overflowing. But, in retrospect, I also wonder if something was making us hold on to her extra tightly. Because as the months passed, in that place in my mind where the greatest fears live, I was beginning to worry about Havi’s developmental progress. I had begun to dread the innocent comparisons other parents would make with their children. In Logan Airport once, we sat next to another couple with a baby as we awaited boarding. He crawled so quickly it looked like he was set to fast-forward.

“How old is yours?” his mother asked me, smiling and chasing her baby around the chairs.

“She’s ten months.” I knelt over to rub Havi’s arms as she sat upright on the floor. It felt rude not to return the question. “What about your son?” I asked.

“He’s eight and a half months. An early crawler!” She must have heard something in my tone.
“Don’t worry, she’ll get there.”

These conversations stung, but the feeling always passed. Matt and I had Havi all to ourselves and our days were long and full. We’d celebrate victories: Havi could feed herself; her posture was perfect, and when she sat on her own, she looked mature; she smiled at us. Havi had an infectious giggle; on some luckier nights, she even slept several hours in a row.

She was making progress. But, a little voice in me said, not enough.

By 12 months, Havi wasn’t pulling herself up and she didn’t babble much. She had crawled a couple of times, for three or four strides to get a piece of challah — her favorite food — but it looked hard for her, as if she were caught in quicksand. Eventually, we grew concerned enough to take her to a specialist, Dr. Siddharth Srivastava in the pediatric neurology department at Boston Children’s Hospital.

“CALL ME DR. SID,” DR. SRIVASTAVA SAID when he opened his office door to us, reaching out his hand as his warm brown eyes met my gaze. “Dr. Sid, I’m Myra,” I said, “and this is my daughter, Havi.” I moved her to my left hip to shake his hand. “And this is Matt,” I said, doing a half turn, “Havi’s father.”

Havi’s cheeks were red from the December chill and her purple jumper somehow made her look even lovelier than usual. “She is beautiful,” Dr. Sid said. “Come in.”

We stepped inside. Matt closed the door gently behind us.

“She can sit on the floor,” he told us. “We are going to start with mental status. Just a fancy way to say we are going to play some games.”
Matt and I sat down with Havi. The four of us made a circle on the hard exam room tiles. I caught a glimpse of Dr. Sid’s phone resting on the floor. His home screen showed two smiling children. They looked healthy. Healthy children, I thought. What a gift.

Dr. Sid was focused on Havi, who sat slightly slumped, her big eyes staring off toward the window. The room was hot and stuffy. Matt unzipped his jacket.

“Does she always startle?” Dr. Sid asked, not taking his eyes off of her.

“Sorry, what?”

“I noticed that Havi startled when Matt unzipped his jacket. Does she do that often?” Dr. Sid now looked to Matt and me in turn.

“Yes. Well, not always. But we’ve noticed it for several months now. We asked Hav’s pediatrician about it. She said it’s likely sensitive hearing.” Dr. Sid scribbled a note.

“Let’s play,” he said, pushing a wooden box with light-up shapes toward Havi.

He pressed the yellow triangle and encouraged Havi to try it. I smiled and let out a sigh of relief when she reached for the box. But she didn’t push the yellow triangle. OK, I thought, maybe she’s too sophisticated for this kind of a game.

And then came the bell. Dr. Sid slowly moved his hand out to Havi’s left while distracting her with the wooden box. The sharp ring of the bell reverberated in my ears. Havi didn’t turn toward it. Then he moved a ball back and forth in front of her. No tracking.

Havi’s movements were always slow and smooth; to me they were deliberate and graceful. But this setting darkened my view. My chest felt tight. My insides were being squeezed. I was clutching the hope that Dr. Sid would tell us, “Everything is going to be OK.”
The eight minutes of the test felt like forever.

Finally, Dr. Sid put the toys away and turned toward us. Matt and I exhaled so loudly it echoed off the walls.

“Well. I have some questions,” he began. “Were you tested for Tay-Sachs?” He began listing indicators: the startle reflex, Havi’s movements, the developmental delay. Matt and I both interrupted him. It couldn’t be Tay-Sachs. We had learned about Tay-Sachs in Hebrew school as kids; it’s a horrific disease, one that disproportionately affects Ashkenazi Jews, but we are a generation that benefits from screening and we had been tested two years earlier. “I’m a carrier, but Matt isn’t,” I tried to reassure Dr. Sid. “She doesn’t have Tay-Sachs.”

“OK,” he said. “I’d like Havi to have a blood test and an MRI on Monday to be sure.”

HAVI’S GRANDI, MY MOM, flew up from Philadelphia to join us at the hospital on the day of Havi’s MRI. We had arrived 30 minutes early, but they were already running 40 minutes behind. Havi still had crusty eyes from a restless night, yet they were big and bright, and as beautifully hazel-green as ever. None of us said much as we waited anxiously, but Havi’s body was relaxed against my chest.

“Havi Goldstein? We’re ready for you!” the nurse finally called.

The nurses struggled to get an IV into Hav’s tiny hand and she cried hard. Since only one parent could accompany her to the MRI, I reluctantly returned to the waiting room. Matt carried Hav back to the MRI suite so he could hold her while they started the anesthesia. Hav let out a little cry as they injected the drugs into her IV but quickly fell unconscious in Matt’s arms. He put Hav down on the bed, and seeing her lying there limp and unresponsive, let out a sob. Back in the waiting room, he sagged into my arms and buried his head in my shoulder.

That afternoon, while the rest of us stayed at home, Matt returned to Boston Children’s, where Dr.
Sid had images ready from Havi’s MRI.

When Matt got back I was in our bedroom, talking on the phone to a colleague about a presentation I had missed. When I saw his face, I hung up.

Matt started to talk in his serious voice: low, soft, and with some medical jargon. Our room started to spin. All I heard was: “Dr. Sid showed me an image of Hav’s MRI and pointed to several areas of her brain. He said that those types of images are characteristic of Tay-Sachs disease.”

As Matt said the words *Tay-Sachs*, I screamed.

What Matt said next comes back to me only in fragments:

*No cure.*

*Rare.*

*Destroys nerve cells in the brain and spinal cord.*

*Symptoms progress until they lead to death between 2 years and 4 years old.*

THE NEXT DAY, Havi stayed with her Grandi while Matt and I drove to the hospital for tests that would eventually confirm a Tay-Sachs diagnosis. Someone had made a terrible mistake with Matt’s earlier test — he was a carrier.

We left the hospital lab and turned onto the Jamaicaway, heading for home. In silence, we followed the familiar curves of the road lined with birch and oak trees, leafless in the cold. We drove past the pond where families walked bundled in winter gear, past the baseball diamond and the grassy field that returns to life each spring with kids playing soccer.
Matt banged his fist against the steering wheel. “I don’t get it. How do we do this?” Tears were streaming down his cheeks. “How do we watch our daughter die? We’re supposed to just watch?”

He reached over and squeezed my leg.

My mind was spinning through a movie reel of a future we would never get to experience. We would never see Havi’s first steps. Never hear her say Mama or Dada. Never watch her play on a playground or make friends or get on the school bus. We would never help her with homework, or take her to soccer games or dance class, or . . . I couldn’t make the list stop.

I pulled my knees up to my chest. Matt’s hand gripped the steering wheel so tightly that his knuckles were white. His question — How do we do this? — hung between us.

“I don’t know,” I finally said, “I don’t know.”

But then, suddenly, I did know.

“We celebrate the shit out of her. We squeeze every ounce of beauty and love into her.”

I paused, uncertain again. “I mean, I don’t know.”

Matt looked over at me with wet eyes. I felt a knot lodge in my throat. I kept going. “Every Friday. Every Shabbat. We’ll celebrate like it’s Hav’s birthday. We’ll fill every week with a lifetime of love, and we’ll mark it with a celebration on Shabbat. We’ll invite our people.”

“Like a combination of Shabbat and birthday? Huh. Could be something like . . . Shabbirthday?”

I smiled. It hurt.

“Yes, Shabbirthday,” I agreed. “That’s how we’ll live. From one Shabbirthday to the next. And that’s it. That will be everything.”
ON FRIDAY, DECEMBER 20, three days after learning Havi had a year or so to live, we celebrated. A group of aunts, uncles, grandparents, and dear friends descended on our home for Havi’s first Shabbirthday.

Sometimes in situations like ours, we’ve heard, loved ones slowly disappear from your life — not because they don’t care, but because they just don’t know what to say or how to help. But Havi’s posse, as they’d come to be called, knew instinctively the best thing they could do was show up. They followed our lead, and no one pretended that the heartache wasn’t there. They showered her with gifts: a onesie; cake and balloons; a plush toy avocado, her first food, which was bigger and wider than she; a warm challah; and an elegant gray dress with white leggings — her first
Shabbirthday outfit. Havi loved every minute of it.

Our home felt full and warm that night. Everyone stayed close to each other as the Shabbat candles flickered and the reality of Havi’s illness swirled around us. We didn’t have to pretend our pain away with fake smiles, nor did we need to hide from honest joy and laughter that can come from the deepest, most painful places. That night, she never left the arms or lap of someone who loved her.

WE KNEW NOT EVERYONE would understand our choice to gather like this.

When people didn’t know what else to say, or how to help, they would inevitably say to go see a rabbi. So, we arranged for a meeting with a local rabbi, who was kind enough to meet with us at the start of 2020.

She led us into her office, looking toward us warmly.

“I’m relieved you two are getting out of the house on your own,” she said. “That’s a very good sign.”


The rabbi offered us coffee, which was brought in by her assistant in small Styrofoam cups. We sat on a couch in her beautiful office surrounded by books and Judaica, and shared our story. The rabbi listened quietly and with compassion. It did feel comforting to be in her presence, someone practiced with grief, and I was hoping — expecting — that she would become a guiding presence for us. She recommended we read *When Bad Things Happen to Good People* by Rabbi Harold Kushner.

And then, with an ounce of enthusiasm in my voice, I started to share the details of how we had turned the last two Shabbats into celebrations of Havi. We called them Shabbirthdays, I told her.
The rabbi suddenly leaned forward. Something had shifted in her face. “I wouldn’t commit to anything like that,” she said matter-of-factly. “You don’t know how you are going to feel two weeks from now. And then, think about when she is gone, how hard Fridays are going to feel. I’d live your life the way you always have and take a lot of photos.”

Afterward, Matt and I drove home along the Riverway through Jamaica Plain, which by then had become our throughway for difficult conversations.

“That was bullshit.” I turned in my seat toward Matt, who was driving.

“I couldn’t believe she said that,” Matt replied in a much more measured tone.

“She’s wrong about that. We’re all in on Shabbirthdays. And I hope one day she actually says Havi’s name.”

SO, AFTER THAT FIRST SHABBIRTHDAY, we held one every Friday night, inviting friends and family for each week’s festivities. And when we traveled west to take Hav to the California coast where her dad grew up, we celebrated every Friday out there. Once all our family and friends had gone home and Havi was asleep, Matt and I would sit down and write a letter to her. On Saturday mornings we’d post what we’d written on CaringBridge, an online journal, sharing it with the closest people in our lives.

On an afternoon hike in the foothills around Ojai, California, we walked through a grove of Pixie tangerines, small orange globes that hung by the hundreds from the trees around us. A sign read “NO PICKING.” Matt reached up and picked one anyway — he held it over his shoulder to show Hav, who sat in a carrier on his back. She giggled — whenever she laughed, we had to as well. Havi couldn’t speak but we never struggled to understand how she felt. I wrote that night in our journal:

*You talk in smiles — perhaps the most instinctive, simple, and powerful form of communication.*
We have full conversations as you make your way through all the smiles of the world. You tilt your head back and let out an open-mouthed smile and we know you couldn’t be happier . . . Then there are your closed-lip smile, your flirtatious smile, your guilty smile, and your lopsided smile. With each one you make us feel like you’re just seeing us for the first time, like you’re so excited to be with us again. Your eyes sparkle and you stare deeply into our souls. Sometimes we have to look away as we wipe tears from our cheeks because you’ve moved us so deeply with your simple smile and twinkle eyes. Speaking of smiles, we know that one of the “functions” you’ll lose is the ability to smile. Dad and I talked about this over pizza dinner the other night. Dad asked me if that was the thing I was most scared of. “I’m scared of it all,” I said, and Dad agreed.

We were learning to live alongside grief, appreciating its power to keep us close to Havi. We were learning that pain and love could coexist. We weren’t risking our hearts, we were expanding them.

FOR MORE THAN A YEAR, that’s how we lived. In that time, we were blessed with our second daughter, Kaia, whose name is from the same Hebrew root, chai, as Havi. We were a family of four now.

On Havi’s 57th Shabbirthday, January 15, 2021, we awoke to a breathtaking sunrise. We took advantage of the warm sun to walk her up and down Heartbreak Hill in Newton. I reached into the stroller and tucked her hair behind her ears, watched as her eyes chased the light, and narrated to her most of the way, imagining some future Boston Marathon we’d run together and making sure to point out where the two of us would start to pass people. I noticed her dry lips. We’d left her smoothie at home.

Havi had stopped eating two days earlier. We could see that she was making it clear she was ready for whatever was next. I wasn’t, of course. How could I be? But I felt so strongly about listening and following her lead, that I simply tried to hold on to whatever moments she had left to give.

When we brought Havi into the kitchen that evening, we found that her posse had worked their magic again. They set the kitchen table with an array of lavender flowers and giant balloons...
spelling out “Havi 57″ hung behind her chair. We ate all of her favorite foods, most importantly blueberry pancakes — which by then had surpassed even challah — and held some of the sweet blueberries to her lips so she could taste them. And we kissed and hugged her and passed her around from one set of arms to another. Our tears fell on her cheeks, and she hung in with us for as long as she could, until her eyes closed and her body relaxed into a sleep. It was bedtime.

After everyone had gone home, Matt crawled into bed, opened his laptop, and, as one of us had done each of the previous 56 weeks, wrote a letter to Havi.

ON THE FOLLOWING WEDNESDAY, at 9:04 a.m., Havi took her last breath, at our home, in our bed, in my arms. She was 2 years, 4 months, and 16 days old.

The three of us lay like origami: Havi’s small body on top of mine, her head resting on my chest, her legs hugging my hips, and Matt’s head pressed against mine with his arms wrapped around both of us. The room was still and silent but for the sound of my heart beating hard in my chest.

Suddenly, a small movement at the window drew our eyes. A tiny, gray, oval shape was crawling up and over the molding. It paused, seeming to look at us from across the room. She sent us a stink bug. Seriously, Havi girl? Matt and I both broke into laughter and tears.
IN ONE WAY, the rabbi was right: Havi’s absence filled everything — her room, our home, and every cell in our bodies. All of the ways I knew how to care for my daughter evaporated. I couldn’t feed or dress her; I couldn’t rock or sing her to sleep; I couldn’t listen for her cries or coos; and maybe most painfully, I couldn’t imagine a future with her. And so, I’d drift between disbelief and anguish, wrestle with the sheets throughout sleepless nights, and consider putting two feet on the floor in the morning a victory for the day.

I continued to write. Every day. I turned toward Havi, each letter beginning with “Dear Beauty,” the way they did when she sat next to me, and I told her exactly how I felt and what we did that day. I still do this, every day.
“Today I feel in denial even though it’s the most gorgeous day here and I’m sure you had something to do with that,” I wrote to Havi two months after her death. “Every part of me wants to collapse onto the floor and weep until I cry myself back to sleep. But I can’t. I want to be okay for Dad and for Kaia. I’m wearing purple. How can you be gone? For good? I thought nothing was permanent. We love you always.”

And yet by letting anguish and celebration run together, we continue to live with Havi. We strung hundreds of photographs around the house. We transformed her room into a haven that continues to give us strength and energy. We toast to her every night: “To Hav.” Kaia is now almost 2, and she lifts her sippy cup and says Hav’s name with us before we eat.

We honor Havi every Shabbirthday with challah and music, and we draw on her posse, our witnesses, to keep her with us every day. They still do little things that feel enormous, like ordering coffee under “Havi” to hear the barista say her name out loud, and sharing poems every week that remind us of her. And every Wednesday, at 9:04 a.m., the day and time of her death, they still send photographs of her to Matt and me to remind us that Havi is still very much here with us.

We know the dominant narrative about grief, that it is something to “move beyond” in an effort to seek “closure.” But we feel differently. There is no safe distance when it comes to loving. Havi’s life and death has to be a part of our lives, now and forever, and we hold on to the gifts of perspective and possibility that she gave us. She exists in every moment — our relationship to her is cellular.

Recently, I reread the letter Matt wrote to Havi on that night of her 57th Shabbirthday. In that moment, we would have given anything for a miracle, for some way she could have stayed with us and grown up in her home, with her sister. And yet, what we trusted then, and believe with even more conviction now, is that she would always be here, as long as we make room for her.

You have a number of days remaining now. The pain of losing you feels different, scarier and stronger. We used to fear all the things we’d have to stop doing together, but now we are
overcome by the fear of just not being with you. We’ve always dreaded this moment — the moment when you would tell us you were ready. But now we are afraid of having to live the rest of our lives without you. We wish we could go with you wherever you’re going. Of course, we know you’ll be with us wherever we are. But please don’t be shy about just coming right in, coming back home whenever you can, whenever you want.

Myra Sack is a senior adviser at SquashBusters Inc. She is a certified Compassionate Bereavement Care facilitator and is writing a memoir about her daughter Havi. She lives in Jamaica Plain with her family. Send comments to magazine@globe.com.