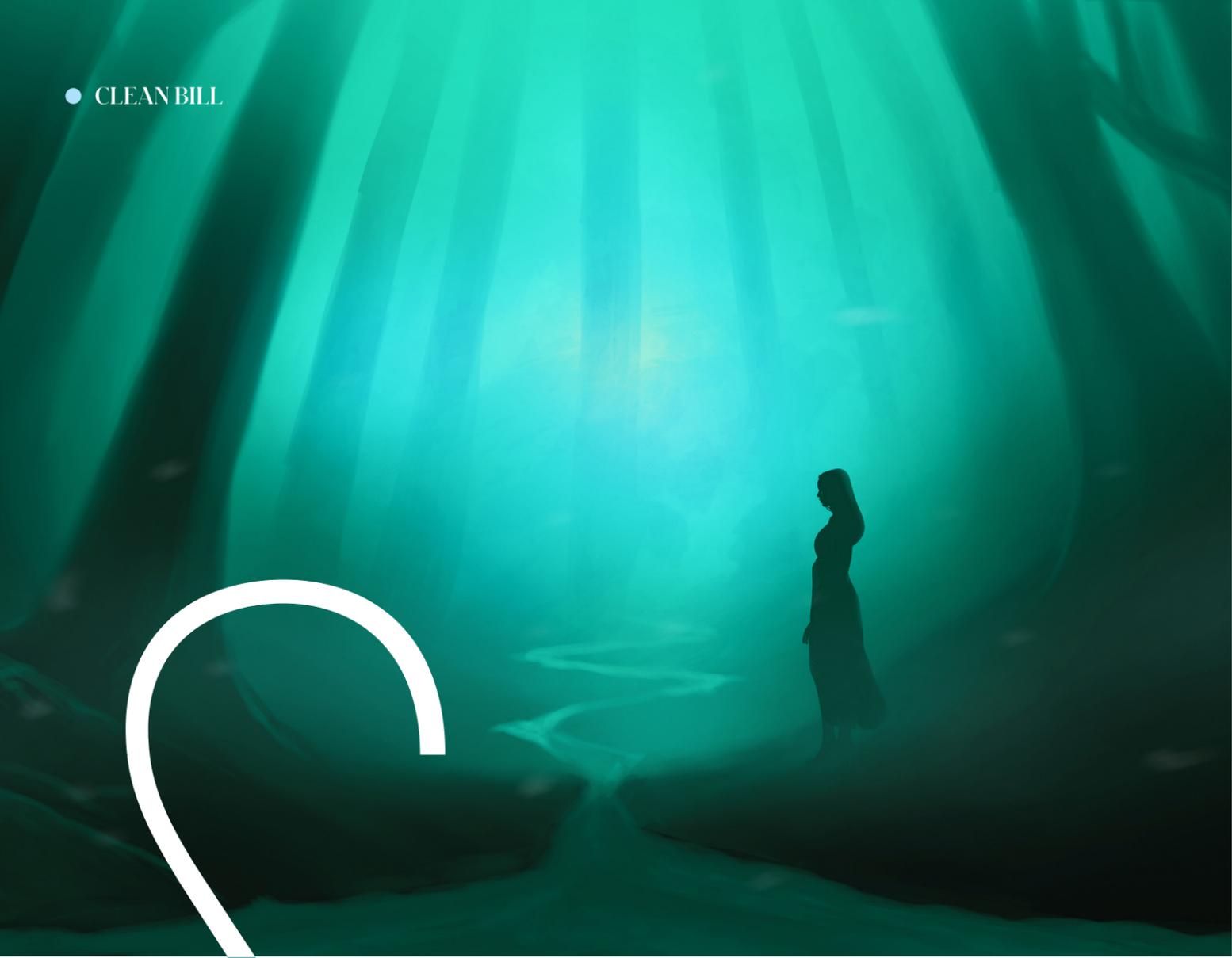


# unnamed pain

COPING WITH AMBIGUOUS LOSS BY ??





S

hmili, my beautiful little boy. As Chana said after her son, Shmuel Hanavi, was born, “*El hanaar hazeh hispallalti*—for this child I prayed.” When you were born you were truly special, but now we know just how special you are.

Before every test I would tell myself, “This is it. This test is going to give us the answer.” But it never did.

At first glance, we look like a perfect little family: Tatty, Mummy, Libby and you. But not everything is as it seems. When you were born two years after your sister, our little world was happy and warm. Everything was wonderful—until it wasn’t.

Even in my sleep-deprived postpartum state, I knew that something wasn’t right. Your breathing was too fast and you would often choke while feeding. When you were five weeks old, after trying to convince our pediatrician that something was wrong and getting nowhere, I took you to A&E (Accident and Emergency; England’s equivalent of an ER), thinking you might have a cold or chest infection. I didn’t realize that this would start us on a lifelong journey.

To make a long story short, we spent weeks in the hospital with you. The doctors couldn’t figure out what was the matter. You had swallowing issues and respiratory distress, but despite running every kind of test on your heart and lungs and putting you under anesthesia not once but twice for internal checks, they found nothing. So they sent us home with a nasogastric tube and a feeding pump after diagnosing you with acid reflux.

But I didn’t really agree with their diagnosis, and continued to try to get to the bottom of it. I started to suspect that you were having seizures and took you to A&E in three different hospitals, but they never believed me. One day, I decided to wait there until they actually saw you convulsing, which you finally did after we’d been sitting there for four hours. They now took me seriously and started running an EEG. This came back slightly abnormal but not in the danger zone, so they sent us home.

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"I'm sad," I replied, "but had you told me his MRI was normal, I would have been even sadder."

By now you were five months old and we still didn't know what was amiss. We had gotten second opinions from so many specialists, from cardiologists to gastroenterologists to ENTs, but there was no consensus. I was desperate for an answer. Before every test I would tell myself, "This is it. This test is going to give us the answer." But it never did.

I started doubting my sanity. Maybe I was imagining things. My friends would see me pushing your Doona and question why I was making such a fuss; you looked fine. The unasked question seemed to be, "Is Malky just looking for attention?"

At six months old, your pediatrician agreed that your muscle tone and movements weren't normal and ordered a brain MRI. When I went with you into the room where they were putting you to sleep, I told the anesthesiologist, "Please find something!" He probably thought I was a nut, but not knowing what was wrong and therefore not knowing what to do was torturous.

A week later we got our answer. The doctor called us in for a consultation two hours before the first candle of Chanukah. She sat us down and said, "The MRI wasn't normal." I felt validated; I wasn't crazy. But then I thought, *Okay, so we have a diagnosis. How do we fix it?*

The doctor said that the next step would be genetic testing. "It can't be genetic," I told her. But apparently, not even the most cutting-edge diagnostic screenings can find everything. It turned out that you have a micro error on chromosome 1. Your condition code is 1q21.1 and 1q21.2.

I was devastated. But your mother is a fighter, my dear little Shmili. I had spent the first six months of your life fighting for a diagnosis, so I continued to fight. I tried to find out everything there is to know about children with this condition. I pushed for your therapies and continued testing. I lived on adrenaline, a woman on a mission.

However, I failed to realize that trying to help you isn't a sprint, it's a marathon. After months of daily appointments and constant medical liaising, I got worn down. It suddenly dawned on me that this wasn't going away. That might sound strange, because we sort of knew what we were up against being the parents of a medically complex child, but such is human nature and the power of denial. I spent a few days in bed, got myself into therapy and started working through my issues, then I got up and put one foot in front of the other.

By then you had been diagnosed with brachycephaly (a shorter than average skull); hypotelorism (an

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abnormally decreased distance between the eye sockets); micrognathia (an undeveloped jaw); dysphagia (difficulty swallowing); choking and aspiration risk; sleep apnea; and myoclonus, involuntary muscle twitches.

Today, you are over a year old but you have the development of a three- to four-month-old. You do not turn over or sit. You can only be on your tummy for very short periods because controlling your head is too difficult. You aren't aware that you have hands. You are hypersensitive to stimuli. Also, because the doctors aren't satisfied with your initial diagnosis, a complete genome sequence is now underway. Every week you receive OT, PT, SLT, vision therapy and hydrotherapy, and there are multiple appointments with various specialists. I am busy with you constantly, and I love you dearly.

You will always smile and shriek with joy when given attention. It's the one thing that fools everyone: you are very friendly. This is both a blessing and a curse. You look normal, but you most definitely are not.

It's not that I'm not coping; I am. But as hard as I try not to, I keep finding myself overcome by sadness from time to time.

I sometimes cry when I try to comfort you and don't know how; you don't like to cuddle. I sometimes cry when we come home from yet another therapy session and I am so sick and tired of doing this. I sometimes cry when I watch clips of your sister at half your age crawling and saying "Mama." I cry when I realize that you are never going to get married. I even cry when people try to comfort me and say, "Hashem can do miracles."

I may also cry when you give me a big smile.

Some people assume that I'm depressed, but it's not true. I spend my days happily and actively looking after you. Nor am I in denial. I am constantly pushing for you to get the best care for your condition. So what is it? Why do I continue to be bowled over by sadness at random times?

Curious, I did some research and also questioned other parents of children with special needs. And I learned that this cycle of sadness isn't unique to me. It's a common phenomenon and it has a name: ambiguous loss.

When someone suffers the death of a loved one, he or she can move through the various stages of mourning and rituals, which enable the sadness to lessen over time. By contrast, living with someone who is physically or mentally "not there" involves constant reminders of loss, leading to a grief cycle that lasts a

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lifetime with no way to dissipate it. I still live every day thinking of the son I hoped to have; the son I still wish you were. I live with continual "moments of loss" and therefore "moments of grief." However, I have come to understand that this is normal—and it's okay. It's all part of the package of being the mother of a special boy.

Shmili, I want you to know that you light up our lives, even though it's a life I never imagined I would be leading. You make me smile and laugh every single day, and occasionally, you also make me so sad that I don't know how I can continue living. But I *do* continue, and I *do* love you more than words can describe.

I will ride this rollercoaster of sadness and joy as both of us journey through life together.

## MEDICAL EXCHANGE

Readers ask for medical guidance from other readers

Seeking to learn more about myelofibrosis. I would greatly appreciate it if anyone can share information about this illness or personal experience they have had with it. Please reach out to [shaindyff@gmail.com](mailto:shaindyff@gmail.com)

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# Grief Caused by a Gap

BY BATYA KOHN

*I let myself cry on Friday; I didn't want to ruin my daughter's special day. I just wanted to revel in the nachas as she gave her speech at her graduation on Sunday, but on the morning of the ceremony, I couldn't help but feel engulfed in a wave of sadness and something that felt like dread.*

I kept picturing myself sitting in the front row of the audience with the glaringly empty chair next to me. My mother would have been so proud to attend her oldest granddaughter's graduation from high school—had she been able to fully grasp what her beloved Shevy had achieved.

So what if Bubby can't proofread Shevy's valedictory speech in advance or travel to Lakewood to watch her deliver it in person?

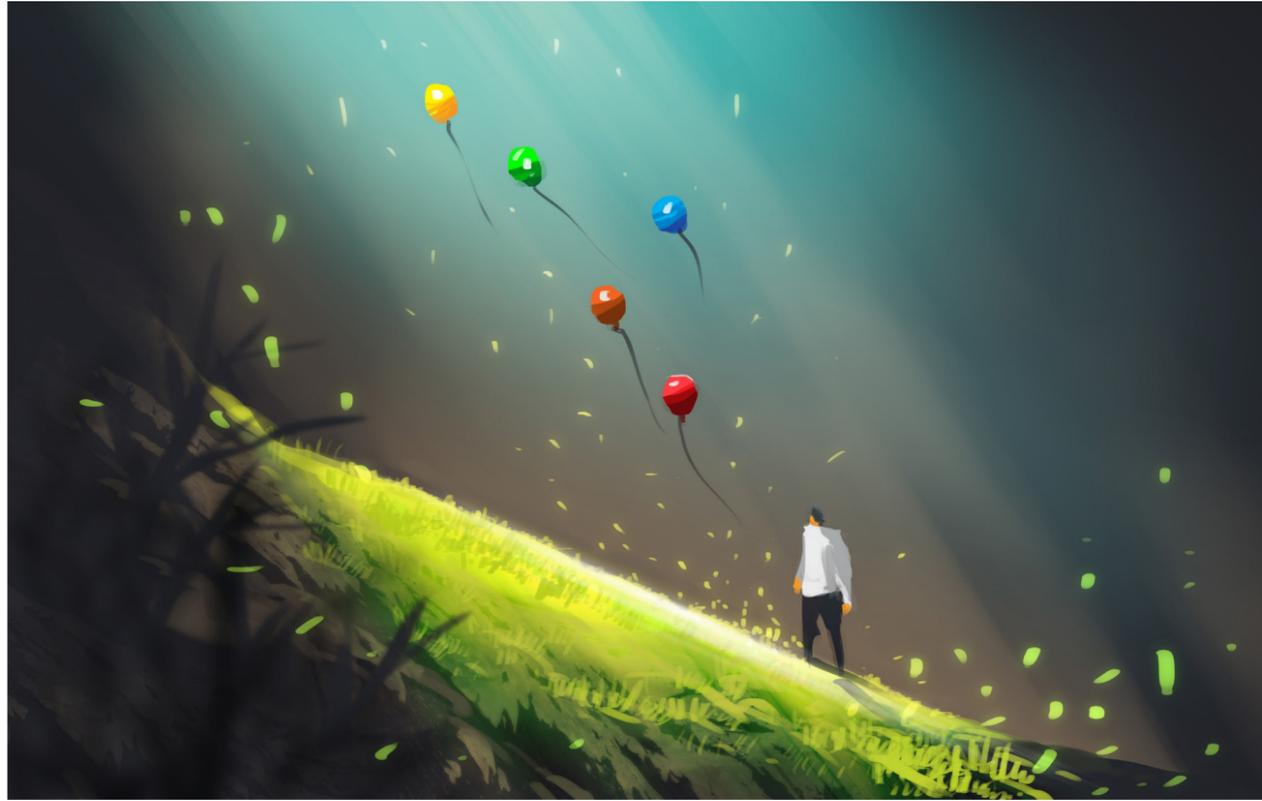
Of course, my sadness was mixed with a big dose of guilt. I had so much to be grateful for; how dare I focus on my pain? The year before, my mother had had a completely unexpected and debilitating stroke despite being relatively young and in the peak of health. But *baruch Hashem*, she was still alive and slowly regaining her speech and the use of her arms and legs, even if cognitively she wasn't the same. So what if Bubby can't proofread Shevy's valedictory speech in advance or travel to Lakewood to watch her deliver it in person? Shouldn't I be overjoyed that I still have a mother?

Then it hit me. It's not that I'm ungrateful, nor is sadness the most accurate description of what it feels like to miss someone who is still alive. In truth, what I am is wistful, wishing for what could have been and what I believe should have been. I am missing my mother from a few years ago. Shevy's graduation is just another reminder of what has been lost. And even though no one can really know what the future holds, I wonder what our family milestones and *simchos* are going to look like. I'm afraid that nothing will be the same. Am I even allowed to mourn that?

Dr. Pauline Boss is a family therapist and researcher who coined the term "ambiguous loss" back in the 1970s. She was studying the wives of soldiers who were missing in action in Vietnam and Southeast Asia, women who couldn't grieve over a death but were mired in uncertainty; their husbands were

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gone but possibly still alive. A decade later, she focused her research on this subject to include the wives of aging veterans who had Alzheimer's disease. These women had husbands who were physically present, but they were mourning what she termed a psychological ambiguous loss.

As the experts explain, the difficulty lies in the fact that when the grief is ambiguous, the sufferer has no sense of closure. The week of *shivah* and all the related *halachos* we observe after someone passes away give the mourners *nechamah*. When someone is suffering from ambiguous loss, the pain is open ended and there is no comfort.

There are various stages of grief people go through when someone dies, but those who are suffering from ambiguous loss can become stuck in any stage. This can result in what's been termed "frozen grief," when people get stuck and become trapped in their sorrow. "It can feel like an ongoing trauma because there is no answer," says psychologist Dr. Kia-Rai Prewitt.

Another unfortunate aspect of ambiguous loss has been articulated as "disenfranchised grief" by mental health counselor Dr. Kenneth Doka, meaning that other people don't see the sufferer's loss as something that requires support. There's no meal train to sign up for or *shivah*

call to pay. Friends and family might not understand the challenges because they look different from those that arise after a death, so the person experiencing ambiguous loss may feel isolated, helpless, hopeless and confused, further exacerbating the suffering.

Research has found that ambiguous loss can even cause physical, behavioral, cognitive and emotional problems like insomnia, headaches, fatigue, avoidance, anxiety, preoccupation with the loss, depression, anger, overactivity, fear and even apathy.

Ambiguous loss is the most stressful kind because there is no resolution. "An ambiguous loss is a situational disorder beyond human expectation," Dr. Boss says.

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# Types of Ambiguous Loss

*There are two main types of ambiguous loss, with a third category postulated by some therapists:*

## TYPE ONE

### A/K/A LEAVING WITHOUT GOODBYE

This is when someone is mourning a person who is physically absent, and it isn't known if he or she is dead or alive. In other words, it's a physical absence combined with a psychological presence. Examples would be when a loved one is kidnapped; missing in action because of a war; a terrorist attack, after which not everyone is accounted for; or a natural disaster like an earthquake, flood or tsunami.

This type of ambiguous loss can also include instances in which you know where the missing person is. Examples of this would be the departure of a spouse due to divorce; when someone's birth family is psychologically present in his or her mind; family members who aren't in contact because of estrangement; when a loved one is incarcerated; or even when you've moved to another city or country far away from your loved ones.

Researchers are also including "ghosting" as a modern example. That's when someone just stops responding and falls out of touch, leaving you without answers.

## TYPE TWO

### GOODBYE WITHOUT LEAVING

This type occurs when someone is mourning a person who is alive but not emotionally part of your life in the same way. It's the reverse of the first type of ambiguous loss described above; there's a psychological absence with a physical presence. The relationship of the past is over, or just very different from before. It feels like this: "I miss the person he or she used to be."

This type of ambiguous loss occurs when a loved one is suffering from Alzheimer's disease or another type of dementia; a traumatic brain injury; addiction; depression or any other chronic mental or physical illness that takes away a loved one's mind or memory.

## TYPE THREE?

### SITUATIONAL GOODBYE

Some psychologists have even coined a term for a third type of ambiguous loss, which they call a "situational goodbye." This occurs not due to a change in a relationship, but because of a situation that can cause a feeling of loss in your life. Examples include the Covid-19 pandemic; a change in future plans; natural disasters; political unrest or a loss of financial or personal security.

# How to Cope

**D**r. Boss has formulated six guidelines to build resilience and live well despite ambiguous losses:

**Finding Meaning.** This involves making sense of the loss and finding a new purpose—i.e., a mother who turns the tragic experience of having a missing son into a campaign to prevent kidnapping.

**Adjusting Mastering.** This means recognizing your degree of control in a situation. As Dr. Boss says, "We may have to live with not knowing something for years, decades or a lifetime. During the pandemic, people could not control the virus. It was no accident that so many people were baking bread. The certainty of an outcome was comforting."

**Reconstructing Identity.** This requires understanding your new identity. For example, a woman whose husband is missing in battle will struggle with what it means to still be his wife. With the second type of ambiguous loss, someone will wonder what it means to be the husband of a wife who no longer recognizes him.

**Normalizing Ambivalence.** This is about coming to terms with conflicting feelings. Someone who doesn't know if their loved one is dead or alive might just wish for the ambiguity to be over. This can lead to feelings of guilt.

**Revising Attachment.** "You can learn to carry two contradictory ideas in your head at one time. You keep your loved one in your heart and mind while you also reorganize your life without his presence," says Dr. Boss.

**Discovering New Hope.** Instead of putting your life on hold, "You have to discover something new to hope for. Frequently, the new hope is to help other people avoid suffering from ambiguous loss as you did."



# Additional Tips

*Other psychologists recommend doing the following:*

**IDENTIFY YOUR LOSS.** Sometimes, just putting a label on it can help with healing. For example, someone suffering from estrangement might miss shopping for a wedding dress together or having inside jokes. It can help to make a list.

**DON'T COMPARE.** It isn't helpful to minimize your grief because your situation doesn't include death. Some have called this the "suffering Olympics," ranking people's level of suffering to decide who has a right to express their feelings and who doesn't. It's also important to remember that grieving can be compounded. For example, a child could be moving out of your nest while you are caring for an ill family member and coming to terms with an estrangement. Separately, each situation might be manageable, but when they happen at the same time a person can struggle with ambiguous loss.

**WORK TOWARDS ACCEPTANCE.** Acceptance isn't the same as closure. Nonetheless, in the absence of it, psychologists say it's important to try to make peace with your new reality.

**LOOK FOR SILVER LININGS.** Maybe something new came into your life because of your situation. A new friendship? Personal growth?

**SEEK SUPPORT.** Family members, friends and support groups can help. Of course, professional counseling is also an option. ●