See Me Through My Grandma's Eyes

First-Person Stories of Health Inequities

See Me Through
My Grandma's Eyes

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Who hears you? To have something to say is one thing; to have someone who hears it is another. To be heard literally is to have the vibrations of the air travel through the labyrinth of the listener's ear to the mind, but more must unfold in that darkness. You choose to hear what corresponds to your desires, needs, and interests, and there are dangers in a world that corresponds too well, with curating your life into a mirror that reflects only the comfortable and familiar, and dangers in the opposite direction as well. Listen carefully. . .

To hear is to let the sound wander all the way through the labyrinth of your ear; to listen is to travel the other way to meet it. It's not passive but active, this listening. It's as though you retell each story, translate it into the language particular to you, fit it into your cosmology so you can understand and respond, and thereby it becomes part of you. To empathize is to reach out to meet the data that comes through the labyrinths of the senses, to embrace it and incorporate it. To enter into, we say, as though another person's life was also a place you could travel to. . .

Empathy is a journey you travel, if you pay attention, if you care, if you desire to do so. Up close you witness suffering directly, though even then you may need words to know that this person has terrible pains in her joints or that one recently lost his home. Suffering far away reaches you through art, through images, recordings, and narratives; the information travels toward you and you meet it halfway, if you meet it.

--Rachel Solnit, *The Faraway Nearby*

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MATILDE CASTILE

Foreword

Do you ever find yourself thinking nostalgically about a moment in the past when you were surrounded by caring family or friends?

I was lucky to grow up in a community where everyone knew one another. I'd go to the beach on a Sunday and look around and find myself surrounded by cousins, friends, nieces, nephews, aunts, and uncles. Everyone had grandparents living with them, and we all took care of one another's grandparents. I was part of a family, part of a community.

Each time in my early life when I faced a seemingly insurmountable obstacle, someone would always reach out to lend me a hand. As a young female Latina immigrant who wanted to be a doctor, I was always an underdog. It was hard to master new material when I was always translating everything from Spanish to English in my head. But the people who coached me through my lessons did more than help me pass tests: they expanded my world and my sense of self. I'd say, "Wow! I didn't understand this before, but now I love it!" And the fact that my mentors believed in me taught me to believe in myself.

Today many of us worry that it is no longer possible to be part of the kind of interconnected community I grew up with. Once when I was going through a difficult moment, I passed someone in the hallway who asked, "How are you doing?" I felt so despondent that I admitted: "Not so great." "Have a nice day!" they responded and kept on walking. They didn't ask what was bothering me or how they could help. It is at times like that when I find myself missing the day when my father would call just to see how I was doing or a family member would come over for coffee and conversation because they thought they heard a worried note in my voice on the phone. I miss feeling part of that kind of tight-knit community.

We have such busy schedules that we may feel too busy for another phone call or conversation, but we will never rebuild our sense of community until we start listening to one another. As a doctor, I've learned that the most important thing I can do for a patient is listen to their story. By listening, I affirm their humanity. I let them know they are seen, heard, cared about, and respected.

If you want to start building a connected community, begin by "listening" to the storytellers in this book share their life experiences. The authors are all members of Worcester's Clemente Course in the Humanities, an award-winning college-level academic program for highly motivated low-income adults. You may be surprised by how much you have in common with these writers. They are committed to improving themselves and their communities. They are determined to build a better life for their children. They are invested in caring for their ill or disabled loved ones. But you may also be surprised by the magnitude of the challenges they have overcome and those they still face. I hope you come away feeling--like I do--a strong sense of respect for the talents, ambition, determination, and resilience of these Clemente authors.

I'm also impressed by the number of people I meet in my work as Worcester's Commissioner of Health and Human Services who have struggled with substance use, homelessness, or incarceration and are still determined to use their talents to build a good life. It is my privilege to serve them. Their stories remind me that I, too, was once an underdog. Who could have dreamed that a young immigrant from Cuba whose father had only a third-grade education could succeed in becoming a doctor and then go on to serve as Worcester's Commissioner of Health and Human Services? Mine is the quintessential American story. But what made it possible was the support of my family and community—all those people who cared enough to help me make the most of my talents.

If we are ever going to enjoy the benefits of living in a connected community, we must begin to listen to one another's stories with curiosity, empathy, and respect. We must recognize all we have in common and learn from our differences. Whether as doctors, teachers, legislators, business leaders, members of religious congregations, or neighbors, it is up to us to build the kind of community we want to live in: one where we listen to one another and then reach out our hands to hold each other up.

LUCIA KNOLES

Introduction

All that may be needed is that the injustice in the world be mentioned so that nobody can ever say, "Nobody told me."—Lucille Clifton

When George finally answered the phone, he explained why he had been so hard to reach. “I’m in the hospital; I had a heart attack; I’m in the hospital.” As a concerned and naturally pushy friend, I immediately challenged him. “Have you been taking care of yourself? Have you been eating right and exercising?” But George just laughed in response, and I froze in embarrassment. Suddenly I remembered that he had spent the previous months eking out a precarious existence in a New York shelter. And that’s where he would return after just a few precious days of respite in the hospital. It was not George’s decision to eat fast food or skip the gym that had put him in this fix. It was the lack of good choices available to him.

I first met George when he was enrolled in a course I was teaching in the Clemente Course for the Humanities. (He is an exemplary student.) Clemente is an award-winning program that offers college level courses free of charge to low-income individuals seeking a better future for themselves, their families, and their communities. In order to qualify for Clemente, applicants need to demonstrate that they are over 17 years old, have a family income of 150% of the federal poverty line or less, and can read a newspaper in English. Nationally, the majority of Clemente students make less than $10,000 a year. In Worcester, virtually all of the students we serve also come from one or more marginalized groups. In addition to being low-income, for example, they are often immigrants, people of color, members of the LGBTQ+ community, people with disabilities, and/or people who were formerly incarcerated.

I have never worked with more highly motivated students. They love learning and they are committed to using what they learn to contribute to the world. George is a perfect example of the intelligence, ambition, leadership, and idealism of his classmates. Before leaving Jamaica, he had studied social work and trained public health professionals on how to interact with people with disabilities. Since coming to the US., he has been a member of his local Human Rights and Disabilities Commission in Worcester, MA, drawing both on his academic training and his experience living with the long-term effects of childhood polio. George was also a featured speaker for community groups on the experiences of LGBTQ+ asylum speakers. Yet there he was marooned in a hospital bed recovering from a heart attack without a home or job to return to upon his release.

Up until that memorable conversation, I'd always assumed health equity meant that everyone should have access to healthcare. But my former student's plight helped me recognize that health equity meant something more fundamental: everyone should have a fair and just opportunity to achieve optimal health. In his story, "From Massachusetts to New York," George describes the stress he felt in the months leading up to his heart attack. He explains: "I felt very, very, very at-risk at that shelter. So many of the guys were substance users, and I'm not talking about marijuana. Some of them who had mental issues were combative and could explode into violence." Later George learned that he had been mistakenly assigned to a facility for the mentally ill and formerly incarcerated—but he could never persuade anyone to correct his record or arrange a move. Could anyone say that living in the shelter provided George with a "fair and just opportunity to achieve optimal health"?

My conversation with George made me take a fresh look at my other Clemente students. Suddenly I realized that most of them were struggling with long term physical and mental health problems that were related to the circumstances under which they had grown up and the conditions under which they lived as adults. These health concerns constrained my students' ability to fulfill their dreams—or in many cases, even their ability to meet their basic needs and responsibilities. What right could be more fundamental than the right to health equity, and what could have more sweeping consequences than health inequity? A person who does not have a fair and just opportunity to achieve optimal health cannot have a fair and just opportunity to live their optimal life.

Clemente students are likely to live in neighborhoods where it is easy to access drugs but hard to buy fresh fruit; easy to get to a liquor store but hard to attend a good school. People in these kinds of environments—and children growing up in these kinds of environment—are more likely to be exposed to lead, overcrowding, chronic noise, violence and other threatening environmental factors. Our students suffer toxic stress from living in toxic environments. They spend their days struggling with food insecurity, housing insecurity, job insecurity. They experience chronic stress related to their race, class, ethnicity, immigration status, disability, gender identity or sexual orientation. When they seek treatment for their health conditions, they may encounter structural or personal bias. And even when they don't encounter bias, they suffer from the stress associated with bracing for battle.

These kinds of factors, sometimes described as Social Drivers of Health (SDOH), impact both physical and mental health. Research suggests that SDOH can trigger potentially damaging changes in DNA, trigger alterations at the hormonal and cellular level, and cause chronic inflammation leading to disease. In addition, chronic stress can impact the brain's capacity for learning, remembering, controlling emotions, and making decisions. Yet in keeping with our national belief in individualism, a 2019 study showed that three quarters of Americans agree that "people are in control of their own health" and "people's health is in their own hands."[1]

As I thought about the health challenges faced by Clemente students, a map of Worcester formed in my memory. I'd first seen the map a few years earlier in a report produced by the Worcester Division of Public Health in collaboration with UMass Memorial Health, the Coalition for a

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[1] 1 Hook C. J., Markus H. R. (2019). [Survey of Americans' attitudes towards personal responsibility for health]. Unpublished raw data. Quoted in Hook, C. J., & Rose Markus, H. (2020). Health in the United States: Are Appeals to Choice and Personal Responsibility Making Americans Sick? *Perspectives on Psychological Science*, 15(3), 643-664. https://doi.org/10.1177/1745691619896252

Healthy Greater Worcester and Fallon Health. One end of the map showed the Salisbury Street neighborhood where my husband and I have spent our adult lives working at cultural and education institutions. The other end of the map depicted the Kelly Square neighborhood where many of my Clemente students live. Measured one way, the distance between the two was a brief two miles. Measured another way, the distance was an astonishing eleven-year difference in life expectancy. I had often driven through Kelly Square but I had always been entirely focused on navigating the precarious traffic pattern. I'd never paused to wonder about the personal stories of the people who were navigating precarious existences in the neighborhood. How could I help people bridge the distance between the geographies of our different lives?

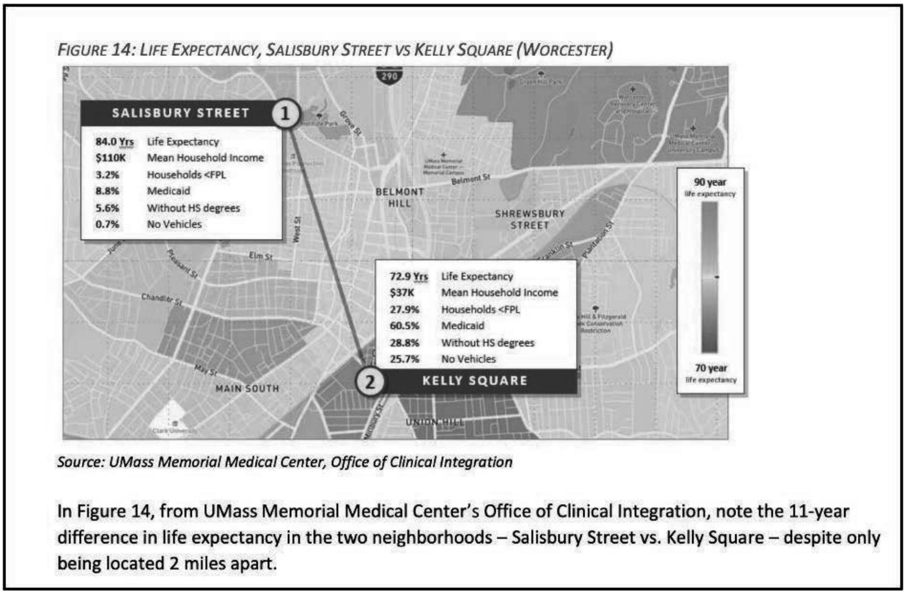


FIGURE 14: LIFE EXPECTANCY, SALISBURY STREET VS KELLY SQUARE (WORCESTER)

Source: UMass Memorial Medical Center, Office of Clinical Integration

In Figure 14, from UMass Memorial Medical Center's Office of Clinical Integration, note the 11-year difference in life expectancy in the two neighborhoods – Salisbury Street vs. Kelly Square – despite only being located 2 miles apart.

Source: 2021 Greater Worcester Regional Community Health Assessment

The thoughts set in motion by my conversation with George led me to offer a 2024 Clemente Worcester summer course called "Storytelling Our Way to Health Equity." Thanks to the support of Mass Humanities, which regularly sponsors Clemente courses across the state, I was able to meet regularly with a group of Clemente students interested in sharing their experiences dealing with illnesses, disabilities, and the healthcare system. During that same time, I was also meeting with a group of medical professionals interested in sharing their experiences of dealing with patients from historically marginalized communities. The stories in this collection--also funded by Mass Humanities--were written by students and doctors who participated in those sessions.

Stories are uniquely suited to helping us connect with one another across differences in experience or perspective. But stories can be dangerous if we only listen to those that confirm our own preconceptions. As author Rebecca Solnit explains in *The Faraway Nearby*, her extended meditation on the relationship between narrative and empathy: "You choose to hear what corresponds to your desires, needs, and interests, and there are dangers in a world that corresponds too well, with curating your life into a mirror that reflects only the comfortable and familiar." Often, we do this unconsciously. It is to mistake the stories of the people like us for the whole story because it is also our own story. It's what we know. It is easy to dismiss health equity as unfortunate but not unjust if we assume everyone enjoys the same range of choices and opportunities. That is why Americans need to hear the first-person experiences of those who live with health disparities daily.

Solnit explains how we can expand our lives beyond the boundaries of our personal experiences by actively listening to stories.

> To hear is to let the sound wander all the way through the labyrinth of your ear; to listen is to travel the other way to meet it. It's not passive but active, this listening. It's as though you retell each story, translate it into the language particular to you, fit it into your cosmology so you can understand and respond, and thereby it becomes part of you. To empathize is to reach out to meet the data that comes through the labyrinths of the senses, to embrace it and incorporate it. To enter into, we say, as though another person's life was also a place you could travel to. . . Empathy is a journey you travel, if you pay attention, if you care, if you desire to do so.

Like Solnit, the authors of the stories in this book are asking that you listen. They are not demanding that you "fix" their lives or the problems of health inequity. They are mostly asking you to see and hear them.

Clemente author Laura DiCaromino closes her story about her mother's stroke, "The Best Day," with this urgent instruction to those who deal with her mom in the future: "No matter how incapacitated she is by her medical problems, she is a human being who deserves compassion, respect, and to be trusted as the expert in her own life experience." And despite the suffering he experienced in the shelter and the hospital, George concludes the story of his heart attack by thanking "the primary care physician and case worker who saw me as a human being. They helped heal more than just my body."

The title *See Me Through My Grandma's Eyes* is taken from the story in which Theresa Buccico remembers the terrible night when she was eleven and the grandmother who raised her was hospitalized after a traffic accident.

> Once at the hospital, all I could think about was when I would be able to be reunited with Ma. But my requests to see her—maybe for the last time—were ignored. Instead, the doctor taking the glass out of my forehead asked me, "Does this hurt?" "No," I exploded, "it fucking tickles!" The doctor immediately stopped treating me and said he was taking me to tell my (grand)mother how I had spoken to him! He seemed to be more worried about his dignity than my physical or emotional pain. However, I was relieved to finally have a chance to see my ma, and when the doctor complained about my behavior, I knew [my grandma] really saw the scared little girl in front of her. Instead of a foul-mouthed brat she saw her ninth grade A student project fair winner. . . Looking back, I wonder why [the doctor] was so offended by my sarcasm that he couldn't see the frightened little girl in front of him. He needed to see me through my grandma's eyes to really see me.

To be seen, to be heard: these are not extravagant demands. But it is only by seeing and listening that we can move beyond the limitations of our life experiences. It took real courage for these authors to share such intimate and difficult moments from their lives with people they do not know. The writers are taking the risk that you might NOT see them through their grandmothers' eyes. But these stories are offered to you in the hope that you will accept the invitation to take a journey, "as though another person's life was also a place you could travel." The authors are placing their faith in Solnit's belief that empathy can be a journey to a more expansive sense of life. If you pay attention. If you care. If you desire to do so.

First-Person Stories by Members of The Clemente Course in the Humanities, Worcester MA

THERESA BUCCICO AKA THERESA QUINONES

United We Stand Through the Cries of an Opiate Orphan

When conversations are taboo, wounds never heal. Pain is passed down from ancestors along with physical traits: I can hear the echoing of their souls' cries. To find a home where I could feel at peace, I needed to uncover the past that had been buried with people, some of whom I'd never met. I needed to discover the family truths that had been tightly wrapped up in secrets and lies. Now my voice, the voice of an opiate orphan, will finally tell the story that heals.

ONE

I am Theresa, named after the grandmother who raised me since I was an infant. I will always refer to her as "Ma" as I am forever her Mija, as she called me ("my daughter"). Ma filled me up with great memories that come back to me time after time. The smell of sofrito when I'm making it as she taught me, the sound of the songs she played from Luis Miguel to Bocelli.

Although I grew up in a basement apartment, Ma made everything beautiful. I can't forget the lit-up dumpsters in the Valley at night. The orange light created ghostly shapes that floated to the sky: the project's campfire. If you'd seen me playing in Elm Park or dancing on the stage at the Latin festival of Institute Park, you would have seen a happy kid. Until I was eleven, life still had innocence.

TWO

It only took a four-hour New York trip to Brooklyn to take away the life I thought was mine. Until that trip, I didn't know the feeling of being less than. Until that car ride, never did I realize I was not Ma's daughter but her granddaughter.

This is how I met my biological mother.

Ma is driving the car, and I'm in the back seat. I had heard Ma say, "This is my daughter," when introducing the woman she calls "Gigi." She has an angelic glow around her. Her white coat trimmed with white fur on the hood is beautiful. When I finally get the courage to engage her, I call, "Gigi!" So why do I get reprimanded?

She looks at me side-eyed, and with an attitude in her tone says, "I'm your mom." How can this be? I have no memories of her, and yet the feeling in my gut doesn't dispute the truth. I look at her and see dimples on her face that I know from my own. She abandoned me!

By the end of that ride, I had grown closer to the painful truth, but it was a truth that brought no healing. Instead, each new experience of my birth mother in my youth increased my anger.

I felt anger when my mother abandoned my baby sister, Jasmine, who was born not long after that car ride. And when Jasmine died at ten months, I felt overwhelmed with pain. Having made my baby sister smile, having held her little body and played with her, I couldn't understand why she was gone. Now I know she was infected by my mother at birth with HIV. I was in fifth grade. It was my first funeral.

By the time I was fourteen years old, I was already used to helping Ma clean out apartments after Gigi would disappear again because of drugs. Unforgettable for me was the pain on Ma's face: that look reminded me it wasn't only me Gigi was abandoning. When Ma would say with a shaky voice, "Mija, be careful of needles," I knew she was warning me about something more than getting stabbed while cleaning. She was worried that I would become my mother. I was never given an explanation. But I would always reassure Ma somehow that I understood: making a silent pact that I would not make the same mistakes.

THREE

By the time I was seventeen, Ma was aging quickly. As she declined, she began to pass on long-hidden family stories.

I was one of seven children born to Gigi, beginning when she was only sixteen. But Gigi wasn't there for any of us because she put drugs and alcohol ahead of parenting. Listening, I became able to imagine my infant self, left alone by Gigi to be scarred both physically and emotionally over hours and days. The scars I still have on my right thigh testify to that infant pain. But I could also picture Ma bringing me home to Massachusetts on a Greyhound bus in 1981 after a painful call from her daughter Gigi. Ma said that it was one of the smelliest rides she ever had, but as I lay still in her arms, we both smiled. "It was meant to be Mija," she'd say. Each time she retold that story, she smiled. I could hear her pride. My older brother joined us when he was three. Home was the three of us. Gigi never raised any of her children.

But Gigi, too, had been abandoned by a parent struggling with drug use: her dad. And at the age of eleven Ma, too, had been abandoned along with three younger brothers by her mother, Emilia Garci, back in Humacao, Puerto Rico. This multigenerational cycle shaped Ma's life experience, Gigi's life—and my own. Yet, despite all the trauma passed down because of abandonment, alcohol, drugs, and mental illness, Teresa Curbelo was able to raise me with love. And that, too, shapes who I am today.

Gigi died in her early forties. Like her father, she was taken by the early '80's inner city tsunami: heroin use with needles led to HIV infection. I was only twenty-four years old, and despite my tacit promises to Ma, I had started down my mother's path. But my mother's death was the turning point of my life. I would never use drugs again. In a sense, that was Gigi's gift to me.

FOUR

Ma's gift for me was the way she nurtured and loved Gigi, my brother, and me in spite of all that pain and brokenness. She never gave up on any of her family members. She always prayed and stayed in faith. She taught me it was not my place to take on ancestral pain or behavior patterns. I had the right to rise up from the brokenness of the past. She empowered me to Live, Dream, and Love! So, I no longer question whose child I am. From the time I was an opiate orphan to the day my flesh becomes one again with the earth, I am and always have been, a child of God and Ma's daughter.

Now time like a thief in the night carries Ma away. I'm thirty-five and although Ma is in her eternal Home in heaven, she carries on with me. Her voice in my heart tells me "Mija, I always go before you, to prepare a place for you, so that you may always feel at home."

And I carry on her legacy. With my husband, I am raising our two daughters, ten and fifteen. My oldest daughter carries her grandma's name as her middle name in English translation, Estrella means Star. And my youngest carries her nickname, we call her Gigi.

FIVE

There was a time in my life when I believed my soul was broken. Looking in the mirror, I couldn't unsee the reflection of Estrella, Teresa, and Emilia in me. Would history repeat in me? Living past the experience of the women who had come before me would take strategy. Could I do it?

Now some wounds have healed: I have beautiful scars. Learning and telling the story of intergenerational trauma is the process I'm using to mend my heart and mind, body and soul. These are no longer the lonely cries of an opiate orphan, but instead the song of a woman who stands united in memory with her mother, grandmother, and great-grandmother, loving them all back to life as Ma did for me.

THERESA BUCCICO

See Me Through My Grandma's Eyes

For the first ten years of my existence, I had the life of a child. But when I was eleven, I found out that the woman I called "Ma" was really my grandma, and my biological mom was her only birth child. Learning this secret caused me to question everything but Ma's love for me. But when I was fifteen, my belief that Ma would always be there for me shattered like the windshield I flew into.

The sun had just set and Ma and I were headed home from the laundromat accompanied by the wonderful smell of freshly washed clothes. As we approached a bend in the road, we were blinded by the light of headlights charging towards us. When the car hit me, I flew into the windshield, smashing a hole in the glass with my forehead.

All my life red had been my favorite color and fresh laundry had always given off my favorite smell. But now laundry was scattered all over the crashed car and everything I saw looked red because of the blood running down my face.

Through the broken passenger window, someone handed me a green and white checkered hand towel. Now I know it was a lady who saw the crash happen in front of her house--she was the first person I saw. After I wiped my eyes, I looked over to my left. Ma was in agony. Although she had a bone sticking out of her left leg, her first words after the accident proved her determination to take care of me. "Are you OK?"

As I said "yes" through bloody tears, my fears overtook my physical pain. My feelings of powerlessness intensified as I watched the jaws of life work to free Ma from the wreckage. I felt alone and overwhelmed. Suddenly, instead of Ma being responsible for me, I would need to advocate for myself—and for her.

Sent to the hospital in a separate ambulance from Ma, my mind continued to grapple with reality. No one would be coming to help me. My biological mother was in a treatment facility for her lifelong substance use disorder. My father—who I had met for the first time only the year before—had no contact with me. My brother was incarcerated.

Once at the hospital, all I could think about was when I would be able to be reunited with Ma. But my requests to see her—maybe for the last time—were ignored. Instead, the doctor taking the glass out of my forehead asked me, "Does this hurt?" "No," I exploded, "it fucking tickles!" The doctor immediately stopped treating me and said he was taking me to tell my mother how I had spoken to him! He seemed to be more worried about his dignity than my physical or emotional pain.

However, I was relieved to finally have a chance to see my ma, and when the doctor complained about my behavior, I knew she really saw the scared little girl in front of her. Instead of a foul-mouthed brat she saw her ninth grade A student projects-fair winner. She grabbed my hand in hers, and in her soft voice looked me in the eyes and said, "Mija, behave". I remember thinking: "Ha, ha, doc! She loves me no matter what." In retrospect, I can see from that point forward all the decisions I made were shaped by my determination to never disappoint Ma. Her love gave me the courage and strength to move forward.

I don't recall the doctor's reaction to this episode. All I know is that he never completed my treatment. Looking back, I wonder why he was so offended by my sarcasm that he couldn't see the frightened little girl in front of him. He needed to see me through my grandma's eyes to really see me. Years later I still had glass coming out of my forehead. Twenty years after the accident, I learned that I still had damage to my neck and a curve in my spine that might have been detected when it happened—but I was never given an x-ray. Instead, I was sent home soon after the doctor complained about me to Ma. I was asked if anything else hurt besides my forehead. Of course, I said no.

I spent the next six months bouncing from one church family's couch to another throughout the city. I started off with a friend of Ma's from church, but the friend was a single mom of two teenage girls and only two weeks and three teens later it was all too much. I never lasted anywhere despite being well-behaved. I never missed school. I would walk or take the public bus from wherever I was. I would work at Burger King on the weekends as a cashier and visit Ma every day after school.

This was the turning point of my life. Life as I'd known it was gone.

Six months after the accident, as I entered the eleventh grade, Ma was finally ready to come home. Each day before I headed off to school, I made sure she had taken her medications and had breakfast. After school, I'd make her lunch before heading to work.

This is when I became responsible for Ma and for myself. Both of our lives—our physical and emotional health, our well-being and growth—were completely dependent on my ability to adapt, learn, and apply what I had learned. I wondered what our future would look like.

Today I am proud to see how far I've come despite the odds. I use my experience as a survivor of multiple tragedies to advocate professionally for marginalized people labeled difficult. As a Massachusetts Certified Peer Specialist, I focus particularly on supporting those with co-occurring disorders of a mental health condition and substance misuse. Over the years I've learned to use communication as an art form to create a portrait of people's needs, so they get the attention, empathy, and help they need and deserve. I know from my own family's stories how important that is.

Today I am calling on all medical providers to humanize healthcare. When people seem silent, ask yourself if you're really listening. When people seem difficult, ask yourself if they have difficult lives. My story was hard—not me! I am pleading for medical professionals to approach patients and family members with curiosity, compassion, nurturing, and holistic healing. Let my voice remind you that someday a story will be told about what you did or failed to do in the course of your career. Make sure that when that time comes, people tell a story about a person whose skill was matched by their empathy as they cared for humanity.

THERESA BUCCICO

My Last Baby Doll

I named my last baby doll Penelope. I was about ten years old and remember thinking, "When I become a mom, I will give that name to my daughter."

When I was twenty-one, I tripped over a phone cord and fell, breaking the radius of my arm to the elbow. But the ER nurse had more important news: I was pregnant. My boyfriend and I were in love and full of excitement about bringing a new life into this world. Over the next few weeks, we went to doctors' appointments and heard the baby's heartbeat. We waited with joy for the ultrasound that would let us see our baby for the first time.

It was finally time for the ultrasound when I was four months pregnant and at the beginning of my second trimester. An ultrasound technician escorted my boyfriend and me to an examination room and had me lie on a table. Following her instructions, I lifted my shirt under my breast. Soon, cold jelly, a transparent blue, covered my bulging belly. Now the lights dimmed as they would in a theater before the grand appearance of the beloved star. I took deep breaths. This would be a breathtaking moment.

There! The baby appears in an instant! We are mesmerized by this tangible affirmation that we are having a baby. A moment frozen in time.

But only a moment.

Where is the heartbeat? I couldn't hear the ultrasound tech voicing any concerns, but maybe that was because the noise in my head was deafening.

Something was wrong—but before I could ask a question, the tech ran out of the room, saying: "I have to get a doctor!"

In an instant joy turned into pain.

Because the ultrasound tech had left the monitor facing us, my boyfriend and I continued to stare at the still image on the screen. Our baby was gone. Penelope was gone.

I am still haunted by questions. Why didn't the tech page the doctor instead of leaving us? Why did she leave us facing the image of our lifeless child? Why did the doctor come in and shut off the screen?

Today, even with my eyes wide open I can still see the image of my lifeless baby on the screen. Losing my daughter was traumatic, but I was further traumatized by the way I was treated that unforgettable day. Since statistics show that ten to twenty percent of pregnancies will end in miscarriage, why aren't we doing a better job of educating medical professionals on how to provide trauma-informed care? I certainly didn't receive any. Instead, I was left alone in a room to dread hearing the words that would finalize the fact that my baby was gone. Left with a cold womb and a bleeding heart to grieve the loss of Penelope, the lifeless baby I would always love.

DUKROA OWENS

The Sun Rose & Mama Roared

Genetics are passed down, DNA is created, a life form is born, we call this birth.

A rite of passage into the world - ideally the newborn is welcomed…what if the newborn is rejected?

Surely it cannot have an impact at all on a being so new to the journey - or, to the contrary, would it act as the catalyst, the black cloud that looms above blocking any light from entering leaving a cold, wet & lonesome environment?

The child(ren) would not realize these are symptoms of this environment because it's the only thing they have ever known.

Adapting to the darkness, coping with the isolation, and suffering in silence--as they say, ignorance is bliss.

This pattern becomes a generational cycle the effects are lasting and most times crippling.

It would impact things such as parenting, the individual's quality of life etc.

I am sharing some of my experiences in hopes of change.

What does that look like? Where do we start?

Is it with the last generation's children who are now the parents? Or is it with the children of this generation lost in "the system"?

How can you choose between the chicken and the egg? Shouldn't we choose BOTH?

These are my humble beginnings. i am the true product of the environment i was raised in …

Poverty, pimping, prostitution, drugs & alcohol etc. you know, "The Life."

One would assume born of these circumstances the outcome would be bleak.

Statistics support this until the variable is introduced.

I, Dukroa Owens, am that variable!

We all have a journey. Today i am going to share some of my experiences as a neurodivergent BIPOC mother with a dual diagnosis (not every disability is visible!) slipped through the cracks in a broken system.

I was born into "the system" prematurely & drug addicted.

My mother was caught up in "the life" at the time of my birth. I spent the first months of life in the neonatal intensive care unit gaining enough strength to go home with my grandma.

So when I think about my earliest childhood memories I remember being in the kitchen with grandma. Everyone called her Mrs. G. While she was prepping and cooking, I would set the table. Then, grabbing a few pieces of raw onion I would sneak underneath, crunching & crying.

When my mom finally found recovery and stability after a few attempts, my siblings and I were going home with her. It must have been bittersweet for Mrs. G. All the cousins were usually piled in practically on top of one another. The bed, couch, and floor in her one bedroom were filled full of love if you ask me. It's all a lot of us knew. Our parents would pop in from time to time, but at the end of the day, it was Mrs. G who held it down.

The truth is I was a little scared to go home with my mother. I did not know what to expect, but I mostly remember being excited. I knew Mrs. G wasn't my mom; we all did. So the common dream in the house was to live with our parents at home and be loved and wanted.

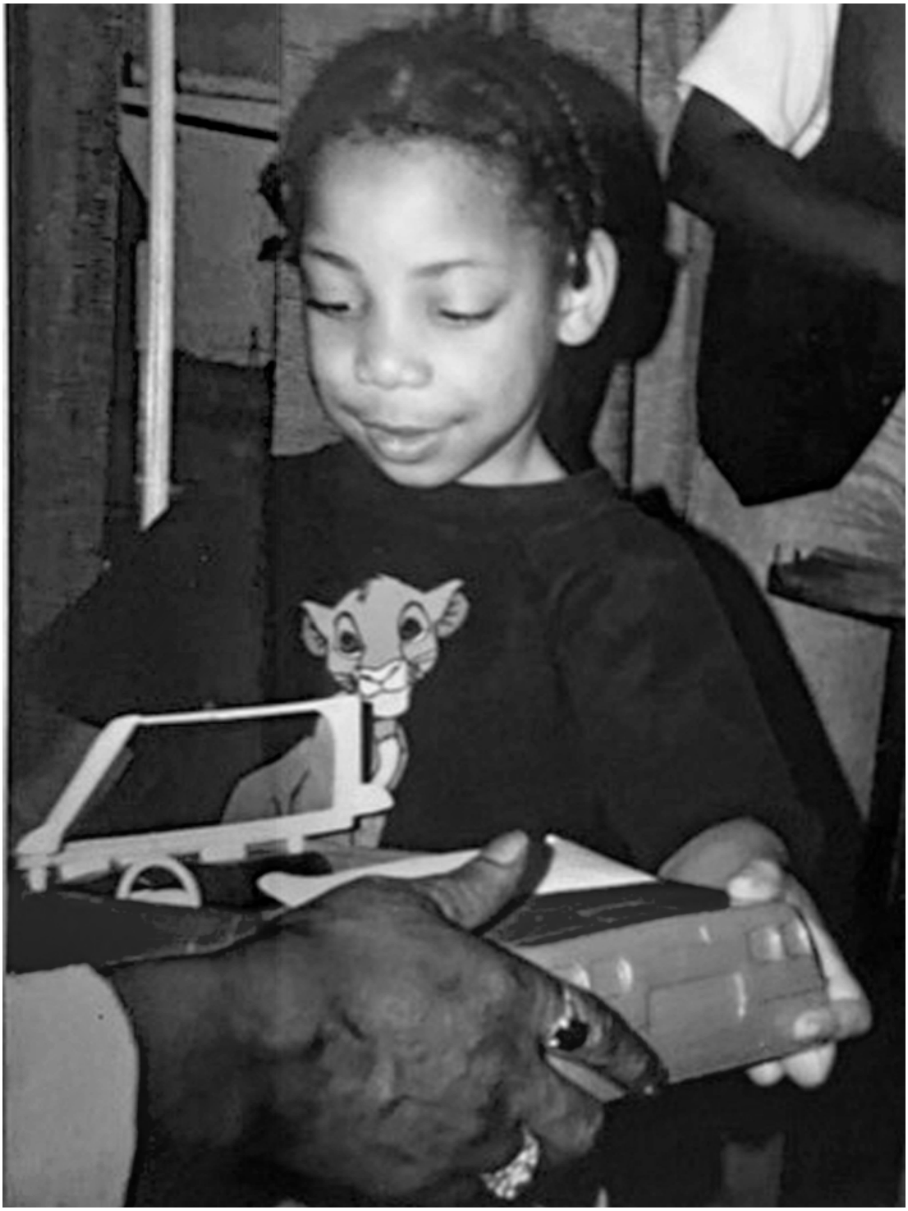
The first time I ever had a party was my ninth birthday, and one of my aunts from Boston came along with a few of my cousins who were visiting Mrs. G from Florida. They brought me a pink and white convertible Barbie car as a present.

Usually, we were not allowed to have any sweets and that was the first time I tried cream soda. I didn't know what it was. I just knew it was sweet and delicious cup after cup. I drank nearly the whole bottle. It was the highlight of my day, to this day it's still my favorite soda.

Around that same time, we had scoliosis checks in school. As I heard the nurse calling classroom by classroom, my heart began to race. I thought, "I can't let them see my back." My hand went up. "May I use the bathroom?" My teacher wrote me out a pass, and said, "Hurry up, our class is next!"

"Okay," I said.

Beginning a light jog down the stairs toward the EXIT in bright orange, I dropped the pass and pushed out the doors. Jogging down the block, I was thinking I'd gotten away. Then a car pulled up and brought me back to the school. In the principal's office with the security guard, the nurse asked if she can check my back. I said, "No." She said, "It's painless." Then she walked behind me, lifted my shirt, and gasped "Oh my!" at the sight of my black and blue back.



Dukroa Receiving a Barbie on Her Ninth Birthday.

They called the Department of Social Services. My mother was called to the school and so were the police. My siblings were removed from class and we were all placed into foster care.

Welcome to being nine. I was not starting the year off right.

All the years she had taken care of us, Mrs. G had kept herself together. One by one her kids began to get their lives on track, and eventually there were no more kids to look after. She didn't need to live for us anymore; she was not in shape when we needed her again.

From that point on, my siblings and I were bounced around from foster home to foster home, group home to group home.

We had weekly visits with my mother for a little bit, then they went to monthly, and eventually to none. My mom's anger, frustrations, and threats had consequences.

During the time of moving from foster home to foster home, I dealt with sexual assault, sexual abuse, sexual trauma. I had already experienced that with the men who would frequently show up to "check on us" when we lived at home. Now it was continuing with other people who were getting paid to care for me.

Eventually, I got placed in a home with my sister, and the same cycle began: grooming, touching, etc. When I noticed the same thing was being done to my little sister, I made complaints to my social worker and the supervisor and even recorded a statement for the District Attorney. Nothing ever happened to that family. But even though I know no one believed me at that time, I was successful in getting my sister moved from that home.

I quickly got a reputation for being "difficult," so my stays were short and moves were frequent. It got to the point where I just stopped unpacking.

My younger siblings went on to be adopted. I got sent to a group home for acting out, and when they decided that I needed a higher level of care for my C-PTSD (Complex Post-Traumatic Stress Disorder), anxiety, dissociative and paranoia disorders, they sent me to an intensive residential treatment program (IRTP) at Taunton State Hospital. This was to be my home until age eighteen when I aged out of “the system.”

Throughout all those years, I was immensely angry at my mom because I was told my mother signed her rights away. That's why I was there: no one wanted me.

This anger fueled me. I got a job, a car, an apartment, and enrolled in community college. Within six months I had to go to a step-down program to manage my gradual transition to independent living. (You cannot just reintegrate into society after the level of care I'd received at Taunton State Hospital.)

Angry upon arrival, I ran away. It only lasted for a day, but that's all it took to be assaulted and end up pregnant. Once my worker found out she said "You should not be a mom. The apple doesn't fall far from the tree." She booked an appointment and took me to the abortion clinic. In the car, she told me to lie down in the backseat, and she threw a blanket over me. I could hear people yelling "baby killer" and throwing eggs that splattered against the windows.

Once inside the clinic, the case worker signed all the paperwork and said, "They will call me when you're done." I sat frozen in that chair in shock.

Naturally, I did not set out to be a mother after that first experience. But at the age of twenty-one, I discovered I was six weeks pregnant even though I had a birth control implant in my arm. I had the baby.

A few years down the road, I was again sexually assaulted and ended up pregnant. This time the decision was within my control, so I continued with my third pregnancy. I was scared to be a mom, but my two beautiful daughters turned out to be my world.

My oldest daughter is athletic and artistic. She goes from dancing and doing acrobatics to drawing anime and sketching dresses. I bought her a sewing machine so she could work towards one of her many dreams: being a fashion designer.

She is very loving, very sensitive, attentive, and a great older sister. She likes everyone to be happy. If her sister or friend wants to play a game, she will play. If someone wants a toy, she will say, "You can use it, I will do something else." She has a heart of gold and a smile that lights up a room.

My youngest daughter is my sweet, spunky, comedic cuddler. Her favorite color is pink in any/every shade. She is clean and organized. All of her toys have their own spots in her toybox. She enjoys being outside and loves to sing and dance. She is fiercely independent and has a laugh that is infectious.

I never experienced a mother's love. (My mother loved me; her love language just differed from mine.) But I decided that love from a mother is sacrifice. It's doing any & everything in your power to put and keep a smile on your children's faces.

It's keeping them warm, fed, and safe, and always letting them know they are loved, they are special, they are wanted, and you believe in them.

I was never a mother to use physical discipline.

I was never a mother who sugar-coated the truth.

As a woman who grew up the daughter of an addict and alcoholic with trauma and undiagnosed mental health conditions, the only way I knew to be a "good mother" was to do the opposite of everything I had seen her do . . . So when I found myself attempting to cope by drinking and using substances, I knew I was headed for trouble. The only thing I could think of was to get a new phone number, lock myself in the house, and send my money out of my reach to a "friend of the family."

Life with my daughters at home was beautiful, but I was dealing with a lot of things. I was going through a med change and was pulled out of work for a medical (mental health) reason. Because of the pandemic, I was trying to virtually homeschool two children in two different grades at the same time even though I have a learning disability. I also had to handle food, laundry, and hygiene—while being evicted. All this I had to do on my own with two girls looking up at me like: "We believe in you, Mama, you always get it done!" (But inside feelings of guilt, failure, and worthlessness were building.) It was more than overwhelming.

Around this same time, I noticed my oldest daughter's breasts growing seemingly overnight. As a survivor of sexual abuse myself this triggered immediate red flags. I began speaking to my therapist about it. She said the kids today are advanced. She asked if my daughter was showing any signs of abuse. I monitored and reported weekly that there were no changes in her mood or personality.

But I could not shake the feeling that I missed something; I could not live with myself if I did. (I would rather be loud and wrong than quiet and right.)

It was a Friday three weeks after my oldest daughter's ninth birthday. I had just received their school pictures. This was a mommy milestone: my girls were in first and third grade. I was thinking about what my sister and I had experienced as young girls, and I went into protective mode. When I took my daughters down to the police station asking for them to be checked for signs of assault, the police asked if I had proof. I said, "No, just a feeling." The officer replied: "Mother's intuition?" I said, "Yes, if that's what you want to call it."

I was given a voucher for a cab and the girls and I were sent home. Feeling dismissed and treated like a crazy person only fueled me being in crisis!

I called the ambulance this time and asked to be picked up so my daughters could be rape kitted. The EMTs arrived, and we went to U. Mass Memorial.

In the hospital room, I had one daughter on each side as we lay on the bed watching TV. As I kissed them both, a nurse popped in and said the doctor was ready to speak to me and that she would wait with them. I told them I would be right back: I was getting help. (It turned out to be the biggest lie I've ever told my daughters!)

Down a few doors I was met by a male doctor. I tried to focus on the contrast between his skin and his dark hair as my anxiety rose, but it didn't work. I knew that everyone I came into contact with at the hospital was a mandated reporter required to turn in suspected cases of abuse or neglect, so I had a full-blown panic attack as I attempted to explain what brought us there without looking like an abusive or neglectful parent.

Seeing my panic symptoms, the doctor said, "What do you usually do when this happens?" I said, "I need fresh air and a Newport." He said I could step outside, and I did.

After about ten minutes, I was able to get myself together and re-entered the hospital only to be stopped as I tried to go into the ward. I said, "I was already here; my kids are back there." Then a social worker walked up and said my daughters were being removed from my custody and placed into the custody of the Department of Children and Families (DCF). I let out a shriek and fell to my knees. The security guard lifted me into a restraint chair and placed a spit mask on my face. I was wheeled up to the psych unit where I was kept for three days.

Upon release, I was given a cab voucher home, some prescriptions to fill, and a court date for the next morning. Eleven complaints of child abuse or neglect had been filed against me. Two of those charged me with abandoning my children by stepping outside the hospital door when the doctor suggested I do that.

If the people at the hospital had called the crisis response team instead of security and DCF things would have gone very differently. I needed to be supported instead of stigmatized. I was hyperventilating and experiencing a panic attack as a result of the severe anxiety disorder I live with. Why wasn't I helped as a patient instead of treated as a criminal? All

I was doing was what I thought was necessary to protect my daughters I love dearly.

When I appeared in family court my public defender told me to waive my right to trial, saying: "They have so much against you that you will lose."

As I stood in front of the judge just off my involuntary commitment in the psych ward, I got lost in all the verbiage. When the judge began to ask me questions, the attorney put her arm around me and squeezed so tight as if to tell me to be quiet and let her talk. After she spoke on my behalf, they placed the paperwork in front of me, and I signed it, agreeing to work voluntarily with the department.

Against my better judgment, I trusted "the system" that had let me down and hurt me so many times before.

It is going on three years and I still have not regained custody of my daughters. I have lost birthdays, holidays, milestones, and time that cannot be replaced! That's the worst part--what “the system” takes from you is priceless.

I had weekly one-hour visits scheduled, but my worker would often cancel my visits at the last minute and either reschedule or offer a two hour visit the following week.

Eventually, I became worried about my daughters' welfare and asked the police to do a check on them, but they didn't take me seriously because I'm "crazy." When I went to the foster home to do my own wellness check, the police came and put me in cuffs. The irony. That was almost a year ago. For ten months I have not seen, talked to, or had updates on my daughters.

All this lines up with the tactics the DCF plays with parents. You end up so depressed you die of suicide, overdose, relapse, go to jail, or just give up. If a child over four has been in the custody of the foster system between fifteen and eighteen months and isn't returned home, adoption automatically becomes the goal. A lot of parents don't know this, and it is discouraging enough for some to say, "F it, I tried. Maybe they'll be better off."

And no matter how well the parent does, the progress is not properly documented to get the goal changed from adoption back to reunification.

Since my daughters were taken away, I've done everything I can to improve myself and my health. As soon as I was released from the involuntary commitment, I began making the calls for a bed at an in-patient treatment facility. Ironically, I did not meet the criteria of "addiction." So instead, I began an Intensive Outpatient Program doing Cognitive Behavioral Therapy and Dialectic Behavioral Therapy groups virtually once a week and really began to address my mental health below the surface level. I created a structured routine and began avoiding people, places, and things that were triggering. Working with my therapist twice weekly, I began to unpack all I had just experienced.

This whole ordeal has given me some clarity as well as allowed me to find forgiveness. For years I judged my mom and hated her. I didn't speak to her for fifteen years straight, all because I was told she signed her rights away and made me a ward of the state.

I harbored this resentment all the way until the shoe fit my own foot. I found myself needing forgiveness and praying for understanding. But how could I ask for such things after the way I've treated my own mother? (I am sorry, Mom, for not understanding. I love you, and I get it now.)

There was nothing left to do but call her, and she answered shocked and lost for words. All I could do was cry. But her "mother's intuition" prepared her to understand my problems even before I could explain everything. She said, "I know, baby. It's going to be okay. This is going to be the ride of your life, so buckle up!" It was an ode to her love that even after we didn't speak for fifteen years, when I needed her, she was there.

I suddenly understood the overwhelming difficulties that lie in wait for mothers trying to raise children with too little support, and too little money, parenting in poverty while battling mental health problems.

I shivered as I wondered, is this the DCF/DSS curse that had afflicted marginalized families like mine for generations? My grandmother, my mother, and I had all been taken away by the state just after our ninth birthdays because of our mother's mental health problems. But each one of us had ended up having mental health problems ourselves and losing our own children at the age of nine. I am here to END THAT CYCLE.

I have been a mom since the age of twenty-one living my life for my children. But “the system” took away my job, my responsibility, my title, my children, and my will to live. For the last two-plus years I have felt worthless and suicidal every day and every night I go to bed hoping I don't wake up.

But here is where I am in my healing journey.

The DCF says I am "unable to adequately parent." So I am redirecting my energies. I am focusing on the classes I am taking, carving a path to a better life.

I have always wanted to be a nurse practitioner and have my own holistic healing practice.

I would like to be a homeowner. I would like to travel. I would like to have my own businesses.

I would like to be an established writer/poet. I would like to be a mother and wife.

I would like to continue to be an obedient universal vessel of the Most High GOD spreading Love & Light.

Right now, I am in the process of making my dreams a reality, laying the foundation for what will one day become my legacy.

No matter what happens I want everyone to know how much I love my daughters. I am severely traumatized from the childhood I experienced, and my greatest fear in parenting was that I did not want my daughters to go through what I had gone through. I would like everyone to remember that the times when I seemed "unstable" or "difficult," I was trying to protect my children. I did the best I could with what I knew at the time.

That's why I called the crisis line. That's why I went to the police station. That's why I called for an ambulance. That's why I went to my daughter's foster home to check on them. The result has been having my daughters removed, having no contact with my daughters for almost a year now--and public humiliation.

At any step in this process, someone could have listened to a mother's fears. Someone should have known that there is a lot to worry about when trying to raise your daughters in this world.

When the girls were little the three of us used to watch Animal Planet on TV, and I would show them that in the animal kingdom, the mom is the hunter and protector. The first visit we had together after they were removed my youngest daughter said: "Mom, I'm not worried, because I know you love us always and forever, and I know that my mama is a Lioness!"

Dedicated with love, to my baby girls always & forever your Mama. A mother's love cannot be stigmatized, for it knows no bounds and is everlasting.

DOREEN SAMUELS

When Love Looks Like Neglect

I only have two memories of my mother. One is me sitting in front of her while she combed my hair. The other is her taking me to visit one of her friends when I was five years old. That was the year she left me with my grandmother to go live and work in England.

While I wasn't in need of food or clothing—probably because my mother was sending back money—there was a void in me. When I was a little girl in Jamaica, the nights were the worst. Although I'd go to bed with three or four cousins, I'd feel all alone. While they slept, I'd stay awake crying, trying to keep my sniffles quiet so they wouldn't hear me. During the day, every time I'd see an airplane over head I would shout, "My mother is coming to get me." Then I would stand and watch until it disappeared out of sight. Once I realized she wasn't on the plane, I would go into one of my moods.

In those years when I was growing up, no one ever told me they loved me, and I needed to hear my mother say she loved me. But we were too poor to talk on the phone, and my mother never walked back through the airport gate to come and get me.

The present my aunt sent me for my thirtieth birthday was a plane ticket and visa so I could visit her in Canada. So I left my six children in the care of their father—the youngest was one, and went for a brief vacation.

But once I was there, I kept noticing all the work opportunities. I thought if I stayed a while, I could send money back for my children. Then I could go back home.

It was hard. I missed my children. When I finished working on a weekday or had free time on Sunday, I would go to the park. Seeing the children playing there and running to the ice cream truck brought me joy because it reminded me of my children, but also sadness because my children were not with me. Sometimes I would hear the voices of other children and in my mind, it would sound like the voices of my children.

When I would get home, I'd see the walls of my room and the top of my dresser filled with pictures of all my children. Sometimes I would sit and watch cartoon shows and wish my children could have been there to see them with me. I almost felt like I was watching the shows for them because they couldn't see them in Jamaica. One day I found a little doll on the street, and I brought it home and put it on my couch so that every day when I came in from work I would see it and remember my children.

But every day I spent in Canada I questioned if I was doing the right thing by doing the same thing as my mom. My only consolation was knowing I was doing this for them. Although my husband had a farm, he couldn't make enough money to support our family. He'd go to the market, and people would buy his vegetables, but then they'd tell him they didn't have the money to pay him. The checks I sent bought the toilet paper and soap and all the other things my kids needed. And because high school in Jamaica is expensive, the money I made in Canada was the only way my kids were able to get an education.

I was thirty-five when I finally heard from my mother by phone.

"Why didn't you come for me?" was the first question I asked. She said that she did not have the immigration documentation to come in and out of the country. She could not leave England to get me in Jamaica and then return to her job. I was surprised but touched to hear her call me "Gem," my childhood nickname. But still, I didn't know whether to believe she really loved me. "Do you remember my birthday?" I asked. "How could I not remember the birthday of one of my children?" she answered.

I understood. After all, I'd had to leave my own much-loved children. I knew that time and distance could not break the love a mother has for a child.

Once I'd heard from my mother by phone, I talked to her every night after work. Sometimes she sounded sleepy because of the five-hour difference between England and Canada, but I was on cloud nine just to have my mother in my life.

But the distance between us and the realities of our lives as immigrants continued to come between us. We lost contact again for a while after I moved from Canada to the United States, but I tracked her down in 1992 to tell her about the birth of my last son. Then after my mother's phone got disconnected in 1997, I wasn't able to locate her. And when I was finally able to contact her by getting her number from a cousin, I learned that my mom was terminally ill with lung cancer.

Her deepest wish was to see her little girl, the little girl she had left so many years before—me! For so many years I had wondered if my mother had loved the children she had given birth to in England more than she loved me. But now she told me she would travel with a nurse to the U.S. just to see me.

She was supposed to come at the end of October 2003. She passed away in the middle of October. Just as my mom had been unable to come to see me when I was a child because of immigration restrictions, I was unable to go to my mother's funeral in England because of immigration issues.

One of my sons went to the funeral to represent me and my family, while I stayed home and grieved alone. I didn't tell any of my friends that my mother had died because I thought they would say, "What kind of daughter doesn't attend her mother's funeral?"

I've never told anyone this story before, but I'm telling it today to let my children know how much I love them. Everything I've ever done has always been for them—especially the times it didn't look that way.

If you have never had to grow up away from your mother or be away while your children grow up, take a moment to think how lucky you are. As an immigrant, I am grateful for the opportunities I've had to work in Canada and the United States to make a better life for my family. But few people understand how much parents and children suffer in this process.

Sometimes I feel as though my children do not understand why I did what I did. It pains me to think of the sacrifices they had to make, and I don't think they fully understand the sacrifices I had to make. Every day I thought about my children, but because they didn't know that, I feel that they are still hurting.

I know how they feel. As a child, I cried in bed at night, wondering if my mother loved me. As a young adult, I felt sad as I watched other people's children around the ice cream truck because I was unable to see my own kids. And as a woman, I grieved alone while others gathered around my mother's coffin.

But although I'm sometimes sad when I think about my mother today, in my heart, I feel at peace. During our conversations, my mother told me she loved me, and I believed her because I know how much I love all of my children. And like her, I know how much you have to love your children to bear the pain of leaving them so they can have a chance at a better life.

DOREEN SAMUELS

Everyone's Son

"Can a mother's tender care cease towards the child she bears?" – Anglican Hymn

Sometimes I worry, and I pray to God asking him to tell me the year I will die. Yes, I know people don't know when they're going to go. But I ask God to see me on my knees and give me anything over ninety. Because my son still needs me.

When I was pregnant with my son A.G., they told me the baby was in distress. But then he was born and everything was okay. In the early stage of growing up, he was just like my other seven kids. But when it came time to go to school, I noticed A.G. was slow at reading, and I had to keep repeating things to him. And sometimes he would take a long time to say something and he kind of stuttered. He would always line up the certain toys he liked, and everything had to be a certain way for him. When he reached nine and I still needed to clean him up after he used the bathroom, I said something was wrong here. But other people told me I had just spoiled him because he was my last child, and the child development specialist at the school wouldn't listen and just told me he had "low self-esteem." So, I started reading every pamphlet and brochure I could find.

One morning, just nineteen days after we had just moved into a new place on the third floor of a building, a fire broke out in our apartment. While I was ironing A.G.'s clothes I heard someone saying "Fire, fire, fire! I started looking everywhere for my son because he was always so different I wasn't sure he would come out on his own. Finally, I went into my room and noticed something moving under the cover of the bed. And that's where I found him; A.G. often seemed to want to climb into my bed as if for comfort.

After the fire took away our apartment, I ended up living in a shelter while taking care of my son, my daughter Alicia, and my granddaughter. That turned out to be an unexpected blessing because at the shelter we met a young college girl who was doing an internship there. She asked me whether I received Supplemental Security Income (SSI) for A.G., and when I said I didn't, she explained that because of the way he was communicating she thought he had post-traumatic stress disorder. She helped me find a therapist for A.G. and helped me apply for (SSI) because my income was nothing at that time.

When they finally tested my A.G., it showed that his IQ was fifty-three and that he would always need someone to look after him. At that point, I had to do a lot of paperwork with a lawyer to try to have myself appointed guardian. As part of the legal process, the court had to see whether his father or any one of the siblings wanted to be guardians instead of me. But I was the only one with any interest in taking care of my son. It wasn't until A.G. was fifteen and a half that I succeeded in having him referred for a psychological evaluation that revealed he was on the Autism spectrum.

When you have a special needs child, the responsibilities of being a parent don't go away when the child grows up. As we say in Jamaica, "Small child small problems, big child big problems." When my son turned twenty-one, he went into a transition program that was supposed to teach him how to be independent. But I wish those programs didn't give people big, big dreams. They need to say: "Some of you will be living on your own if you're independent enough, but some of you won't."

After going through the transition program, A.G. didn't want to live with me because he thought of himself as an adult. But when we took a tour of the place where they offered him housing, he was horrified when all the residents came out to meet him with their walkers and wheelchairs. He was young—he didn't want to be around all those "old people." A.G. said, "You guys think I'm stupid bringing me into a nursing home. I don't want to be in a nursing home." He moved there when they promised that other younger people were coming, but when that didn't happen A.G. insisted on leaving.

All A.G. has ever wanted is to be treated like a regular human being. He wants the privileges that other adults have, and he wants basic respect. Although he wanted to have a girlfriend like everyone else when he was a teenager, he couldn't even get near girls. A friend who also had a special needs son once explained to me that parents would tell him: "Don't you dare get talk to my daughter!" I noticed that A.G. took a lot of cold showers in that period. Those kinds of experiences drive kids like my son into depression.

It's hard for A.G. to feel like he fits in. When he was a small boy, he used to go around giving bear hugs to people, but now that he's a man people squirm away in discomfort. When people talk to him like he's a child, A.G. naturally gets annoyed. They don't seem to recognize that he has his own form of intelligence. He may not be able to read very well, but he works at the Big Y three days a week and knows a lot more about computers than I do. It's hard for him to see he can't have the life or respect that others have.

Sometimes my son feels like I don't defend him when people treat him like a child or when I take him grocery shopping and people stare when he is yelling because he wants to pick out the most expensive item in the supermarket or something from the electronics department. He goes on Amazon to send me pictures of the things he wants me to order, and sometimes I order them but sometimes I can't because they're too expensive.

Right now, A.G. is living with one of my daughters, but there's not enough money to pay for his upkeep even though he contributes to the rent. In fact, my son would really like to be out in a place of his own where he could make friends and invite them over. What grown man wouldn't feel that way? But is there really any hope that he will ever be fully independent? Whenever something confuses him—like when his transportation doesn't turn up when he expected—he calls me to tell him what to do. And I feel guilty if the phone ever rings and I don't answer.

When I went back to Jamaica in January, I needed to take my son with me. It was his first time on a plane, and I had to explain what it would be like when the plane took off. I also had to warn him that it would be bumpy when we landed so he wouldn't be scared. You have to be consistent with people who have special needs: you need to take care of them but not baby them. I love my son very much. But I'm going to be seventy-two in August, and my body is weary. I wish I had a chance to live my own life and go where I want to go.

In 2007, I was on my way home from a trip to Florida when I got a phone call from the police saying that my son had gotten into a fight with my daughter and threatened to push her down the stairs. Fortunately, this time the police understood how to deal with a person with special needs and asked me if there was a friend he could stay with for the night. So for this one time, I was able to keep him safe. But the chronic anxiety that comes from caring for a son with a chronic illness has worn down my body and my mind.

I've done everything I can to get A.G. into programs that can help him, and I've joined a lot of boards that are supposed to help people with autism. But a lot of the time the boards just want to talk about kids, not adults. They don't realize that those kids are getting older all the time—and their parents are getting older. I wonder what will happen to him if something happens to me.

People tell me I should let go of my son because he's an adult. They say I should put him into a group home. But most of the time I think it's not right for him. I fear he would sink into depression. I find myself thinking of the line from the old hymn that asks: "Can a mother's tender care cease towards the child she bears?" But I am not getting any younger. I've been taking care of children since I was sixteen, and I'm tired.

When A.G. was a boy, I used to run a group in the Denholm Building in downtown Worcester with parents of children with disabilities. Each time one of our children would reach a milestone, we would share the story. We would celebrate the first time my son washed, and the first time he could go to the bathroom without calling, "Mom, come clean me." The first time he opened the door. For some people, it's no big deal. They don't know what we go through. But the group helped us feel like we weren't alone—we were all in this together. It made us feel good. I wish I still had that kind of group to turn to now that my son is an adult.

Even though caring for my son is a source of stress, caring for people brings me a deep sense of joy. When working with people in recovery, I know that each one is somebody's brother, somebody's mother, somebody's friend. And working with students with developmental delays as part of my job is also deeply satisfying. The two students I work with individually can't even talk, but I feel deep empathy for them because I know what they're dealing with. Like my son, they deserve respect. They are human beings too. If we could all look at people who need us as somebody's son, then maybe we could go one step further and see them as everybody's son. And if that ever happened, I could finally stop worrying about living past ninety because my son needs me.

ANA HERRERA

Lost and Alone in a Labyrinth of Symptoms

To the Massachusetts Department of Public Health, the Consumer Affairs and Business Regulations Division of Insurance, the ADA, and the Board of License Dentistry Registration--when you don't enforce the laws, the lives of human beings are put at risk.

To all those who work in dental health—general dentists, oral surgeons, and endodontists: please listen to your patients.

I began a terrible, tiring, emotional, and expensive journey on May 16, 2023. I was scheduled to have an endodontist perform two root canals. Endodontists are dentists with special training in tooth pain and root canals. My general dentist had originally referred me to an endodontist who the insurance company refused to approve because he was "out of network." Instead, I had to go to the one my insurance company selected. And that's where my Calvary began.

I suddenly felt a sharp pain from the top of my nose to the center of my head while the endodontist was working on my teeth. The sensation was so strong I could not speak. I raised my hand. The endodontist asked me if I was in pain, and I said, "Yes!!!" She applied more anesthesia and continued working. After completing the first phase of repair for the first tooth, I asked: "What about the second tooth?" Even though I had scheduled to have both done that day, the endodontist replied: "I can't keep my assistant after 5 p.m.." The receptionist gave me an appointment for a date over two months later.

By 10:00 that night the anesthesia wore off and the pain began. The experience was frightening! I never remembered having such pain after previous root canals. Although I did not want to worry my family, many questions came to my mind. All I could do was take Ibuprofen. By the next day, the pain was still there. The temporary filling was wearing off more each time I rinsed my mouth. When I called the office, the endodontist just told me to keep taking Ibuprofen and antibiotics and to call my general dentist as soon as possible. Despite my agony, the endodontist wanted the generalist to cover the root canal work with crowns without doing any investigation or repairs. Later she emailed: "You should go to your dentist ASAP and get the crown done. You should not wait until the other one is done since we are booking out so far."

Four days later, I emailed her again to say that even though I was still taking Ibuprofen and Tylenol and almost done taking the course of antibiotics, there was pain all over the right side of my face and I was desperately scared. Two days later I received a message from the office: "Good morning, would you like to come today around 2 pm to see the doctor again? That is all I have open for the next six weeks."

When I arrived at the office that day, the endodontist indicated that she would work on me if one of her afternoon patients did not turn up. After taking me in and giving me anesthesia, her first scheduled patient turned up and I was sent to the waiting room. Two and a half hours later I had my second partial root canal. I was happy to think that after eight days of pain, I would finally experience relief.

But the pain continued day after day! Again, I begged the endodontist to give me another appointment. Once again, her response was she didn't have anything available, but to just take the antibiotics and Ibuprofen and "not to worry." Following the endodontist's instructions, I went to my general dentist to get my crowns, but she told me that first I needed to heal from the root canal before I could get my crowns AND that I should have a follow-up with the endodontist to find the source of the pain. But when I asked him if he would call the endodontist to discuss that with her, he declined.

After more pain and consultations with more specialists, I returned to see my regular dentist to see if she would tell me the truth of what was happening. I couldn't stand to wait any longer to get an appointment to speak with my endodontist. By that point, my face was tender and swollen, the skin beneath my right eye was purple, there was a lump growing on the gum above the site of my root canals, and there was pain in my gum and across the right side of my face. At the front desk, I had to use my personal credit card because my insurance wouldn't pay for the X-rays the dentist ordered. I begged my dentist to call the endodontist because I felt she was not listening to what I was telling her about my suffering. While at first, the dentist seemed willing to intercede on my behalf, she eventually declined to do it. Instead, she told me my only option would be to "go back to the endodontist who performed the root canals to solve the problems."

The soonest I could get an appointment was a full month after the suffering began. While I waited, I called my insurance company to see if they would pay for a second opinion because I could no longer stand the pain. The insurance representative said I could submit a grievance but it would take thirty days to get the response.

Finally, I returned to the endodontist, and she took X-rays. I asked for the truth: did it show that the root canals were failures? She replied: "Oh no, Honey, you are well healed! Something else must be going on with you." I asked if that was the case, why did I have a lump growing on my tooth root? She claimed that my sinuses were draining into my gums.

I was shaking. I went outside and called my primary care doctor to rush a CT scan for my sinuses. Then I went back inside the endodontist's office and requested a referral. She printed a note that concluded: "Patient has pain. BOTH TEETH HAVE HEALED WELL. PT may be grinding on this tooth. Ref PT to see a sinus specialist or O.S."

What followed was a series of visits to a series of doctors. One put an endoscope up my sinus track to look for problems. I consulted with specialists in Ear, Nose & Throat who took blood and checked me for strep throat. They gave me throat sprays, allergy meds, pain meds, and antibiotics. Nothing helped. I remember one of the many physicians said: "Unexplainable pain."

In the hopes of finding an escape from my pain, I spent my own money to get a second opinion from another endodontist and another kind of X-ray called a Cone Beam Scan. The pictures showed that one tooth was broken and needed to be extracted and the other was unclean and infected. The "unclean" tooth could have been saved, but I was in so much agony that I was determined to have both teeth out.

When I went to the oral surgeon to get the two teeth removed, I had to provide a credit card in case I needed to have a bone graft done. In fact, because of the mistake the endodontist had made, I did need the graft.

A week and a half later, I left with my family for a previously scheduled three-week vacation. After enduring so much physical and mental anguish—and spending so much money—I hoped my problems were finally behind me. Instead, it turned out that my oxygen was low, the infection was spreading, and my family had to use money set aside for our vacation to pay for private treatment in another country. Although I'd gone on vacation despite my pain for my children's sake, I don't think they enjoyed themselves.

Three weeks after we returned home, I had an appointment with the chief of the Otolaryngologist (ENT) department, who did an x-ray. Only a few hours later he called to tell me to go back to the oral surgeon who did the extraction and bone graft because I had an infection where the two teeth had been extracted. In the meantime, he was kind enough to send a prescription to the pharmacy for stronger antibiotics.

As soon as I got off the phone, I called the office of the oral surgeon to say that the Ear Nose and Throat specialist had found an infection where the tooth had been extracted. The receptionist complained: "Every time you call here, you have new symptoms!" I just hung up the phone.

Although I knew that my bone graft needed to be removed, I had no idea how to find someone that I could trust to repair mistakes made by others. I was afraid of ending up with another dentist with a bad work ethic.

Around this time my husband had an emergency with his wisdom teeth, and a friend recommended a new oral surgeon. Although I was trying to hide my own pain so I could concentrate on helping my husband, one of the assistants noticed I looked unwell and asked if I was okay. Seeing how they helped my husband and paid attention to me as well, I decided this was the place to get the help I finally needed.

Four months after I first experienced that shocking jolt of pain that shot from my nose to my head, I was placed under general anesthesia and my new oral surgeon (my hero) removed the infected bone grafts. I was sent home to recover with a drainage tube inside my mouth and a list of upcoming appointments. At last, I was in the hands of a medical professional I could believe in.

Finally, eight months after that first botched root canal — after numerous doses of Tylenol, Ibuprofen, allergy medications, throat sprays, eleven courses of antibiotics, innumerable x-rays and scans, visits to all kinds of specialists, countless calls to doctors' offices, and more hits to my credit card than my budget could survive — I was pain-free. Finally, I would not have to struggle to go to work to support my family, and I would not have to struggle when I came home to care for my children. But it would take much longer to deal with the psychological pain of having to deal with medical professionals who would not listen to what I had to say, respond in a timely way to my suffering, and treat me with respect. I am still haunted by their dismissive words:

"Oh, Honey, you are well healed. It must be something else going on with you."

"There is no reason to worry."

"Every time you call here, you have new symptoms!"

Late in July 2023, I got a letter from my insurance company regarding the complaint I had filed against my endodontist. "Upon review of the submitted treatment notes and x-rays from DR. XXXX, we determined the service was necessary and performed with the standard of good dental practice. Unfortunately, your grievance has been unsubstantiated." Shocked, I wondered how much more evidence the insurance company needed.

I am sharing this story to remind all dental professionals that our lives are in their hands. By refusing to tell the truth and delaying treatment they put my life at risk. And all the medical professionals who refused to admit that mistakes had been made by the endodontist and oral surgeon also failed me.

But I am also writing to pay tribute to my three heroes: the chief of the Otolaryngologist (ENT) department who called me personally a few hours after my x-ray to confirm I had an infection; my new dentist, who listens when I say I am experiencing a problem; and the oral surgeon and his staff, who noticed my pain and did something about it. I will always remember the moment when my oral surgeon said: "Trust me, I'm not leaving you alone." I finally felt heard. I finally felt hope. Thank God for the work of good doctors like these who care about and listen to their patients. They are true heroes.

Sincerely A.H.

WE
DESERVE
A
FUTURE

GEORGE ODOMAKO

My Mom and I: A Story of Home

I was the only one of my mother's six children to live with her in childhood. We lived in a wooden 7' by 10' room in an urban village in Jamaica. There was no electricity or running water. But even though our life was hard, my mother always made sure that our home was a place of warmth and togetherness.

My older sister and three of my older brothers lived with their fathers or my maternal grandmother so that my mother could go out to work and help support us. The brother closest to me in age contracted an eye condition that left him legally blind, and I remember him being shipped off to a boarding school for children with vision problems.

However, my mother kept me with her because I was the youngest and because she felt I needed special nurturing. At the age of just four months, I'd contracted polio and although I hadn't become totally paralyzed, I had been left with serious disabling conditions. I have vivid memories of her fierce and loving determination to instill a sense of pride in me. Thanks to her, I grew up with a sense of confidence.

Certainly, my mother's entrepreneurial efforts made her a great role model. She started by cleaning other people's houses and taking care of other people's children. But later she began to sell peanuts on the streets as well as hard-boiled eggs, offering people salt and pepper to season them before eating. Eventually, she set up a stall where she sold boiled corn on the cob, nubbly or spiky-skinned breadfruit the size of volleyballs, boiled crabs, and roasted yellow yams with salted codfish topped with onions, cucumbers, tomatoes, and fiery hot peppers. Every morning she'd roll her two-wheeled cart to the stand and set up her cook stove and pots and pans. Every night, she'd put everything back in the cart and wheel it home.

The confidence I learned from my mother turned out to be very useful when I went to school. Polio meant that I couldn't do a lot of the things my peers could do. For example, although I loved sports, I couldn't play soccer. Once there was a raffle in school, and the big prize was a leather soccer ball. I won. With my mother's encouragement, I would take the ball to school every Friday and let the other guys play with it. One week while I was watching them, I became overwhelmed by the feeling of being left out. I demanded the ball back, went home in tears, and threw the ball under the bed. But at times like that, my mother would always be encouraging and reassure me that things would get better someday.

I think the spirit I got from my mother helped me get a group of friends who looked up to me and were always protective and supportive. Whenever I had a need, I would just say to my friends, "I need to …," and at least two or three guys would step up and say "Let me do it for you!" They would literally fight over getting to do things for me. Even today people continue to look up to me and do things for me, and I'm glad to have them in my life.

But just as friends help me, I always help others because my mom taught me the value of giving. She believed that when you have a need, you should give out of your need. For example, if you have a hundred dollars and someone asks for ten, you should give it freely. Then when you get to the store where you were going to buy a hundred-dollar suit, you should strike a deal to get it for ninety. Somehow, my mother taught me, it would all work out.

It is this belief in myself, in my friends, and in giving that stays with me today and makes me feel at home even though I'm many miles from that 7' by 10' room on an island in the middle of the blue Caribbean.

GEORGE ODOMAKO

From Massachusetts to New York

I left Massachusetts for New York when I was offered a job taking care of children that would have provided me with income and a place to live. Unfortunately, the job fell through.

In the early years of my adulthood back in Jamaica, I studied social work and served with the Disabilities Association and the Social Development Commission. As a research assistant at the Centre for Disability Studies at the University of West Indies in Kingston, I conducted interviews, ran focus groups, and presented a series of lectures on "Interacting with People with Disabilities" to over one hundred recruits and graduates of the Jamaica Constabulary Force and over one hundred public health professionals.

During my early years in America, I served as a member of the Human Rights and Disabilities Commission in Worcester, MA, and was a featured speaker for community groups on the experiences of LGBTQ+ asylum speakers. I also earned college credits through the Clemente Course in the Humanities and became an active member of the Clemente community, publishing several essays and memoirs in their books.

Now I was homeless in New York.

I went to an intake shelter, and the people there sent me to a temporary holding facility for one week and then to another temporary facility for about four weeks. Then I went to a Brooklyn shelter and from there to a shelter in the Bronx. It's weird. I don't know why they move you around so much.

I ended up living in the shelter in the Bronx for two years. Although I have a mobility impairment because of childhood polio none of the shelters were equipped for people with disabilities. I have a hard time walking and it is very difficult for me to get up and down stairs. The Bronx shelter had one elevator that was never working. During fire drills, I was allowed to stay at the top of the stairs with the other disabled resident, but I wondered what we would do in a real emergency.

On my first night there, an intake officer said to me: "What are you doing here? This is not for you. Why did they send you here?" But I didn't have any answers to his questions, and I didn't have the power to get placed in a shelter that accommodated my needs.

Months later, I had an appointment with the jobs specialist, and she asked me why I'd been incarcerated.

"Have you ever been accused or convicted of being an SO?"

"What's an SO?" I asked.

"Sexual offender," she answered.

At that point, I was rattled. "Where are you going with this?"

"Please speak with your case manager," was all she would say.

As soon as I could get in touch with the case manager, I asked: "What is this I hear about being a sex offender?" And he said, "Well, it's on your form." I have never had an encounter with the law either in Jamaica or in this country. So I found a copy of the sexual offenders list and didn't see my name anywhere. I didn't even find someone with the same last name. That was a terrifying and depressing moment. But even when I cleared up the mistake on my intake form, I was still in the same shelter with formerly incarcerated people and individuals with mental health problems.

I felt very very very at risk at that shelter. So many of the guys were substance users, and I'm not talking about marijuana. Some of them who had mental issues were combative and could explode into violence. There was one particular guy I would talk to whenever he was upset and in danger of erupting. Sometimes all I'd need to do is say, "Hey, buddy" in a friendly voice, and he would calm down. One time when he was on the brink because of being agitated by another resident, I went over and said in a quiet voice: "Just chill." And he sighed and walked away—and then flipped a whole bed across the room. I got through all of that through the grace of God. My faith has always been my foundation.

One night at the shelter I was having heartburn and nausea and regurgitating like a goat. I tried all the remedies that I knew: vinegar, baking soda, Pepto Bismol. Nothing worked. Finally, when I started feeling a pain in my left arm, I thought about what to do. Eventually, I asked one of the guys to let the folks downstairs know I needed an EMT. They took me to the hospital, where the emergency room doctor said: "It's a good thing you came in. You're having a heart attack."

As soon as they stabilized me, they sent me to Bellevue in an ambulance. Bellevue is famous for its early work as a psychiatric hospital, but today it is famous for medical excellence—including in the treatment of heart disease—and for its work as a safety net hospital, providing healthcare for patients regardless of their ability to pay. They paid great attention to me at Bellevue: they went over and above to make me comfortable. Even the non-medical staff helped me feel at home. I met a cleaner there from Jamaica, and we exchanged our memories of home. When she mentioned that she sometimes brings Jamaican food to the hospital to sell to her coworkers, she paused and said: "You know, I'm going to bring YOU some food!" And I like to think that when she brought me a traditional Jamaican dinner of rice, kidney beans, and chicken it was part of the healing process.

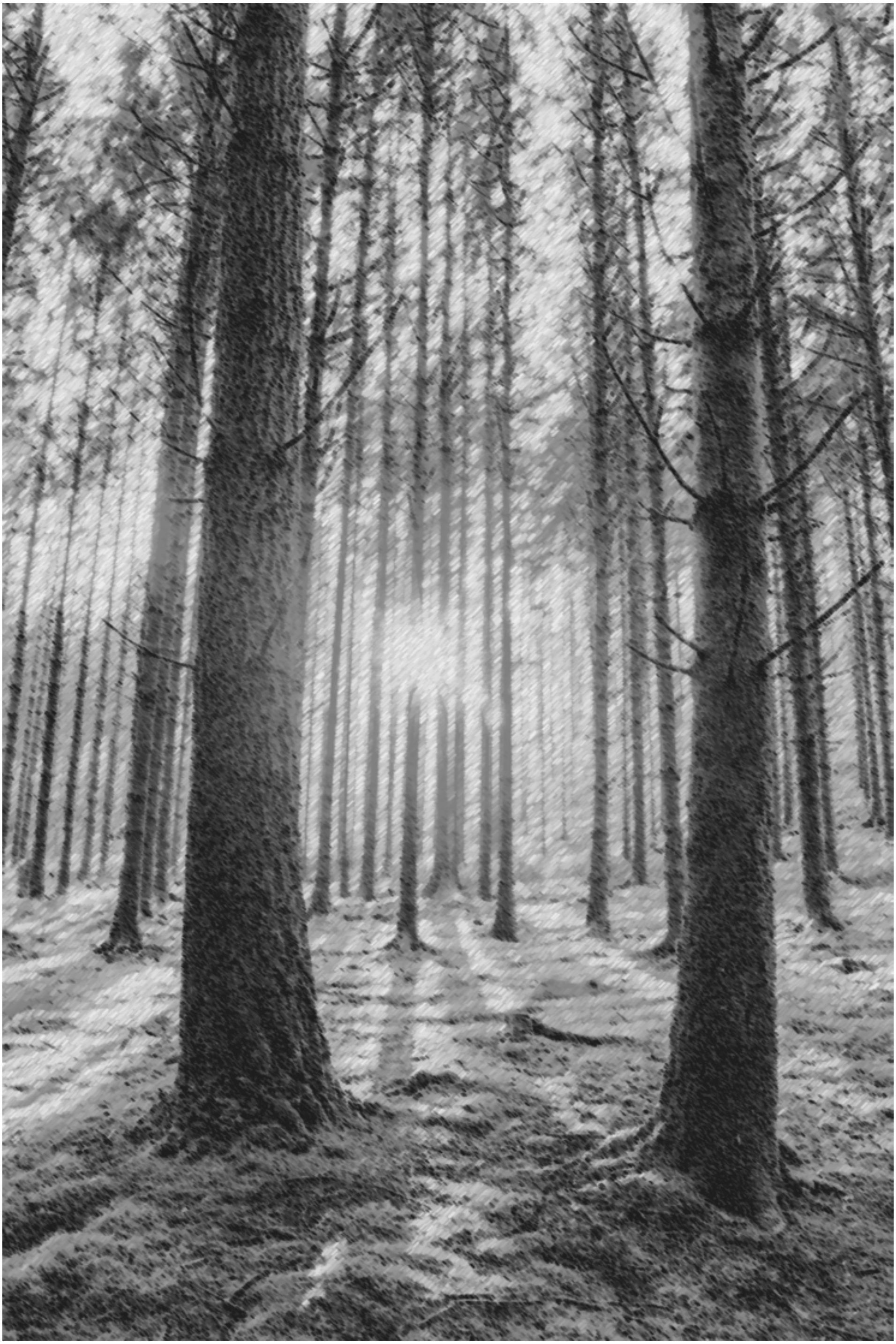
I think I bonded with each doctor in a particular way. I believe that I have the ability to connect with people and meet with them in their own space, stay with them on their own level. One doctor became interested in trying to get me transferred into a shelter that was more appropriate for my needs. But despite his efforts, he couldn't arrange a change. So back I went to the same place.

One day at a regular appointment my primary care physician asked me how things were coming along with my application to move into a subsidized apartment. My answer was: "I need to get out of that shelter right away. It's urgent." Living in the shelter was affecting my health—who knows if I would have had a heart attack under different circumstances—but it was also hard to keep a grip on my sense of who I was. Because the doctor decided to see what he could do, the very next day I got a call from a social worker who started to check agencies to see what was available. Eventually, she got me into a program that arranges housing for people who are in the healthcare system.

Once I moved out of the shelter, I just stayed in my apartment for days, soaking up everything. Being in my own space. Not being afraid. Not hearing the fire alarm and shouts of "Get up! Get up! Get up!" And I no longer had to get out of the place where I lived every morning and then rush to get back in before the doors closed. I was finally out of prison. That's what it felt like—a prison.

All my life I had worked hard to have a good character, build strong bonds with people, contribute to my community, keep learning, use my voice to make a difference. But now I was in "the system", and I had been sorted. And who I was, what I had accomplished, and what I needed as an individual didn't matter anymore. What mattered was what the code on my intake card said—even if it was wrong. How can the individual survive being part of "system"?

I am grateful to the people at Bellevue Hospital whose attention made me feel seen and heard. And I am grateful to the primary care physician and case worker who saw me as a human being. They helped heal more than just my body. If you encounter someone who is ill, disabled, or homeless I hope you will remember the humanity that resides in each of us. Remember each person has a story. Empathy will allow you to connect with anyone. And by celebrating their humanity, you will also celebrate your own.



A.J.

Becoming

The worst I've ever felt in my life was when I was with my high school classmates on a cruise during a class trip to Washington, DC. I felt bad because I was wearing a dress. I just remember feeling very uncomfortable in my skin.

I didn't want to be in a dress at all—I wanted to be in a suit just like my boyfriend. And I wanted to have my hair cut short. I just didn't know what was wrong. I kept going outside on the boat and looking over the water. I just wanted to be free like the birds that were playing across the water. When we got back to the hotel, I just locked myself in my room and fell asleep crying in the tub.

Shortly after that I went to a therapist and told him about the experience. And he told me that I was trans—something I'd never heard of before. And he explained to me that what I was feeling was called "dysphoria"—another thing I'd never heard of.

Here's how the Diagnostic and Statistical Manual used by psychiatrists explains those terms.

Transgender: People who have a gender identity or gender expression that differs from the sex that they were assigned at birth.

Dysphoria: Clinically significant distress or impairment related to a strong desire to be of another gender, which may include the desire to change primary or secondary sex *characteristics. Not all transgender or gender-diverse people have the desire to medically transition.*

That sounded like me. By the time I was about ten or twelve, I was bouncing between feminine and masculine clothing styles because I couldn't figure out what I wanted. By the time I graduated from Middle School, the gender dysphoria had started to set in, and I struggled with severe depression and anxiety.

Even though the conversation with my therapist had helped me recognize myself as a trans male, I knew I wouldn't be able to start any kind of body-altering treatment until I was eighteen because my parents didn't approve of my decision.

As a result, I waited a couple more years to socially come out to my friends, loved ones, and peers. And That meant I went through high school still going back and forth between male and female clothing. But I only felt comfortable using the male toilets. While I was using a bathroom stall, I would sometimes hear people threatening me just outside the stall door.

I remember celebrating the day AFTER I turned eighteen and could finally start hormones. Since then, I've had countless surgeries to help me become who I am, and countless conversations with my therapist. I am constantly working on my mental health.

Maybe it's because of my own mental health struggles that I notice others who are struggling. A while back I had a friend who was having a hard time trying to fight addiction and substance abuse. One night he randomly asked me to go with him to Hampton Beach at ten at night. We just drove out there and hung out. We were talking on the beach when he decided to run out towards the waves. I knew I had to tackle him because I had an idea of what he was doing. I told him that his life was worth it and that he mattered. Just saying that just seemed to change him for the better. And he's doing better now, I think.

Like my friend, I've come a long way in the past few years. I know I look good now, right? But looks aren't everything. I didn't look like this in the beginning and used to be referred to as a girl quite frequently, even when I asked to be referred to by my proper name and pronouns. I've lost many friends and family family members, and I have even been treated with disgust and hate for just being who I am.

And I still face anxiety and depression every day with my social interactions because I never know how someone is going to respond to me, and I'm under attack no matter where I go. My guard is always up.

The next time you interact with someone, just know that you may not know about the personal battle they could be facing in their own head. Maybe all they need to hear is that you think they matter.

A.J.

To the Moon

The phone rings. I am anxiously awaiting the call. "Hello?" My voice cracks with anxiety. I am waiting to hear my mother's diagnosis.

It is December of '22 and my relationship with my mother is on the rocks. We have always fought and we've always been close despite that, but in the past few months, our fights have gotten so bad that I've moved out.

Even though we fight, we always talk on the phone every day. My mother definitely keeps me busy. By the end of our talks, we always try to make up, or I at least call or text her back and say, "I love you."

But I've been watching her health take a steady decline. She's been losing weight and getting sick almost daily. On December 15th, 2022, my partner and I rush my mother to the ER. She receives an emergency surgery and the diagnosis I've feared for my whole life.

Cancer.

On the day I get the phone call, it is both snowing and raining heavily. The roads are weighed down with layers of sleet. I'm anxious and exhausted from the night prior. No sleep. Too worried.

When the surgeon calls, I have a long list of questions ready. In fact, all I manage to get out is "okay," nodding like I'm there in person. Inside I'm pleading for a second chance.

As the surgeon explains where they found the cancer, what type it is, and how it has spread, I realize my mom's battle is over even before it's started.

I would take it all back if I could. Every word I've said, every fight we've had, everything. I remember the embarrassing moments, the hateful moments, the moments I would take things out on her. And I know from the moment I hang up the phone that I need to change my relationship with my mother in the short future we will have together.

But we can never change the past.

Growing up, it is always rough witnessing the fighting, the different stages of anger, the rage in my family. Over and over again I run out of the house to find sanctuary in the silence of the trees.

I am eight years old when the state takes me away from my mom because they think she's abusing me. They're wrong, but when they asked where I wanted to be I chose my dad. But after I move in with him he just stands and watches when my stepmother hits me and throws me around. She calls me fat and tells me I'm not worth anything. She shouts that my mom and I are both stupid bitches.

My sister ends up in pretty much every mental hospital in Massachusetts because her biological dad is sexually abusing her. She tells me that hospitals are a way out—a place to escape and be safe where people won't hurt you. Later she changes her mind. She tells me: "Be careful with that because I got hurt in the hospital." It seems like nowhere is safe.

By the time I'm a freshman in high school, I move out of my dad's house and drop out of school. Eventually, I find an alternative high school that helps me graduate while I go back to living with my mom in Leominster. I don't know when the anger comes into our relationship: I think I kind of hate her for moving us to Worcester.

But there are other problems too. She's always overanxious about me, and I get angry when she hovers. When I'm seventeen and eighteen and having drinking problems, my mother tells me about her own past with alcohol. Now, she says, every time I drink it makes her problem worse. That just makes me want to drink to spite her.

When I tell her I'm a lesbian she's okay with it but she never likes any of the people I date. And when I change my name to Adrian and begin my gender transition, it takes three years for her to use my new name and refer to me as he.

At the time my mother is diagnosed with cancer, things are particularly bad between us. I'm not doing well with my drinking—and it doesn't help that there's a liquor store around the corner from her apartment. She sees me going into a spiral and gets on my case. I move out.

Strangely, other things are going well for me. I'm taking college classes and have a great internship. But when my mother gets sick, I have to give both of them up.

In the weeks after my mother is diagnosed with cancer, I become her caregiver. Every day is the same. Get up early to prepare her meds before she wakes up. Watch "Grey's Anatomy" and Desperate Housewives" on TV with her. Make treats out of Cream of Wheat and bananas and feed her one spoon at a time. Hope she lasts one more day.

At night she sleeps on a couch in the living room. I sleep on the recliner next to her, waking up when she becomes restless. When she becomes too weak to walk, I lift her eighty pounds and carry her in my arms to the bathroom as if she is a bride. One night she wakes up at three and can't get back to sleep, so I give her some meds, dim the light, and we listen to Coldplay together.

Sometimes the cat nestles up with my mom as if to comfort her pain. One night my mother says: "Make sure you take care of my cat. Don't give her away." And I say "Absolutely!" even though the cat is always spiteful to me. A lot of the time, my mom and I just hold hands and talk in the dark moments of the night. She likes to reach up to touch my face or lean up and kiss me. At moments like this she always tells me that she loves me to the moon and back. It means the world to me.

I am exhausted. I am overwhelmed. I hate to see my mother in pain. The weight of all this is hard to bear, and I start to abuse both drugs and alcohol heavily. I stay sober for my mother's care as long as she is awake but drink myself to sleep after. It is rough.

The hospice nurse warns me that at some point my mom will just eventually just stop breathing. The thought terrifies me.

One day I give my mother her meds, kiss her, and go upstairs for my online alcohol therapy. In the middle of the meeting, the hospice nurse comes up and says, "Your mom's not breathing." I go downstairs and can't find her pulse and can't see her breathing. I want to call an ambulance but the hospice nurse says not to. I feel guilty I wasn't with my mom when she died.

After my mother's death, I move from caregiving mode to panic mode.

I have to move all her stuff out of her two-bedroom apartment into the small studio where I'm living now. I have to go through all her things. I have to go through her bills. I have to switch her accounts. Next week I'm losing my job. And if I lose my housing, I'm done. I can't help but feel helpless.

Somehow, I can't manage to tell people she died. When my mother got sick, I wrote to my teachers and the people at my internship that my mom was in hospice. And they were all like, "Oh my god, I'm so sorry! We're here for you!" They were amazing. Now I can't stand to tell anyone my mother's dead. Occasionally I want to bring up my mother in conversation, but I can't. Since people know she was in hospice I guess they'll eventually just figure it out.

I'm turning into more of an adult than I want to be. From this point on, it's up to me to figure out what to do with my life. Before my mom passed, I had my gender therapist come to my house and have a session with her. Afterward the counselor said: "Your mom wants you to be sober, and she loves you very much." And I said to myself: "I have to get sober. This is what she wants." That was helpful: it gave me some direction. I'm also planning to go back to school, although I don't know how to apply for funding without my mother's signature. I want to be in the classroom learning instead of sitting on the couch like a zombie playing games.

Now I live surrounded by boxes of my mom's stuff. I wear some of her clothes that happen to be my size. And I also have her cat. Although she misses her mom, the cat's attitude adjustment has been huge. Ever since my mom has passed, I've been the cat's person. It's kind of weird to see her be the perfect little creature. I want to say to her, "For the past ten years I've known you, you've been like hell, Beast. I don't get it." But when I moved her to my studio, the cat climbed up my partner's back and just lay on top of him. And now she rolls back on her legs and gives us kisses. Honestly, having my cat has been the closest I felt to my mom since she died. It seems like the cat is adjusting better to my mother's death than I am.

My relationship with my mother still feels complicated even though she's dead. The hospice nurse thought I did a great job taking care of my mother. She even said, "If I was your mom, you're the person I'd want with me." But I still feel guilty that I treated her like shit. Sometimes I worry that even though we were close at the end things didn't get all patched up. Other times I remember when the two of us would be awake in the middle of the night and she would tell me that she'd love me to the moon and back.

And I know it's crazy but I find myself thinking that sometime in the next ten years my dad's next as he's going down the wrong path. I'm not looking forward to it, because I know I'm probably going to end up being the one who takes care of him.

A.J.

If It Was Up to Me

It's about midnight and the sky is black out over the neighborhood. Although the air is warm, I feel chills break out across my skin. I start to walk a little faster to my destination and I see the person I'm looking for. My words catch in my throat as I ask: "Do you have any hard?" Cocaine. I've used it on and off since age seventeen. I walk back to my apartment and begin the usual pattern: weed, crack, and a bowl. I know what will happen next: paralyzing waves of nausea that will leave me locked in the bathroom or a decent high that will last me ten minutes.

Lately, I've been struggling with not feeling real, or feeling totally detached from my body, like a whole separate entity from myself.

When I started on Testosterone, I felt at home in my body, free to be myself and happy. But lately – ever since my mother passed – my anxiety and depression has come back. I'm just not feeling stable, and I don't know how to bring back those feelings.

The other day, I was in a lot of pain because I needed a root canal, so I went to the ER. I sat there for three hours and normally I didn't mind waiting but I was in a lot of pain. Then suddenly I realized this was the same hospital I had taken my mother to when everything had started, where she had started to decline. This was where everything began, so I left.

When I was growing up my family members – parents, siblings, everybody – had depression, anxiety, and PTSD, all of the run-of-the-mill mental health stuff. My father suffered from depression and PTSD because of his experiences growing up with an angry military dad. My mother spent days locked in her room: that was depression too. (I've been diagnosed as major depressive. Which I guess is a "step up.")

I've had problems all my life with anxiety and other things. I feel like some of it probably comes with being born hydrocephalic—with fluid on my brain. I know that's probably the cause of my migraine and vision problems and sometimes hard times functioning. The doctors put something called a "shunt" in the left side of my brain at birth to help drain the fluid. After that my parents had me wear a helmet every time I played any type of contact sport. So I tried to avoid any of that. When I was a freshman in high school the doctors thought I had more fluid buildup in the right side of my brain and had considered putting another shunt in. My parents said no because I seemed fine. I was incredibly grateful; I didn't want another reason to be labeled as an outcast.

When I was younger, I used to hide in the woods when the world around me got too loud. I loved to listen to the sound of the wind blowing between the trees, and the birds. Reading and learning about new things also helped me feel better.

Watching my mother is where I learned how to use art as a coping skill, she used to paint and often got lost in her art.

A lot of people in my family have addiction issues. One of my earliest memories was pleading with my older brother during an intervention because he was addicted to heroin. He looked terrible, like he was dying. I remember pleading with him to stop because I needed him to be my big brother.

I recently got a call from my other brother saying he had overdosed on some weed mixed with fentanyl. They had to revive him three times to get his heart restarted.

When I was a teenager, I used to drink alcohol just to shut down my brain. My ex-girlfriend's mother was a bartender on the weekends, so she had a full bar. I could never drink one or two drinks. I just knew how to go straight to blackout.

The first time I got really high it was an accident. I smoked some weed that had a bit of meth in it and it was incredibly scary; I was cold and hot at the same time, hungry and nauseous, and my breath came in short pants that made me feel like I was going to pass out. The second I walked in, my mom could tell I was high. I broke down and told her the truth, that I didn't know what I had just smoked. I wanted to go to the hospital but didn't want to be labeled with the stigma of being an addict. So my mom had me sit down, wrapped me in some blankets, and gave me a glass of cold water. The high eventually passed.

I went to rehab three times—the first two times for alcohol and the third for crack. It was super easy to get distracted because everyone was constantly bouncing in and out. It was on Zoom. Bad internet connection, clinicians pulling clients, and so forth. After the last treatment, I managed to stay sober for about three months.

My most recent problems began in the early days of my mother's illness. Even though we didn't yet know of her cancer, her skin hung from her face and her body was starting to waste away. It was clear to me that something was wrong and it was clear to her neighbors. One afternoon, I went out to the backyard while she took a nap. The two men who lived next door called me over to offer me some of their crack. They asked me "Do you want to get fucked up?" I said I did. I could already see what was coming for my mother, and I needed not to think or feel. That was the beginning of the end of my sobriety this time around.

When I was taking care of my mother in her final weeks, feeding her, picking her up to take her to the bathroom, administering meds, and watching the occasional late-night movie with her, there were times when I could barely stand it. Once she fell asleep, I'd have a drink or two to keep me going. At the same time, I'd often have to ask my partner to go out and buy groceries because I was afraid to go out into the neighborhood where there were chances to buy alcohol or drugs every few steps. In the days after my mother's death, I got worse. In fact, the reason why I need a root canal is because I got so depressed that I stopped taking care of my teeth – and using crack made it even worse. When the dentist saw my teeth, he didn't even need to look at the X-rays. He just told me that I definitely needed a root canal. I feel like all of this pain is my own fault.

After my mom died, I'd sit on the smoker's bench outside her old townhouse and keep watch on things just to make sure everything was okay. A variety of different thoughts flew through my head. How the hell am I going to survive without her? She was – is – my person. Is the cancer that killed her coming for me? Where am I going to live?

Up until her death, I knew I would always have a place with her. When she passed, my landlord only gave me two weeks to move out. I was quickly moved into a studio apartment across the parking lot. As a result, I had to donate or throw away a lot of her things. What hurt the most was losing some of the art she had painted. I managed to keep a few of her paintings which are now hanging on my walls.

If it was up to me, I would move out, start over somewhere new. I would take my partner and everything I own and get out. I would be able to go to the woods anytime I wanted to and escape and just breathe.

VALERIE SAINTINE THOMAS

A Journey of Hope

I grew up in a third world country where you don't go to the hospital unless you’re very sick. Private healthcare is used by patients in the upper class who have insurance or can pay out of pocket. Those people receive state of the art care. But because of lack of infrastructure and affordable healthcare, the rest of us usually have to rely on inadequately equipped hospitals staffed with recently graduated doctors, nurses, and community workers. The community center is where most people go when they’re sick, and it’s usually managed by a nurse who is responsible for first aid, wound care, and vaccination delivery.

But here in America it is different, and you receive a very high quality of care. When I felt sick one day after I had come to America and my blood pressure didn’t respond to my medications, I went to the emergency room. At the time, the only health issue on my mind was the fertility issues my husband and I had been struggling with. Suddenly I found out that I had end-state kidney disease. I was used to being healthy, and suddenly I had to start going to dialysis X times a week for x hours a day. I was shocked, sad, and in pain, and I didn’t know what to do. However, I was grateful that the American medicine gave me a diagnosis while there was still time for me to take care of myself.

When my health declined, I needed to rest all the time. I also had to concentrate all my remaining energy on staying as healthy as possible. I put everything but the most essential activities on hold. I felt sick, lonely, and depressed. I was also worried about money because I was relying on Medicaid to pay for my medical expenses, and when the government went into shutdown the dialysis center stopped my anemia treatment. There were days I wondered why I was still alive.

At the same time, I was also sheltering a woman and her children in our home while she was trying to escape from a bad relationship with her husband. Originally, I had met her while we were at school, and then we lost contac.t Years later, we reconnected around the time she had an altercation with the parent she'd been living with. I welcomed her and her children with open arms. We provided for the family, and I spent a lot of my time picking up her kids from school and taking care of them while their mother was working. It was the worst mistake I ever made. During the period when I was disabled, she and her children expected me to do things that might have seemed normal to them but were above my level of strength.

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During the six years I went to dialysis some people kept their distance. Some close relatives said they were choked up and did not know what to tell me. They kept their distance and didn't call or visit. Maybe it was their way to share my pain.

But during that same time, I also had the pleasure to meet with some wonderful nurses, dialysis technicians, doctors, pastors, and family members. They provided food, clothes, and money, drove me to my medical procedures and appointments, helped me attend church, and sometimes bought me things I didn't even need.

I also worked on my own to try to have a normal life or at least maintain control of my mind and find some happiness. That's why I visited family and did some volunteer work. One of my favorite activities was serving as a member of the women's ministry. Our goal was to sing for the Lord, pray for those who are ill, and visit the elderly member's church members.

Fortunately, all the nightmares associated with my end-stage kidney failure ended when I was blessed with a kidney transplant and was able to go back to living life to the fullest and taking care of people who need me including the young daughter we had adopted.

Because of my own experience of sickness, I now try to teach other people about how to take care of themselves. Education is the best step toward health equity. Some of the things I teach have to do with basic hygiene, like hand washing, and food safety, like washing fruits and vegetables before consuming them. Diet is also important: for example, avoiding salty food and high carbohydrate drinks. I am writing a book regarding the kidney-friendly diet. And it's probably not surprising that I believe in the importance of early screening: mammograms for breast cancer, pap smears for uterine cancer, PSA for prostate cancer, and prenatal and postnatal care. Kidney disease early diagnosis should be mandatory because 808,000 people in the United States are living with end-stage renal disease. A lot of people actually wait a very long time for a kidney transplant.

But education isn't enough on its own: we also need health equity, and the empathy and respect of health care workers. I know I will always be grateful for the healthcare workers and members of the community who helped me during my toughest times. But we also need affordable healthcare. The members of the working class work hard to earn degrees and get jobs that will make our children's lives easier. Shouldn't we be able to get affordable insurance that meets all our needs? Because of inequality, poor people die of AIDS while rich NBA players have access to early experimental antiviral drugs and are still thriving 30 years after they're first diagnosed. It's' time for a health revolution that demands the best preventative health care for all. Until then, we must all be our own best health advocates.

Regardless of where we were born or how much money we have, we need to realize how strong we are. We need to look behind us and realize that the storms we've already walked through could not take us down. Instead, we stood up and kept walking. One by one we must move forward step by step until we succeed in achieving medical equity.

LAURA DICARONIMO

The Best Day

My mom always called my birth the best day of her life. To celebrate my twenty-fifth birthday, my mother wrote me a poem. Something written in love is always special, but my mother was a wonderful writer. In the poem, she talked about the origin of my name, the right angle of the "L" providing the backbone for the "aura," all coming together to create me, Laura! I told her it was the best birthday gift I had ever received. This is a big deal because my mom always made sure my birthday felt like a national holiday, parties with friends with cake and water balloons were the norm, and when I was older, we would always find the nicest restaurants, the prettiest drives, the loudest karaoke bars to celebrate in.

Mom was always a huge advocate of celebration, even though life had given her little to celebrate. Although my mother, father, and I were insanely poor, my mom—with an Aries' typical diehard optimism—always insisted we were "middle class." My dad was in many ways a question mark to me. Even though he was present for my childhood he wasn't emotionally present the same way mom was. He played in bands and prioritized his time away from family over time in the backyard with us.

Mom met my dad in high school and had married in their mid-20s. Their relationship lasted for thirty years before disbanding, and while it is not my story to tell, it was painful for my mom to a depth that I don't think even I was aware of. My dad had profound mental health struggles and even as mom was glad that a bad marriage was ending, she was still empathetic to him and did her best to make sure he was taken care of financially and emotionally. She had many sleepless nights worrying about him as he struggled with first health problems, then homelessness. His rock bottom was a lesson for me in both advocacy and letting go: I made phone calls to find him a place to sleep, but respected that he was a contrarian to the core and sometimes the best way to advocate for him was to let him be himself.

While my mom and I were both depressed, the experience brought us closer together. And although my mother was clearly dealing with a great deal of stress, she continued to believe that a good attitude and hard work would see her through. So, she worked her usual forty-hour weeks, did her usual meditations, and thought the worst was over.

Her stroke came out of nowhere. I was in my office waiting for a friend to call and tell me to pick up her wedding favors, so when the phone rang, I picked right up. A voice I didn't recognize asked my name, asked me if I was Susan's daughter. I confirmed. They told me my mother was in the hospital and had had a stroke, could I get there? I said of course. The woman paused. I heard her sigh. "Drive safe, but you'll want to make it fast." When I got to the hospital two women were waiting by the emergency room doors. They looked tense, arms crossed, eyes scanning the crowd. Instinctively I went to them. "I'm Sue's daughter, where is she?" I couldn't help but almost scream the words. Nobody took issue with my tone. The woman who I would later learn was the chaplain just put her arms around my shoulders and led me in.

My mom's lifeless body was on the table in front of me. She had been dead at that point for almost an hour; there was no denying it. Her skin was pale like the surface of the moon, utterly desolate. The chaplain and nurse were so gentle in their questions about my mom's beliefs in the afterlife. They were so soft with me when they asked if I wanted them to keep giving her CPR. Why did I apologize when I told them that I wasn't ready to lose her yet? It was as if I was afraid it was impolite to fight for her life. Although she needed to be moved to a better-equipped hospital, a life flight was out of the question because it was starting to rain. And so, I found myself desperately trying to follow the speeding ambulance through the growing gloom.

At the next hospital, they asked if I wanted them to shock my mom's heart back into rhythm, and when I answered affirmatively, they tried to make me leave the room. "It can be very hard to watch." "It can be very hard to hear." Also, there was the risk she would die. All I said was: "I can't let her die alone." The doctor nodded as though he understood and said, "Let's go." In retrospect, this was the first massive kindness we were to be given, though I didn't feel it's depth in that moment. To be allowed to do something simply because it's what I owed her as my mom felt was a huge courtesy that we wouldn't always be given.

A doctor was holding paddles that had brought electricity to my mom's heart and got it beating properly. There were four other people working frantically to make sure my mom would survive, and I am thankful to them on a profound level. But half a decade later and what I remember most clearly of this moment was the look the nurse was giving me. Pity, but soft pity, the pity you give someone when they don't know just how bad things are, yet.

As I sat in the corner, a nurse by my side, I noticed my mom's breasts were exposed as they worked on her. I was talking to the nurse, just rambling. I said, "Oh, my God, my mom's soul won't even come back to her body. I think she would rather die than have her whole boob exposed to a room full of strangers." The nurse calmly walked through the fracas surrounding my mom and covered her breasts with a blanket. I started wailing, thanking her over and over again.

She was smiling gently but there were tears in her eyes, too. She laughed and said "Don't worry about it! I'd feel the same way as her." For that nurse to identify with her patient right then is something I think about every time I meet a nurse. To have that much empathy for a woman who you had only ever met as a corpse showed me the depths of what empathy could look like. That nurse's name is Danielle, and I will never forget her. I never saw her again after that.

My mom wound up surviving, but she was in a coma. I was fortunate to have a job that let me work remotely, and I was constantly next to my mom's bed. I would wake up contorted in a chair with another chair in front of it. I would wait for the nurses and doctors to come by and run tests or draw blood, so I could try to get a handle on what to expect. A social worker would come by and ask what our plan was. I didn't know what our plan was. It was the end of the month, should I bother to pay her rent? Would she ever go back to her third-floor apartment? I didn't ask any questions. I didn't know what questions to ask that could even be answered.

Occasionally a nurse would tell me I should go home and get some rest. Occasionally a doctor would say something like "We're in this for a marathon, not a sprint, you need to save your energy." For what? I wondered. For a funeral? To have my mom live with us? To not simply fall over and die myself? I was being too polite an advocate, I wasn't advocating. I was too intimidated by doctors to ask them to pause over some detail with me. I felt like a statue, uselessly growing moss over my unmoving limbs while someone would stop in front of me, look me over, then say nothing. Nobody ever did any meaningful follow-up with me.

Not once were we offered outside resources for families of people with traumatic brain injuries. Not once was it suggested that we find a support group. Not one mention was ever made of the myriad nonprofits and social service agencies that could've helped us. I felt hopelessly adrift in a world that would simply chew my mom and me up and spit us out, the bills were already piling up and her landlord was already stressing me about when he could expect payment because "even if there's nobody living up there, I still have to make my mortgage." I paid her rent, which I could not afford on top of my own bills, and cried. My heart couldn't accept what I was starting to logically realize: that our lives were about to be completely turned upside down with no safety net.

It was my fault no one answered my questions. I was too afraid to ask them. I was too panicked to have words. I was too overwhelmed to have ideas. So instead, I was curled up in a ball in a chair, taking up as little space as possible. The next time you see a person not asking questions, ask yourself a question: how can I help? What do they need to know?

Four days into my mom's coma, my husband and I had tickets to a concert in Boston. I was beside myself. I loved this band and I had been looking so forward to a fun night out with my husband before our world shattered. I was devastated because I knew deep down, that this wouldn't just be something I'd miss to take care of my mom, it was just the first thing. The first of many. I would watch the sun set from her window that day and my body wouldn't have danced, my lungs wouldn't have shouted out cathartic lyrics. Okay. I could do this for her. She had done so much for me as a child, what's one night? I was sitting next to her bed, just staring into space as usual when one of her nurses came in, his name was Josh. He had been kind to me before this, showing interest in the CDs I was playing for my mom and overall being really polite to me.

He asked how I was doing and I said, "Honestly man can I bitch for a second?" He laughed and said, "Well if anyone can, you can". He was right! "Look, "I said, going into rant mode "I have tickets to see Cohead tonight. And I know it's so fucking stupid, but I wanna go. I'm so scared and miserable and if she dies when I'm out I would never forgive myself. But I am so fucking sick of this room…" Josh was laughing openly at that point and I interrupted myself "I know, I know, the world's biggest asshole can't hold it together for one more night?"

"Laura", he said "Are you secretly a cardiac surgeon?" I shook my head. "Then what are you going to do if you DO stay here? We are going to be the ones that take care of her, if anything we'll just want you out of the way. If she's going to go tonight, she's going to go tonight if you're here or not. You're still alive." I blinked. I knew I was still alive, thank you. "You're going to have to keep living."

I went to the concert. I tried my best to have a good time, but my heart was still next to my mom's bed. What this nurse gave me, though, was the beginning of a very important lesson for me as an advocate. Sometimes, doing your best means knowing what you can't do. Means knowing when to try to catch your breath. Getting this permission from a medical professional to step away for a moment was one of the biggest gifts I was given early in my mom's recovery. It was more than the empty encouragement to rest I'd been getting from doctors who barely looked over their reading glasses to admonish me. It was someone who was taking the time to see me and make a specific recommendation about a specific circumstance.

Eventually, Mom was well enough to go to a rehab facility. This felt like a monumental victory for us. She sometimes was still confused, thinking that the letters on a keyboard she saw were teeth, or being terrified of passing helicopters thinking she was to be put in one. The mood was tentatively optimistic as I and a few nurses got her checked into her room. "Name?" one of the nurses asked. Mom answered accurately. "Day of the week?" the nurse asked, and mom wasn't sure but at that point, well, it was late. Confusion was understandable. They asked a couple more questions and then handed my mom the pen to sign herself in. Her elegant fingers enclosed it and then stopped. Mom laughed softly, her awkward chuckle I remembered from moments of slight embarrassment. "I'm sorry," she said, voice soft, "I'm not quite sure how to do this…" There was a hellish moment where neither the nurses nor I said anything. Then, cheerfully I said "No worries, Mom, let me help ya out. We'll get you figured out." And I took the pen and signed her in. I said I had to use the restroom and managed to get about five steps out of the room before I completely broke down. I started crying and shaking. A nurse led me to a small room and put her arms around my shoulders. I kept trying to explain to her that Mom was a writer. That she had written beautiful poems and insightful articles and now she couldn't even sign her name. The nurse sat with me for a moment, then had to attend to a patient.

Now, years later, I know that fine motor skills are often impacted by a stroke. Mom can now sign her name no problem. I wish that someone had told me in that moment, or before, about common issues for stroke patients. If I had known more about what to expect, this moment wouldn't have felt as bleak and alienating. I didn't know how to address it with Mom; I didn't want to make her feel worse about losing such a fundamental skill. Nobody stepped in then, or ever, to help me communicate with her about what struggles she may face, what's normal or not.

Weeks passed. Middle of July. My birthday. I'd barely slept the night before; the depression had a strong hold on me at that point and it didn't feel like I had anything to celebrate. Unbeknownst to me, Mom also barely slept the night before. She was awake and she was causing a ruckus at her rehab. "I have to call my daughter! It's her birthday!". They held her off from calling me until 8 AM. When we did talk, I was amazed. "Mom, how did you remember?" My mom laughed "Well you are my only child. It was a pretty memorable day!" We made plans to see each other and when I got there, my mom was outside in a gazebo, under a beautiful flowering tree with one of her aides. She was beaming at me, not just happy to see me but happy to be right. I felt an optimism blooming in my chest as lovely as any of the flowers of the tree we were sitting under. My mom relayed the story of my birth accurately and with detail to her aide, and her aide glanced over at my crying face. "She's right," I said, hardly able to speak, "That's always the story I was told." My mom spoke directly to her aid and said, "Just because I had a stroke doesn't mean I'm not her mumsy!" and we all laughed.

But to me, that was the beginning of navigating our new relationship together. She had been right about my birthday, about wanting to be in touch with her sole source of support on a sentimental day. Her nurses, armed only with the assumptions they may hold about patients with traumatic brain injury, assumed that she was wrong about the day. Before her stroke and coma, Mom was a smart woman, hilarious travel companion, loving mother. After her stroke and coma, she is a strong woman. She is a hilarious travel companion. She is a loving mother. No matter how incapacitated she is by her medical problems, she is a human being who deserves compassion, respect, and to be trusted as the expert in her own life experience. And stroke or no stroke, no one will ever be able to stop her from remembering the best day of her life.

LATOYA LEWIS

Daring to Hope for Home

When you called to invite me to the reunion—and told me that your side of the family loves me even though we've never met—I had to put you on hold so I could go throw up. All my life I've believed that I'm not enough, that I don't deserve love because growing up no one ever made me feel otherwise. Everyone who has come into my life has abandoned me, so I've learned not to get close to anyone so they won't betray me. You are offering me something I've never had, and I can't help wondering how my life would be different if I'd met all of you long ago. If you will take a walk with me back through my life journey, perhaps I can help you understand.

When I imagine a home, I picture safety, security, nurturing, love, joy, family, and happiness. Home is the place where your family, from the day of your birth, teaches you values and passes on traditions. But I've always thought of myself as never having had a home -- only houses where I've lived.

The house I lived in for the first twelve years of my life was the House of Loss. It was the place where my mother died before my third birthday. It was the place where I learned of my dad committing suicide after he killed his girlfriend who was pregnant with my sibling. And it was the place where my beloved brother was taken away from me. As a child trying to survive in an apartment where nine people had constant shouting matches, I learned that I needed to take care of myself. If I cried, someone would give me something to really cry about.

The only affection I ever received as a child came from my brother, Scott. The two youngest of sixteen siblings, we tried to make a home for one another. Scott would reassure me that one day we would escape from that house, and until then his love made me feel seen, heard, and protected.

One night my sister and her husband and kids were watching “Soul Train” on the old boxy black TV when Scott suddenly started making strange sounds and convulsing. His body was jerking, and his head was jolting up and down. My brother-in-law picked my brother up and ran down three floors and out the door to the hospital right across the street. I remember shaking uncontrollably and screaming my brother’s name, but no one consoled me. When, hours later, my sister and her husband came back from the hospital without Scott and I asked what happened to him, I was yelled at for asking questions.

After Scott was released from the hospital, things were never the same. The brother who had once protected me was diagnosed with a seizure disorder. Rather than keeping him at home, my sister signed Scott into the custody of the Department of Social Services. Looking back, I can see that my sister really had a lack of knowledge of her rights to my brother and was overwhelmed by her own life and not asked for responsibilities when my parents passed.

However, that meant that the three people who might have given me a sense of home—my mother, my father, and my brother—were all gone. When the house finally burned down, I watched the flames shooting through the roof and thought it was the wrath of God. But who was the target of that wrath?

At the age of fifteen, I moved with the other members of that Wrath of God House into a neighborhood where girls walked the street half-naked with boots up to their thighs. There I found myself surrounded by streetwalkers and pimps, drug transactions and raids, shootings, and other things straight out of New Jack City. You couldn't come in or out of the building without interrupting a drug deal, and once you came inside you were greeted by the welcome home roaches. When you are exposed to that kind of environment as a child, it can shape the kind of adult you eventually become.

But the thing that really made me grow up fast was realizing I needed to take responsibility for another life. When I became pregnant at sixteen and refused to get an abortion, my sister kicked me out.

After spending the first six months of my pregnancy homeless, another sister finally took me into her home but not her heart. When I'd open the refrigerator or cabinets, I would see that she had labeled all the food with the names of her children. I wasn't allowed to eat any of the labeled food, which pretty much was everything. When I would come home from school in the afternoon with my infant daughter, we would have to sit on the porch some days and wait until my sister came home from work to let us into the apartment. The winter was the worst. The neighbors would see me and my newborn sitting on the porch—sometimes in blizzard conditions—and say, "That baby's going to get sick!" or "You can't be outside with a baby in this weather!" As if I would really choose to be sitting outside in a blizzard with an infant! It was bad enough that I was a teen mom. Being put in these situations I was starting to feel like I was also an unfit mom. Sometimes the neighbors would invite me and the baby into their homes and would buy me baby formula since mine was locked in the apartment. As soon as I turned eighteen, I escaped from that house and moved with my daughter into my own apartment in public housing. Although I had to sleep on the floor because I had no furniture, it was a relief to feel like I was at a safe distance from bad treatment by some of my family members.

In that moment of my life, I was always questioning, always asking why. Why did my life have to be so challenging? What did I do to deserve this shitty life? Unfortunately, I began to believe there was only one answer: I must not be worthy of love or capable of success. The thing I had always feared seemed inevitable: the story of my life would be just the same as the story of every family member who had come before me

And so, I started to become the person I said I'd never be. My apartment in Great Brook Valley was party central. Growing up I was never acknowledged. Now I got attention—the wrong kind of attention. I was attracted to the fast life, the money, and the lifestyle, and dated someone who dealt drugs.

Predictably, my house got raided, and I was arrested. Worst of all, a family member had to take my daughter for a little while. It was one of the first big scares of my adult life—but not the last.

I was always looking for validation in others, wanting to be acknowledged by the people I needed, wanting someone to make me feel like I mattered and I was loved. I thought I needed people when I really needed to find me.

When I turned 21, I fought for guardianship for my brother Scott and won. Because of his seizure disorder, he required 24-hour nursing, which meant I couldn't keep him with me at home. But I was able to get Scott into a group home in Palmer. I vowed to protect my brother in his situation and to never give up on him the way everyone gave up on us.

While in the state's custody, Scott had been put through multiple surgeries to decrease his seizures but in reality, the procedure reduced his quality of life. Scott lost all motor skills including the ability to walk, talk, and eat. But one thing he never lost was his spirit. I admired my brother for the strength he had without even knowing--or maybe he did know but just had no voice to express it.

My brother was my motivation never to give up, and my daughter became my motivation to live. I knew that she deserved better, and my brother Scott deserved better, and I deserved better too.

But for a long time, I was fighting fire with fire when I really should have been on my knees talking with God. During that time, I went from one child to four, from recreational drug use to battling addiction. I had things deep inside me that I needed to figure out. It was only when I discovered the spirit and the spirit came alive in me that I began to find my way forward. As it says in the Bible: "For if you live according to the flesh you will die, but if by the Spirit you put to death the deeds of the body, you will live." It was then that I went from being a victim of domestic violence to being a survivor. I went from being dead in spirit to being risen.

Now I can say with pride that November 10, 2023, marks six years of maintaining my recovery. I am the first on my mother's side to graduate high school and receive a college education with a BA in Psychology. I am a graduate of the Clemente Course in the Humanities. I am a commissioner on the board of Human Rights. I have my certification in Alcohol and Drug Addiction Counseling. I work as a Re-Entry Navigator for Justice-Involved individuals with an amazing organization named Open Sky. I will be returning to school in January for my LMHC. I am actively involved in my community.

Life as I had known it as a child was not what I wanted for myself and my children. But the fact that I never experienced home as a child did not mean I could never have a home. Now my children give me life and light every day. We cuddle, we play, we fight, and we laugh, but one thing that is always present is love. When they smile at me and I smile back I know we are home.

On the phone you say: "Latoya, we get to love you from a place of how God loves us. We can love on you the way that he loves on us. Accept this light we're trying to give you because you deserve this." And then you ask: "Why do you think you don't deserve this?" The answer is "Because I've never had it before." I had a childhood filled with nightmares, and things I experienced I wish to never remember. The people I loved deeply have one way or the other left me. I always knew I could never rely on anyone. I find myself wondering what my life would be like today if I'd found you when I was a child. But then I put that thought aside and I exhale giving thanks to God for a time such as today. I am finally home.

First-Person Stories by Medical Professionals

JOEL POPKIN

Visits with Henry

Our medical assistant rolled her eyes. "He's waiting for you."

After the door knock, Henry said "Yeah," which was my invitation to enter. He was actually smiling this morning when I greeted him. Bedecked in a dazzling neon white jumpsuit and bright red sneakers, it looked like maybe he had recently fallen upon better times.

"So, how's it going, Henry?"

"Well, pretty good, doc. I'm on parole, and they're looking for work for me. Doing some side jobs, making a few bucks."

"Sounds pretty good. Everything smooth on the outside?"

"Cops are still crapping on me, but I'm cool."

"Excellent!" We reviewed his medical history and current medication list. He listed what he was supposed to be taking, and it seemed like this was going to be the easiest visit ever with Henry. His history of multiple altercations with the police had earned him the nickname of "Hammering Hank." He was a massive guy, who looked like he could take down a moose, and the documented collective injuries were not casual. With his history of impulsive striking out, I confess that I had never been completely at ease in the exam room with him, and our nurses were even less so. Henry's blood pressure needed some fine-tuning, so I had him come back in a week.

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Our medical assistant didn't roll her eyes this time. She just wanted out of there.

White neon had turned ratty; red sneaks were now gravel stained. Henry was able to make the visit with me because the cop he assaulted didn't show up at the hearing.

"Henry, I get it that you were just walking down the street minding your own business. The cop that called you that is an idiot and a racist. Are you going to let a total jerk win a battle by going after him? He'll always win because the cops aren't going to side with you."

"What would you do, doc?"

"Well, I'd be really pissed off, for sure, just like I've felt from racist comments I've gotten myself over the years – although for me there've only been very few, and I know that you've had many, many more. I think and hope I'd walk away, so I wouldn't give him the satisfaction of a fight that I'd either lose on the street or in court. In the long run, some battles – even though they're justified – just aren't worth waging because the end's always the same You can always think about legally challenging him later – after things have cooled down."

"You're not a Black man, so you just don't understand."

"You're right. There's no way a White guy could ever understand completely. But I get better at it the more you talk with me."

"Like, why do you always wash your hands after you touch me? Black skin bother you?"

"Henry, I don't want to bust your theories, but I wash my hands before and after every patient I see. It hasn't anything to do with anyone's skin
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color." It was time to reduce the room temp. "Have you seen a picture of my family?"

He let out a breath. "Doc, you have an Asian wife?"

"Pretty good for a racist, huh?"

I joined Henry's first smile of the visit. My wife had unknowingly upgraded the relationship between Henry and me. And although we didn't invite him for dinner, office visits ultimately advanced to a level of mutual comfort that percolated even through our nursing staff. For the first time I felt that Henry seemed to be easing into a complex, confrontational, and often unjust society.

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And then one day Henry no-showed his appointment. After lots of calls, we found out that he had been arrested for assaulting a state trooper. It hadn't made the news, nor could we get details from law enforcement, ostensibly due to confidentiality and legal issues. Soon afterward I retired from practice, and I've never yet been able to find out details of the arrest or how Henry eventually fared – although I'm sure it didn't go well.

Guilt trips are a basic part of standard medical practice – what could I have done to prevent this? While Henry was not always happy with me, he was never mean-spirited.

What were the factors that led to the evolution and triggering of Hammering Hank? Something that was done – perhaps repeatedly – to him or to a loved one? My knowledge of his background, past and present, was woefully inadequate, as primary care docs are hampered by a lack of training as well as little if any, time needed to adequately address these complex kinds of "Henry issues."

But until the practice of medicine and its societal support system finds a way for doctors to treat the whole person, we will continue to lose the Henrys of this world and be left only with the Hammering Hanks.
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ZENIE POPKIN

Why You Need a Primary Care Doc for Your Little Sore Throat

While growing up in the Philippines, I don't ever remember going to a doctor's appointment. Medical care in my family involved herbal brews from the Chinese drug store – mostly bitter, boiled concoctions followed by a sweet sugar candy to tame the taste. Western medicine was available but prescribed to people who would go to a specialist doctor for specific complaints. And hospital stays were rare: traditionally, among Chinese, at least, hospitals were places to go when you were beyond cure.

Since coming to America to train and work in an American hospital lab in 1969, I've realized how inadequate the practice was back home. Health care is available to people who can afford it, while the poor ly on free clinics and emergency rooms in government hospitals when available. Three to a bed in the hospital is standard fare.

When people experience problems, they go to a specialist: chest pain, call the cardiologist; belly pain, the gastroenterologist; and so on. But it's up to the families to diagnose their pain, choose a specialist, and keep records that any new physician or subspecialist would need (assuming they have the money).

Missing from this system are primary care doctors, who evaluate you, perform initial tests, refer you to specialists, and generally coordinate your treatment. Because of the work of internists, Americans have a much better chance than people in the Philippines of receiving the correct diagnosis and appropriate treatment from a specialist at an early stage in their illness when problems tend to be more treatable.

For ten years, my mother quietly suffered from intractable neck pain and lost her voice intermittently while trying every ancient herbal remedy available in the Philippines. She would go to one of her local Chinese drug stores and say, "Well, I got this little sore throat, and I've got this little pain. Give me something." As a primary care physician, my husband has traditionally taken responsibility for sorting out treatment for my family when traditional methods have failed, so in 1980 he and I decided to bring my mother to the United States for further care.

Unfortunately, an x-ray showed a suspicious tumor on her lungs, which proved malignant. After a year of unsuccessful therapy, she passed at the young age of sixty-six. Had she lived in the United States, her primary care physician would have responded to her complaints by looking closely at her throat, taking x-rays, and referring her to an ear nose, and throat specialist. The outcome of her case would have been quite different if the x-ray had been taken ten years earlier. She might have enjoyed many more years of life. Unfortunately, whether rich or poor, there are very few families in the Philippines that have access to the kind of primary care service that might have helped.

But it is also unfortunate that primary care doctors seem to be disappearing in the United States while subspecialists are proliferating.

So, who's coordinating your care? Patients who have lost their primary care physicians are now having a hard time replacing them as the physicians retire (many prematurely) or move away. Even those who can afford blue-chip medical insurance have a hard time finding primary care doctors, and it's far worse for those in need. My husband regularly tells me about the desperate plight of the patients he sees in a weekly free care clinic.

I still remember how impressed I was when I first witnessed the workings of the American healthcare system on my arrival in this country nearly sixty years ago. I was so proud to become part of that system and proud of my husband's work directing an internal medicine residency training program. Today that pride has changed to alarm over the dwindling supply of internists. With a large percentage of primary care physicians reaching retirement age, all of us need to call for greater support for young people hoping to enter this important field. Otherwise, who will be there for us when we need someone to look down our throats, order us an x-ray, send us to an ENT specialist—and earn us some additional precious years of life?

PETER LINDBLAD

Eye-Opener

"The good physician treats the disease; the great physician treats the patient who has the disease." -- Sir William Osler, founder of the John Hopkins University School of Medicine

The patient said, "I have worms." What followed was a real revelation.

In the early part of my medical career, I never required an interpreter for patients, all of whom had backgrounds like mine. I had confidence in my ability to interview patients and felt I was a good diagnostician. Immediately after medical school, I worked in Worcester for twelve years, several years in New Hampshire, and then moved to Boston. I started work with an organization that serves a predominately underserved population of patients most newly arrived immigrants and non-English speaking mostly Portuguese, Spanish, and Haitian Creole. My experience at this institution changed my understanding of myself as a physician, as well as my understanding of the patients I was serving. One patient brought about that change.

Madeleine was a recent immigrant from Haiti, who spoke only Haitian-Creole and came to the United States with her husband and children trying to make a better life for her family. Through the interpreter helping me obtain her medical history, the patient explained that she had worms. My questions focused on the worms. Did she have anal itching? Did she notice any white rice-like particles in her stool? Did she have any abdominal bloating? I was taught, when working with an interpreter, to look at the patient, not the interpreter. Madeleine kept her eyes focused on the interpreter occasionally looking at me; I kept my eyes focused on her. For the next five to ten minutes, I asked a series of questions related to an infection with worms drawing on my previous experience dealing with a US population of English-speaking patients.

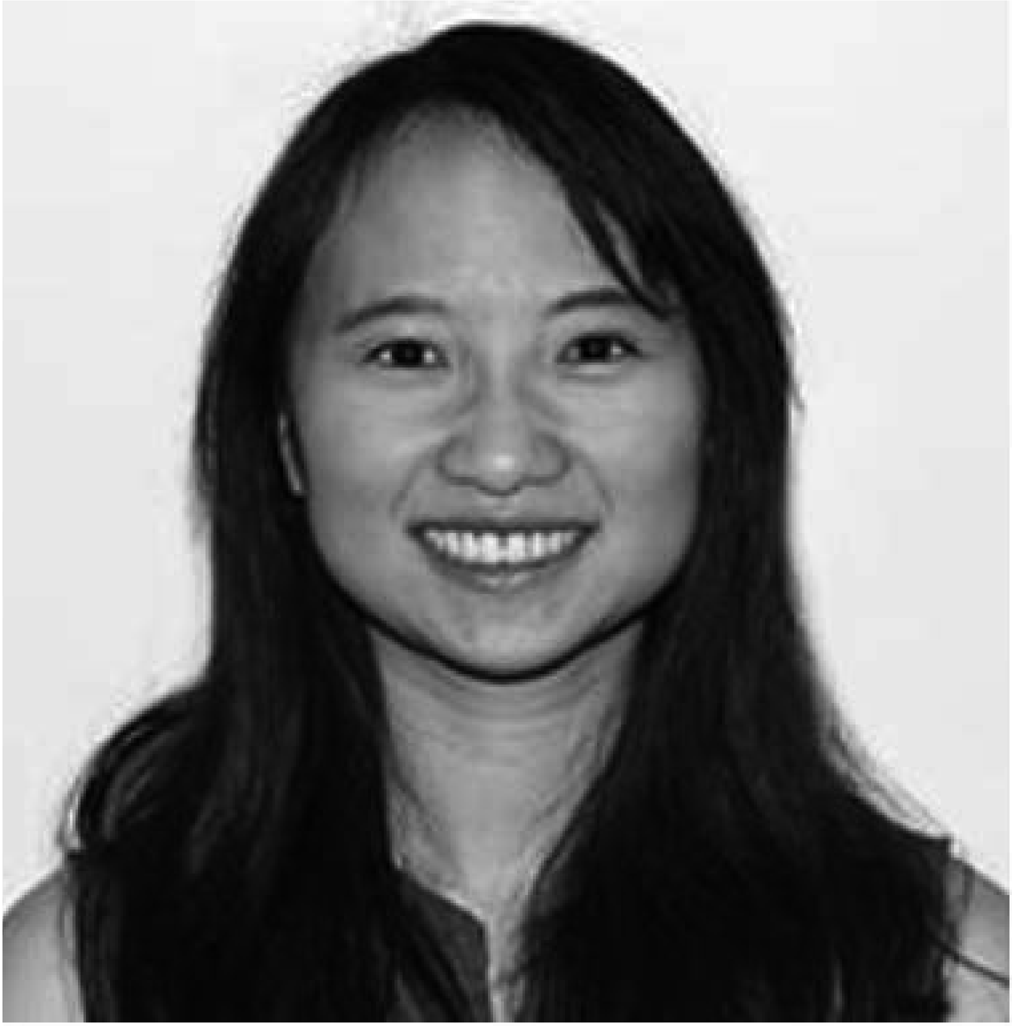
With each question, the patient would give me a strange look. I turned to the interpreter and asked, "Am I missing something?" She said, "In Haiti when you have abdominal pain, you most likely have worms." Boy was I going down the wrong rabbit hole with my line of questioning! I suddenly realized how dependent I was on the interpreter not just to interpret the difference in our language, but also to help understand the cultural differences between myself and this patient. My cultural background and life experiences would not contribute to making a diagnosis for this patient. I needed to adapt and better understand the history on her terms.

After I completed the patient interview more focused on her abdominal pain, I felt much more confident in my plan to work up her complaints. I was in for more surprises.

As I continued to see her on follow-up for her complaints of abdominal pain, she no-showed multiple times. It was extremely frustrating, and I became angry with her. I had worked hard to make sure to get the tests scheduled in a timely manner, but she missed all her appointments for X-rays and ultrasounds. The next time we met, I asked her why she didn't show up for any of the diagnostic visits my office had arranged. She explained to me that she was working three different jobs to support her family and could not take the time off. She wanted to make sure her children would have a better life than she did, and she was working all those jobs so they could go to college. At that point, my frustration and anger melted away, and I developed a feeling of great respect for this woman. I was relieved that she felt comfortable enough to tell me the truth. My past background and experience kept me from truly understanding this patient.

Going forward, I arranged the tests at a time that was convenient for my patient and shortly we had a diagnosis of gallstones. She had surgery and did extremely well afterward. This one experience changed my whole approach to interviewing and managing patients. The patient's behavior and complaints are a symptom of their past and present life experiences and culture, which are very different from mine. You must treat the patient who has the disease.

Madeline taught me that we need to flip the script. Healthcare systems and physicians need to move from "You are the patient, and this is what you are going to get," to "You are the patient: what do you need?" The current design of healthcare delivery can be based on what is convenient for “the system”, not the patient. A patient's behavior is almost always a symptom of their life outside the exam room. I tell my medical students when a patient comes in and isn't making sense or behaving as expected, they need to ask more questions and LISTEN to the answers. By asking more questions you can discover the "why" the patient's behavior has changed. For example: the mother died of breast cancer recently, and now the patient is worried they may have cancer. Sometimes you need to PULL this information out of the patient. A great technique independent of culture and background is to sit back and say nothing. Studies have shown it takes approximately eleven seconds before a doctor interrupts a patient during an interview. By listening to Madeleine, I learned that the workup for her "worms" would require some flexibility on the part of the system to support her dreams of a better life for her children.



MOLLY ZHAO

Party at the bedside

What would be a good death for a patient?

Eight months into intern year, I encountered my first death as a doctor. He was an eighty-nine-year-old gentleman with leukemia, whom I had admitted on full code so he would receive all measures of resuscitation including chest compressions and intubation. As part of his admission process, I had to contact his wife, who was his healthcare proxy, to reconcile his medications and to confirm his code status. Over the phone, she had a cheerful voice, her uplifting spirit apparent as she listed each and every one of her husband's medications, with minimal corrections from her daughter in the background. Little did they know, that was the last hospital admission that they would have to perform for their husband and father.

The following night, I met my patient's wife at his bedside. She had a grandmotherly figure and hair with streaks of grey, with remnants of a smile crinkling the ends of her eyes. We reviewed his code status again, talking about whether he would really want to undergo potentially rib-fracturing chest compressions and be kept alive by a breathing tube.

He had been DNR/DNI but was just recently changed to full code. His wife explained: "He is a stubborn man; he always bounces back." Her husband had been a police officer for much of his life. After he retired, he was diagnosed with acute myeloid leukemia, the most aggressive type. Always resilient, he had completed several rounds of chemotherapy and had endured an unknown number of hospitalizations, ultimately entering remission. He had been receiving weekly blood transfusions to maintain his blood and platelet levels, until this most recent episode of nosebleed put him into the hospital again.

When he was in the Emergency Department, nasal packing was placed in his nostrils to temporize the bleeding, His lab work showed dangerously low blood and platelet levels that would require him to have additional transfusions. His kidneys were also failing – which meant he would need dialysis to continue living. After reviewing all of these findings with his wife, she asked me, “Can I tell his children that I don’t want him to go through dialysis?”

As his wife started to contemplate the meaning of a good ending for her husband, I also started this speculation as one of his primary physicians. The next day, he reverted to DNR/DNI because he had become hypoxic overnight from the blood and platelet transfusions.

During my third night with him, my patient was a different person. Before he had been able to talk and grunt; now he could barely express his pain. Dry, dark blood coated the inside of his mouth, making it difficult to swallow or taste any foods. His wife was no longer smiling, her eyes grim and hard. He could only lightly touch his forehead to let his loved ones know that the nasal packing and the oxygen mask were hurting him. I felt like a failure. We were supposed to heal and do no harm. Both his disease and the advanced medical treatments had turned a strong-willed and upstanding man into this ragged, bruised, breathless doll on the bed unable to protest and voice his feelings.

Every day after leaving the hospital, I wondered if we should remove the nasal packing. As I would fall asleep, thoughts about his end of life would drift in and out of my dreams. Was it right to continue giving him transfusions, while hoping his lungs and kidneys could withstand the fluid? Were we making him suffer with the oxygen mask? Were we healing him with the constant lab draws and powerful antibiotic treatments?

On my patient’s fourth hospital day, I returned to working day shift. I consulted the palliative team that day, and together we met with the patient's sons and daughters. Calm and collected, they made the decision to release him from all life-saving treatments, including transfusions, antibiotics, and oxygen therapy– and to focus only on comfort. They decided to leave the nasal packing in until the next day, when it was due to come out. After I had ordered the fentanyl and Ativan as needed for comfort, I told nursing to wean him off the oxygen with the medications. Later I realized that the slower we weaned his oxygen, the longer the family would still have with him.

Later that night, I went into the patient's room, and his six children and their spouses were chatting cheerfully, drinks in their hands, around their father's bed. For the first time, I saw a smile on his wife's face. On the wall was a child's drawing, which said "get well soon, from Lottie." After I said my good-byes to his family, a sense of calm and peace washed over me, the same feelings that would normally arise after rectifying a mistake.

On the following morning, I was surprised to learn that he had pulled through the night. Seconds later, my phone sounded with a message from his nurse -- he no longer had a pulse. In the panic of rushing to his bedside, I forgot my badge. When I finally arrived, I saw familiar faces-- people I knew. Her eyes red from crying, his wife came to me and told me that he had stopped breathing a few minutes ago with no struggles at all. As my attending announced my patient's time of death at the crack of dawn on his fifth hospital day, I found myself remembering the many moments that I had stood by his bedside with his wife, listening to her talk about his stubborn personality during the twilight hours. I hugged his wife; I placed my hand on his daughter's shoulder to express my condolence. I said my blessings to his son. Quietly, I exited the room for the family to say their goodbyes – the process was sad, but all was calm. I notified the medical examiner and signed the discharge summary, my last acts of service for this family.

From the admission note to the discharge summary, I experienced the circle of life. It is our utmost privilege to share these valuable moments with other passengers on this Earth. It makes me so thankful to be a family physician, a role that allows me to attend births and to guide the process of death. It was a privilege to connect with this patient's family and to be part of their celebration at his deathbed. One day, it will be my end, and I want to be celebrated. That is the meaning of a good death.

HUGH SILK

What Kevin Taught Me

"Okay if we come over?" my colleague called out as we approached the two tents. He wanted to show the men we were visiting the respect they deserved.

We had come to see Kevin. A volunteer who worked with homeless people in the area had contacted me to say that Kevin's leg appeared to be infected. Ironically, getting out of jail often results in people becoming homeless, relapsing into substance use, and experiencing worse health because few services are available for them.

So often when people get out of jail or prison there is a void of care that can lead to worsening health, relapsing with substances, and homelessness. I was glad to be making contact with Kevin. As part of a homeless outreach program, my team and I provide care for people experiencing homelessness in our office, in a mobile RV clinic, and on foot. We tend to fill gaps in the system.

I removed my backpack.

"Hi, I'm a doctor and I wanted to see if you needed any medical services."

Not only did Kevin have cellulitis on his leg, but it had originated from an ulcer on his foot. He also had diabetes and was drinking again.

"I don't use any drugs man, I swear. It's just the booze." He paused. "Does that cause the foot infection?"

I removed supplies from my pack and cleaned the wound while I chatted with Kevin. I dressed it the best I could and pleaded with him to come to the hospital. I knew he would refuse. This was always a process. I wrote prescriptions for insulin and antibiotics and provided a bag full of wound care supplies. The social worker who was accompanying me made a plan to return with the medications later that afternoon. We left water, clean socks, and Narcan.

"I appreciate you," Kevin called out as we headed down the dirt path.

Kevin became difficult to find after that. The city had cleared out the tents, disrupting our connection to him and others in need. I heard he had ended up in a nearby hospital at some point. About three months later I saw Kevin's smiling face in line to see me at the temporary winter shelter set up in a local church.

"Man, am I glad to see you!" I said when he sat down to see me.

You're glad to see me, doc?"

"Yeah, I was really worried about you. I am so glad you are staying here. How are you?"

He had been in and out of shelters, tents, and the hospital. His foot would heal a little then get bad again. His sugars were all over the place. His drinking had led him to miss some curfews at shutters so he ended up sleeping outside at times. He had suffered frostbite, which only made his foot issues worse.

"Kevin, I want to work closely with you. I can have a nurse change your dressing every few days, get you on some vitamins, help with your diabetes, and you'll be in much better shape."

He nodded.

"If we don't, you're gonna lose this foot at some point." His eyes showed he understood. "And we have to work on the booze. It's killing you."

We talked about our peer counselor visiting him. I would provide naltrexone tablets to help reduce his cravings.

He said yes without hesitation. He was ready. He was scared. He did not often make eye contact but was looking deep into my eyes now.

"I'll be here with you. I don't know what you're going through, but my dad, brother, and sister all suffer from alcohol issues. I do know it is not easy. But I have faith in you, Kevin."

We had made a connection.

I wish I could say he surprised me, but predictably he had many setbacks that winter. He went nights without returning and then would show up and sleep all day after a bender. However, he did work with the nurse. He did work on his diabetes. And week by week his foot got better. I learned about his life in prison. I learned about his lack of family. I got to know him, and I got to like him. We formed a loose bond. We looked for each other at the shelter to do updates. He would smile when he saw me – a sign of recognition and relationship.

Every December 21, people around the country come together on the longest night of the year to honor those who are homeless who have died during the year. Last year, Kevin was the person with lived experience who was selected to give a speech. He was great. He talked about his own struggles and eventual improvements. He was recently sober. He was proud to be where he was. He bragged to me later about having a job. He said to the crowd, "If I get rich one day, and can buy a big house, I am going to fill it with people who don't have a house. Why would I want all those extra rooms empty?!" Tears came to my eyes. Kevin had made it.

I didn't see Kevin on the last week the winter shelter was open. It was an occupational hazard to lose track of patients. They could disappear for a long time. But I heard that Kevin got housing. I saw him a few times. He was making progress. There was light at the end of the tunnel.

Weeks later I got the news. Kevin was dead. He had been found alone in his room. There was no sign of foul play. No sign of an overdose.

Why?

Getting a housing placement does not save lives on its own. People all too often die once they have a place to live. They get lonely. They don't have a friend with them if they overdose. They lose many of the support services they had when they were in the street or shelter.

Kevin and our friendship taught me a lot. And his death taught me that we need a lot more very affordable, permanent, supportive housing. We also need to keep a close eye on newly housed people – it is a high-risk time for most and for quite a while. For those who are not used to having their own place, it can be scary. We can do better. We have to do better.

Thank you, Kevin. I miss you.

The Clemente Course in the Humanities is a free college-level seminar for highly motivated low-income adults seeking to build better lives for themselves, their families, and their communities. Graduates who successfully complete the coursework receive credits from Bard College. Both the program founder, Early Shorris, and the program itself have been awarded National Humanities Medals.

Students in the Clemente Course hosted in Worcester, Massachusetts study art history, literature, American history, philosophy, and critical thinking and writing. Summer courses funded by Mass Humanities provide opportunities for alums to continue their education alongside entering students.

The memoirs included in this volume were composed by Clemente students enrolled in the summer 2024 course on Storytelling Our Way to Health Equity, and by medical professionals participating in a workshop on the same theme.

Worcester's Clemente Program is sponsored by Mass Humanities in partnership with the Worcester County Poetry Association and other local organizations and donors.

Cover photo:
Childhood Photo of Clemente author Dukroa Owens

MASS HUMANITIES

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