The Language of Care:

Stories from the Penn Medicine Listening Lab

Aaron Levy,
Stephanie Kindt,
& Teya Sepinuck,
Eds.

Penn Medicine Academy, Slought Foundation,
and Health Ecologies Lab, Philadelphia

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“Listening… enables us to give democratic shape to our being together in the world.”

— **Susan Bickford,** ***The Dissension of Democracy*** (1996)

Kevin B. Mahoney
Chief Executive Officer
University of Pennsylvania Health System

Preface

The first time I picked up one of the round, white handsets in the traveling exhibit for the Penn Medicine Listening Lab, I heard the voice of a patient describing the care she had received and how it made her feel. She talked about giving feedback and what that could mean for future care. The story was about being vulnerable, and the effects of listening in a healthcare setting felt all the more real to me.

At its core, the Penn Medicine Listening Lab is about bringing people together in a safe space to be heard. It celebrates authentic listening in everyday moments using the powerful modality of storytelling. Stories have incredible power to drive organizational transformation. They help us take a second look at our own belief systems through someone else's lived experience.

At Penn Medicine, we develop thousands of cutting-edge treatments and cures that are nothing short of miraculous. We strive to deliver care with compassion at every touchpoint in the care journey. Deep listening is imperative in delivering compassionate care that truly heals.

Stories have the capacity to not only teach us but nurture our desire to feel connected to others. They have the capacity to bring us together and remind us of the communal bonds that make us who we are. They represent the collective wisdom of our community. As you experience the stories bravely told by members of the Penn Medicine community, I hope they will inspire you, challenge you, and encourage you to connect deeply with others, as they have done for me.

Foreword

Several years ago, I had a conversation with Kevin Mahoney, Chief Executive Officer of the University of Pennsylvania Health System, about innovative ways to integrate the arts into healthcare. We discussed my developing a project to engender community in healthcare through the simple act of listening and storytelling—a nearly twenty-year vision of mine. Together, we saw this project as a unique opportunity to recenter humanism in medicine, foster empathy and compassion, and model collaboration between universities and health systems.

I began by gathering a team of leaders and educators to focus on creating what has now become the Penn Medicine Listening Lab—a project featuring audio stories of patients, caregivers, staff and providers throughout the health system. We developed a series of guiding principles, followed by a public-facing website featuring audio stories, a physical exhibit that traveled across Penn Medicine, and now this book.

At a moment when there are so many crises in healthcare and society, and many feel unheard, this work has become more and more urgent. As we all work to confront inequity within medicine and our society, listening and storytelling has a unique ability to create relationships that enhance communication and understanding between patients and healthcare providers.

I remain immensely grateful to the many staff, providers, patients, and caregivers across Penn Medicine who have shared their lives and their stories with the project and this community. Our storytellers, in allowing themselves to be vulnerable, have given a gift to the entire health system. I also know none of this could happen without the effort and expertise of a diverse team of thought partners and collaborators who have believed in this vision and made this work possible. The trust and support of the Penn Medicine Academy, specifically Cindy Morgan, Vice President, and Craig Loundas, Associate Vice President, as well as the sponsors of the Penn Medicine Experience Leadership Team, provided a platform that enabled the project to organically develop and impact the Penn Medicine community.

Key to the implementation of this project is Stephanie Kindt, Senior Consultant for the Penn Medicine Experience, an extraordinary leader and connector who has brilliantly integrated our work across the entire health system. Teya Sepinuck, a member of the Patient and Family Advisory Council, HUP, and director of Theater of Witness, herself contributed one of the defining first stories and has empathically partnered with us to nurture the participant experience and record and shape their stories. I also want to thank Karen Anderson, Dr. Jeff Millstein, and David LaMotte, who engaged this project since its inception with singular commitment, sensitivity, and expertise. Our work continues through the dedication and innovative contributions of a diverse system-wide project team, as well as the many students, educators, designers, and others at Penn Medicine, the University of Pennsylvania, Slought Foundation, and Health Ecologies Lab, who are all named in the acknowledgements section of this book.

The past years of societal upheaval have been destabilizing and unprecedented. Having the opportunity to address these challenging times, together with a community of storytellers and collaborators, has been one for which I am immensely grateful. As it has so profoundly for all of our team, I hope this publication, in turn, will generate meaningful connection, listening, and inspiration, and that the stories themselves will ripple outwards and impact all who hear them.

Introduction: A Community of Listeners

"The experience of sharing my story really helped me grow as a clinician, and cracked something open in my heart."

— Julia Schott, MSS, LCSW

The Penn Medicine Listening Lab is an online audio platform that features short stories of six minutes or less by patients, caregivers, staff, and providers. Fundamentally a storytelling initiative, the Listening Lab embraces the simple act of listening and sharing and advocates for the power of listening as a form of care. As a gathering place for stories from across Penn Medicine, the Listening Lab affirms and celebrates listening as essential to the work of healing. In giving voice to the lived experience of patients, caregivers, staff, and providers, it embodies the tenets of patient-centered care, nurtures a cohesive culture of caregiving, and provides an innovative complement to traditional approaches to medical education and patient experience analytics.

In our first years of existence, the Listening Lab has become a powerful tool for humanizing healthcare, addressing inequities in our healthcare system, and providing an integrated and holistic view of the human interactions that define the Penn Medicine experience. This book is a compilation of the nearly fifty stories recorded so far for the Listening Lab. It includes storytellers from a diversity of backgrounds and experiences, including chaplains, medical students, grieving spouses, transplant recipients, nurses, physicians, sexual abuse survivors, and social workers, to name a few. More than mere transcripts of the original audio stories, this book offers us another way of listening to the voices of an interwoven community of storytellers that come alive here through the written word. These words and stories also advance a bold vision for how the arts and humanities can contribute to the work of healing in healthcare.

Penn Medicine is a unique kind of social organism that weaves together the lives and experiences of patients, caregivers, staff, and providers. In listening to these juxtaposed stories, we can see and understand the intersection of our experiences and the oftentimes mysterious connections that bind us to one another. These stories have the capacity to also change how we see and experience the places in which medical care is provided. As we get to know the people in these stories, the places in which they work and receive care feel more familiar and knowable.

This commitment to transforming how people feel within the physical spaces of healthcare today compelled us to create an accompanying immersive exhibition that toured through various hospital lobbies across the Penn Medicine System. With a quiet, gentle, and unobtrusive presence, the exhibit featured three listening stations that invited visitors to hear a story that might help them feel more welcomed and connected. In so doing, the oftentimes sterile and formidable aspects of modern healthcare gave way to a new kind of architecture of story, animated by people's unique voices and feelings.

*

Being sick or ill often entails the experience of pain and suffering, which can isolate and destabilize one's relation to self and other. In Latin, the word 'patient' means 'one who suffers,' or 'I am suffering.' Everyone at Penn Medicine has a relationship to the reality of suffering, whether they are directly experiencing it as a patient or in their capacity as a family member, staff, or provider. It is a fundamental conceit of this project that there are multiple ways in which people are affected by suffering. Family and friends may experience fear and helplessness in the face of a loved one's suffering, while staff and providers may feel overwhelmed with feelings of responsibility and the limits of biomedicine to cure every disease.

In addition, grief and loss are often embedded in medical settings, and may engender a tendency to hide vulnerability and to not seek emotional support. In these difficult moments, the Listening Lab offers people the opportunity to express their emotions and experiences and to know that they are being listened to and heard. This process encourages the storyteller to translate their experiences into a new narrative form that connects storytellers and listeners, and reveals their shared humanity. If our storytellers have adversity in common, they also share the belief that deep listening can make a difference in the healing process.

Throughout this process, we are careful to make sure that we do not violate the privacy of others, including anyone who may be referenced in someone's story, and we entrust stories of personal grievance or legal complaint to Patient and Guest Relations. Our team has developed several guide-lines to elucidate our values and commitments, both to the storytellers and the institution:

- We seek stories from patients, caregivers, staff, and providers from across Penn Medicine.
- We seek stories about listening and being listened to.
- We acknowledge that there is an emotional truth to all stories.
- We welcome any story, including those that may be challenging or are still unfolding.
- We recognize and respect that storytelling can reveal vulnerabilities in individuals, relationships, and communities.

Once an individual reaches out to the Listening Lab team with a willingness to share a significant life experience, we conduct a brainstorming session to help give it narrative form, followed by a facilitated recording session and intensive editing. We seek the storyteller's consent several times, recognizing that their perspective on sharing various aspects of their lives may change with time. Following that, we strategize the dissemination and release of the story with the storyteller and our team. Once the story is released to the public, we often stay in touch with one another and reconvene from time to time.

Because sharing stories often elicits vulnerability, the storytellers and we as facilitators often experience deep moments of emotional connection. This becomes the first line of listening and often models the sense of affirmation and empowerment that comes from having one's story witnessed. Once the story is made public, this sense of being witnessed ripples outwards, and storytellers connect in their vulnerability with the broader Penn Medicine community. The sense of community and connection that this entire process engenders is as important to us as the recording itself.

For listeners, opening oneself to stories about someone else's lived experience can help us gain a new perspective as well as become inspired by their strength and resilience. In this sense, the experience of listening to another's story can be a threshold that helps us reflect on our own lives and possibilities for change.

With this in mind, we have made a concerted effort to integrate the project into the Penn Medicine workplace. From the electronic inbox to the clinical environment, the Listening Lab stories are embedded in the daily routines of employees. They are incorporated into new employee orientation, shared at the beginning of leadership events and staff meetings, integrated into medical and nursing education/training, and featured in institutional platforms promoting mental health and resilience. On the patient-facing and caregiving side, we have partnered with Patient and Family Advisory Councils systemwide and created a direct link to the project on patient tablets in each hospital room. In a similar vein, this book will be made available to our community of listeners and storytellers throughout the entire healthcare system.

*

There are many challenges facing healthcare today, not the least of which is the paucity of time, and one of the first things that often gets lost is the stories that bring meaning to our lives. This project is a way to return them to a central place in conversations around caregiving today.

The impetus for envisioning the Listening Lab emerged in part through our research into the challenges facing patient/provider communication.

In a 2018 article for the *Journal of General Internal Medicine,* Ospina and Philips found that on average clinicians interrupted the patient after 11 seconds. And in a 2011 article in the journal *Health Affairs,* Lown, Rosen, and Marttila found that it only requires 40 seconds for a healthcare provider to communicate with kindness and empathy, yet a majority of the patients they studied reported having interactions with providers that lacked compassion. We have found that even a short 5-minute story can have an impact. Listening may not have the capacity to extend the time that patients have with their physicians, but it can change the quality of that experience.

It can be empowering and therapeutic to hear and feel heard by another, particularly when one is experiencing or supporting someone who is struggling with illness, isolation, or trauma. Storytelling drives connection with patients and providers, creates shared experiences, and improves well-being. It helps strengthen skills in the areas of active listening, empathy, and perspective-taking, and helps to facilitate discussion about the wide range of emotions and experiences that our patients, caregivers, staff and providers are experiencing throughout the intersecting pandemics of COVID-19, racism and more.

One of our goals has always been to destabilize the traditional ways in which people are heard in healthcare and to support the democratization of who gets to speak. With this in mind, we have encouraged contributions from environmental service workers, transporters, call center staff, and other staff who have not always been recognized as equal members of the care team. The concept of community that we have highlighted in this work then, is one that recognizes the capacity of everyone within it to facilitate healing. These connections across the broad spectrum of the healthcare system can change the listener as well as the storyteller.

*

The stories featured in this publication offer examples of the intersection of listening and care in the context of a health system. Together, they offer several roadmaps for the future of healthcare, driven by the patients, caregivers, staff and providers who are living and working at the front lines of caregiving. We believe that these narratives of lived experience can educate all of us who are delivering or receiving healthcare today.

The Listening Lab is a kind of seismograph, adjusting and responding to the time in which it is situated and quite literally of the moment. The personal stories our storytellers share make palpable the implications of what is happening right now in healthcare and society and provide a human dimension to oftentimes abstract concepts of equality, justice, and community.

We invite you to join us in this work by sharing these stories, as well as your own, with your friends, families, colleagues, and broader community. And we hope that in reading this publication we will all be inspired to become better listeners. Each of our stories can be seen as a seed to addressing some of healthcare's most pressing challenges around communication and connection. The very act of listening has the potential to heal broken places within us, and offers a radical possibility for healing to occur within healthcare and society as a whole.

Stories

While the stories that follow aspire to uplift and empower, they may also describe experiences of trauma and suffering. We recognize that listening can be a vulnerable experience and may prompt a need for additional resources and strategies for those seeking help.

Whether you are in the Penn Medicine community or beyond, we recommend the following resources to support your own mental health and wellness:

PennMedicineTogether offers strategies to help people cope, which we all do differently.
https://www.med.upenn.edu/PennMedicineTogether/

PennCOBALT is a tool for the Penn Community that uses targeted assessments to direct you to the right level of coping support. Anonymity is an option.
https://penncobalt.com/

National Suicide Prevention Hotline:
800-273-8255

Patient Stories

Listen online at pennlisteninglab.org/stories/

This story explores themes such as disability, gratitude, listening, physician vulnerability, relationships, spirituality, and transformation.

How does the experience of reading this story alter your feelings and influence your future behavior?

Alan Stein, MD, PhD
March 4, 2020

Becoming Vulnerable

I'm Alan. I'm a physician, a scientist, and an engineer.

In May of 2019, my life changed dramatically. During that time I had a bleed, a hemorrhage in my brain called a cavernous angioma, which occurred out of nowhere. It led to tingling in my arms, first in my right hand, spreading up to my arm, my left hand, and my right leg. It impacted me in many ways. It was life changing.

As a physician, I was entering the healthcare system also as a patient. I was nervous, I was anxious, depressed. When I went to the emergency room, people heard my clinical story, but they didn't hear me emotionally and how important my anxiety and depression were. And that hurt, because for me that was most important; that was what was concerning to me. It's not how bad my symptoms were at the moment, it's: "Are these symptoms going to be with me for the rest of my life? Is this the way I am? What will happen to me?"

Emotionally it was very traumatic for me. One of the residual effects of the brain bleed that I had is that I've lost sensation in my hands, and have decreased ability to tell where my limbs are, or where my fingers are. Some people we can look at, and we can sense that there's a disability there. For myself, I think others look at me, and they don't see that disability. The difference in expectations that people may have about how I do things... I'm different than I was. It's something I have to come to terms with. We can't see disability necessarily, but it's there.

> "I'm different than I was. It's something I have to come to terms with. We can't see disability necessarily, but it's there."

As I watched the interactions of others who have the rare disease that I do, I see that they're hesitant to expose any vulnerability or any disability. That's because with that vulnerability, they may not be as valuable in our society. That's changed me—both the way I live, how I view medicine, how I view healthcare. I think that after all of the technical interventions that medicine has to offer, it's the emotional aspects; it's how we make each other feel, how we listen to each other, and whether we really hear each other as we talk.

As I thought about where we listen to each other in our healthcare system, it came to me that hospice is the place that we listen, because there's nothing left to do. Perhaps that's where we should start. Medicine sometimes confuses quantity of life for quality of life. There's a lot of healing that happens even when medicine doesn't have anything to offer.

Because of that, I've become a hospice volunteer. In the training, people thought it was funny that there was a clinician in the class. I thought it was kind of funny that it wasn't filled with clinicians. How can anyone practice in medicine if they don't know the perspective of the patient? So I think that that's perhaps the most important thing that healthcare can do: provide love, provide compassion.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as COVID-19, gratitude, healing, transformation, and physician vulnerability.

How does the experience of reading this story alter your feelings and influence your future behavior?

Feeling Cared About

Helga Yang: My name is Helga, and I am a patient at Penn Medicine.

Mathew Beshara, MD: My name is Mathew Beshara, and I am an obstetrician-gynecologist at the University of Pennsylvania. I suffered a COVID infection with complications of a stroke. And it has subsequently affected my medical career. My story was heard by a former patient of mine, Helga.

Hi Helga, it's good to see you again.

Helga: I don't know if you remember me, but you did a procedure. It was supposed to be routine, but it had a very unfortunate, unexpected outcome. I had a seizure coming out of anesthesia. And what specifically stood out for me was the way that you took care of me. You just showed so much care and compassion that it completely changed the situation.

Mathew: Well that's gratifying.

Helga: The reason that I reached out is that I listened to your story about having COVID and not being able to perform surgery now. It really impacted me. I felt the sorrow, and I was obviously very heartbroken. I actually experienced a loss along with you.

Mathew: Thank you. Because of my own experience, I'm very interested to hear the salient points of care that I delivered to you that got you to the point where you felt safe and taken care of.

Helga: Well, for starters, I had been through five previous surgeries prior to the one you performed. So I have quite a bit of comparison points. What really stands out for me personally is: here's where something very serious happened—not your fault, obviously—but the way you responded to it, you didn't come out being defensive. And you didn't try to push the blame on anyone else.

You explained, "This is what happened, and we're going to take care of you. We're going to do everything we can to make sure that you're okay."

It was very sincere. It actually surprised me that I wasn't upset over the situation. And I think that goes to show how much you can make a difference by what you do, how you present yourself.

Mathew: I probably was a little bit fearful for you as well. In my life as a surgeon, I've had people have cardiac arrest. I've had people have seizures, like you. I've had people have complications here and there. It's always very scary from the doctor or physician and surgeon side as well. You just fear for the person.

"I wasn't upset over the situation. And I think that goes to show how much you can make a difference by what you do, how you present yourself."

I would sometimes in my head think, "Why am I doing this? Who told me I could take care of people to this capacity, and put their life in my own hands?"

You start questioning the power or the gift that you have. And when you see a complication like that, you start to fear the worst is imminent, and you really worry about someone's mortality.

Helga: You showed so much concern. And it really showed that there's a human there.

A lot of times doctors put up a wall. You don't really get that connection. I have to say it's a lot harder to be mad at someone who you have a connection with.

Mathew: Yeah. It does make a difference. You know, I was in the ICU for many days, and I had a lot of complications. Some of the attendings that took care of me, one in particular, was very humanistic. She held my hand. She told me, I had a stroke, she spoke to me like a person. She cried with me.

"I remember my nurse; I held his hand, and I said, 'Don't ever leave me again.' I was so hungry for feeling a connection."

I was so hungry for a human touch. It was the middle of COVID, so I didn't see my family. I knew I was in the hospital that I worked in, surrounded by people that loved me or supported me. But I didn't feel a connection to anybody, other than my team. And I remember my nurse; I held his hand, and I said, "Don't ever leave me again." I was so hungry for feeling a connection.

Just recognizing that person as a person, and not a patient, can really be important. It was for me, and it sounds like it was for you.

Helga: Definitely.

When I listened to your story, I was kind of expecting more of a cautionary tale like, "Hi, I got COVID, I recovered. Everyone, get your shots." And to hear that you've been so profoundly affected by it, I personally felt the loss. And I think the whole patient community has experienced a loss too.

Mathew: Well, I appreciate that. Thank you.

The thing I miss the most about practicing medicine is seeing the patients, and taking care of people like you, and making them feel safe, to be honest. All I would have wanted was to take good care of people but also to make you feel you were well taken care of.

Helga: Well, I would actually change the wording a little bit. Instead of "caring for," I'd say "cared about." I felt that I was more "cared about" than "cared for."

Mathew: Well good. Then my work is done here.

Now that I'm in the twilight of my career, and my career in medicine is most likely over, I'm able to look back, and reflect. And so I feel really gratified by the outpouring of patients like you. I don't think many physicians and surgeons get that feedback. And it has made the end of my career, which I felt like, ended very abruptly—it has given it some closure that I didn't expect.

And you have helped.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as the care team, disability, healing, and transformation.

How does the experience of reading this story alter your feelings and influence your future behavior?

David Lynch
February 22, 2020

Keep Truckin’

My name is David, and this is the story of how I recovered from an amputation due to necrotizing fasciitis.

My knee hurt for about a week. I went to a local hospital, and that night they amputated my leg from the knee down due to infection. And that hospital realized they couldn’t handle me, so I was transferred to Penn, where they spent the next month knocking the infection down with several surgeries. I was set to go home on Thanksgiving. A nurse found me that night slumped over and unresponsive in bed. I spent the next month in a coma. I suffered heart and liver failure, kidney failure, two collapsed lungs, and a stroke.

The day after Christmas, I woke up and realized I was in a different room, and I was on a ventilator. A nurse realized I was conscious and explained to me exactly what happened. The rest of my leg had been amputated after several surgeries, from the knee to progressively up my leg, eventually to the pelvis.

I spent the next month recovering. I had to learn how to do everything all over again. I couldn't sit up by myself, nothing. The patience of the therapists there was utterly amazing. They would hold me up each time something bad happened. They convinced me to keep going. I'm a very stubborn person, and I could get discouraged easily. "Just keep going; everybody has a bad day," that's what they would tell me. And that's what I did, I just kept truckin'.

> "They convinced me to keep going. I'm a very stubborn person, and I could get discouraged easily. 'Just keep going; everybody has a bad day,' that's what they would tell me."

I was released in March from the hospital and I went to Good Shepherd. One of the nursing staff told me she had worked there and that they were very hard on the patients; they made them work. And I said, "Well that's fine with me, I had 12 years of Catholic school."

I started in March and started playing with baby toys and clothespins and blocks, because that's where I had to start. I couldn't tie my shoes. I couldn't write my name. I told the doctors, "You put me back together enough that I can go fishing in a wheelchair, I'll be happy." Well, one of the therapists one day surprised me. I came in to do my normal work, and there was a fishing rod in the corner. It was her husband's fishing rod. We stuck a paperclip in it, tied a line to it and I was able to cast it across the room. That just gave me the want to do it again.

After about a month, I went in for my regular therapy session. They had me go over to the parallel bars; I didn't know why. One of the therapists grabbed this large metallic knee brace, and they strapped it onto my right leg and they told me that they were going to have me walk down the parallel bars.

At that point, they seemed to grab every available therapist who was anywhere near me, probably about eight of them, standing around me in any possible supportive position you could think of. And I staggered down the parallel bars, which is about 16-20 feet. That was the first time I had walked in about four or five months.

Even though they told me it was only 1% of the people that were going to be able to walk again with my particular amputation, that didn't bother me in the slightest, because I had just managed to walk. I staggered to the end of the bars, and the entire therapy room was clapping. 1 percent or not, I was going to walk again.

So three years later, I have a prosthetic. I'm able to walk by myself with a walker. I'm part of a team here. The therapists have been beyond helpful. I can't thank them enough. After everything I went through, the coma I was in, and my level of amputation, how could I give up after I woke up?

Listen online at pennlisteninglab.org/stories/

This story explores themes such as death and dying, listening, relationships, spirituality, and transformation.

How does the experience of reading this story alter your feelings and influence your future behavior?

Peter Matthews and Emily McGinnis
February 27, 2020

My Second Life

My name is Peter Matthews. About two years ago, my life was saved through a liver transplant. I got really sick really quickly, and I was told I didn't have that much time. This was in September. I was told Thanksgiving may be out of my range. The only way I was gonna make it was if I got a transplant.

I had to trust the people at Penn. I just did not think they'd let me die. And my family and I waited until we got news that there was an organ available. We got our hopes up. Unfortunately, that didn't work out.

Then one day after a few weeks as I floated in and out, I saw someone before me. I couldn't make out a face, and then I heard a soft voice and realized it was a young man.

And I could make out an outstretched hand, and somehow he knew I was an Aussie, and he said to me, "Here mate, this is for you." To this day, I'm certain I heard his voice. Later that day, the medical team told me that a liver was available. Then, a few weeks later, I asked my team about the donor, and I was told that identities are withheld. And I said, "Can you tell me if it was a young man?" "Yes it was." From there, everything moved really quickly. I had the transplant not long after that. My life changed forever.

I'm trying to live a life of gratitude and purpose. I'm trying to make my life count for something. I'm also trying to live for the kid, because I really do think I'm living for two people.

When I feel joy at just breathing, I struggle with survivor's guilt. I've learned that this is a real, palpable thing that's experienced by many organ recipients. My guilt has two sources. First, for the young man. For me to be speaking to you, he had to lose his life. Second, because I was transplanted ahead of so many others, so many who'd been waiting for a long time.

I think the only way I've been able to deal with it is to have a purpose in my life. I sometimes feel the young man in me. He's close to me. He's gonna grow old with me. I hear my breath going in and out. I think that's when he talks to me. I swear I feel him just under my rib cage; I get a little something, and he is trying to get my attention. And then some days when I have a little problem

I'm trying to fix, I say, "Kid, what are we going to do about this?"

"I sometimes feel the young man in me. He's close to me. He's gonna grow old with me. I hear my breath going in and out. I think that's when he talks to me."

It's really hard to express how I feel connected to this young man. I don't know much about him. I think about the life he lost. All I can do with my second life is live it in a way that would make him proud.

*

My name is Emily. My father has had two distinct lives. One pre-liver transplant and one post. Since October of 2017, my father's purpose, his life goal, has distinctly changed. He believes in paying it forward, honoring his young donor's life, and not taking one single second or mundane detail in his life for granted.

He has become a champion for organ donation, for giving away what you have but no longer need.

I take great comfort in knowing that however long the rest of his life may be, I will know that he was happy, and he was fulfilled. And he had a life full of gratitude and was indebted to a young man that we will never know.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as COVID-19, disability, grief, healing, mental health, and speaking up.

How does the experience of reading this story alter your feelings and influence your future behavior?

Kate Brett
April 21, 2021

My Superpower

I'm Kate Brett. I received treatment for obsessive compulsive disorder (OCD) at the Center for the Treatment and Study of Anxiety at the University of Pennsylvania, and I remain involved as an advocate.

My story starts in February 2018. My father was diagnosed with ALS, Lou Gehrig's disease. It took a while for it to get diagnosed, and as a family, we had been dealing with that for a little over a year when everything turned upside down.

It was the first week of March, and it was the last memory I have where I remember being happy. That Wednesday my 42-year-old healthy, exercising, beautiful brother passed away of a stroke.

My brother passed away on March 10th. And as we were planning his funeral, things were closing. When we started planning his funeral, we were having a 400-person Mass. By the time we actually had his funeral on March 17th, the world was closed.

My father slowly but surely continued to deteriorate, and by July he had also passed. So I lost my brother and my father within four months of one another. I almost didn't notice COVID because I was so very deep in my own grief and my own depression. Grief entered my body, and it took up permanent residence.

I had suffered OCD pretty significantly in my mid-20s. Having been treated at Penn Center for the Treatment and Study of Anxiety gave me the tools to maintain the upper hand in a way that was truly life-changing.

My OCD manifestations, my fears, are that I'm going to somehow be responsible for harming others—animals, other people. When the messaging from the government became, "If you go to Thanksgiving and see your grandmother, you could kill her," my OCD woke up with a vengeance, and so I had to really try and figure out how to manage my grief, my depression, and now my OCD.

It became a really difficult and confusing time. I had to revisit all the tools I had learned. From there, it became about how do I focus on my healing? And how do I focus on what serves me? I talked to a lot of people who have OCD in our monthly support group, and I try to be a peer support. I try to reach out to people.

Living with uncertainty is kind of our superpower, because once you go through the treatment, that's what it is. The treatment for OCD is leaning into doubt, leaning into uncertainty, and bearing it. Identifying the worse-case scenario and walking yourself through it. Those of us who had been through the treatment, who thought to apply our OCD tools to this new world of "We have no idea what's going to happen," we learned to apply the tools to those uncertainties as well.

> "Grief entered my body and it took up permanent residence."

I think that those of us who suffer from mental illnesses or anxiety disorders, perceive ourselves as broken, as somehow weaker. A lot of the things that are manifestations of my mental illness, the things that make me susceptible to it—empathy, a strong imagination, a really deep ability to put myself into another situation mentally—those things helped me survive a period I never thought I would have to experience.

I started by focusing only on the next breath. And then it became, "Okay I survived that, now maybe I can survive an hour." Feelings would come, and they wouldn't kill me.

I was in my healing cocoon, and Thea was one of many people who reached out and said, "How are you doing? How can I be a resource to you?" And I said, "I just wish there was something I could do that would allow me to use my story to help people." A couple weeks later, we got some fancy microphones and started a podcast.

Nobody with OCD really wants to talk about their OCD, because it's stigmatized. If me talking about it opens the door for one person to say, "I think I might have that," and they can get the treatment they need, then my four years spent having OCD and being paralyzed by it before I knew what I had will have been worth it.

I think showing up for people has been something that's been of great benefit to me. I've seen a lot of hearts open to me because I've been vulnerable out in the open. And I think that that's really the superpower.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as listening, speaking up, and transformation.

How does the experience of reading this story alter your feelings and influence your future behavior?

Teya Sepinuck
August 5, 2019

Small Changes

My story is really one about giving feedback.

I've had to have many endoscopic procedures, and always the nurse waits until there's no one else in the room and then asks the question—two questions—about whether you've ever been abused, and whether you're depressed.

I had a terrible experience with one nurse who was sitting with her back to me, facing the computer and she said to me, "Any abuse?" and I said, "No." and she said, "Are you depressed?" And I could feel my stomach just curdling, and I said, "No, but I just want to say to you, if I was, I wouldn't tell you, because I don't feel like you care. You have your back to me, and you're just abruptly asking these questions."

And she said, "Well, I just want to tell you that people do respond." And I said, "Well, that's great, but I wouldn't be one of them." And I left there feeling really terrible, thinking: "Is this really how we ask vulnerable people traumatic questions about their lives?"

Many endoscopic procedures later, I was back in the suite, and nobody asked me the question. But the nurse started to drive me to the room where I was going to have the procedure, and as we were in the hallway, she leaned gently over me and kind of whispered into my ear, "I just have to ask, do you have any abuse in your family? And are you depressed?" And I was so overwhelmed with how beautifully she did it.

> "She leaned gently over me and kind of whispered into my ear, 'I just have to ask, do you have any abuse in your family? And are you depressed?'"

I said, "Oh my God, nobody has ever done it like that. That is just so beautiful, thank you." And as we were talking I said, "I just want you to know I had this horrible experience once with this nurse," and I reiterated what had happened, and she got this strange look on her face. And she said, "That nurse was me."

And I couldn't believe it, I just looked at her, and I said, "No." I didn't recognize her at all. I said, "No, you couldn't be the one who went from being the worst to being the best." And she said, "No, it was me. I was multitasking, and you called me on it, and you were right." And I just kept thanking her and thanking her and just saying how amazing it was that she made these changes.

And it gave me a lot of hope about the possibility that even just giving feedback once, somebody may change.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as health equity, listening, and speaking up.

How does the experience of reading this story alter your feelings and influence your future behavior?

Timothy Young
January 6, 2020

The Interaction

I am a 25-year patient of the University of Pennsylvania Health System. I'm a caretaker, and I'm also an ombudsman. This is a story about doctors willing to learn something new from their patients and building up an exchange of trust.

I was scheduled for a procedure. I was getting prepped—my doctor, the anesthesiologist, and nurses all around me getting me ready. The anesthesiologist asked me if I was allergic to any medications? And I told him, yes, I was.

This particular medication, he was not familiar with it. And he did not know that it affected people of color. He did not seem to have any knowledge of that interaction.

So after I explained it to him, he looked a little perplexed. But I told him I suffered from the most mild form of it, but I've known people who had the more severe reactions.

After that, he left. And my doctor came up, and I told him about the experience. And I was really looking for another anesthesiologist, because I wasn't comfortable. But I was willing to go [forward] anyway.

After about ten minutes, the anesthesiologist came back, apologetic, shook my hand, and thanked me. The fact that this doctor came back, humbled himself, and told me that yes, he had researched it, and I was right—that had a great effect on me. And I really feel that was just something that I'll never forget.

"The fact that this doctor came back, humbled himself, and told me that yes, he had researched it, and I was right—that had a great effect on me."

This experience really, really changed how I felt about doctors and also my fear of communicating with my doctor. I just felt more open to talk. I felt a certain trust. And I felt that, wow, we should listen to each other and also learn from each other.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as gratitude and transformation.

How does the experience of reading this story alter your feelings and influence your future behavior?

Jennifer Gobrecht
March 12, 2021

A New Kind of Transplant

My name is Jennifer Gobrecht, and I am a patient at Penn Medicine. I was their first uterus transplant recipient and the second person in America to have a uterus transplant from a deceased donor. I have what is called Mayer–Rokitansky–Küster–Hauser syndrome, or MRKH. It affects one in 4500 women.

The condition means I was born without a uterus. I will never, without a medical intervention, be able to have my own child. And that was a lot to take on as a young woman, and as I became active in the Community of MRKH, I learned that my story was similar to many women, where we were given this infertility diagnosis at a young age. And we were told our options were to adopt, to be childless, or to do IDVF and have a gestational carrier surrogate.

One thing that really brought to light our stories being heard was the amazing physicians in the global world that heard our plight of not having a lot of options to have children. And something that Penn Medicine really heard, and specifically

Dr. O'Neill and the team that she created, was that she heard our plea for more options. And she knew that she could really make a change in this community throughout the world.

So I applied for the trial. I actually saw it advertised on a Community Board that was on Facebook. Not even three days later, I heard back from the lead investigator, Dr. O'Neill, that she wanted to, you know, meet with me. She read through my application, and she felt that I really met the criteria.

So after meeting with Dr. O'Neill, I met with a plethora of different teams within the Penn system. Everyone from transplant, to social workers, to maternal fetal medicine, to pharmacy, to dieticians, to the surgery team.

The next big step was getting listed for an organ transplant, which would be just like any transplant, like a kidney, liver, heart. You would go through an organ transplant performance procurement network.

Some of the challenges with having a transplant is the medical and medicine regimen. You're taking, you know, sometimes upwards of 30 pills a day. You're always getting labs drawn. It was a lot of time commitment, but I would say that Penn was super flexible throughout the entire process. I could call my transplant team 24/7, and I did. They did get calls at four o'clock in the morning at times when I had questions or was concerned about something. And one day we get the call that they had a matching donor. I had about a 10-hour surgery and about six weeks recovery before I was kind of back at work. And then six months from there, I was able to start embryo transfers. I was lucky to have my first embryo transfer work, and a few months later, I was able to give birth to my son, who is 16 months old now.

> "Being in that delivery room, I was awestruck. I have a million different teams in there. You know, there was like 30 people in this room."

Being in that delivery room, I was awestruck. I have a million different teams in there. You know, there was like 30 people in this room. I know my transplant nurse was holding my hand, and she'd been like my right hand literally through the entire process. And she was with me as they prepped me, until my husband could come in. I felt like that team was really invested in my birthing experience and everything about our journey. Finally, the baby comes out, he's like, "It's a boy!" And the whole room is cheering. It was just like such a crazy excitement. And I'm crying, and my husband's crying, and we're just overwhelmed at that point in time of care and love and happiness. And he is happy and healthy, and I am forever grateful.

Something that was so beautiful, that the donor's family shared, was a letter that the mother of the donor had put together. And something that will always stick with me, is that their daughter was the best mother they ever knew. And they could not see anything more fitting to her legacy than to have shared the gift of motherhood with somebody else. I will never forget that, and now my son is on this earth and that legacy will literally live on.

You don't always have to settle for the boxes that you put yourself in. The world can sometimes present you with the dreams and the hope that you never thought you had.

The Penn Uterus Transplant trial really heard my dream for motherhood and made it come true.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as healing, health equity, gratitude, and speaking up.

How does the experience of reading this story alter your feelings and influence your future behavior?

Sarah Klein
November 26, 2019

The Sign

This summer I walked into the radiology department at Penn Medicine Radnor for an MRI. The nurses were finishing up with another patient, so there was nobody out in the waiting area.

As I was waiting, I saw the most beautiful sign on the check-in desk, and it said, "A chaperone may be requested for certain physical exams." The reason this meant so much to me is because I am the first known victim of former Olympic gymnastics team doctor Larry Nassar. I was abused for 17 years, starting at the age of eight years old.

My abuse took place in another academic medical institution, and Larry was a doctor who should've been protecting us and healing us, but that institution failed us. Some of my sister survivors today have panic attacks at the mere thought of going into a doctor's office, and others won't have children because they are unable to see an OB.

Often when we think about listening, we think about conversations with other people, but to me, this sign meant that Penn Medicine was listening. No one knows who is walking through the door at the doctor's office. And no one would've known that night that they had someone who had been abused as a child. But that sign made me feel safe, it made me feel heard, and it made me feel cared about.

> "No one would've known that night that they had someone who had been abused as a child. But that sign made me feel safe, it made me feel heard, and it made me feel cared about."

Today I'm an activist, and I'm a lawyer representing survivors of sexual abuse. I work day and night trying to change the protocol at institutions that are not doing it right. These institutions approach this issue of safety reactively, when something comes up or there's a problem. But this was the first time that I walked into a doctor's office that was being proactive and was doing it the right way, just for the sake of doing it the right way.

I have a four-year-old daughter. I think a lot about the life I've lived and how institutions can and hopefully will change in order to do it better. I think a lot about the world in which she's growing up. I'm so thankful that my daughter's generation and anyone vulnerable will get a different kind of care than what I've experienced. And while it was just a sign, it gave me a lot of hope.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as listening and gratitude.

How does the experience of reading this story alter your feelings and influence your future behavior?

David LaMotte
March 5, 2020

The Widowmaker

I'm a retired English teacher and a hospice volunteer. The practice of deep listening has been essential to my work both in the classroom and at the bedside. And so when I first heard about the Listening Lab, I thought I would share a story about my work in hospice. But the story I'd like to share with you is not about deep listening but about being deeply heard.

At the end of a recent routine check-up, my cardiologist—I'll call her Dr. M—asked me if there was anything else I'd like to discuss. Hesitantly, or maybe I should say half-heartedly, I mentioned that for some time I'd been experiencing a vague, mild sensation of fullness in my chest, no pain, no shortness of breath, just sort of heartburn without the burn, I told her. She asked me a few questions, then paused and said, "I don't like this story."

The next day, I had a nuclear stress test to measure blood flow through my heart at rest and at peak exertion, and a few days later I met again with Dr. M to go over the results. Though they were entirely negative, she said, "I still don't like this story. You don't strike me as a complainer, and the symptoms you describe, however mild, suggest that there's something going on." We agreed that I would have a cardiac catheterization here at PMPH, a simple out-patient procedure that would give us a clearer picture of blood flow to my heart. Then we'd meet again to decide what treatment to pursue.

However, that first catheterization revealed a 90% blockage of my left anterior descending artery, a piece of plumbing so essential to the heart's healthy function that its nickname is the widow-maker. I was admitted immediately for monitoring overnight and the next morning transported by ambulance directly to the catheterization unit at HUP in Philadelphia to undergo a second catheterization and stent implant.

> "I might not have been here to share this story with you if my cardiologist had not been listening to me more carefully than I was listening to myself."

That procedure successfully removed the blockage, and I am on the mend, but I might not have been here to share this story with you if my cardiologist had not been listening to me more carefully than I was listening to myself, and listening intently enough to hear beyond the noise of negative test results.

In her book, *What Patients Say, What Doctors Hear*, physician and author Danielle Ofri says this: "For all the sophisticated diagnostic tools of modern medicine, the conversation between doctor and patient remains the primary diagnostic tool." I'm living proof of just how true that is, and I'm lucky to have a cardiologist who lives that truth in her practice.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as community, death and dying, gratitude, and transformation.

How does the experience of reading this story alter your feelings and influence your future behavior?

Kia Graham
August 20, 2020

Three Months to Live

My name is Kia, and I've worked 24 years in medicine. I've worked at pretty much every hospital in the City, and in 2018 I came to Penn Medicine. I had a lot of love with my co-workers and managers and supervisors, and we actually got to support each other a lot.

And then right before COVID hit, I had this horrible diagnosis—stage five renal failure. I needed treatment immediately. I was basically given three months to live. I don't know if I was in denial, or if I simply wanted to continue my life as normal, but I didn't leave work. I was sick pretty much every day, but I stayed at work.

And in this process, it felt like I became more human every day. I thought that I was really in touch with people. I've been in human services. I get to deal with people on the daily, but hearing them cry and hearing their pain, it was my pain. So, they were me, and I was them. Each day their struggle for medications and doctors and appointments, hanging on the phone just to wait for somebody to answer, became very significant for me, because it was all of the things that I was currently going through.

It got to the point of where my situation became really dire. I had to kind of announce it to my community, and my world, that this is what was going on. And last but not least tell my parents, which was my biggest hurdle. It felt like the end of my life. I said I would just take the cards as they lay. Everyone was like "You're not leaving here, you have to stay here." I went to the hospital finally—three weeks left if I didn't come in.

Dr. Kolasinski, the head of my practice, came to my aid. She asked me on my bed if it was okay if she referred my name to another doctor who was well known to me, world-renowned and I was like, "Little old me?" And I was thinking, "How would he have time for me?"

I was home maybe a few days out of the hospital, and I got a phone call. It was Dr. Merkel, who was asking me how he could help? He just wanted to know what he could do. And I was like, "You're taking time out your schedule for me?"

And so, I look at my journey as what I call "Return the Favor." I've been in health care. I've been a clinician. I've cried with patients; they've cried with me. I've stayed after hours to work with patients. I've stayed on the phone. I listened. And now it was my turn.

He referred me to a wonderful doctor whose name is Dr. Aggarwal. He called me day and night. Talked to me constantly, helped me. I mean literally staying on the phone with me for an hour and a half. Just to make sure I was okay.

I just spent eleven days in the hospital, and I came home last Saturday.

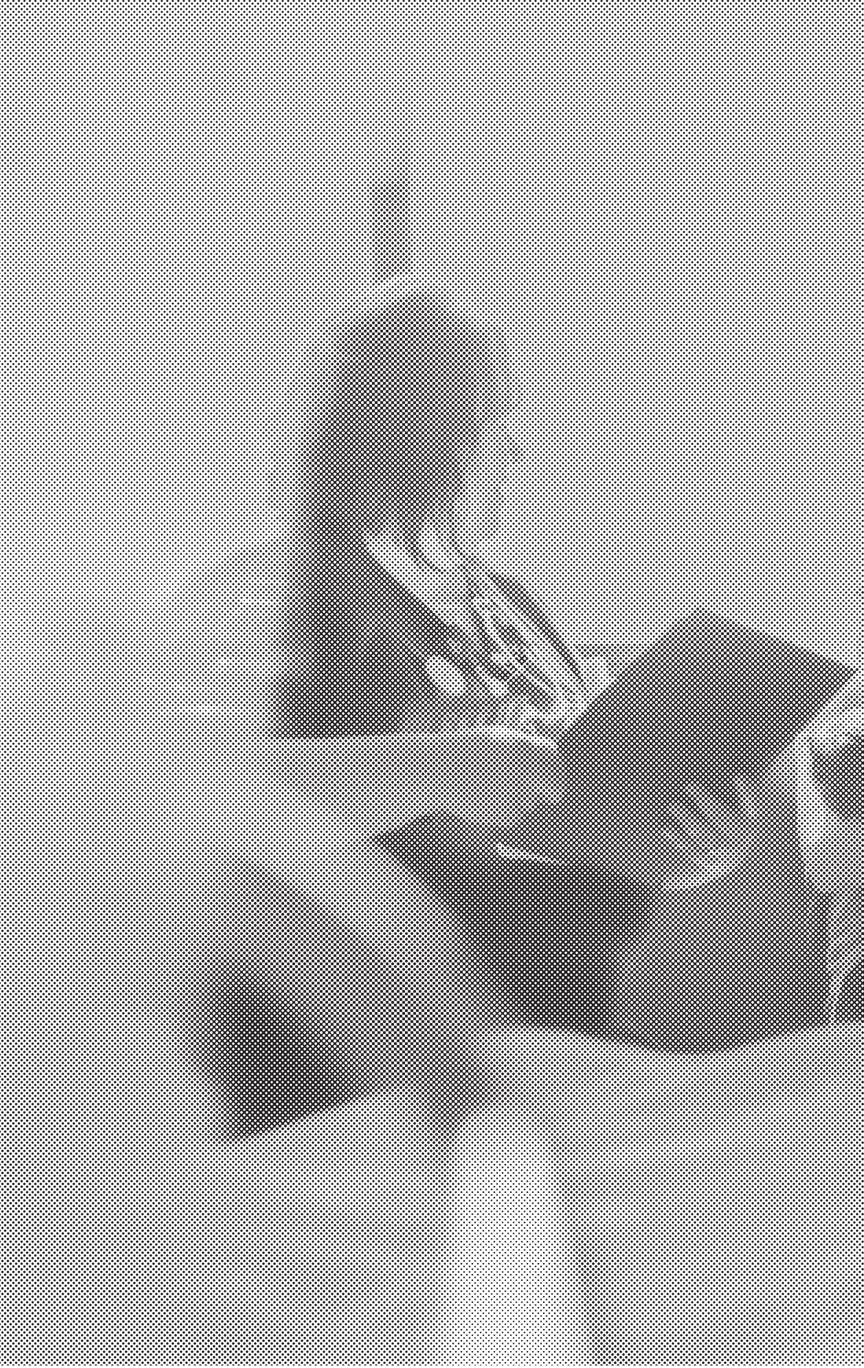
"You have to kind of store up your treasures in heaven while you can. You don't know when you'll need those treasures to come back."

And I just wanted to tell you about my angels, while I was there, who took time to stay with me and support me, even down to the cleaning lady. And this is what I call "Returning the Favor." I played music to lift my spirits every day, and the cleaning lady happened to come in, and it was like her favorite song. And so she spent an extra ten minutes with me every day, just to dance and listen to this song.

Two nurses, Sahar and Megan, stayed after shift with me every day. When I came home from the hospital, I announced it to my whole community via social media, and I asked them to thank Sahar, and to thank Megan. Sahar happens to now be my Facebook friend, and she's received about 100 thank you's. I have medical staff who became more than their title, more than the letters behind their name. They showed me love, and it was reciprocated.

I think the biggest lesson that I'm continuing to learn is, every day we become more human. You never know what's going to happen. You have to kind of store up your treasures in heaven while you can. You don't know when you'll need those treasures to come back.

And people have become more human to me.



Caregiver Stories

Listen online at pennlisteninglab.org/stories/

This story explores themes such as disability, grief, relationships, and transformation.

How does the experience of reading this story alter your feelings and influence your future behavior?

Anita McGinn-Natali
December 20, 2019

A Good Face

Twelve years ago, my husband had surgery for oral cancer. His incision started behind his right ear, arced down along his neck under his jaw, and ended under his chin. It was a long surgery, about nine hours, and I remember that night when I saw him for the first time, around 11 o'clock, I remember the incision to me looked pretty messy. And I was surprised by that. I was expecting it to be neat and tidy and clean, and it actually was very bumpy, pulpy, and looked like ground meat.

My husband was not interested in seeing his reflection until about five days later. He requested that the nurse bring him a mirror. Now this surgery meant that my husband had a tracheostomy and a tube in his nose for nutrition, so he was not able to speak and communicated to me by writing down what he needed or wanted. So the nurse brings the mirror to him, and she says, "Are you ready?" And he shakes his head yes. He holds up the mirror, and when he saw his reflection, his whole face, his countenance, completely dropped. And I panicked, because my instinct was, how am I going to fix this? How can I make him feel better? I didn't know what to say, I didn't know what to do. But he was horrified by his reflection. And he took a pen, wrote down on a piece of paper, very angrily, "I look like a freak!" And it broke my heart. The nurse saw this and she said, "You're right; it doesn't look good today. But every day it's going to look better and better."

And I was so appreciative that she stepped in when she did, because she saved me from having to come up with something to say to my husband to make him feel better. And what impressed me was she told him the truth. She recognized that he saw that it wasn't what he expected, that it looked bad.

"In that moment, he's looking in the mirror to discern his own worth. But he's also looking into my face to see reflected back what I see."

Years later, my husband still looks in the mirror and will say to himself, "I look like a freak." His face has completely changed from what it was prior to these surgeries. And instead of saying, "No, you look fine," I say, "Clark, it's not the same face you had, but it's a good face." So what does it mean to say he has a good face? I understand that, in that moment, he's looking in the mirror to discern his own worth. But he's also looking into my face to see reflected back what I see.

Today, 12 years later, as his spouse and caregiver, my role is far more elusive. I no longer change bandages and perform trach care. Now, I reflect back what I see when I look at his good face: his compassion, courage, and fortitude in living and loving through these life-changing experiences. And he also sees I embrace him as he is.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as cancer, the care team, gratitude, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Brad Aronson
April 28, 2020

Acts of Kindness

My name is Brad, and I was introduced to Penn Medicine the way most people are, with a bad diagnosis.

My wife was diagnosed with leukemia, and we were told that she would need two and a half years of treatment. You immediately go to the hospital for a month, and then, if all goes well and in that month you're in remission, you then get to go home. But you're back every single day, at other points four days a week. We got to spend more time than most people at Penn.

We really appreciated the culture and the people. And it starts from the second you get there. When you go for your treatment you pull into the parking lot. All the people working are so friendly and kind. And it just makes you breathe easier.

And then you get to the elevators. And we always parked on the same floor. The woman was so nice; she would talk to us, and learned about our son Jack. It was just part of that friendliness that carried through, and it made a huge difference.

I cannot say enough praise about the nurses. We spent a lot of time with them. They must see dozens of patients a week, but every patient is an individual. They're not just treating you, they see you as a person, and they have conversations. And those conversations really matter. I remember one time, when we were talking to one of the nurses, Abby, and we were telling her about our son's obsession with baseball. Jack loves the Phillies; he has five different Phillies shirts that look the same. And I remember one time we got a call at home, and it was Abby. I was at first a little bit nervous, like, "Why is a nurse calling us at home?" And she said, "I just wanted to let you know that my boyfriend has season tickets to the Phillies, and he has extra tickets tonight. And we thought maybe you'd want to take your son to the game." And that was awesome.

I remember another nurse, Sharon. When I was in the waiting room, I saw a woman who was having trouble walking. And Sharon walked up to her, and didn't say, "Can I help you walk, can I offer assistance?" She said, "Can I walk with you?" And then kind of grabbed this woman's arm, and the woman was happy, and they were walking along. It was such a friendly way for her to offer help.

And there was Claire, who was hilarious, and you know, told us the story of accidentally basting her Thanksgiving turkey in Pine-Sol. Cause she had done a late-night shift and didn't realize what she was doing, and she woke up and said, "Oh my goodness!"

You don't laugh that much when you are in treatment; it's kind of tough. I see my wife feeling really bad, and you know, Claire could always get us to laugh.

> "I started writing other people's stories. Stories about a small act of kindness that helped save a life, and then stories about the butterfly effect of an act of kindness."

And one thing I also remember is, so we're going through this long treatment, and the nurses are suggesting that Mia and I go to this conference for young cancer patients and their caregivers. When we were there, a patient advocate spoke who had been through the same treatment as Mia. This woman said, "If you are going through two-and-a-half years of treatment, you need to come up with projects. A project will distract you, a project will give you focus, and help you get through this."

Mia decides she's going to write in a journal. Our son Jack, who was about five-and-a-half at the time, decided his project was going to be playing 200 days of Wiffle ball in a row. And my project was, I was going to write a book about small acts of kindness that transform people's lives.

It started with the acts of kindness when Mia was going through treatment, from the people at Penn, from our friends, from our family members, from strangers. Acts of kindness that got us through that tough time. I started writing other people's stories. Stories about a small act of kindness that helped save a life, and then stories about the butterfly effect of an act of kindness.

The treatment was two and a half years, and I don't remember a ton about it, which is probably a good thing. But I remember those little actions that give you the strength to carry through.

When Mia began treatment, I thought of myself as the primary caregiver who's got to make sure everything works. What I quickly learned is that caregiving takes a village. It was everyone who was playing a part: it was our family, it was our friends, it was our physician, it was the nurses, it was the parking attendants. Everyone helped with that experience, and every bit of their help added to our strength to get through it.

For all of you out there who helped us, and there are many, many of you, thank you.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as death and dying, grief, healing, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Jessica Anderson
August 5, 2019

Caregiving as a Form of Love

I first became caregiver for my mother when I was fourteen. That was about the time I entered high school, and it meant that I wasn't able to do a lot of the things that other kids my age were able to do.

As I was trying to become involved in classes and sports and make friends, it was always at the back of my mind if I could do these things and still be able to take care of her. I had to make sure that I was able to organize all of the different medications she had to take, feed her, and help her with her physical therapy. I was worried that if she was alone all day that something may happen to her, and she had liver cirrhosis from her alcoholism, so there was a risk of her developing internal bleeding.

My mother, who was supposed to be my caregiver, became the person I cared for more and more each year as she became less able to take care of herself. I was caring for the person who was supposed to be caring for me, and it made me so angry.

This continued throughout high school and college until I arrived home for winter break my freshman year. My father called me when I arrived at the airport saying, "You need to come straight to the hospital. Your mother might not make it through the night."

"My mother, who was supposed to be my caregiver, became the person I cared for more and more each year as she became less able to take care of herself."

I showed up at the hospital; and, due to her condition she wasn't able to make decisions for herself anymore. Since her liver had shut down, it wasn't able to filter out toxins produced by her body. The result was hepatic encephalopathy, and she had lost much of her memory and her ability to process what was going on around her. The question was not one of whether or not she would get better, but one of how long she had—and the doctor wanted to know what I wanted to do.

Since I was the informal medical proxy, I was supposed to decide if she was to be treated aggressively to prolong her time here, or if we were to provide her palliative care, comfort care, in her final days. I went to my mother to tell her what I'd decided. I sat down and told her that the medications weren't going to work anymore, that there was no more getting better from this.

I was going to do my best to make sure she wouldn't feel any pain any more. I don't think she understood that. But, I think in that moment, all anger I had from all those years melted away. And all I felt was this compassion and love for the person who had endured so much pain in front of me. Those are the last words I remember having with her.

She passed away the next day, and it was December 23rd, 2017. And we were planning her funeral the next day, on Christmas Eve. In the weeks that followed, I was going through her things and cleaning the house before I went back for another semester of school. That's one example of how caregiving goes beyond medical care and decision-making; it often means you have to assume the role that they have in the family and the responsibilities that they would normally have.

This process of filling in my mother's absence has continued long after she passed away; in many ways, I have continued to be a caregiver for all of those around me like an ingrained behavior. The ability to intimately be a part of her story and her struggle as her caregiver brought me to mature much sooner than my peers, but it also endowed me with an ineffable feeling of compassion for those who are suffering.

Through caregiving, I was able to recognize compassion as a form of love, and I will carry this with me for the rest of my life.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as death and dying, gratitude, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Rochelle Sauber
March 10, 2021

Giving It All

My name is Rochelle Sauber, and I was the caregiver of my husband Douglas for almost four years in his journey through colon cancer. He was diagnosed right out of the gate with stage four.

We pretty much knew that we wanted to be at Penn. Of course, what we wanted to know that first day of meeting with the oncologist was, "How long does he have to live? Tell us the truth. Tell us what we're dealing with." He said, basically, "We'll keep you alive as much as we can with chemo." We were told that day that if he did not use chemo, he would die in six months. And with chemo, he had about two years to live. He went almost four years.

The oncologist always said, "It's a balance of keeping you alive and your quality of life." And as a result, after my husband began chemo, we went on three major vacations. Our oncologist worked with us, in order for us to do those vacations. And truly it made a huge difference. I hold onto those.

When you're in treatment, you go to Perelman Center every other week. A man who was really significant to us, Mark Matthews, was at registration for scans. You know, we go up, and my husband gives his name and birth date, and the gentleman is just friendly and warm, and he goes, "Oh, your birthday is on Halloween! Mine's the following day. We're birthday buddies!"

And from then on, we would see him at later scans. He'd know us! He was sort of like, "Hey, come on over here." Like you know, we were buddies already. And that calmed us at a time when we needed calming.

They came up with this idea of something called radioembolization, and that was in a totally different area. And there we see him again. It was like this welcome greeting, you know. We saw our friend. There he was, and we're in a totally unfamiliar place, but we had our guy, kinda. And there was time to talk, and we literally became friendly with him. He had a daughter; she was nine. We talked about traveling. We even exchanged emails.

When my husband died, I reached out to him. And he wrote back to me with caring. And I have an ongoing relationship with him. I wish him happy birthday. He was important. He made a difference for us.

It is a gift to be a caregiver. It's not a gift to watch the person you love die. But it is an honor. It's a privilege. And I learned that; to be able to be the person who can give care to your loved one. And give it all.

I never knew I had the strength I had. I never knew I could be as loving to him as I was. We were together for 36 years. In some ways the last four years were the most loving.

> "It is a gift to be a caregiver. It's not a gift to watch the person you love die. But it is an honor. It's a privilege."

To be able to be there and be with them and help them through it is a learning experience filled with awe. It's service to our loved one. It's the deepest and most awesome service. I feel like I am a better human being than I ever was before. I am more empathic than I ever was, and being a caregiver taught me all of that.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as the care team, death and dying, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Charlotte Walton-Sweeney
August 29, 2019

The Gift

When you're dealing with a loved one who is really very sick, and you're going to be in the hospital for a long time, and you really just don't have a lot of answers, the weeks start to pass by, and the time becomes a bit of a blur and a fog. And you fall into a new routine as if you're going to work, and you get your cup of coffee, and you go to your loved one's room, and you sit and you wait, and you hope and you pray, and you do all these things that have now become your new norm. And you look for the opportunities to have hope.

My story begins with my daughter being a student in a local college. And she's not feeling that great, so she goes to the nurse, and the nurse decides that she's probably dealing with pneumonia and calls me and says, "Please meet your daughter at the emergency room." It was near the holidays, and we went to the emergency room. Indeed they did feel she had pneumonia and that a few days of antibiotics would be the ticket, and she'd be home by Thanksgiving to have turkey with us. What we didn't realize was that she was in a disease process that was not at all like standard pneumonia and that she was getting progressively worse. To the point that she was moved from Med Surg to a critical care bed and intubated on Friday, the day after Thanksgiving.

From there we kind of began a rollercoaster ride. Sometimes the hope comes in very small little packages. A nice little lady would come to wash Amanda's hair every couple of days, make sure that her hair was clean and blown dry. And she would make sure that Amanda's hair was done exactly the way she wanted it, even though, for the most part, Amanda was sedated most days. We think she was unconscious, but we do believe she heard and understood what was going on.

And so those little moments mattered. Whether somebody brought you a coffee, or made sure that you had lunch, or made sure that you were taking care of yourself. Knowing that they were caring for me, making sure that I was well, those are the things that matter.

> "I have a lot of gratitude to those folks, who I don't know. I don't know their names, and I don't know who they are."

I have a lot of gratitude to those folks, who I don't know. I don't know their names, and I don't know who they are. And I'm guessing they would never remember me, but if we could thank them, we would for the work they did for us and our child.

After she passed away, we knew immediately she had to become an organ donor, because she wanted to be one. And we know for a fact that she impacted five lives; two kidneys, two eyes, and a heart were donated. And somebody got an awesome call that day. I can't say enough about what that means to us as a family to know that that happened. When we were at our worst, somebody else was able to move on. And it's really important to me to know that the worst possible day of my life became somebody else's gift.

Staff and Provider Stories

Listen online at pennlisteninglab.org/stories/

This story explores themes such as COVID-19, disability, gratitude, grief, healing, and physician vulnerability.

How does the experience of reading this story alter your feelings and influence your future behavior?

Mathew Beshara, MD
August 20, 2020

56 Days

My name is Mathew. I'm a minimally invasive surgeon in the Gynecology department at Penn, where I'm an Associate Professor.

I contracted Coronavirus very early, and then I rapidly deteriorated during the first week. I had a weird cough. I was fearful that it was Coronavirus, and it was.

By Saturday the 14th of March, I was in the Pennsylvania Hospital emergency room to get a chest x-ray, thinking I was just going to stroll in there and stroll back out. And that quickly turned into the need to admit me. I stayed at Pennsylvania Hospital for a week. And I was on a variety of medicines, but my oxygen requirements were rapidly increasing.

On the 27th of March, they recommended that I be intubated, because they didn't feel like it was safe for me to continue the way I was. They started talking about transferring me to HUP, which I think was the right decision. So I was intubated. I remained in the intensive care unit for about 56 days, and I remained on the ventilator for over 30 days. I was critically ill. I suffered a stroke early on.

For about two weeks while I was in the ICU at Penn, they noticed that I wasn't really moving my left arm. And they noticed that I wasn't moving the whole left side of my body. I lost part of my vision in the process, so I can't see peripherally out of my left.

I'm trying to be pragmatic and optimistic. It could have been catastrophic. I could have lost the use of my right arm. I could have developed aphasia, and I wouldn't be able to speak. I'm still communicative. I can still see the world. I'm going to take it for what it is. I can enjoy life.

During the process of me being under, I was aware of a lot. Much more than I thought I would have been. I was aware of bright lights, lots of sounds. And I kept thinking to myself, is this what the ICU is all about? This is torture. I thought I should write a book for students and for physicians to say the ICU is just loud. It's booming, it's bright lights, it's strobe lights.

Of course it's not all that, but that's how I was interpreting it. I had ICU delirium. And I remember thinking, when I get out of this joint, and I talk to my patients, I won't talk to them like this, I won't touch them like this. I won't be this way. I'm going to try to be a better physician.

"But as a physician, I wish someone had told me that your patient might be looking at you but be interpreting things very differently. The patient's experience might be very different than your own."

I don't think there's anything they could have done differently. But as a physician, I wish someone had told me that your patient might be looking at you, but be interpreting things very differently. The patient's experience might be very different than your own. So you may be speaking in a whisper, but your patient could be hearing a scream. And I think having that understanding as a treating provider, that the experience you're trying to give to a patient may not be the experience they're actually getting, and that there's a disconnect. I wish they would have said, "How do you feel, what do you need?"

I don't think as a physician, we're empathetic to the plight of patients who are dependent upon us for their everything. Patients would come to me hemorrhaging, and I would try to reassure the patients, "Don't worry, the blood doesn't bother me." They would look horrified that I was going to witness them in that vulnerable state.

But you know what? I didn't really get it. It's a vulnerability that you don't want others to see. One of the most traumatizing things for me as a patient was lying in my urine and feces. For a month I was vulnerable, and I hated it. All I could think of was, "Somebody please come and clean me up."

Oftentimes during our rounds, we say, "We'll see you later." What does later mean? Tomorrow? Next week? I'll see you in the office? Patients lack the ability to know that, "Oh, you'll probably be back tomorrow on rounds." Because that's what we really mean. And I remember thinking, "You know what, I'm gonna start saying what I really mean to my patients. I'll see you tomorrow morning." I was an attentive physician, and I am an attentive physician, but I feel like I could have been more. Through this whole process and my rehabilitation, I realized that I'm probably not going to be practicing medicine again—which is very hard, because I identify as a surgeon. But I can't really use my hand the way I would normally. So, I don't think I'm going to be operating on anyone soon. And that's fine.

I'm going to reinvent myself. I don't know how, but I'm going to find a way to be resilient and to have a career at Penn. I may not operate, but I will do something that I find important and worthwhile. We all go into medicine to help others. And there's still that need to help. I think that helper gene is going to be there for me forever.

Thank God for Penn and for saving me. Thank God for the team for putting their life at risk to take care of me. I look forward to practicing medicine again, if I can. And if I can, I think I'm going to do it very differently.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as disability, gratitude, grief, healing, and physician vulnerability.

How does the experience of reading this story alter your feelings and influence your future behavior?

Lyndsay Hoy, MD
November 5, 2019

A Thank You Card

What follows is in lieu of a Thank You card, something I should've sent to this doctor a long time ago. I often think of our encounter when taking care of my own patients in the operating room.

As an anesthesiologist, I am the last person my patients see before they drift into unconsciousness for their surgery and the first person they wake up to when it's over. In such moments, people expose their vulnerability, their humanity, and what truly matters to them. As they fall asleep, I try to allay their grief and anxiety about whatever is happening to their bodies that brought them under my care with quiet words and a comforting touch. I know I can't eradicate their problem, but I can show them they are not alone and their suffering is acknowledged and real.

A few years ago, that patient was me. At the onset of my anesthesia residency training, I was diagnosed with an extremely rare, progressive lung disease called lymphangioleiomyomatosis and have been navigating the murky waters ever since. LAM afflicts only a few thousand patients and primarily targets young women in the prime of their lives. The end game for LAM is ultimately a lung transplant.

Due to the risk for pregnancy-induced LAM progression, my husband and I decided to pursue IVF treatment for potential surrogacy. After eight labor-intensive weeks of constant bloodwork, ultrasounds, painful injections, and a weekend from hell in Canada for a family wedding, whereupon I forgot my medications, prompting a frantic trip to a suburban fertility clinic an hour before the ceremony, it was time to harvest my eggs. I told myself it was just like any of the other numerous procedures I'd already undergone for my lungs, but my heart knew it was much more. With some luck—something I hadn't had much of lately—those eggs would turn into embryos, and those embryos represented a future. A modicum of hope.

As the intravenous sedation was administered, I remember hearing the distant beep of the pulse oximetry in the quiet procedure room and feeling a rising sensation in my chest. A culmination of that horrible year—the grief, fear, physical pain, and emotional suffering—was coming to a frenzied peak. And then I was crying. Not just a few quiet tears, but gulping, gasping sobs. The infertility specialist performing my procedure, whom I had just met moments earlier, had her back turned and was organizing her surgical instruments.

She stopped what she was doing, turned around, pulled up a stool next to me, and sat down. She took my hand in hers and said, "I know what a hard year this has been for you. You're so brave, and you're doing the best you can." I fell asleep.

> "She took my hand in hers and said, 'I know what a hard year this has been for you.'"

We successfully froze a few embryos. Grandchildren in a petri dish, my father jokingly says.

Every time I think of this physician's kindness in my moment of despair, I am moved to tears and so grateful for her compassion. If she is listening, thank you.

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This story explores themes such as the care team, COVID-19, death and dying, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Michelle deCastro
May 13, 2020

Against All Barriers

My name is Michelle deCastro, and I am a Trauma Surgical ICU nurse at Penn Presbyterian Medical Center. I wanted to tell you a story about a husband and wife. I cared for the wife who suffered a traumatic fall and a stroke and was unable to have any surgical treatment offered to her. And she was beginning to transition to hospice. It was a difficult decision made by her husband, who actually was also a patient at our hospital. He had surgery for an amputation for his leg.

In the environment of COVID, there were completely different circumstances affecting the two of them as a married couple. There was a lot of barriers. What was unique to this story is that while both patients were patients at Presby at the same time, our nurses made a really strong effort to work with the nurses in 3 East to have both patients together, and care for them together, in the trauma ICU.

For the last couple of days while she was transitioning to hospice and he was recovering from his surgery, they spent days and nights together just like they would at home for 62 years of their marriage, in our hospital in one room in the ICU. No one asked us, "Why are there two people in this room?" It just happened. Just the fact that our nurses became their support, allowing them to just stay together in a room in our ICU during their hospitalization, was just magical.

Over those last few days, they spent every day together like they would at home. He would talk to her, she could not respond, but we could see by the look in her eyes that she understood that he was there and with her, and that helped her through these days.

We were getting ready to transition both these patients to another Penn entity. She was going to Penn Hospice, and he would be moving onward to rehab at Good Shepherd Penn partners. There were a lot of people that helped organize them leaving and discharging on the same day. But what was important to me was that I wanted them to be together, because I knew her days were fleeting.

So when I spoke to Donna at Penn Hospice, I really wanted to see what she could do for the husband and wife to encourage a continuation of care for these people, just the way we were doing it organically in our unit. I got a lot of barriers, a lot of no's; no visitor policies, mostly because of COVID. All I wanted was a miracle for them to spend more time together.

> "He would talk to her, she could not respond, but we could see by the look in her eyes that she understood that he was there and with her, and that helped her through these days."

When I asked her, "Can we make this happen where they're going? Is it going to be possible for him to stay in the same room with her just like we're doing now?" She initially said, "No, there's a lot of rules at Penn Hospice. There's rules because he's going to rehab. Because of everything with COVID, there are no visitors." "But he's technically a patient!" I just had way too many questions, and I just didn't understand why it was so difficult to try to get this done. I felt I needed to ask more questions about it, and keep pushing the envelope a little bit. I only had four to five hours before they were picking them up. So I really asked Donna to do more.

Donna was very instrumental in helping me to do that. I think it was such a victory. The miracle happened because of a team. A team of people getting ready to take care of this husband and wife at this very precious time. I think that's the beauty of Penn, that we will work together as a team. We'll collaborate. If there's a barrier, we will figure out a solution and work together. And that makes me proud to be a part of Penn Medicine.

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This story explores themes such as the care team, health equity, relationships, and spirituality.

How does the experience of reading this story alter your feelings and influence your future behavior?

Richard Watson
January 15, 2021

Back and Forth

Hi, my name is Richard Watson. I'm a patient transporter here at the hospital in the University of Pennsylvania for 11 years.

Transporting is more than just moving patient from A to B. It's a form of caregiving in a way, whereas we connect with the patients on multiple levels—spiritually, emotionally, even physically. Some patients, they want hugs; they're touchers.

I'm stationed in radiation oncology. These patients go to radiation every day of the week. So I'm taking them back and forth every day of the week. I become very connected with them. It's an emotional roller coaster, because you see some that are sick. You take it on. Me personally, I give it to God, because it's a lot to bear, seeing it every day. But it brings you joy when you start to see them getting better, and they're getting more energy. So everything that they're carrying, we're carrying as well.

Years ago, I had a patient, and we got him on a stretcher. And then the nurse, she just was like, "Oh yeah, he's fine to go." She gave me a brief report. And I'm just like, "Well, I need more," and she walked away. So as I'm assessing the patient, getting him hooked up, and something just wasn't right about him. And then before I knew it, his eyes rolled back in his head, and he just coded. So I was able to get him back in the bed and started doing compressions. And then when a team got there, I was told, "Get out." And I'm like, "I'm in the middle of compressions. I'm not gonna stop compressions until my round is up. Then I'll get out." She took my name down and everything.

> "People only look at us as, you know, 'Oh they just move patients,' but we're so much more than that. We are the extension of the doctors and the nurses once they leave that floor."

We ended up saving him at the end of the day. A few nurses came up to me and were like, "Oh wow, we didn't know you guys know CPR." We're EMTs, and they didn't know that. It's on our badge. This is why we ask you all for a full report. Just like you get a report in the morning, or when leaving from your nurse, we need the report because we're an extension of you guys when a patient is off the floor. Other people up there saw my determination to help and save the patient and recognized the signs that something was going wrong early enough to actually save him. And for that, I was given an award. To know that others recognized me and put me up for an award was gratifying. It made me feel, like, less inferior.

People only look at us as, you know, "Oh they just move patients," but we're so much more than that. We are the extension of the doctors and the nurses once they leave that floor. These patients essentially become family members, because they're here all the time, and we see them every day. I prayed with one so much. He was giving up hope, and then as I was dropping him off, I was like, "You're fine, you're good, you're in good hands." I was able to come back and pick him up, take him back to his room and his wife was there. Then they asked me to pray with them. And I see him a few more times throughout the week, and then I didn't see him no more. He was discharged. Probably about a month and a half later, I'm walking across the atrium, and I hear somebody calling my name. And I'm looking like, "Who's this guy running towards me?" 'cause I didn't recognize him. And the doctors, they said he'd probably never walk again. And he ran towards me. He was dancing and doing circles. It just brung tears to my eyes.

I've touched so many people's lives. And honestly, a lot of the patients have touched my life. I used to complain a lot when I first started working here. And then you start seeing sick people, and you start talking to them, and you start thinking, like, "What am I complaining about? I'm young, I'm healthy. I have a job. I need to stop complaining." And once I realized that, God started using me to touch people. Give them hope in hopeless situations. Nowadays, patients can't have family members here. And there's no visitors unless its terminal. And so sometimes they need that extra form of care and love. Just knowing that somebody cares about them.

These patients are fighting a different battle every day with sickness. The more you talk to them and they fight, it helps you with something else that you may in your own personal life, say, "You know what, I'm probably just going to give up on that." That fight in them, the joy in them, and you know they may have a terminal illness, and they say, "You know what, I'm happy. I am good." And that right there transfers over to me, and it's just like, "You know what, you're right!" So I just love to be a helping hand to others. As much as we help them, I believe they help us even more. They're walking right alongside us, whether they know it or not. They're walking right alongside.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as death and dying, grief, physician vulnerability, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Jules Lipoff, MD
October 1, 2019

Don’t Fear the Reaper

I knew my grandma Eleanor couldn’t have many years left. She was 96, and though her mind was unrelenting, she was increasingly physically frail. The last several years, I tried hard to savor every moment I had with her, every time I spoke with her on the phone. Do you know that feeling, when you know every conversation might be your last? Do you hold on to voicemails, just so you have a recording in case they die?

Eleanor was a force of nature and endlessly opinionated. A former biology teacher and principal in New York City schools, she was on the committee to design the sex education curriculum for the school system in the 60s. Later, she taught an adult education class at the 92nd Street Y in New York, entitled “Controversial Conversations,” on topics ranging from abortion to transgender issues.

Had you knocked on her door, she would answer, “Friend or foe?” Yet she would open no matter what your answer, because, she explained, a foe might make for interesting conversation. She spoke frankly about the world and had no illusions—about justice and fairness, about sex, about religion, about life and death. She told me that it was ridiculous to say the elderly were living their "golden years." "In what way exactly is life great," she would ask, "when your body falls apart piece-by-piece, and one by one all your friends die?"

Starting medical school, I was startled when she first bluntly shared her end-of-life plans. "Jules, I don't want any life support. I've lived a good life. When it's my time, let me go." As a young doctor, no matter how hard you try, how can you really understand a person being so comfortable with her life ending? Furthermore, Grandma's forthright wishes made me realize how some patients might worry less about death itself and more about their death's impact on others.

Years ago, when my wife and I traveled out of the country, Grandma gave instructions that I was not to be told until after the trip in case she died, because she didn't want her death to ruin any vacation.

I see many older patients with cancers and premalignant lesions. Grandma taught me the importance of not thinking about diseases in terms of cured vs not cured but rather to individualize and ask, does a treatment really add value to a patient’s life. If a lesion has a tiny chance of turning into a cancer or even if it’s a cancer, unlikely to be life-threatening, opting out of treatment is more than a rational choice.

> “As a young doctor, no matter how hard you try, how can you really understand a person being so comfortable with her life ending?”

You might forgive me for thinking that I was prepared for her death, given how much we had talked about it. We had done all the right things, signed the DNR form, and knew that she didn’t want interventions. After we initiated hospice care, it was very difficult; she had a rapid decline. Despite all my medical knowledge, all that my grandma taught me, and all that I’ve seen through medical school and all of my training, I’m still learning to accept the inevitability of death. Eleanor hadn’t seen death as a foe.

As physicians, we like to think we understand everything, but the truth is we have more questions than answers. Still, I think my practice is stronger, the greater my humility and acknowledgment of my limitations. I hope my patients trust me when I tell them, "I don't know." I think I was afraid I would forget my grandma Eleanor, but through her example and many lessons, I know she remains with me.

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This story explores themes such as the care team, grief, healing, and listening.

How does the experience of reading this story alter your feelings and influence your future behavior?

Louis Mello
October 18, 2019

Everybody is Going Through Something

My name is Louis, and I work as a Red Coat Ambassador at the Hospital of University of Pennsylvania. So, when people come in, we are the first faces that they see. We try to be as helpful as possible and sometimes, you know, it's easy to help someone. Sometimes not so much.

I remember a story from a little over a year ago, where I had helped an elderly couple. They had a long day, and they were at their last appointment in radiology and were upset because they had misplaced their car keys. And I could tell that the wife was really upset with her husband, and I had asked them if they retraced their steps. I asked them what their car looked like. I went over to the parking garage by way of shuttle bus and was able to find their make and model. Their keys were in the ignition and luckily the doors were unlocked so I was able to get the keys very easily. I brought them back to them, and it was a great ending to the day. They were very thankful.

But sometimes it's not always a pleasant experience. Everybody is going through something. About two or three years ago, I encountered a tall gentleman coming over the connector bridge, and he was carrying a lot of bags. I could tell he was emotionally struggling, and I said, "Sir, is there anything I can do to help you? Are you going to be okay carrying those bags down to the parking garage?" And he looked at me and said, "You're always very chipper and happy, but I don't want your help. It's not always a fun place to be." And I found out that he had lost a family member, so he was grieving. I knew it was nothing personal, but because I was talking to him, I enabled him to grieve. And I learned sometimes the most helpful thing you can do is just listen.

"And he looked at me and said, 'You're always very chipper and happy, but I don't want your help. It's not always a fun place to be.'"

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This story explores themes such as community,
health equity, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Courtney Schreiber, MD
December 11, 2020

Feeling Like a Queen

I'm Courtney Schreiber. I go by Cori. I serve as Chief of the Division of Family Planning at Penn Medicine. I lead a clinical program called PEACE, which stands for Pregnancy Early Access and Assessment Center. We are hoping to bring a sense of peace to patients who are in distress in early pregnancy.

This week I took care of a patient who I'd never met before. She came into our office, having been told by a couple of other health care providers that her pregnancy was non-viable. There was no growth of the pregnancy over time, and there was no heartbeat. I went into the consultation room primed for a discussion about miscarriage. But she told me expressly that she was hoping I was going to undo all the information she had previously heard. I said, "Okay, we'll look together at the ultrasound, and then we'll talk about what it means."

I showed her that the pregnancy had not grown since her last evaluation, but she absolutely could not wrap her head around it. It's not the outcome anybody wants, but pregnancy loss is a part of the process of reproduction. Between her idea of what it means to be pregnant and her reality, there was a chasm. I tried to explain what was happening to her, but I felt I didn't have the tools to fill that chasm. And I could tell that the tools I usually use were not the right tools.

She said to me, "Well, I've heard stories of women being told that their pregnancy isn't normal, but that the doctors were wrong. So how can I trust you? How do I know that what you're telling me is true?" I had thought she was coming from a place of a lack of knowledge. But she was actually coming from a place of a lack of trust. And she had a lack of trust in me, and maybe in healthcare in general. I wonder if I was actually influencing her ability to hear and process information well. So building trust had to be my first intervention.

I have worked hard to be good at establishing trust. There are times when I will say, "Do I have your permission to take care of this problem with you? May I help you?" For me, this was one of those reflective moments.

We have a patient who's homeless, who comes in every now and then. Sometimes it is because she's having a pregnancy complication, sometimes she's not. The last time she was in our office, the nurse said, "This is our VIP patient." Our goal is to help the patient leave this encounter feeling better than when they come in. They may come in feeling like this is the worst thing in the world, or that they are the smallest person in the world. But they should leave feeling like a queen. And different people need different things to get to that space. This is the most precious aspect of medicine to me: to not only physically help someone overcome a barrier or a problem, but to help them get on the other side of it emotionally as well.

> "I tried to explain what was happening to her, but I felt I didn't have the tools to fill that chasm. And I could tell that the tools I usually use were not the right tools."

I have struggled in the past to communicate clearly with this VIP. But when I went in this time, she sort of put me at ease right away and said, "You know Doc, really I'm fine. I don't really need much from you today. I just missed you guys.

I was hoping to get some of those cookies and maybe a pair of underpants." And I said, "Okay, great. But, what else do you need today? You know, there are other things we can do for you specifically from a gynecological perspective, besides underpants."

It seems like there maybe aren't a lot of people in her life who she can trust and who have her back. She clearly has a chaotic life. She struggles with mental illness, not having a home. So feeling like she can trust us is important. For her to feel like she can come to us when she needs something so basic as a package of Oreo cookies and a new pair of underpants makes me feel like we're really doing our job well. That we can be there for people who need us in whatever capacity.

"We can be there for people who need us in whatever capacity."

And I think that in this way, she has become our VIP just because she deserves it. We've had the chance to learn a lot from her, to have that gratifying experience of going from the frustration that comes with difficult communication to being able to communicate well together. And the clinic feeling like a place where she can just come for a check in. A place where she can leave feeling like a queen.

There's really nothing more intimate and personal than deciding whether or not to parent, whether to be pregnant, and the timing of all that in a person's life. And there is no better expert on that than the patient themselves. We consider each of them to be the expert of their own life, and that's how we deliver what I hope is truly equitable care.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as COVID-19, healing, death and dying, listening, mental health, and transformation.

How does the experience of reading this story alter your feelings and influence your future behavior?

Thea Gallagher
May 25, 2021

Grace in Difficult Times

I'm Dr. Thea Gallagher. I am the Clinical Director of COBALT, and the Director of the Outpatient Clinic at the Center for the Treatment and Study of Anxiety here at the University of Pennsylvania.

As an anxiety therapist, this past year plus has caused people who have anxiety to have more anxiety and people who maybe never have experienced anxiety to experience anxiety. The definition of anxiety is really the intolerance of uncertainty, the fear of the unknown. And I don't think any other two phrases better capture what we've been experiencing.

During the pandemic, I had more contact with my patients than my friends and family in a lot of ways. It was almost like we were walking along the journey together. I think there's been this clinician-patient relationship that's been almost hierarchical. For me, during the pandemic, it was something that we could share in our humanity.

There were days where patients would say, "How's it going? How are you?" And some days I'd say, "Oh, this is a tough week." But I could relate to how they were feeling in maybe a different way, because I was living some of the same elements of the same journey. And so I think it's really been a powerful year that's changed me as a therapist.

My younger sister was diagnosed with cancer when she was 11 and I was 14. I think that just has a big impact on your view of the world, on your view of mortality, and the fleeting nature of life.

I had the opportunity to be her bone marrow donor for her transplant. It was a really powerful, probably one of the most powerful, moments of my life to get to do that, after so many years of seeing her sick and kind of feeling helpless, other than being able to be her sister. It actually felt like I could do something.

My sister really only had about a year left to live and she really lived that life that year to the fullest, which was pretty amazing to watch. She was basically in hospice care for the last month in our home, and we had the opportunity to walk with her as she died. And I remember feeling very overwhelmed by that journey and not knowing what that was going to look like.

We had a psychologist from CHOP who was there. She said, "You can ask me anything." I was like, "How do you walk someone kind of to death?" She was like, "You just hold them, and tell them you're with them, and it's going to be okay." Even just hearing about that, I would feel very overwhelmed or scared, but it actually was kind of a beautiful peaceful journey. It was kind of amazing to walk with someone through that and to almost have the opportunity to say, "It's okay, you can let go now, like you fought a really good fight."

"I remember thinking, 'I want to do that for people, like I want to be the person that can help people walk through these dark moments and support them.'"

What stuck out to me was remembering that psychologist who so much helped us walk through the scariest moments of our lives. I remember thinking, "I want to do that for people, like I want to be the person that can help people walk through these dark moments and support them." Then I embarked on a journey of becoming a professional counselor and a licensed clinical psychologist.

One thing that has some real roots to my career trajectory was training to be a professional ballerina. Some of the main tenets of ballet are to have poise, balance, and discipline.

When I think of balance, I think that you find it, and then you have to keep adjusting to maintain it. With regard to poise, it's showing that you can handle something, even if you feel like you can't. With discipline, it's realizing when you're tired and exhausted and in pain, getting out there and showing up with what you have.

There's a lot of radical acceptance that many of us have had to do over this last year when we couldn't change a certain situation, and we didn't know what was happening next. Where we really had to radically accept the present.

Watching my sister fight a seven-year battle with cancer, it was really powerful to watch her walk through such intense suffering at such a young age. And speaking of poise and grace and presence, she stayed very present in her life, and that was something that I always found very inspiring.

That's a great way to look at our lives, too. Like how do we have grace in difficult times? And how do we do the best with what we have, and continue to show up? At the end of the journey, I really love what I do. To be that person who walks with people through some of the toughest moments of their lives.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as the care team, healing, physician vulnerability, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Amanda Swain, MD
October 24, 2019

Hand Holding

In the pre-dawn darkness of an August morning, I prepared to start my surgery rotation. It was the first day of my third year of medical school, the first day I would actually be in the hospital instead of sitting in a classroom. My stomach churned as I double- and triple-checked the location where my "team" was meeting for daily rounds. Once located, I stood at the periphery of the messy circle of surgical interns and residents.

Surgery quickly showed me that I knew nothing, not even how to wash my hands. A quick-talking scrub nurse briskly showed me how to do so correctly, using the betadine-soaked scrub brush and moving slowly from nails to fingers to hands to wrists to elbows. When an area was clean you continued upwards; repeating territory meant contaminating yourself and starting over. Once I was "scrubbed in" I had to remember not to touch my face, glasses, clothing, or other "dirty" surfaces in order to avoid contaminating anything in the sterile surgical field. Needless to say, I didn't get the hang of this right away.

Everyone had a purpose and knew their role. The energy in the OR was palpable, intense yet controlled. It didn't seem possible that I would ever find a place in this intricately choreographed dance. Then the patient was wheeled into the operating room. An older man with graying hair under his surgical cap, he lay on his back on the gurney in the center of the room staring up at the ceiling. We were both out of place, islands of silent contemplation amidst a sea of activity. His left arm was extended outward in my direction, strapped to an extension of the bed, his IV already in place waiting to receive the anesthesia. His arm seemed to beckon, and I stepped forward slowly, unsure if I was breaking a rule of some kind, "Thou shalt not speak to a patient before surgery." I introduced myself and then, as we made small talk, I put my hand on top of his. The anesthesiologist who came over to confirm the patient's name and date of birth gave me a slightly questioning look, but only to confirm that I wasn't actually doing anything of importance.

My instinct to reach out to the patient came from my own experience as one. At age 14, I was the one on the gurney, shivering by myself in a pre-op area. Wearing only a thin cotton gown, I felt very small and vulnerable, waiting to be wheeled into the OR. A nurse came to my bedside. I have no memory of what she looked like, or what words were exchanged. All I remember is her taking my hand in hers; the sensation of heat from her palm was immediately comforting. Her touch alone somehow conveyed the caring and support I needed in the moments before my operation. As a medical student just starting a clinical rotation, I probably needed some of that same caring and support.

> "All I remember is her taking my hand in hers; the sensation of heat from her palm was immediately comforting."

I held the patient's hand until his eyes closed and he was fully "under" from anesthesia. I worried that the attending would see those moments as a distraction from the "real" work of doctoring. Leave the hand holding to the nurses, they were the ones supposed to spend time with patients. We were there to do surgery; the "real" work of medicine was the curing of disease after all, not comforting patients.

Now almost twenty years later as a practicing physician, I think of the concept of "therapeutic touch" somewhat loosely. A hand on the back while guiding a patient to or from my office. Holding my palm against their shoulder as they take deep breaths during the lung exam. When it's feasible without being awkward, I try to be mindful of the power of actually reaching out and touching my patient, letting them feel the warmth and pressure of my hand, reminding them that I am right there next to them and will remain so.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as cancer, the care team, listening, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Sonia Vitullo
September 26, 2019

How This Feels

In the beginning of my career at the Access Center I had a lot to get adjusted to. Having years of experience working face to face with patients, I had to learn how to show our callers that I could connect with them and really hear them.

Working at what we call the virtual front desk we have days when we just want to show the patient and the callers that we are trying our best to connect them to their care team and set them up in the best way possible. And some days that can get more challenging than others.

I can remember one moment, one call, where I spoke with a patient's daughter whose mother had just been diagnosed with cancer. And she was very upset and nervous about how this treatment would go. She explained to me that this could potentially be fatal, that she was scared that this was affecting her, and that she was too young to lose her mother. And when I proceeded to try to get her set up the best way I could, she wasn't very pleased with having to wait, and she mentioned to me that there isn't much time. At one point she said to me, "You have no idea how this feels."

And in that moment, I had to struggle through my own emotions, because just a few years prior, I actually lost my father to the same diagnosis. And I too felt that I was too young, that it was difficult to schedule his appointments, and share the news with everyone. I knew it wasn't easy. But I also knew I couldn't tell her those things, that it wasn't about me. And I wanted her to know that I heard her story and I understood her.

> "But I also knew I couldn't tell her those things, that it wasn't about me. And I wanted her to know that I heard her story and I understood her."

So, what I actually said to her was, "I do understand, and I hear you." And I think she heard me too; we paused for a moment, and I think she felt more calm. She allowed me to recap the next steps and talk through what we could do for her. And we eventually ended the call with her thanking me for being patient and working with her.

And I feel like, right now in our world, we're so used to getting that instant answer and having everything work so quickly, but sometimes we can't get that. And that's, you know, one of the challenges I had in that moment. But I think that being able to speak to her and listen to her and relate to her, I think that's what really connects us.

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This story explores themes such as grief, healing, listening, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Cynthia Davis
October 3, 2019

In the Silence of Compassion

I am trauma chaplain Cynthia Davis at Penn Presbyterian Medical Center.

As my journey continues together with the lives that I touch, I don't see people the way I used to or take their lives for granted. When you have a mother who just falls into your arms, all you can do is hold her and pray. And then I ask God to give me what to say or say nothing at all, just hold them. Will you one day think that you may never see them again? Or will you remember, there go I but for the grace of God.

In the silence of our listening, we hear the heartbeat of another. And with compassion, we value the person's voice. If we listen closely, a hush surrounds their countenance, but the expression on the face can say, "Help me. Is there anyone listening?"

The presence of listening allows us to feel joy, pain, and the sorrow of the heart. Can you hear them in the silence when the tears run down the faces of friends and parents and siblings? When their loved one is gone, will your arms reach out to hold them in the silence of compassion?

I think of the Scripture 4:23, "Keep thy heart with all diligence; for out of it are the issues of life."

"When their loved one is gone, will your arms reach out to hold them in the silence of compassion?"

I'd like to leave you with a few inspiring words from Henri J. M. Nouwen:

"Compassion asks us to go where it hurts, to enter into the places of pain, to share in the brokenness, the fear, confusion, and anguish. Compassion challenges us to cry out with those in misery, to mourn with those who are lonely, to weep with those in tears. Compassion requires us to be weak with the weak, vulnerable with the vulnerable, and powerless with the powerless. Compassion means full immersion in the condition of being human."

Listen online at pennlisteninglab.org/stories/

This story explores themes such as the care team, gratitude, and health equity.

How does the experience of reading this story alter your feelings and influence your future behavior?

I’m a People Person

I’m Teresa Bullock. I work for Environmental Service, which is housekeeping, and I’m a housekeeper. I’ve been here at Presbyterian Hospital for eight years. And I just love my patients, and I love my job.

I think the most important part of my job is not just cleaning, ’cause anybody can clean. But somebody just needs to hear something good sometimes. Some people up there by theirselves and don’t have no visitors, and nobody like that, so somebody want to hear kind word or something nice.

I’m not going to sit here and say “Oh I love to clean.” No. I’m a people person. So it’s being around the people and cheering them up. That’s where my heart is at. That’s where I get the joy at. If I can cheer somebody up that’s having a bad day, then I’m fine.

The pandemic is a hard thing. Just them being up there by theirselves. They need something; they need somebody to say something to them. They need a hug. You can't treat people like they're some kind of a virus or something like that. People are still people. And people just want you to say something, or touch them, or pray with them. Or let them know it's gonna be all right. So COVID ain't gonna beat me. I'm gonna beat COVID.

You want me to go into the story of the lady? Well, it's a normal day, and usually I just start off coming up on the floor, get my cart together, and go to each room. And I go in and on the board, I put on there "Feel Better." And I always put a SMILEY face. I went into the room, and I was talking, and I was putting my message on the board for her. And she wasn't saying nothing, so I turned around and looked, and she was like slumped over. Drool was coming out of her mouth, and I knew something was not right. I pressed her button to alert the nurse, and I said, "We need somebody in here right now!"

Then I went out in the hallway and said, "We need somebody in here right now!" They came running to the room, and then they called a code. And I just stayed in the hallway. I just kept on praying. "Oh Lord, please just let her be alright." So they worked on her. They took her to the PACU (Post-Anesthesia Care Unit) side. They told me that she was going to be all right, and that's all I wanted to hear. And the nurse thanked me, and everybody was thanking me, like for just being alert and just being aware.

> “Sometimes I just feel like I don’t count, but in my heart, I know I do. We are very important, because even though the doctors and the nurses coming in, they can’t see everything all the time.”

Being a housekeeper, they just think we the bottom, you know, sometimes that we don’t matter. Sometimes I just feel like I don’t count, but in my heart, I know I do. We are very important, because even though the doctors and the nurses coming in, they can’t see everything all the time. So we might be the last person in the room. We have to be alert, just like we all have to work together, we’re all a team. Even though I’m a housekeeper, I’m a part of the team.

I have had difficult patients that have cussed me out. They might be having a bad day. I don’t know what the doctor might have told them, they might have got bad news. They might be battling for their life. The way they reacting to me, I can’t react back. So I'll usually just say, "It's okay, I see you having a bad day, this too shall pass, and I'm gonna say a prayer for you." Then I just usually leave out the room. We have patients that we get close to; they might have been here for a while and they might pass on. We might go to the side, or somewhere we might cry. We done have patients that have been there for like months, and when we see them leave, we just so excited, we just clapping and we taking pictures all together.

When I go up on the floor, it's something that a patient done said to me that made me laugh or cheer my spirit up, and I let them know that. I said, "You know what, I needed that! You cheered me up!" and they were like, "Ah Teresa, I cheered you up?" "Yes, believe it or not, you cheered me up!" And they say, "No, you cheered me up!" And I say, "No, you cheered me up!" So we've been back and forth laughing at each other and stuff like that.

At the end of the shift, my last room, I just say, "Lord, thank God, I made it through." I go set up my cart for tomorrow. And I just thank God, I said you made it through another day, and I'm just going to start this day over tomorrow. And that's that.

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This story explores themes such as COVID-19, physician vulnerability, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Ara Chalian, MD
March 27, 2020

Quarantine

About ten days ago, after finishing about six hours of surgery with my nurses and my chief resident, I was notified that I had been exposed to a colleague who had tested positive for COVID-19. I was considered in the high-risk group to potentially get infected. I needed to immediately proceed into quarantine status. I changed; I packed up what little I bring into the hospital, and I walked out of the hospital on to the front circle. And I looked at the street in a very different way than I normally do.

So I am getting ready to call my wife and tell her what I have just heard, and I don't want to make this call. My wife is pregnant; she is three weeks away from delivering. Quite honestly I am afraid she might be infected, or the baby, or the child we have. And then on top of that, I don't want to miss the delivery. So it was one of the hardest calls I had to make.

I had settled in my head that I was going to the hotel. My phone was dying, and in some ways I felt like I was all alone. I think I really was. There was a list of little things I had to solve. They were all made more complicated by the fact that I wasn't going to get to go home and give little Ara a hug and my wife a kiss.

I remember I was crossing the Walnut Street Bridge feeling really lonely. It felt really long and slow. I thought I would feel better if I planned, so I planned a little what I would maybe do when I got to the hotel, and how I would spend my days. It didn't really feel like I was in charge of much of anything at that moment, besides staying away from everybody.

"It didn't really feel like I was in charge of much of anything at that moment, besides staying away from everybody."

I walked out of the hotel to pick up my bag from my wife, and you could tell she wanted to hug me. And I go, "You can't hug me." And she goes, "I hugged you this morning." And I go, "Yeah, but now it's different." She goes, "It's not really different." And I go, "It feels different. I feel like I can't hug you because I don't know what's going to happen next. So trust me, and don't hug me."

It was a long nine days. But fortunately, I didn't get sick. I felt good when I had my routine. I felt good when I was able to do a virtual clinic, and when I made my bed, and folded my clothes, and when I got to see my family over FaceTime, and watch videos of my life at home unfolding without me. Because it was the next best thing to being there.

As I envisioned going back into the society that I just left, the hardest thing for me to imagine was how to package my two biggest fears. Can I keep my family safe, can I be healthy for them? And then the fear that I would be unable to help others. This incredible urge to be present at the hospital, helping take care of people that are in need, but also being there as a colleague who supports other colleagues in what we do.

Almost everybody has the chance of getting sick. I realized I'm one of hundreds already, and these conversations, these inner fugues, are something that almost everybody is going to feel. You have to put it on the table that you're willing to go back and do what you love, what you care about, what you're committed to. For me, I realized that all of those two or three circles—you, your family, your job, your commitment—they all belong together, especially now. They really belong together.

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This story explores themes such as community, COVID-19, and health equity.

How does the experience of reading this story alter your feelings and influence your future behavior?

Abike James, MD
January 11, 2021

Leaning into Hope

My name is Dr. Abike James, and I am the vice chair for diversity, equity, and inclusion in the department of Obstetrics and Gynecology at Penn.

I'm also a mom, wife, daughter, and sibling of Nigerian and Guyanese descent. I chose to get the COVID-19 vaccine for my family, my community, my patients, and to be an example in the face of debilitating mistrust amongst Black and Brown individuals about the vaccine and its potential effects.

I'm the middle daughter of five children. The morning after my first shot, I had an intense argument with my siblings who are scattered across the globe. My elation about receiving the vaccine was met with reprimand from two of my siblings, telling me to just make sure I did not influence our mother to get it. That under no circumstance should she be used as a guinea pig. I was devastated. My high became a low. My mother is the highest risk amongst us, and in my opinion, should get it. The isolation during the first part of the pandemic, when she couldn't see her children or grandchildren, was too much. We could see the depression set in, and I made the decision to bring her back into my bubble. But every day since then, I've walked around with the fear that as a health care provider, I could bring COVID to her and the rest of my family.

If you asked me three months ago would I get the vaccine, I would have said "No." It was too new, and we didn't know enough. But then the third surge of COVID-19 cases hit right around Thanksgiving. Staff I work with got COVID. A dear patient of mine lost her mother to COVID. Family members had significant exposures. I felt as if COVID was crowding in on me, that it was just a matter of time. I felt hopeless. Would I have to return my mother to her isolation? Would this go on forever?

It is right around that time that news reports were suggesting the COVID-19 vaccine would soon be available. Now I had a glimmer of hope. I have the privilege of working at Penn with access to experts in research and trusted friends and colleagues to lean on. I talked to the experts, I did my research, I listened. I learned that while the vaccine was new, the technology was not. I learned about where the first trials were done, in the UK and Germany—not Africa, as was rumored. I read about the side effects, most of which were mild to moderate, and most importantly, resolved rapidly. I believed the science. The vaccine was safe and effective. It prevented disease with 95% efficacy and severe disease with 100% efficacy. This sounded much better than leaving it up to chance. I was sold, but some of my family members clearly were not, and it soon became apparent that there wasn't just hesitancy amongst my family. It was matched by hesitancy amongst my Black colleagues, friends, staff at work—literally everywhere I turned. I understood why.

> "I felt as if COVID was crowding in on me, that it was just a matter of time. I felt hopeless."

There have been terrible injustices against Black and Brown people in the US and across the African diaspora, in healthcare and beyond, and the trust just isn't there. But the COVID-19 vaccine is different. We've been fortunate to have Black scientists involved in the technology behind vaccine development and involved in vaccine trials. We've not been guinea pigs this time. I balanced this knowledge with the reality of the COVID-19 pandemic itself. The legacy of systemic racism in Black and Brown communities, and in healthcare, created fertile ground for this pandemic to disproportionately ravage people of color. We're getting sick and dying at higher rates than our White counterparts.

> "The legacy of systemic racism in Black and Brown communities, and in healthcare, created fertile ground for this pandemic to disproportionately ravage people of color."

Ethnic and racial disparities already pervade my specialty of Obstetrics and Gynecology. Black and Brown people have poorer family planning and gynecologic access, higher cancer rates, and worse obstetrical outcomes, including higher preterm birth and maternal mortality.

If as Black and Brown individuals with access to the vaccine, we turn around and then decline it, where does this leave us in a few years? Our communities are losing so many lives to COVID-19. What happens when COVID-19 slows down for the vaccinated community, and continues for the non-vaccinated?

So, I made my decision. I leaned into hope. I got my shots. I was amazed to see myself surrounded by colleagues, many of whom were Black and Brown, there for their shot also. We bonded by this opportunity to receive our shots together.

My mother is patiently awaiting her shot. Two of my siblings may still need more time. But that's OK. I feel privileged that I could share with them, and I intend to keep the conversation going.

As a community, we have to be all in. We cannot afford to continue to lose those nearest and dearest to us. And we cannot afford to let the divide continue to grow.

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This story explores themes such as COVID-19, death and dying, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Julia Schott
October 19, 2020

Long Days, Short Years

My name is Julia. I'm a medical social worker with Penn Home Palliative Care. My job on the team is to help the patient tell their story in terms of what matters to them most now at this stage of their lives. I view symptom management as a basic human right that we should all have access to regardless of where we come from.

When people hear what I do for a living and remark on how difficult my job must be, I tell them that it restores my faith in humanity on an almost daily basis.

Last week, I visited an 85 year old woman suffering from both Parkinson's disease and dementia, who was being exquisitely cared for by an inspiring pair of devoted, exhausted tag-teaming sons. One son lived with her full time, and the other son was working third-shift job and then coming back to give his brother brief respite.

During our time together, she was lethargic and soft spoken but beautifully coiffed and kind to a fault. She was reclined in her favorite bedroom chair next to an open window, snuggled beneath a set of handmade blankets and wearing a mask her sons had considerably placed on her lovely face.

It was clear that this woman's decline had accelerated in the past few weeks, difficulty swallowing and walking, weight loss, less lucid and more lethargic. A hospitalization to address a urinary tract infection. And so gingerly I talked with the patient's sons to understand our common goals while she rested serenely by our side.

> "And so gingerly I talked with the patient's sons to understand our common goals while she rested serenely by our side."

As our visit closed, and I said farewell, she opened her eyes with effort and said quietly. "It's starting to get chilly out there. Are you sure you don't want a sweater?" She took my breath away with her kindness delivered even through the foggy end-stage of two cognitively debilitating diseases.

Even though she had dementia, she was talking repeatedly about going home. And she was in her home where she had raised her own children, but to me it seemed like she was talking about her spiritual home, and she was asking her loved ones how to catch the train or a plane to get there. That symbolic language goes to the essence of what people care about and really shines through during serious illness.

In palliative care and hospice, we talk a lot about how there are so many similarities between the beginning and end of life. The sons described to me that the patient was having sundowning episodes during the afternoon and evening. The patient gets their days and nights confused, and that's what happens a lot of the time for people who are starting to die.

One of the things that I've learned from my patients is that the days are long, and the years are short. In the midst of a pandemic, it can feel like, "How are we going to get out of this? I just want this to be over." And then I know, from experience, this time is just going to go by in a flash. The memories that are going to last for me are those connections I've made.

It's really a blessing to be able to do this work. We're going through a really hard time right now. But then I walk into a patient's home, and they could be going through the worst of illnesses, and there can be so much love and compassion between the patient and her family, the patient and me.

It's therapeutic and soothing for me to tell the stories. I think a lot of people are afraid of stories of suffering; they're afraid it's going to wash on to them or make them sad. Or they're thinking that my job must be so depressing, and they don't want any of that in their lives. But storytelling and listening is part of what makes us human.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as COVID-19 and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Cyra Uy
June 11, 2020

My First COVID Patient

My name is Cyra, and I'm a registered nurse at Lancaster General Hospital. I'd like to share a story about my first COVID patient, David.

At this point, you didn't know how the virus was being transmitted. It was obviously nerve wracking, and we weren't really sure what to expect, how fast we were going to peak, and how everything was going to be. Everyone was being cautious and wearing N95s and wearing PAPRs [powered air-purifying respirators] and all that. What if protective equipment actually didn't protect you from it?

That day I came in, of course I was nervous and scared as to what to expect, especially since David was very young. And I was surprised, because he was in his 40s. You could tell that he's able to walk, he's able to do everything independently, but at that moment he couldn't do anything. And there is barely anything I could do. So a lot of the anxiety was knowing that I had to care for someone that I didn't know how to care for.

On our floor the nurses drove everything. We didn't have housekeepers, we didn't have aides, we didn't have respiratory therapists or anyone. So basically we were trained to do everything our patients would need.

> "So a lot of the anxiety was knowing that I had to care for someone that I didn't know how to care for."

Just the garbing part of our PPE [personal protective equipment] was very nerve-wracking already. The hospital was pretty strict about donning and doffing. I had to make sure that I was going to be prepared for it, and I was going to be protected.

The first time I actually went in his room, I spent about an hour and a half in there, you know making sure he was OK, giving him his tray for food, cleaning his room, making sure he showered and all that. So while he was washing up, I was wiping down his room, and making sure it was nice and clean and tidy. And I got to know my patient.

I feel like at that moment my patient also had more anxiety than me. His family wasn't there. No one was allowed to visit. You feel very isolated in a room, and you're not sure about what's going on, because you just see it on TV, and it's happening to you.

I just figured my job would be to make him comfortable, make sure that he knows that there are people around him, and that we're there to help him. There was no one else on our floor; there was no one else he could talk to. I was the only person coming into his room besides one other doctor who was there ten minutes once a day. We built our relationship on what we were both facing.

That day that he left, I actually wasn't his nurse. But I saw him roll out of our unit, and I realized that he couldn't even recognize me having my PPE on. And that didn't make any difference to how I felt, because I know that I had made a difference in his life, and he had made a difference in mine.

With this pandemic that we're dealing with, with everything going on, it's the relationships that will help us get through.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as healing, listening, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Sarah Frankl
October 4, 2019

My First Patient

Starting medical school, I was feeling rather lonely after having moved far away from my family in Alaska to Philadelphia. I had made the drive myself, and through the mountains of Montana and the long plains in South Dakota, I had had a lot of time to reflect on my excitement in starting a career where I was going to be able to help so many people. I hadn't really anticipated that the first year would be full of books, followed by books, followed by more books.

We did have some time with patients. On my first day of medical school, we had a panel of patients, and in the front of the auditorium, was a patient in a wheelchair with an oxygen tank, telling my class the story of how a doctor had hurt her feelings. She brought herself to tears along with a lot of my class, including me.

I had the fortune to be paired with this patient for a class assignment, in which I was instructed to attend all of her doctor's appointments in order to better learn what it was like to live with a chronic illness and spend a lot of time waiting in waiting rooms. I was also assigned to go to her home and cook meals at her house once a month. Of course, we got to know each other better as people—she always asked after my boyfriend and my parents, and I would always ask after her family. Soon I got to know both the intricacies of her family dramas—who was coming to Thanksgiving this year, who was backing out, as well as the more intimate details of her life story—which included being orphaned at a young age, raising her younger siblings, then raising her son, then raising her grandchildren. Not to mention along the way, she helped raise many a child that she babysat in the suburbs. Her only regret was that she never went on vacation.

"At times, I felt a little frustrated with myself. Wasn't I in school to learn how to help people lose weight, to keep their blood sugars down?"

My patient also had some health problems that I got to know about. She had high blood pressure, high blood sugar, bad lungs. At most doctor appointments, the doctors would encourage exercise, eating healthier, but these were hard habits to change. Even with me spending multiple hours a month showing off the most organic fruits and vegetables, that didn't mean that when I arrived in her kitchen there weren't usually a few cakes lying about.

At times, I felt a little frustrated with myself. Wasn't I in school to learn how to help people lose weight, to keep their blood sugars down? But then, I would receive a text from her saying, "Sarah, thank you so much for listening to me today. I appreciate you so much." And I realized that maybe being a doctor is about more than just the numbers on the lab slip and pounds on the scale; it's also about the ability to simply listen to our patients.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as ageing, death and dying, relationships, and transformation.

How does the experience of reading this story alter your feelings and influence your future behavior?

Jason Karlawish, MD
March 19, 2021

Sparks of Clarity

My name is Jason Karlawish. I'm a geriatrician, and I'm the co-director of the Penn Memory Center at the University of Pennsylvania.

I want to tell you the story about a patient whose family member changed the way I thought about the personhood of persons living with advanced dementia. My standard practice at the Memory Center is to talk to a family member, someone who knows the person well. And I want to tell you a story about a daughter who I was seeing in the company of her mother—her mother was my patient. And the daughter volunteered that her grandfather, her mother's father, had Alzheimer's disease, and that he had died of his dementia. And then she tells me the story of how her grandfather was in hospice. It was understood that he was going to die of his Alzheimer's disease.

And as she started to tell me that story, all the sudden she let forth this great sob, like a wave crashing on a shore, like a sudden cloudburst. And she explained to me how her grandfather was quite ill; he was in hospice. And she walks into the room, and he looks at her, and he reaches out and takes her hand. He calls her by her name, he tells her how much he loves her, and they talk. And then, he stops. And she tells me it was very peaceful; he knew who she was, and he knew, obviously, who he was. This moment of just paradoxically lucid connection. And two days later, he died. She told me that in the year prior to that, she would visit him regularly, weekly even. And maybe he would speak, sometimes often, sometimes not at all. Often he didn't seem to really recognize her. But here it was, this moment of complete connection, complete clarity.

"I started to discover this hidden world of interconnected minds and mind perception, between these caregivers and these patients with very advanced dementia."

Prior to that, I had heard rumors about these kind of events that occurred in persons with advanced dementia. Intense connection moments of unusual clarity. Sometimes they occur prior to death I had heard, but oftentimes not. But I'd really not asked about them; they weren't part of my routine assessment when I saw someone with advanced dementia. I didn't ask the family members about them. Worse, the few times that they told me about them, I was really quite dismissive. I paid it little mind, if you will, because I reasoned that these people really didn't have much of a mind, and that this was just sort of the unusual behavior that comes from a failing mind.

But this experience, this granddaughter's tears, really changed me. It caused me to question that, and to question my indifference. And so I did what a doctor does. I started to ask about episodes of unusual clarity, unusual lucidity, really good days, moments of intense connection. And things started to happen. I started to discover this hidden world of interconnected minds and mind perception, between these caregivers and these patients with very advanced dementia.

One son spoke of his father's sparks, and how there were these moments where the sparks came. And, for example, when he gave his father the ballot to vote, his dad was actually able to express what he wanted to do, and why. Another spoke of his mother's shooting stars, where she had intense connection about things she wanted. Some felt these things with their relative hidden inside, almost trapped, and able to periodically sort of come out. But otherwise sort of locked inside. Some almost thought of them as incantations. Some of them really mourned these experiences, because they've had this glimpse of the way the relative was, and that went away. And they would struggle to do things to bring it out. Some just didn't know what to make of it.

The point was that these weren't in their perception just a brain firing mysterious things, a failing brain. It was very meaningful connection with people who, if you met that person, particularly if you knew that person before, but even if you never knew them, you would say, "My gosh, how disabled they are!" So that one moment with that daughter was transformative. It changed the way I thought about patients with advanced stage dementia, the way I connected with their family members about their care, and how they perceive them.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as COVID-19, death and dying, grief, health equity, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Jhenny Carpio
September 16, 2020

Support from Afar

My name is Jhenny Carpio, and I work for Lancaster General Hospital. I've been a certified medical assistant since about 2007, so I have direct contact with patients. Throughout COVID, I worked the whole entire time.

What I was going through made me think, "That can be my mom, that can be my dad, that can be my brother, that can be my sister." As drained as I was, we were pulling it through.

My entire family, they live in New York. They all got COVID. My mother, my dad, my aunt, my two sisters and their husbands, and my niece and nephew, they had COVID. I was not able to go and see my family. I was able to help them fight the symptoms. It was very hard emotionally, physically, mentally, because I had to be here and work and be focused. My thoughts and everything else was with my family in New York.

My dad has a heart condition, and he had bypass surgery two years ago. His health was going in decline. His oxygen, his blood pressure—it was a whole mess. With some of the knowledge that I have learned throughout the years, I was able to help my dad with his blood pressure, with his oxygen levels, and try to fight some of the symptoms that he had.

They were afraid to go to the hospitals because the hospitals were so overwhelmed. He actually refused to go in every single possible way. He knew if anything bad will happen to him, he was not going to be able to see his kids, my mom. My sister, she needed guidance no matter what time it was. She was able to hear those words of support even if it was 2:00 in the morning. Sometimes when she called me because she couldn't breathe, I was able to say, "You have to take a deep breath, you need to relax." Sometimes we used to pray together and remember things.

I had two uncles. They died one after the other one. I was the support system for my aunt because he went to the hospital, there were no beds, they sent him home. One day she says, "He's not doing well. He's fighting to breathe." I said, "You need to call 911." They couldn't find a bed in a hospital in Queens, so he ended up in the Bronx. She was not able to see her husband. It was hard not to say a goodbye for someone you care about and someone you love.

That affected the whole entire family—the mindset of everyone as well. He didn't have a funeral. There was no body for us to be able to grieve. My aunt did Mass on his name a month after he passed away. And I hope one day we all can be together, and he'll be able to smile like he always did.

> "It was hard not to say a goodbye for someone you care about and someone you love."

I have learned to appreciate every single day. COVID has taught me to be compassionate and thoughtful. Don't judge because they have COVID. There's a lot we can do without having contact with a person who is positive, but we have to be caring.

We cannot discriminate, no matter what color you are, no matter where you've come from. I've been here in the United States since I was 14. 30 years in the United States, and my accent hasn't gone away. We have to have a heart for others, for the human being, because we don't know what can happen tomorrow. And maybe the people that you never thought you need, those are the ones who are going to give you a hand.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as grief, listening, spirituality, and transformation.

How does the experience of reading this story alter your feelings and influence your future behavior?

Jeffrey Millstein, MD
July 11, 2019

The Envelope

When I met my patient Jack a number of months ago, it was the end of the day, the end of the afternoon. He was the last patient in my schedule. And as I reached in to introduce myself and shake hands with him, I noticed he was clinging fairly tightly to an envelope, a large manila envelope.

And I think there was something about the way he was gripping the envelope or his tight possession of it that told there was something special about it to him. That I think prompted me to break with tradition a little bit, pull away from the computer and ask him, "Jack, is that something you'd like me to look at?" And he handed me the envelope, and he looked relieved. I think he was surprised that I asked to see the envelope.

I opened it, and inside were a stack of papers memorializing his son's death. His son had died at around the age of 30 or 32 after a long battle with cancer. I felt very sad, expressed that to Jack, and told him I was so sorry for his loss. And it made me think of my own son and wife and how awful it must be to lose a son in the prime of his life.

And what I learned from talking with Jack afterward was that he had really ignored his own health for many years. This was the first time he had been to see a doctor in probably ten years or more. And he had made some attempts to see a physician in the past but had never really gotten very far, because he was waiting for someone to allow him to tell his son's story. And more than that, he was looking for a chance to tell his son's story before he told his own story.

"He was looking for a chance to tell his son's story before he told his own story."

So I felt very fortunate that somehow I had this instinct to ask about this envelope before delving into my usual history and physical. Because had I not done it that way, I think I would've missed an opportunity to connect with him. And I would've lost an opportunity to hear his story and to be a part of his story going forward.

I reflected on this for a number of days afterward. I was thinking about how I really in some ways did something very similar to what Jack did, in the sense that he needed to break with tradition in terms of how he was seeking care. He needed to tell his son's story in order to have at least a modicum of closure, enough to be able to talk about his own health.

And similarly, I forced myself to break with my usual tradition of extracting the history from someone by asking a series of questions, and proceeding through the usual sequence of examination and assessment, and plan to just hear his story the way he wanted to tell it.

"If you listen to the patient," as the saying goes, "he or she will tell you what is wrong with them." And I realized after talking to Jack that there's something that's missing from that statement, which is that in order for a patient to tell you their story so that you can help understand their diagnosis, they have to trust you, and you have to establish some sort of a connection.

You have to listen to the patient, show curiosity, and offer presence and interest in their life, and then they will tell you their diagnosis. And I've tried to live by that ever since then.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as community, health equity, and speaking up.

How does the experience of reading this story alter your feelings and influence your future behavior?

Florencia Greer Polite, MD
December 2, 2020

The Journey

I am Florencia Greer Polite. I'm a 2002 graduate of the Perelman School of Medicine. And I currently serve as the Chief of the Division of General Obstetrics and Gynecology here in OB-GYN.

The week of June 5th was a pretty stressful week. After the murder of George Floyd, I was in a number of meetings and realized that I felt like I was going to cry. And I said that to one of my colleagues, and he said, "You should just cry." And I said, "I did that already, and I don't actually feel any better."

I took time to write an email to our division about what it felt like to be a Black person coming to work every day after George Floyd. And how as a leader specifically, we had to pull ourselves together. That immense stress and pressure was, for me, almost insurmountable.

One of my colleagues was in the midst of organizing a protest type event and she asked me, "Would you lead it?" And I said, "Absolutely." We thought it was going to be fairly small, and it ended up being thousands of students, staff, faculty, doctors, cafeteria workers, the custodians at Penn… It was at Penn's Franklin Field, and it was massive.

It was ten times more emotional than I thought it would be. Just to look out at the faces of everybody. People were very focused and crying, and I could see what I was saying was resonating. I talked about how we, at Penn Medicine, are in a very privileged position, and that our responsibility as caretakers and physicians goes beyond just the practice of clinical medicine. We needed to acknowledge systemic racism in our country. This particular moment was not just about ending police brutality. It's a movement about dismantling every aspect of structural racism.

When we knelt for the eight minutes and 46 seconds, I acknowledged that it was going to be painful and that we owed it to ourselves because we have been comfortable for too long. And I asked that during that time people reflected on two to three actionable items that they would actually do in their own lives to address structural racism.

And the hope of kneeling was that George Floyd didn't die in vain, that Ahmaud Arbery didn't die in vain, that Breonna Taylor didn't die in vain, and all the names that we didn't have time to recite and the ones that were not even recorded.

> "This particular moment was not just about ending police brutality. It's a movement about dismantling every aspect of structural racism."

One of the first people to come up to me was the custodian for labor and delivery, who I speak to all the time. I ask about her family, and she literally came and gave me this huge hug. And just told me that she was proud of me.

Patients both White and Black have engaged me in a different way after that event. I had one older White female patient, when she saw the media coverage, who said to her daughter, "That's going to be my doctor." And she was so excited to come into the office in a few months to see me. She was really proud to have a doctor who she viewed as being sort of socially conscious.

It's hard to be a member of many communities. To be a member of the Black community, to be a member of the Philadelphia community, and to be a member of the Penn Medicine leadership team.

As doctors, we are literally helping people every day, patients who don't have the educational wherewithal to engage in their care. But I felt very much in that moment that what needed to be said was that that's not the only way that we can make a contribution to our patients and to Penn Medicine and to Philadelphia.

I love Philadelphia. And I think that we can be and should be better. I love Penn. I think that Penn can be and should be better. And so, I am interested in making both of those places better. Penn wants to be a leader in research and clinical medicine. Why would we not want to be a leader in the work to end systemic racism? I'm optimistic about that.

This is the journey. We are working towards an outcome that I don't know that any of us in our lifetimes will ever see. What I want at the end of my time here is to know that I have contributed to moving this journey forward. To moving us to a place that's better for my children, and that creates a better environment for the patients who are the reason why I came into medicine in the first place.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as community, healing, relationships, and spirituality.

How does the experience of reading this story alter your feelings and influence your future behavior?

Mary Evers
February 20, 2020

The Last Stop

My name is Mary, and I work at Penn Medicine Princeton House. I try to help women heal from their trauma.

My experience has been that many women are struggling with addiction, because they've never had an opportunity to heal from their trauma. Some have never had an opportunity to even speak about their trauma.

My story is about a client I met about a year-and-a-half ago. She came in, she was struggling, and she was pacing; she was agitated. I wasn't exactly sure if I would actually see her again. She was addicted to cocaine and alcohol, and in the past, she had been using meth on and off. She came with a severe history of abandonment in her childhood, physical, sexual abuse. She was broken in many ways—spiritually, emotionally, physically—just broken. And she said, "This is it, this is my last stop."

Working with her was challenging. She struggled to concentrate; she struggled to focus. I often had to move really close to her in session, directly ask her to make eye contact with me, watch her body language, and wait for her to soften. The tension was so intense for her. It was extremely hard for her to talk about what she was feeling.

Because she was relapsing and struggling in our treatment, we thought she needed a higher level of care, and I worked to make that happen for her. She lasted nine days. She did call me and say, "I can't do this, I'm out. But I'm okay." And I knew that she wasn't okay; I could tell. My fear was that I would never see her again, that she might not make it. I have attended many funerals, and that's a real fear.

It is difficult to work in this field. It's hard, because you don't know outcomes. And my experience has been, working in the inner-city and in an ER, that it's frustrating. Many people do not want to work with addicts. And I would go, and I would find a chair, and I would pull the curtain around, and just sit there. And sometimes just hold them, and tell them it's going to be okay, and offer them services. Many times, that was a great time for them. Sometimes it's finding the right fit to be able to talk about this. Women can say these are things that happened to me, and I'm hurting.

So three weeks ago, she called me out of the blue, and told me that she was doing really well. She has been a year and a half sober. She told me that what haunted her was me asking her to sit still and feel. And she said she just wanted to fight that. All she knew how to do was run. And she knew in her heart she needed to sit still and feel.

> "All she knew how to do was run. And she knew in her heart she needed to sit still and feel."

She just really wanted to thank me for all the work that we did together, and it just felt so good to me to hear her voice and how proud she was of herself. It made me feel proud of her as well. So I invited her to come in and speak at the 12-step group that I do on Wednesday, and she was ecstatic. And just seeing her when we made eye contact, it was just so meaningful to see her smiling, to see her sober, to see her gratitude.

So many people see the addiction. They see the dirty, filthy woman. I see the pain, I see the hurt, I see the heart of someone who's really struggling. And it's not a choice—it's a life. And it's a life worth trying to help.

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This story explores themes such as COVID-19, relationships, and spirituality.

How does the experience of reading this story alter your feelings and influence your future behavior?

Jennifer Lipski
May 8, 2020

The Prayer

I'm Jennifer Lipski, and I am a chaplain at the Hospital of the University of Pennsylvania. I'm also a former nurse.

So I've been out at my parents' home taking care of them. They are challenged with health issues, and I've been supporting them during this time of a quarantine, which has made it not possible for me to be in the hospital with my colleagues, with the staff, with the patients. I have not been able to be on the front line. And that's been difficult for me in some ways because that is a place where I feel like I need to be. I realized that one way to help others to be with their emotions is to be with my own, to allow myself to feel vulnerable too.

So, one night when I was going to sleep, I prayed for insight into whatever needed to be heard. What did I need to know? Because there's been so much uncertainty in a lot of ways for everyone, including myself. When I woke the next morning, what had come to me just as soon as my eyes opened was a prayer to my Guardian Angel:

> Gather me closely and enfold me in your
> broad pure wings.
> Keep me safe and guide me in a sacred way.
> Encourage me to help others.
> And remind me of all that is good.
> Lift me up to softly stand strong.
> And help me find my strength to sing my
> own heart songs.

That prayer came to me as a blessing for a colleague who was working for me that very day. She was covering my shift, going in on my behalf. And this came in I think as a blessing for her.

And it made me wonder, what else we can all do to help to comfort each other, bless each other, honor each of us? I don't think you have to have religion to be able to do this.

> "And it made me wonder, what else we can all do to help to comfort each other, bless each other, honor each of us?"

This time of history is really allowing a pivot point for everyone. And hopefully some of the good things that can come from this are that people will be inspired to be in touch with each other and with their hearts and to make effort in a way that uplifts humanity. We really need it.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as the care team, death and dying, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Sara Holland
August 21, 2019

The Son

As a primary nurse in the ICU, I know that we need to go beyond the boundaries of understanding the patient and what's happening with them and understanding the family and the dynamics.

It wasn't too long after I started caring for Phil that I really knew that the care had shifted towards his son, John. John was a medical student and was currently starting his fellowship. He had this heavy sense of burden to not only care but make decisions on his father's behalf because he really wanted to save his father's life. And over time, I just watched John struggle so much with knowing that he wasn't going to be able to save his father.

It became difficult to care for Phil because John was demanding information instead of working with the team. The conversations went from sort of being a collaborative member of the team to why weren't we saving his father. So one day when I was taking care of Phil, I told him exactly what I was thinking: "John knows that he's going to lose you, and I want to be able to help John through this. Is it OK if I talk to your son alone about this?" And I know that Phil understood what I was talking about, because he squeezed my hand.

So John and I were able to sit down alone and talk in a conference room. I asked John, "Tell me about your father, what was he like?" And he just started talking about his dad and talking about what a wonderful relationship they had and by his own will he was able to say, "I know my father wouldn't want to live this way." John was able to come up with the whole plan of what the right thing to do was. And Phil was able to pass in comfort, and he didn't have to suffer anymore.

*

I had formed a very strong bond with the family, and they had invited me to Phil's funeral down in Cape May. I sort of felt compelled to go; I felt that there would be some closure for myself. So my daughter went with me, and it was two days before hurricane Sandy was supposed to hit the coast of New Jersey.

After the funeral, they had invited me to the burial. The cemetery had dug the wrong grave for Phil. And it was the first time I saw John just laughing about the sequence of events with Phil.

We went to where Phil was supposed to be buried and we had a nice little service for him there, but they had to wait until Hurricane Sandy had passed before they could really find closure in Phil's death.

"We look for closure; we expect things to go a certain way and sometimes they don't."

We look for closure; we expect things to go a certain way and sometimes they don't. But we have to just be open, and embrace the way that things unfold, so that we can always be there for our patients and shift our care to really help them in the end.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as cancer, the care team, death and dying, gratitude, and relationships.

How does the experience of reading this story alter your feelings and influence your future behavior?

Clarice Maggio
October 1, 2020

They Taught Me How To Live

Hi, my name's Clarice Maggio. I've been a nurse at the University of Pennsylvania hospital for 38 years, currently working at the Abramson Cancer Center, and I'm very close to retiring.

There are many stories that I have. There's quite a few that affect your life and in some ways that can even change your life. Every day could turn out to be really serendipitous, or it could be really tragic. People always say to me, "How do you do that?" And you know, it's not always bad news. I've seen people who were literally being wheeled out to hospice who are golfing today because of the therapies and the relentless passion. And that's something that you can't find in a regular job, right? You can't reach in and put a string of lights on a computer, but you can reach in and put a string of lights on somebody's heart. It's an amazing feeling to be able to do that.

A few years ago there was a patient. She was, I think, at the time 27 years old and she was pregnant, and she was diagnosed with Hodgkin's lymphoma.

She was seen in an outside hospital, and they had said to her, "We have to start treating you. We have to terminate this pregnancy." And it was her first pregnancy, and you know you're young, you have cancer, and you're pregnant. So you go from this excitation to, "Oh my God, I might die!" They had set her up for therapeutic abortion. And she went ahead and scheduled that. And in the meantime, she went to have a second opinion at Penn.

The doctor set her down and said, "I have an idea. Why don't we hold off on your therapy, if you're willing to do this, and wait till it's safe to give you chemotherapy and possibly save both of you? You know, the baby and yourself." She said, "I like that option a lot better." When she came to us, we had to give her these chemotherapeutic agents that were really irritating and cause damage to your veins, so most of the time you need a central access. She made it very clear to me that what wasn't going to work for her was if she had to go through one more procedure, because she just couldn't handle it.

So my goal was to be able to do something I wasn't sure I could do. And I said, "Here's the deal. I don't know that I can get you through without a port, but we can certainly try." But it was six months of therapy. So every two weeks

I would soak her hand. She would have this one vein and this one vein only, and I would say, "Okay, this is it." I would kind of mentally get myself in a state.

"So my goal was to be able to do something I wasn't sure I could do."

The fact that she knew that somebody was willing to do that was one less thing that she had to worry about. But every two weeks, that day would be uncontrollable for me because, oh my God, her veins were horrible.

I can't even tell you what that last treatment was like. It was a tremendous relief for me, but nothing could compare to the joy when she brought her daughter in for us to see for the first time. A perfectly healthy baby girl. I could cry now thinking of it.

There are some patients that you just can't help. Sometimes they just don't make it. There was a patient, she was an artist, and on her bucket list was to see the Andy Warhol Museum in Pittsburgh. Two nurses and I bought her a ticket to Pittsburgh, and she wasn't well enough to go by herself. So we went with her. And we had a blockbuster weekend. I never knew a person who could just say, "Dr. Loren, just tell me how much longer do I have?" Dr. Loren said, "You know, Norma, I think you have about six months." Six months later, she emailed the doctor and said, "You know, I'm running out of shampoo. Should I just get a little bottle?" And the truth is, she lived for two years after that. My patients have taught me how to live. Even when they were dying. They taught me how to live.

The greatest lesson I learned was the importance of human kindness. It's sometimes the simplest gesture, a hot cup of tea, warm blanket holding someone's hand. All those are expressions of caring; they don't take a lot of effort, but they have a profound effect.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as community, death and dying, grief, and physician vulnerability.

How does the experience of reading this story alter your feelings and influence your future behavior?

Anish Agarwal, MD
November 9, 2020

We Run

My name is Anish Agarwal. I'm an Emergency Medicine physician here in West Philadelphia. I work at our trauma center at Penn Presbyterian Medical Center.

I have the honor to treat vulnerable populations and to see anyone who comes through our doors. The other day, another young man was brought into our emergency room. He represents, unfortunately, a very common thing. An epidemic of violence of young Black men being killed. A tragedy here in West Philadelphia.

We wish we had a chance to know him. We wish we could show his family that we did everything we could. We wish that they could see that we cared about him, and we still care for him.

I wish families could see all the things that we do. How we move, how we mobilize teams, and jump into action. In the emergency room, the nurses, the doctors, the unnamed army of people come to try to revive people. We struggle, because we don't know what happens outside of our doors. What we do know is when we get an alert that someone is coming in, we literally drop what we're doing, and we run to our trauma bay. There's probably twenty people that come together to form a team, laser focused on one person, one action. Attempting to save someone's life, to bring them back to life.

It's hard in the emergency room to really process things in the moment. I've struggled personally, and I struggled with my community to think about how in the ER we live in this very unique setting. An intersection of vulnerable people, societal changes and demands, mental health and violence. We see more violence every day.

In the ER, all we see are the people that come to us. It's been hard. I found myself grieving for someone that I cared for, for the first time. For so long, we've been siloed in terms of where healthcare providers are. There are few who can span both the clinical care and the advocacy within communities. I think part of the healing process for me has been thinking about how do I step out of the ER, but bring my clinical perspective to advocate for change?

This terrible situation and this terrible death, and here we are from the healthcare side and we can't talk to anyone. We sort of have to reach out and find one another. I was talking to one of the nurses the other day. For us to talk, it was a moment of connection we hadn't had, and now we do have. Here we are, feet apart in the ER, but we never connected about how we both are doing.

> "Here we are, feet apart in the ER, but we never connected about how we both are doing."

There have been countless young Black men who come in, and are shot, and are dead. And I've never had a colleague reach out to me ever. And I've never reached out to a colleague either. With the national attention, people are coming out of the woodwork to actually focus on it, and hopefully lift up that rug, where we all sweep under the emotions that we initially feel.

You know, I'm a father, and I have young children. And I can't imagine what his parents and his family are going through right now. I don't know that I've ever really grieved for someone I didn't really know, but someone who I was so intimately, at least for a short period of time, focused on saving.

I know my colleagues are grieving. I know West Philly is also grieving. I hope families know that when they bring people to us in the emergency room, we treat whoever is in front of us. Our doors are open, and they will always remain open to help protect and care for and provide support for whoever walks through our doors.

I hope that his family knows that we ran, and we will continue to run, not only for him and for them, but for everyone in our city.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as death and dying, listening, and spirituality.

How does the experience of reading this story alter your feelings and influence your future behavior?

Jason Han, MD
August 15, 2019

Will You Pray For Me

As a second year resident in the ICU, I came to encounter and care for one of the most memorable patients in my residency.

She was an elderly woman. Her terrible kidney disease and need for dialysis had irreparably laid waste to her coronary arteries. She was in shock, and she was just tenuously surviving on a device called an intra-aortic balloon pump. It was placed inside through an artery in her leg and working in synchrony with her heartbeat to reduce the strain on her heart.

She was a genuine woman who laughed loudly and often; we developed a rapport quickly. She was the first person I checked on every morning and the last person I said bye to every night. She was always surrounded by her loving family, telling jokes and recalling life stories late into the night. If you met her, you would never have guessed she was one of the sickest patients in the entire unit.

Days dragged by before anyone discussed her prognosis; it was apparent to all of us that she was rapidly approaching the end of her life. We asked her how did she envision this chapter? She confided that being on this device was not the way that she wanted to spend her final days.

Her room was never silent; the pump was audibly laboring day and night. Because it was placed in her leg, it prevented her from sitting up, eating her favorite foods, and holding her loved ones. She wanted it out.

The team acknowledged her wishes but said to her solemnly, we want you to understand if the pump comes out, there is a not so small chance that your heart could arrest. She remained silent for a moment, then nodded. She was willing to take her chances.

After avoiding her room for hours I final mustered enough resolve to walk into her room. She greeted me with her usual smile. As I laid out the supplies, I explained to her exactly what I would do. It helped calm my nerves, as much as it did hers. And finally when I told her I was ready, she remained silent. I looked up to find her in tears. So I held her hand, and with the other, I grabbed her hand as she reached up and gently placed it on my face. She said to me in that moment, "I'm so scared, Jason, I'm so scared." I told her it was okay to be scared. She nodded and closed her eyes.

For the first time in days, there was silence in the room. The drumming sound of the balloon pump had stopped. I held firm pressure where it had exited her body to stop the bleeding. I told her I would need to do so for an hour.

> "She said to me in that moment 'I'm so scared, Jason, I'm so scared.' I told her it was okay to be scared. She nodded and closed her eyes."

The initial moments were filled with a palpable apprehension of what I feared would be imminent death. I was terrified she would pass away right before my eyes, from the very action I had just performed. Her heart would now have to pick up the extra work. We remained motionless for the first ten minutes.

Then suddenly, the heavy air was pierced by a beautiful, transcendent melody. Her two sisters had begun to play gospel songs from their phones, the ones they had grown up listening to and singing. Immediately, the tense lines began to fade away from her face, and her entire body relaxed. She began to sing, at first quietly, but more passionately with each passing minute. Her two sisters joined in, surrounding us in their warm voices. They looked at each other and laughed. We listened to more than ten songs together that afternoon. She sang as many words as she could remember in joy, without chest pain, shortness of breath, arrhythmia, or death.

As we neared the end of the hour, they stopped singing and began to pray out loud. They prayed for her heart. They prayed for her soul. They prayed for those whom she had touched with her presence during her life and those who had touched her. They prayed for her doctors and nurses. They prayed for my hands that were controlling her bleeding.

In more ways than physically I felt connected to her that spiritual afternoon. For the first time in my life, I, too, closed my eyes and prayed for her to thrive and to be at peace for the remainder of her life. Then I gently lifted my hands from her leg, which was now dry and placed a clean dressing, signifying a closure to what had been a heavy, yet heartfelt hour. She left the ICU a few days later. And the following day, she passed away.

Listen online at pennlisteninglab.org/stories/

This story explores themes such as the care team, listening, relationships, and speaking up.

How does the experience of reading this story alter your feelings and influence your future behavior?

Andrew Quigley
August 14, 2019

Softening

Usually with my particular position, we're more along the lines of the front lines. We're the people that patients will call in, and we'll be the first person to talk to. A lot of times, patients will call us, and they'll be dealing with a lot. They'll be dealing with circumstances with the medical issue that they're having; they may have circumstances going on with their family or with their jobs—and it can be stressful sometimes, but it also allows us access to really be with the person and actually listen to that.

There was one woman that called me last week, I want to say. She started talking about a lot of different complaints, a lot of complaining with how she wasn't getting adequate care, a lot of complaining with the issue that she had which was a right-foot injury. Just kept on going and going, and most people would generally get very annoyed at that, but I actually listened intently to make sure I didn't miss anything.

At the end of what she was saying, she had this emotion of desperation, almost like she was trapped, and she couldn't find a way out. She said, "I just want my foot to be better." I sat with it for a second. And I said the first thing that came to my mind, that was, "We want you to be able to be better, too; we want you to be able to walk, too."

> "She was someone that really just needed a person to hear what she was going through."

In that instance, there was a real connection of vulnerability, almost like we touched our own humanity in a sense. After she said that, and I said that, she softened a little bit and started talking to me a little bit more. She was someone that really just needed a person to hear what she was going through.

Working here allows me the opportunity to be with people one-on-one, no matter the circumstance, no matter what they're dealing with, to just be able to listen to them, and to just be able to connect with them in a way that most of us don't connect with our own people in our life.

Discussion Guide & Storyteller Reflections

It's difficult to be present and meaningfully listen in a digital age. Being present means slowing down and acknowledging the moment. This enables us to be touched by the stories we receive and share. Feeling a sense of connection also encourages people to take action for their health and the health of others.

We have developed this discussion guide to facilitate conversation with colleagues, friends, and family about the stories featured in the Penn Medicine Listening Lab. The guide has been designed to affirm your desire to listen intentionally and help us better care for one another.

We offer the following suggestions for hosting or facilitating conversation:

1. Begin your session by creating a safe space for listening and sharing. Establish ground rules. Skilled facilitators are available should you need support. Let everyone know that participation is voluntary, and participants are welcome to leave the room at any time.

2. The stories featured in the Listening Lab aspire to uplift and empower. They also describe experiences of trauma and suffering that may cause discomfort or vulnerability. Be mindful, and share resources on our website with those needing support.

3. The stories are intimate and powerful, and can be transformative for those who hear them. After sharing the story, allow for silence. This enables individuals time to reflect, make connections to their own lives, and emotionally prepare to share.

4. Provide participants with space to respond by asking open-ended questions, such as the following: "Can you share your reflections about the story you recently heard and how it made you feel?" "How does listening to this story help you reflect on your relationships and how you communicate with others?" Perspectives may form by listening to the responses of others.

5. Share why you selected this story and what resonated. Be thoughtful and restrained in sharing your perspectives, so as not to overdetermine the conversation.

6. In closing, acknowledge the impact of the story. Express gratitude for those who have shared and the healing that may have occurred.

Many of our storytellers have been impacted by the experience of sharing a story. Read their reflections below:

"In many ways, I look at the Listening Lab as an antidote to the culture that we've created in medicine. Having gone through it, I feel more confident about being able to share vulnerabilities with my colleagues. More and more my colleagues are comfortable coming to me with their personal stories."
— Jason Han, MD

"There's a real value to storytelling. It's not something that we're used to doing as a clinical team to people outside of the clinical team. The experience of working with you, it helped me a lot. It helped me grow as a clinician. It cracked something open in my heart."
— Julia Schott, MSS, LCSW

"I feel proud that I could share a story like that, and people were so willing to listen. And that people want to hear what we do. I'm just grateful."
— Mary Evers, LCSW

"People have been still to this day emailing me and calling me, telling me that that they heard my story. For me, this whole process has been cathartic and positive. For most of my family, you know, it made them proud that I was able to share my vulnerability. My chairwoman sent me a text and said she's proud for me to be her colleague. That meant the world to me."

— Mathew Beshara, MD

"In sort of the landscape of navigating a chronic illness, it's an opportunity to shed light on a more kind of nuanced encounter that may not have been, at face value, incredibly meaningful, but with time, and then reflection, you realize 'Oh that was actually a pivotal moment for me—just a moment of extreme care given to me by somebody else.'"

— Lyndsay Hoy, MD

"The benefit I got out of listening to others' stories was incredible, and especially during these challenging times. It's such a great platform. It really is. Listening is something that we rarely find time to do. We're kind of running around through life, and it's something that I will cherish at the end of my career. And I can tell you that for certain."

— Clarice Maggio, RN

"This should be a mandatory part of medicine. Healthcare is how we treat each other."

— Alan Stein, MD, PhD, and patient

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Penn Medicine

Storytelling | Narrative Medicine | Organizational Transformation

As a gathering place for stories from across Penn Medicine, the Listening Lab affirms and celebrates listening as essential to the work of healing. This book is a compilation of stories recorded for the Listening Lab by patients, caregivers, staff, and providers at the front lines of caregiving. These stories have the capacity to change how we address some of healthcare's most pressing challenges around communication and connection. The simple act of listening has the potential to heal broken places within us and offers a radical possibility for healing to occur within healthcare and society as a whole.

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