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# DisABILITYissues

*Providing people with disabilities, their families, friends, and advocates with relevant information that enables individuals to improve the quality of their life, health and employability options.*

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## TABLE OF CONTENTS

**From the Editor...** | Marianne DiBlasi

**Adaptive Yoga** | Sandy Alissa Novack

**Formerly Clueless: A Personal disAbility Saga** | Raymond E. Glazier

**Walter's Place: Tragedy and Triumph: A Family's Disability Saga** | Joan Burrows

**Love & Intimacy Corner: Father-Daughter Love** | Ms. Love

**The PCA Corner:** *For PCA Surrogates* | Raymond E. Glazier

**The Bookshelf:** *Compassionomics* | Mary Grimley-Mason

**Information Briefs:**

- Changes for Uber and Lyft Rides at Logan Airport
- 15th Annual "Focus" on Vision Impairment & Blindness Conference



## *From the Editor....*

Dear Readers,

In this issue, we bring you a variety of articles with personal stories of triumph and tragedy that capture the reality of living with a disability. Constantly negotiating life with places that are inaccessible, people who don't always "get it" and broken systems can take its toll on a person's mental and physical health. While reading and editing these articles, I noticed a pattern – purpose, meaning and kindness fosters greater resilience to move through life challenges. I acknowledge this is easy to say and much harder to live, as I'm once again experiencing.

My dream was to become a parish minister, so I enrolled in graduate school to obtain a Master of Divinity degree and serve as the minister of a Unitarian Universalist congregation. I'm currently doing a two-year ministerial internship at a congregation. This internship has brought me face-to-face with the realities of living with a disability in ways I didn't expect. Partly because, although most churches are accessible for congregants, the pulpit is rarely accessible for ministers. And, partly because as I get older, I'm experiencing more mobility challenges. I am continually learning how to adapt and do things differently, or sometimes, admit that I can no longer do what I used to – including some aspects of being a parish minister. It's hard, it's frustrating, and it's depressing. It means I am in one of those transitional places where I'm wondering how to serve as a minister, while also accepting the realities of living with a disability.

Purpose, meaning and kindness are helping to guide me toward a different expression of ministry. Instead of parish ministry, I'm considering being a spiritual care chaplain at either a hospital or long-term care facility; which are often fully accessible. They are also places where living with a disability and

knowing the fear and grief related to aging, illness or injury can be of service to others. It's a place where having a visible physical disability and using mobility assistance devices is actually a benefit. When a patient sees me walk through the door, they assume I have experienced suffering and loss, thus enabling me to relate to what they are experiencing. As one patient told me, my disability gives me instant credibility and helps to quickly establish trust. Then, I have to deserve that trust by engaging with kindness and wisdom.

To support my mental health and increased capacity for compassionate presence, I meditate daily using guided meditations by Adyashanti, a Zen Buddhist. Whether its meditation, adaptive yoga, daily contemplation or something else, the benefits of engaging in a practice that supports emotional, spiritual and physical well-being is a kindness you offer yourself first, and then others.

Marianne DiBlasi, Editor



Marianne DiBlasi has been the editor of *Disability Issues* since 2011. She was born with Spina Bifida and uses a combination of crutches and wheelchair to assist with mobility. Her background is in sales & marketing and disability inclusion training. Currently, she is attending Meadville-Lombard Theological School and is working towards a Master of Divinity degree.

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## Adaptive Yoga

(Part 1 of 2)

By *Sandy Alissa Novack*

Sara Kochanowski brought adaptive yoga to Boston Center for Independent Living (BCIL) a couple of years ago. She is a certified yoga instructor who has had ongoing health spine-related issues for the past 20 years. Originally trained in many forms of yoga, with her spine situation Sara needed to practice a more slow and contemplative yoga.

At one point, she volunteered with the **Hands to Heart Center** in Boston. They

provide yoga to under-served populations, including people who are incarcerated, homeless, and children in school. She was asked to teach yoga at a middle school in Boston. She arrived and quickly noticed half the children used assistive devices for mobility challenges. She wondered how she was going to teach these children how to do yoga. One child in particular showed her how she must teach: The child had limited ability to move her limbs and used a power wheelchair. Sara had to think about what the common denominator was – the essence of yoga practice – for this child and, therefore, everyone else.

Sara started teaching what she calls “inside the pose.” For example, the **Tree Pose** requires getting grounded by balancing on one foot with the other foot raised to the inside of the first leg; arms are raised up with extended awareness of the position. She explains, *“The experience of the pose is to sense where you are in space, to feel like you are growing roots into the floor. The cue ‘feeling grounded’ does not make sense, we do not grow roots, we are human beings, but the interconnectedness is that we can all feel grounding, expansion, balance, and rhythm. When you are more grounded with arms up, you are expanding upwards. Balance does not mean we can stand on one foot. Adaptive yoga is taking yoga to the essential practice of connecting to the world around us. Adaptive yoga does NOT mean inactive. It is trying to find the part we can do that we maybe did not know we could do. A tree moves in the wind, so you have to be balanced to stay up. The little girl was so happy, and the feedback from all the children at the middle school was that they wanted more of this sort of yoga.”*

Sara began reading about the creator of adaptive yoga, Matthew Sanford, and his programs in Minnesota. She eventually went out there to train with him in adaptive yoga. The fundamental rule and goal of adaptive yoga is to trust your body, explains Sara. By listening to your body, not your teacher, you discover the benefit. For example, with Sara's spine issue she has a neurological deficit. Despite this deficit, she can still experience a different kind of connection to her body. She asked herself, *“What if I try to feel into the place that I was told I cannot feel? Maybe it will be another kind of sensation.”*

Another example Sara provides is of Matthew Sanford himself. Matthew was paralyzed from the chest down at the age of 13 following a car accident. He was told by his medical providers not to expect anything from his lower body.

But, with adaptive yoga, there can be subtle shifts. Despite Mr. Sanford's paralysis, he could still experience a subtle energy or prana by *receiving* the yoga pose and listening to his body. The motivation with yoga is a different paradigm from physical therapy and other medical treatments.

Sara describes adaptive yoga: *"Yoga is kind of like learning to play an instrument: No one sounds great the first time they pick up an instrument. It takes practice. You can start with just five minutes rather than a whole hour class. Whatever resonates in you during your class, come back and practice that again. You can also do everything laying down, if that is the best situation for you. Do not expect your practice of yoga to be like what other people are doing. More important is your experience of a pose."*



Dan Harris and Sara Kochanowski

Sara says her body "locked up" after she had surgery and she asked medical providers what to do; she did not trust herself after surgery. Later, she asked herself what did she need to bring to the table to help herself? She began

listening to her body and trusting herself, including the little day-to-day issues, like knowing when she needed to wear her neck collar to support her well-being.

I asked Sara, what someone who can't move much can do? *"We don't have to move to feel the expansion, grounding and balance of yoga,"* Sara replied. *"You do not have to move to change your energy. Yoga is going from the smallest cell of us to connecting to the whole universe. And you do not have to move to do this. Let's go back to the Tree Pose exercise: Take a moment to connect to your body. Does your skin feel cool or warm? Ground yourself and drop down into your awareness. But there is also awareness up. Grounding and expansion are part of the same coin."*

I asked if adaptive yoga could be beneficial for *Disability Issues* readers who have a mental health condition. Sara is trained in trauma-informed yoga and said, *"It is about letting yourself do what your body needs. If a yoga student can't sit still, then don't. You can stand and be grounded; you do not have to sit. You can share with the yoga teacher what you want to share. You do not have to tell the teacher you have anxiety, but the teacher could help you with a variation that might work with your anxiety. Sometimes adaptive yoga is done in a circle so there is a sense of community among attendees. There are also props available to help people feel the adaptive adjustments. But you do not have to stay or sit still if you, for example, feel too angry, and you can leave class if you're not having a good day."*





Kaitlyn Coppola

At the end of each class, there is an exercise to mark the ending. There are eye pillows, and people can put their feet up. This is often the scariest pose for someone who can't relax or sit still. *“Building awareness when you do not want to close your eyes; giving yourself the opportunity to feel what is going on and experience the freedom to do what your body is telling you to do is an important part of yoga. People expect adaptive yoga is not going to be challenging, but it is, and you have to have space to feel what your body's reality is. We are a goal-oriented society, and there are not many places we can go to slow down, and feel our bodies soften.”*

BCILs adaptive yoga classes are offered Tuesdays, 2 – 3pm. \$5.00 donation to BCIL per class recommended. RSVP appreciated but not required. To RSVP and for more information, contact Shaya French at BCIL: 617-338-6665 or [sfrench@bostoncil.org](mailto:sfrench@bostoncil.org)

### **Sara's suggested adaptive yoga tips and resources:**

#### **Matthew Sanford:**

<https://www.mindbodysolutions.org/about/matthew-sanford/>

Includes resources in different states.

#### **Online Adaptive Yoga Class:** taught by Mathew Sanford:

<https://www.youtube.com/watch?v=LWc1XuKyDD8>

**Mindful Yoga for All Abilities at Spaulding in Medford:** Six-Week class geared toward those with injuries or health conditions. January 20 - February 24, \$60 for all 6 classes. No experience necessary. Contact: Rick Frank, OT, Registered Yoga Teacher at [rfrank@partners.org](mailto:rfrank@partners.org) or 857-238-4942.

**Love Your Brain:** yoga and meditation for people with brain injuries: <https://www.loveyourbrain.com/yoga>

VA hospitals, community organizations and nonprofits offer adaptive yoga; regular yoga studios usually do not. Classes for people with autism or who use wheelchairs are becoming more available.



*Sandy Alissa Novack, MBA, LICSW, ACSW, CSW-G is a social worker, and a consumer advisor on the Beth Israel Deaconess Medical Center's Universal Access Advisory Council.*



# Formerly Clueless: A Personal disAbility Saga

*By Raymond E. Glazier*

As a small boy I joined my buddies in taunting Charlie, the neighborhood cripple (as we called him then) in that cruel way little boys go after the vulnerable, the different. Charlie was an adult with lumbering gait who rode a giant, custom-made tricycle because his balance was off. I now realize he must have had cerebral palsy. Later in life, I regretted that cruelty. Charlie apparently kept track of me, even after we had moved to a nearby town when I was seven years old; he hadn't forgotten but he had forgiven. Many years later Charlie, smiling, shakes my hand in the receiving line at the open wedding reception in my Ohio hometown after my marriage to a Harvard University classmate.

During my early twenties I took glory in being 'severely able-bodied,' cutting a striking figure at the office in my bell bottom three-piece business suits, dancing a limbo twist with wild abandon at Saturday night parties. A new national magazine for yuppies was preparing a story on me as an attractive young man in an exciting new career: The research start-up I joined after college was training me as a simulation and games designer, working on political simulations for the Pentagon and social studies games for elementary classrooms – heady stuff for a twenty-something.

Four years later, on February 17th, my wife Martha and I are driving from our Cambridge, MA home to Ohio for a final visit with my dying grandmother, who has only days to live. I am driving cautiously on the Massachusetts Turnpike in a sudden, blinding snowstorm. Two cars ahead are backing up in parallel toward the exit. By the time I see their backup lights, I cannot brake hard enough. A collision like the end of the world occurs.

My chin hits the steering wheel. Because my jaw doesn't break, the impact is transferred to my skull behind my right ear. The skull fractured, but I am unaware of that. I am ambulatory, but in shock. Some 45 minutes later I stagger into the hospital ER where the State Police have taken me. I climb onto a gurney to be examined. The doctor turns to a nurse, "Sister, bring a suture kit."

He is going to sew up the gap below my lower lip, where my bottom teeth have come through. He has a kind face. The lights go out.

I am unconscious with an inter-cranial bleed. A neurosurgeon is summoned from a nearby hospital. Emergency brain surgery. The bleeding artery is cauterized, permanently cutting off the blood supply to the motor tracks that control the left side of my body. When I awake a month later, I am in an ambulance that is transferring me to a Boston hospital for 7 months of recuperation and rehabilitation. Another consequence of the brain injury is a frustrating speech impairment; only my wife can understand my attempts to speak. Most questions to hospital staff or communications with fellow patients must wait till late afternoon for translation during Martha's daily visits.

It is apparent that after my discharge from the hospital I cannot return to the third floor walk-up apartment we had lovingly furnished with antiques. Martha signs a lease for a first floor place in the neighborhood, but the resident landlord tears it up when I arrive in my wheelchair to check it out ahead of our move; he doesn't want a cripple in his house. After being discharged from the hospital and moving to a different first floor flat, I return to work in a manual wheelchair, with a full-time aide and translator. Luckily, the little company's founder and CEO has a very progressive mindset and is willing to take a chance that a brain-damaged employee can still cut it in this high-pressure work environment. I don't know either whether I can handle it, but I have hospital bills to pay. The company's new office building has a level entrance and my office is on the first floor, although the men's room door is too narrow for a wheelchair.

My wife / sole caregiver and I engage in a *folie à deux* that surely this situation cannot be permanent. But we slowly realize that I will never walk again. My world has begun to collapse inward. A deep organic depression sets in, blurring even the joy of a son's birth two years later. Suicide attempts. My wife cannot take the constant depression, the efforts at deserting her, as she sees it. She leaves after the almost successful final suicide attempt that puts me into a 3-day coma, followed by months in a psych. ward.

Meanwhile, the lawsuit against the two idiots who were backing up on the Mass. Pike in a snowstorm four years before finally comes to court. The out-of-court settlement nets me enough for down payment on a house – good,

because my Cambridge landlady is evicting me for trying to commit suicide in her house. I end up buying a two-story side-entrance colonial that it is only one mile from my office so I can drive to work in my power wheelchair on the sidewalk in good weather. I will sleep in the downstairs den and hire caregivers who can live on the second floor. My work propels me past recurring suicidal thoughts.

In my new life, I find myself part of an innovative trend: persons with disabilities living in the community, independent of families and institutions. I begin to make friends with others like me and become involved in disability activism. Having overcome years of ambivalence about identifying with other persons with disabilities, I am chosen to direct coordination of the National ADA Technical Assistance Initiative in the wake of President H. W. Bush's signing of the landmark Americans with Disabilities Act of 1990. For the first time I am working alongside talented, knowledgeable people with all sorts of disabilities. They are so cool, each with an amazing life story and a different struggle – blindness, paralysis, deafness, depression, amputation, chronic illness, bipolarity. Among the accomplishments in Year One of the project; establishing the toll-free line 1-800-949-4ADA that still automatically routes callers, based on their area code, to the appropriate Regional ADA Center for information, guidance, and training.

The founder and president of the small company where I worked, had promised to make me a vice president if only I could rehabilitate myself to the point where I could speak clearly enough to give public addresses and walk well enough to travel the country. It was a well-intentioned motivational carrot, as if I needed one. In my new position I travel the country relying on assistance the airlines are now required to provide, and helped by locally recruited on-site caregivers and speaking at conferences via hotel PA systems. Disability-related government contracts are awarded the company through my efforts. I earn a doctorate in social policy at nearby Brandeis University. The promised promotion never happens.



I retire after an unprecedented 47 years with the international research organization that has grown from the little consulting start-up I joined after college. My rancor at those two idiot drivers has faded. More time now for basking in the sun, for rolling around the park across from my home. A neighbor kid smiles and waves at the white-haired codger rolling down the street in his bright blue power wheelchair. How far we have come, Charlie, how far. But not enough. Now, at last, I get it.



*Raymond E. Glazier, Ph.D. is founder and Principal of disAbility Research Associates in Belmont, MA and a designated member of the MA Architectural Access Board.*





*An ongoing series of articles about Walter Kiver who lived with Muscular Dystrophy (MD); as did his son, daughter, and grandson. Articles are written by Joan Burrows, Walter's wife, in memory of her beloved husband who passed away in 2001, to honor his legacy of living life fully and helping others while facing his own challenges.*

## **Tragedy and Triumph: A Family's Disability Saga**

*By Joan Burrows*

Dealing with personal feelings in a family where every member has a disability is a real challenge. Walter's family dealt with Facioscapulohumeral Muscular Dystrophy – his son, daughter, and grandson. Each one dealt in their own way; there are both similarities and differences.

Their personalities differed, but Walter's choices had a big impact on the others. There were other issues, such as having someone to be there for them – not only personal care people – but a person to share love with. As I met Walter later in his life, some stories have been related to me through him and his daughter and his grandson. It was not something any one of them liked to discuss, so I am putting together what I heard and saw and remembered.

I'll begin by telling you briefly about Walter. For 15+ years Walter used a respirator, a feeding tube, dealt with two broken legs, and had several minor surgeries. With these challenges, he became a Community Access Monitor with the state, co-founded the Acton Commission on Disability with me and chaired the group for over seven years. He graduated from Jr. College with high honors and a degree in Social Work. He spoke to school children, raced with them, and let them into his van. He took two trips to Cape Cod, one to Washington, DC, and NYC, where he took in all the sites, including the Art Museum (his first love), and enjoyed horse races in NH as often as possible.

All this was not easy with an electric



wheelchair and a respirator, then later a feeding tube. We had to pack a lot of machines and supplies. He did it because he loved life and wanted to make the most of his... and he did! Walter accomplished everything he could and in doing so, he helped others. In the early days of our relationship, Walter asked me why I wanted to be with him. He was only thinking about his dystrophy instead of the wonderful person he was. Walter died of kidney failure at age 73 ½ years old.

Walter's son, Dennis, was a double major in college. For many years, he provided personal care for his dad. Then, Dennis moved in with his long-time girlfriend. He lived close by and visited his dad, sister, and nephew often. One day, he had trouble lifting up his motorcycle and he knew his body was experiencing dystrophy, like his dad. Soon after, a "friend" called him to say his girlfriend was sleeping with someone else.



Shortly afterwards, Dennis chose to die by suicide in his car. I used to wonder if he had only held on a little longer, he would have seen his dad's life change for the better. But his note said he could not live without his girlfriend, so it's hard to tell how much of his decision was about the dystrophy and how much was about his girlfriend.

Walter's daughter, Marcia, left her abusive husband and took her son with her. After Dennis moved in with his girlfriend, she took over her dad's care. She was a strong person. Walter once told me, "She ran the house at age two!" I believe she was diagnosed with Dystrophy after the birth of her son, at age 20, and she was told

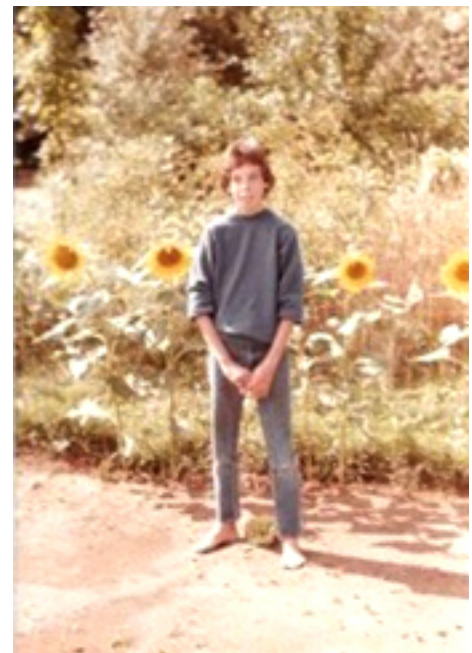


that her son had the same illness. Sometime later, she also learned her son was deaf and had a low IQ.

As a single parent, she fought for her son every day, while also caring for her bed-ridden dad. There was no family counseling and little outside help. Marcia and Walter had many emotional yelling events (probably more than I witnessed), each one ending with Marcia screaming, “It is your fault I am like this!”

After Walter moved in with me, Marcia and Walter’s relationship improved dramatically. Marcia realized I loved her dad and would not leave him. She also had less work and worry. Doing her dad’s care was hard for her, while also dealing with Dystrophy herself and caring for her son.

Walter’s grandson, Justin, was 12 years old when I met him. He had hearing aids and his gait was off because of the Dystrophy. He had trouble in school, but in his bedroom, he had many toys and art supplies (his favorite). One day, Justin said he wanted to plant a garden in their large backyard, so I took him to the garden center. Justin spent a lot of time carefully looking over all the seeds packets. He chose several, which was a lot to plant, but he wanted them all. It was hard for me to watch this slim, not physically strong boy work the soil in the back yard. I offered to help but he refused. (Stubbornness ran in this family and probably helped them get through a lot!) All his hard work paid off. His sunflowers were beautiful. We ate a lot of zucchini and other vegetables that summer!



I do not recall any discussions about Muscular Dystrophy with the family other than what I have written here. It was not a subject anyone wanted to discuss... too much pain, I imagine.

Marica had some relationships after her divorce, but at the time when her BiPAP machine was no longer working and she was too tired to work, she decided not to go on a respirator. She once told me if she had a relationship like her dad and I had, she would use the respirator. We talked a bit, but knowing her as I did, there was no changing her mind. Her dad was in a coma at home and I could not offer her much help. She died three weeks before her dad in 2001, with myself and her best friend by her side at the hospital.

Justin told me many times how great it was that his Grandfather had a better life with the respirator, and he would use one when it came time. But he did not. He had some relationships, but when his breathing was getting harder and his BiPAP was no longer helping, he chose to die. Justin had once told me he would never choose suicide after experiencing the pain of his Uncle Dennis's death. Yet he did. He was just short of his 37th birthday. I asked him what he wanted for a present and, as usual, he asked for a gift for his beloved cats. Cats and dogs were a part of all three members of the Kiver family. The wonder of pets to love, and who love us unconditionally!



*Joan Burrows studied music in NYC and later taught piano. She was a nursery school owner, teacher, and music director. Joan began the Acton Commission on Disability with Walter Kiver. She is a caregiver for people with disabilities and seniors.*







## Father-Daughter Love

*By Ms. Love*



My father was ahead of his time. He demonstrated inclusive behavior before most people probably knew the term “inclusive.” I grew up watching him go the extra mile to have relatives in wheelchairs, inaccessible housing, hospitals, and nursing homes be included as much as possible in family life. He also included roommates and others on the floor we met in our relatives' hospitals and nursing homes in conversations. Sometimes we made long visits to these people in addition to the time we spent with relatives.

There was a family picture of me at two months of age being held up to the window of a nursing home so an elderly relative could see me, the family's youngest, in the days when nursing homes did not allow babies to enter. I believe my father wanted the elder to meet me and be able to welcome me into the family. I believe he wanted to instill in me a lifetime of connection and respect for people who are frail or have disabilities.

A memory of my dad that I think about often dates back to when I was in college and having pain in my lower arms. I had an appointment to be evaluated by a hometown doctor. I was to take a bus into my hometown's bus terminal, where my dad would meet me and take me to stay with my parents

until my medical evaluation the next day.

It was late in the evening when my bus pulled into town and my dad asked if I had eaten anything before my trip. No, I hadn't. He said he had already eaten dinner with my mom, so he suggested we stop at Friendly's so I could have late dinner, while he had an ice cream to keep me company. I managed fine eating a Friendly's fish fillet sandwich, because I could hold it in both hands. My father was surprised I didn't order a hot fudge sundae, an opportunity I never passed up.

“You sure you don't want one?” he asked. “No, I'm fine with just the sandwich.”

Five seconds passed. “Since when do you ever turn down an opportunity to have a hot fudge sundae with chocolate ice cream?” he wanted to know.

I leaned across the booth we were sitting at and whispered, “I can't hold the spoon.”

Another few seconds passed, and he said, “Order the sundae.”

The sundae arrived with a lucky two cherries on top, and I immediately moved my dish closer to my father so he could spoon off one of the cherries; we had been sharing sundae cherries with each other for years. I brought the dish back to position in front of me and tried to get a grip on the spoon to eat it. I tried multiple times, just like I had been trying for weeks back at college to hold utensils. This time, I didn't dwell on my inability to hold the spoon because my dad reached across the table to take it from me. He dipped it into the ice cream, then the hot fudge and moved a spoonful to my mouth. Then another mouthful. And another. Soon I had eaten the whole sundae. And, dear readers, it was delicious.

I felt self-conscious of my father feeding me in public, but my dad did not seem at all concerned if anyone in the restaurant was watching him feed his adult daughter who could not hold a spoon. He himself acted like it was perfectly normal to help his daughter eat when he saw my hands were in too much pain for me to hold a spoon myself.

To this day, when people belittle me if I can't do something because of a health

issue or disability, I think of my dad and I at Friendly's that night many years ago. It isn't acceptable to belittle someone for having an illness or a disability; I can't do what I can't do and belittling me isn't going to make a difference; it won't make me suddenly able to do what I am not able to do. Instead, it's more beneficial, and kinder, to roll up your sleeves and problem solve, like my dad did.

I also learned what an intimate thing it is to be literally fed by another. Sometimes, in the years since the Friendly's experience, friends who have a temporary or more permanent illness have struggled to want to eat or to physically handle the eating process. Our relationship has only deepened when I helped them to eat, just like my dad helped me that day long ago. I have learned the cadence of their chewing; whether they eat quickly or slowly, inhale their food or seem like they chew each morsel hundreds of times. I have learned whether they prefer mingling their green vegetables with their potatoes and if they need to sip their beverage after each mouthful or they don't drink anything until having tea with dessert.

I see their face light up when I'm feeding them a special treat I brought – a bowl of berries, a muffin, a piece of chocolate. Sometimes all a person may have to look forward to is the food they eat, and hopefully, someone to eat with them. We get to laugh together, cry together, maybe listen to music together while eating and, most importantly, to have a dining companion.

It was a simple father-daughter interaction at a Friendly's many moons ago, but I have relished the figurative taste in my mouth from the experience ever since, and I want to pass it on to others. But it really wasn't a simple interaction. If I had been out with someone else, maybe that person wouldn't have felt comfortable feeding an adult or maybe they wouldn't have thought of a creative way to let me enjoy the sundae. Isn't it interesting how sometimes the supposed smallest things we do can make the biggest differences to others?



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*The Love and Intimacy Corner welcomes questions and requests for topic areas from readers. Please send all comments, questions and suggestions to Ms. Love at [DI.LoveandIntimacy@gmail.com](mailto:DI.LoveandIntimacy@gmail.com) Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy, and may be edited.*

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# **The PCA CORNER**

## **For PCA Surrogates**

*By Raymond E. Glazier*

After learning that 70 percent of the consumers in the MassHealth PCA Program use surrogates, we realized that PCA Corner has not in the past always provided information useful to surrogates. We have focused primarily on the minority of consumers who directly manage their own PCA services. However, many of the tens of thousands of PCA Program users are persons with intellectual disabilities, underage children, or frail elderly (one in four consumers are over 65) for whom services management is a burden they cannot shoulder alone. Surrogates can help with, or assume full responsibility for PCA recruitment, interviews, hiring/firing, training, supervision, and review/approval of expended hours. For this article we

share some imagined, true to life examples of predicaments surrogates may encounter.

*“My daughter’s new PCA is working out splendidly despite not being literate in English. This after much searching and unsatisfactory hires. However, I recently realized that Mary’s medications are not being correctly provided to her. How can I convince Eva that all little white pills are not the same?”*

You cannot teach Eva to read overnight, so a workaround is called for. A suggestion: You could label each medication bottle with a different bright-colored label, then prepare a daily meds list with times, med color, and number of pills to be administered. (For liquid meds, be sure to indicate quantities in milliliters, as only the U.S. still uses non-metric measures.)

*“Today I made an unannounced visit to my nephew’s apartment and was shocked to find his PCA performing an intimate act that is definitely not in his service plan. Billie, grinning from ear to ear, was certainly not an unwilling participant. Even though he is physically adult, Bill is not capable of consent to sex. I am of a liberal mindset when it comes to such things, but... I’m somewhat uncomfortable with this. What to do?”*

Firstly, it should be made clear that in this circumstance the PCA should be the ‘adult in the room,’ even if it was Bill who initiated the encounter. Secondly, both the PCA and Bill, to the limit of his comprehension need to understand that sex has no place in the dynamic of this relationship and is destructive of it. Thirdly, let them know that random unannounced visits will be the new norm. Lastly, testing for STDs (including the insidious Hepatitis C) should be performed on both parties.

*“My husband’s mild dementia seems to be affecting his judgment about his PCAs’ performance. I can’t be home all the time now that I’m the family breadwinner (even though I work a lot from home). I was lucky enough to find two PCAs with excellent references to take turns sharing the afternoons when I can’t be home. When I return, I always ask Harold how things went. I won’t name names, but he always praises Person A, who strikes me as sloppy and disorganized, voicing some (relatively minor) dissatisfaction with Person B, who is very efficient and energetic. I want Harold’s care to be optimal. However,*

*given our finances and the limited number of approved hours from the PCA Program, it looks like I will only be able to keep on one of the two individuals. But how to choose?"*

Maybe Harold sees qualities in A that are not apparent to you and conversely for B; after all, he spends the most time with them, dementia aside. Perhaps you should defer to him in making this decision, unless you feel that A's job performance poses a serious risk to Harold's health, safety or general wellbeing.



*Raymond E. Glazier, Ph.D., has decades of personal and professional experience with PCA issues both as consumer and researcher. He is the founder and principal of disAbility Research Associates, Belmont, MA. Please email questions or suggestions for future columns at [raymondglazier@gmail.com](mailto:raymondglazier@gmail.com)*

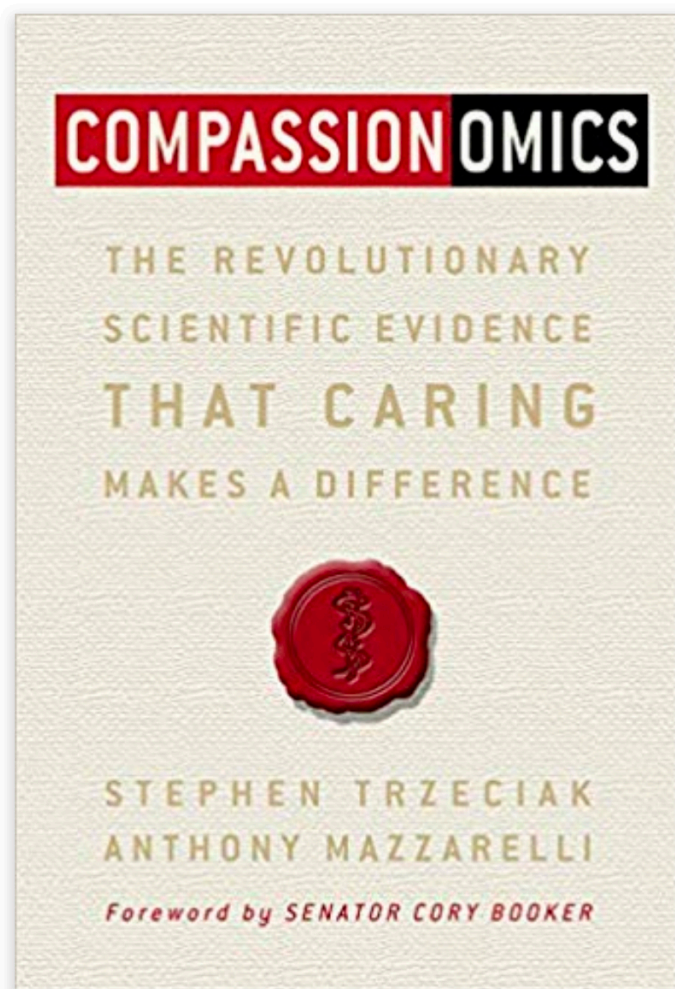


## **The Bookshelf**

**Book Review: *Compassionomics:  
The Revolutionary Scientific Evidence  
That Caring Makes A Difference***

*By Mary Grimley-Mason*

This book came about when two doctors, Stephen Trzekiak, MD, MPH



and Anthony Mazzealli, MD, JD, MBE, who were colleagues and had experience in scientific research, found they both felt that American healthcare was in a crisis because of a lack of care and compassion. Developing a hypothesis that caring and compassion improves outcomes for patients, they spent two years in a review of biomedical literature, gathering and synthesizing the data from more than 1000 scientific abstracts and more than 200 original science papers. They concluded that their hypothesis was correct...

**compassion matters.**

*“Compassion is defined as the emotional response to another’s pain or suffering, involving an authentic desire to help.”* This definition, given at the beginning of the book, helps to clarify the authors’ scope of reference. Using a narrative style, that often combines patients’ stories with the hard data of percentages and graphs, the authors provide a persuasive argument that compassion matters for patients, for patient care, and for those who care for patients.

The underlying assumption throughout the book is that the role of the physician or caregiver is not just a job but also a vocation. However, the authors acknowledge that for a number of reasons, there is a considerable amount of “burnout” among practitioners, resulting in emotional exhaustion, a feeling of a lack of personal accomplishment, and de-personalization. A loss of empathy and rapport with the patient can bring about “compassion fatigue.” Although 50% of US physicians are suffering from burn out, the authors argue that practices of caring can be relearned and renewed.

Two chapters cover the actual evidence of the physiological and the psychological health benefits from compassion. The physiological benefits, based on biomedical research include, among others, the healing of stress and trauma and migraine pain, the improvement of the quality of life in palliative

care and the lowering and control of blood sugar in diabetes. One study concluded that *“heart attack patients with a lack of emotional support, had three times higher odds of death.”*

In the discussion of the psychological benefits of compassion, the authors quote a recent systemic review: *“Compassion based interventions in psychiatry were effective in the treatment of patients with psychotic disorder, post-traumatic stress disorder, major depression and even patients with recently attempted suicide.”* They emphasize the importance of the **person** of the individual psychiatrist or therapist, including the nursing and other staff members, and their ability to connect with the patient. *“Sometimes taking the time to communicate better is the greatest act of compassion that a health care provider can give.”*

Taking on the argument that compassion based care can contribute to the rising costs of medical care; the authors argue that costs are reduced. They cite studies showing that physicians who are more invested in their patients' well-being, are more competent, order fewer tests, have fewer absences, and are less likely to have malpractice suits. Furthermore, when patients rate the care they get, they often choose an institution that provides human connection caring over institutions with greater prestige.

Healthcare institutions are beginning to acknowledge the crisis in patient care and have started training programs to help health care providers learn how to connect more with their patients. Surprisingly, some programs concluded that it can take as little as 40 seconds to at least convey to a patient that you care and will be there for them.

The two authors end their study on a personal note. Dr. Trzekiak reveals that he too, relearned compassion after a “burn out” that led him to take on this research. He was able to renew his commitment and vocation as a physician. He says he took the “research nerd” approach and experimented on himself. *“I connected more, not less. I cared more, not less. And that was when the fog of burn out began to lift for me.”*

Dr. Mazzealli gave an example in his life when compassionate care mattered more than he could have imagined. He and his wife faced the reality that their unborn baby had no heartbeat and would not live. The quiet support and



compassion of the physician and the nurse at the hospital – though their words were few – was a moment he will never forget. *“The memories of those moments – and the compassion that was shared then – will be replayed again and again in the years to come.”*

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*Mary Grimley-Mason is a PhD Professor of English emerita, Resident Scholar, Brandeis University's Women's Studies Research Center, and author of; “Life Prints: A Memoir of Healing and Discovery, Working Against Odds: Stories of Disabled Women's Work Lives”, and “Taking Care: Lessons from Mothers with Disabilities.”*



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## **Changes for Uber and Lyft Rides at Boston Logan International Airport**

Massport’s new ground access plan for Logan Airport includes relocating Uber and Lyft (Ride App) rides to and from Logan Airport to new dedicated curbs in the Central Parking Garage. This provides a more comfortable experience for passengers and reduces congestion on the roadways. The new areas are connected to all terminals, weather protected, complete with passenger services, and constructed with universal design standards. Self-identified

passengers with disabilities going to or coming from Logan Airport have the choice to be picked up and dropped off in the new area in Central Parking, or continue to go to the accessible locations at the terminals curbs.

As part of Massport's mission to improve the travel experience for all passengers, it was important to our leadership to include people with disabilities as key stakeholders in this process. The Massport Board endorsed the creation of the **Advisory Committee for Logan Airport Ride App Users with Disabilities** as a forum for collaboration between representatives of the disability community, Massport staff, and Uber and Lyft to ensure consideration of the needs of all passengers.

The members of the Committee are a diverse group of professionals, advocates and subject matter experts who have been instrumental in setting key elements of the new plan. This collaboration is considered "first in the nation" as no other airport has directly partnered with local organizations that focus on accessibility for persons with disabilities while making such an operational change. *Logan Forward*, Massport's commitment to improvements at Logan Airport, is leading the way in aviation design and planning by incorporating universal design principles from project conception through implementation instead of a "retrofit" approach.

Thanks to the work of the Committee, Uber and Lyft are piloting an "Accessibility" function in their respective apps through which persons with disabilities are able to indicate their pick-up or drop-off location. In the Lyft app, Accessible rides can be selected when the passenger is located at the designated location on each terminal curb. In the Uber app, Accessible rides can be selected after entering the code BOSCURBACCESSIBLE.

The Committee was also involved in the design of the new areas in Central Parking, which are ADA-compliant and include designated areas for accessible drop-off and pick-up. Passenger services are available, including luggage carts, wheelchair services, meet and assist, and bag check service for domestic flights. Airport representatives who are trained and educated on the plan will be available to assist passengers as needed.

The relocations to Central Parking has rolled out in phases, as follows, for passengers who will use the new pick-up and drop-off locations:

**October 28:** Ride App pick-ups in Terminals A and C  
relocate to Central Parking

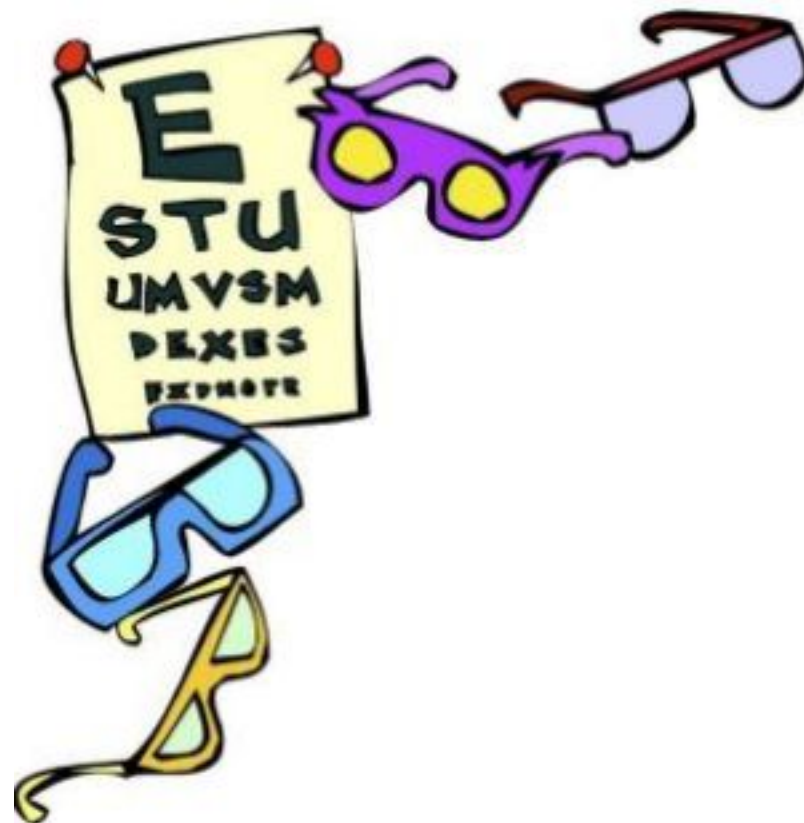
**November 4:** Ride App pick-ups in Terminals B and E  
relocate to Central Parking

**November 11:** Ride App drop-offs between 4 a.m. and 10 a.m.  
relocate to the lower level (Arrivals) terminal curbs

**December 9:** Ride App drop-offs relocate to Central Parking  
(except for 4 a.m. to 10 a.m.)

Being aware of and understanding the changes to Logan Airport and the new function in the Uber and Lyft apps is important. Further information can be found through Massport at [flylogan.com](http://flylogan.com) or through Uber and Lyft.

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**SAVE THE DATE**

**15th Annual**

**“Focus” on Vision Impairment  
& Blindness Conference**

# Meeting the Needs of Individuals with Intellectual Disability & Vision Loss

**March 11, 2020**  
**8:00 am - 3:30 pm**

Four Points by Sheraton, Norwood, MA

## **Keynote Speaker**

**Felipe A. Jain, MD**

Director - Healthy Aging Studies, Depression Clinical Research Program

Massachusetts General Hospital

Assistant Professor of Psychiatry, Harvard Medical School

## **New Ways Caregivers can benefit from Guided Imagery: a focus on Mentalizing, Mindfulness and Connectedness**

Registration Forms available December 2019:

NEW this year!! Option to pay by Credit Card!!

Registration Brochure and Form, including CEU information,  
will be downloadable from:

[focusonvisionandvisionloss.org/conferences--workshops.html](http://focusonvisionandvisionloss.org/conferences--workshops.html)

and

<https://www.perkinselearning.org/events>

**Registration needed by February 20, 2020 to attend.**

**We look forward to seeing you on  
March 11, 2020**





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