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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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From the Editor...

Dear Readers,

As I write this, it is two days before we ring the new year. I imagine most of us are ready to say farewell to 2020. This year has been a year of emotional travel whether we left our homes or not. We have been tested and tempered by suffering and in the stillness of isolation, a multitude of feelings have surfaced including sadness, grief, anger, and confusion.

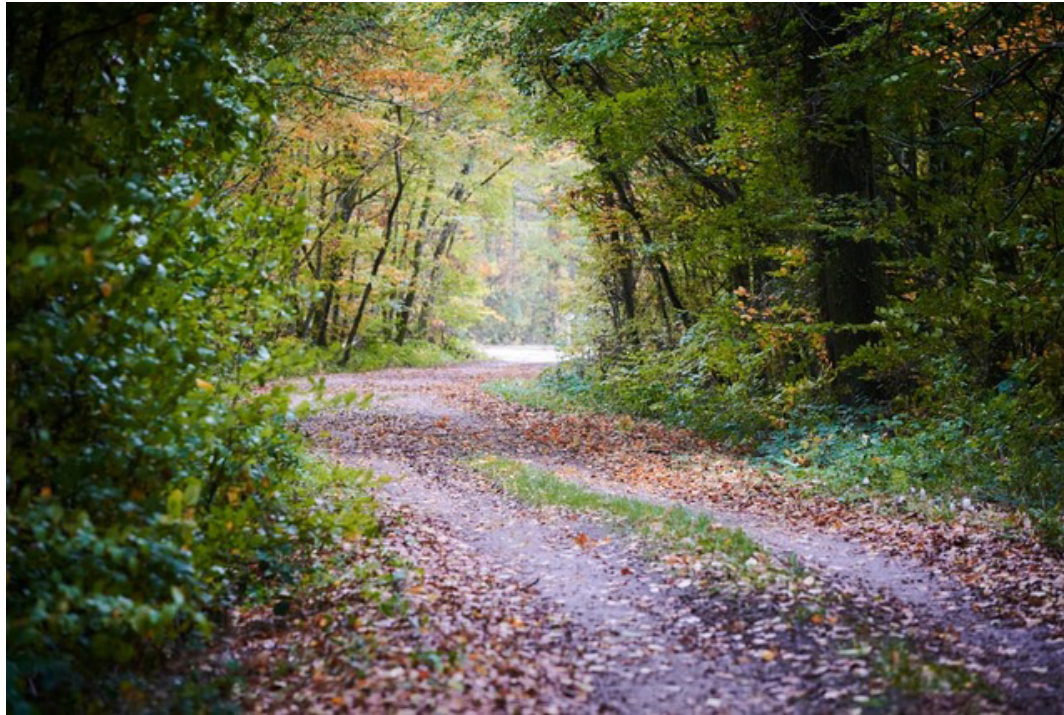
Yet, rising up in us is also curiosity, wonder, creativity, and hope for the promise of what the new year might bring. 2021 will be a year when the COVID-19 vaccine will be rolled out. With protection against this virus, we will begin to travel outside ourselves to new frontiers and... we will grow, we will overcome, and we will love and give love.

Whether your travels take you on slow walks donning your own custom-tailored suit of protective gear, or recovering from Covid-19, or hiring a new PCA with greater clarity about responsibilities, or engaging in simple acts of kindness, may the journey keep refilling your resilience and nurturing your spirit throughout 2021.

To usher in the new year, I offer you excerpts from a poem by John O'Donohue, [*For the Traveler*](#), to honor the Traveler that each of us will be this year.

Please stay safe on your journey and... warm wishes for a Happy New Year!

Marianne DiBlasi, Editor



For the Traveler

by John O'Donohue

Every time you leave home,
Another road takes you
Into a world you were never in.

New strangers on other paths await.
New places that have never seen you
Will startle a little at your entry.
Old places that know you well
Will pretend nothing
Changed since your last visit...

A journey can become a sacred thing:
Make sure, before you go,
To take the time

To bless your going forth,
To free your heart of ballast
So that the compass of your soul
Might direct you toward
The territories of spirit
Where you will discover
More of your hidden life,
And the urgencies
That deserve to claim you...

May you travel safely, arrive refreshed,
And live your time away to its fullest;
Return home more enriched, and free
To balance the gift of days which call you.



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. In May 2020, she earned a Master of Divinity degree from Meadville-Lombard Theological School.



Creating Post Covid-19 Outpatient Rehabilitation Program and Response

By Tim Sullivan

The Covid-19 pandemic has not only greatly impacted society, but exposed and exacerbated inequities to health care and access. Spaulding Rehab as a frontline response organization saw the need to not only deal with the initial challenge but find creative ways to create an opportunity to improve access to care, especially for vulnerable populations.

From both a research and care perspective, Spaulding researchers rose to the challenge. In early Spring, as the first people who survived Covid-19 hospitalizations were discharged, it became evident to caregivers that they would face significant and urgent needs for rehabilitation medicine. Led by Drs. Joanne Borg-Stein, Ginger Polich, Hannah Steere, and Jeff Schneider, Spaulding established one of the first outpatient-based rehabilitation programs.

“We are finding that many people that experienced a severe COVID-19 infection leave the hospital and continue to face persistent symptoms that include physical, cognitive, and psychological issues. Our hope is that a COVID Recovery clinic, focusing on the physical medicine and rehabilitation needs of this population, would help these survivors in their recovery,” said Ginger Polich, MD, Staff Physician at Spaulding.



Among the many innovations and adaptations created was a significant increase to access of telehealth and tele-visits. In March, Spaulding physicians conducted more virtual telehealth visits than the last three years combined. This enabled patients with travel issues or quick questions to get seen sooner and begin to find options for recovery. Especially for persons with disability this can be an important option to ensure access to care.

The [Spaulding Post-Covid Clinic](#) welcomes patients who have had a positive laboratory diagnosis of COVID-19 and continue to experience recovery symptoms. The clinic provides a number of services based on each patient's individual need. The multidisciplinary physician-led team consists of physiatrists, physical therapists, occupational therapists, speech language pathologists, and case managers.

Services provided include:

- Patients will have an initial evaluation with a physiatrist to assess their neurologic, musculoskeletal, cognitive, and psychological needs,
- Physical therapists will conduct evaluations following discharge and design an individualized, home-based exercise program to address the patient's musculoskeletal, and neurologic impairments
- Occupational therapy sessions will be offered to help patients who have difficulty performing activities of daily living including eating, bathing, dressing, and toileting.
- Speech language pathologists will be offered to provide assistance with swallowing and cognitive impairments.
- Ongoing rehabilitation care can be continued at one of our convenient Spaulding Outpatient Center sites when in-person visits are appropriate.
- Translator services are available for non-English speaking patients.
- Virtual visits, outpatient rehabilitation, and home-based

rehabilitation are available.

To learn more about the Spaulding Post-Covid Clinic visit:
<https://spauldingrehab.org/conditions-services/post-covid-19>
or call 617-952-6220.



Tim Sullivan is Director of Communications, The Spaulding Rehabilitation Network & Partners Continuing Care.

The PCA CORNER



Hiring and the Importance of Contracts

By Ray Glazier

With the temporary relaxing of COVID restrictions as of this writing, the [MA PCA Directory](#) has seen new activity with potential applicants posting their qualifications and availability. With so many people out of work due to the pandemic, especially those not in positions with a career track, PCA work has new appeal. But once the economy

bounces back these same folks may find greener pastures. So consumers and their surrogates need to exercise an extra degree of caution in the hiring process.

Many PCA relationships are entered into on a shake-hands-and-go-at-it basis. In that moment of glad connection, neither party is anticipating the connection coming apart. Yet no PCA arrangement is forever (maybe this holds for any relationship, even 'till death do us part' bonds). [The PCA Signature Form](#) that all new hirees sign in the onboarding process has some elements of a contract. But the print is so fine that few signatories probably actually read it through.

The Signature Form specifies the parameters of job duties: the list of **Basic Activities of Daily Living** (mobility/transfers, passive range of motion, taking medications, bathing or grooming, dressing or undressing, eating, and toileting), as well as **Additional Activities of Daily Living** (laundry, shopping, housekeeping, meal preparation & clean-up, transportation to medical appointments, and maintaining adaptive equipment). There is also a list of specifically prohibited tasks like babysitting or lawn mowing at the bottom of the **Personal Care Attendant Job Description** available on the website of your Fiscal Intermediary.

The lists that appear on the **Signature Form** and the **PCA Job Description** are of activities the PCA is able to do under a MassHealth care plan, not what she or he is supposed to do for a specific consumer. But these lists, in all or in part, can form the core of a simple written contract between the new hire and the consumer or surrogate. It is worth noting that the Signature Form also provides for the expectation that "My employer is responsible for giving the check to me (unless I requested that my check be deposited directly into my bank account)." A basic contract for a new PCA should outline the responsibilities of each party and be signed by both parties.

Here is a suggested format:

The signatory parties agree that:

- a. The Employer shall endeavor, in conjunction with the Employee / PCA, to confirm that all payroll records for hours worked by PCA are completed and submitted to the Fiscal Intermediary on a timely basis to ensure prompt payment to the Employee.
- b. The Employer shall provide adequate direction and appropriate performance feedback to the Employee and may terminate the Employee for performance-related shortcomings.
- c. The Employee commits to perform all tasks assigned by the Employer that fall within the lists of legitimate activities set forth in the PCA Signature Form and the PCA Job Description on a timely basis as directed. [You may want to list specific tasks with days of the week and shifts (morning, afternoon, evening – even approximate times) for each task. But be aware that specificity is a double-edged sword. You may in the future hear: “But that is not in our contract.”]
- d. Either party may terminate this contract for any reason with 14 days written notice to the other party; during which time the PCA may be expected to perform routine duties and be compensated for same.

Be aware that this author is neither a lawyer nor a consistent contract user in his own PCA relationships. This article is advisory only, and the outline above does not constitute an enforceable contract. No warranties are expressed or implied. The document is more properly considered a memorandum of understanding. But it is better than leaving these matters open to misunderstanding.

Hiring PCAs during this pandemic warrants exercise of special precautions, not the least of which is regular COVID testing, of course.

In fact, a provision for routine COVID testing and stipulation for who bears the costs for it should be included in any contract or memorandum of understanding.



Raymond E. Glazier, Ph.D. is a longtime MassHealth PCA Program consumer who has studied PCA issues for decades. He is currently founder and Principal of disAbility Research Associates in Belmont, MA. Contact Ray at RaymondGlazier@gmail.com with questions, comments, or suggestions for future columns.



The S-l-o-w-e-r Motion Commute in a Pandemic

By Ms. Love

These days I wake up earlier than even I would normally do, and that is saying something for an early bird. I need the extra time to layer up before I can leave the house for an appointment or an essential errand. You probably think I am layering up for winter, right? No. I am layering up to be safe in the pandemic.

First, I take a precious face mask that I waited in a long line to buy out of the container where I am storing my disposable face masks. It is a bit big, so I go into the bathroom to tighten the wire around my

nose and minimize slippage. This isn't as simple as it sounds, but with each passing month, I have gotten better about firmly placing my eyeglasses over the top of my face mask to hold it in place. If it is raining out, I carry spares with me. On hot days, I put on my sunhat and pull the brim as low as possible over my eyes to protect them not only from the sun but from droplets of virus that may hang in the air as I move around town.

Then it is time to put on gloves; two pairs if it's warm and three pairs if it's cold. Experts say people do not have to wear disposable gloves, we just need to wash our hands or use a hand sanitizer. But since I use a walker and other people frequently move it, depending on what appointment I have, I wear nitrile gloves until I can get home to sanitize my walker. Early in the pandemic, I learned that taking off disposable powder-free gloves can be difficult, so I wear cotton gloves underneath. This lets me whip off the nitrile gloves easily. On cold winter days, I keep my hands warm by wearing mittens over the two pairs of gloves. I take the mittens off when I have to write something down or once I arrive at my destination. I carry spare disposable gloves in case I need to replace soiled ones.

Many months ago, my eye doctor kindly offered to give me one of her precious-during-the-pandemic face shields. She was concerned about me riding public transportation and wanted my eyes to be protected. She wears a face shield during eye exams and showed me how she cleans it between patients. Initially, I was only wearing the face shield when I took public transportation. But with the uptick in coronavirus cases, I began wearing it as much as possible when leaving the house. But not always. Why? Because if it is a cool or cold day, the air I exhale through my face mask steams up my glasses and I can't see. Add a plastic face shield over that, and there is more fogging up and droplets of water sliding down the face shield that blocks my vision.

What I find particularly interesting is, most days people don't even take a second glance at my so-called astronaut suit of protective gear

because everyone is putting together their own custom-tailored protective suit. Some people wear two or more different face masks to close gaps and give themselves extra protection. Others wear an array of comfortable, casual clothes; the kind of outfits that are being worn more often since more people are working from home, if they are working at all.



Now picture me leaving home in my astronaut suit. I live in a dense neighborhood and the sidewalks are often full of pedestrians, bike riders, scooters, and more. It is normal in non-pandemic times for many unthinking people to try to squeeze by me and my walker on a narrow sidewalk or to abruptly cut in front of me to enter a store without waiting for me to pass by the entrance.

Even now, when we are told to stay a minimum of six feet away from others, many people are still so much in their own world they come too close despite a pandemic surge going on around us. Sometimes I see five people walking abreast coming towards me. They often expect me to hop out of their way because according to the new pandemic and ableist math, five is more important than one using a walker.

My town has an interesting concept; perhaps yours does too. On a handful of streets, they have replaced on-street parking spots with barriers so pedestrians can hop into the street if the sidewalk is too crowded for social distancing. This would be a great idea except many

walking on the sidewalk either don't know they can use the street pedestrian lane, or they want to be closer to the shops and don't hop into the street. Hence, very few people walk in the special pandemic pedestrian street lane. I would love to use the pedestrian street lane when sidewalks are crowded. The problem is, there are no driveways or curb cuts, which makes it difficult for me to get down to street level and back up with my walker. I have spoken to town officials about the need to promote giving sidewalk priority for people with mobility issues, but the issue continues.



I note that the "Fast Walkers" from pre-pandemic life are walking even faster as they try to steer clear of other people and their potential virus-filled air. Because of my gait and walker, I am a "Slow Walker" and don't have the luxury of being able to speed up. This means I often come face-to-face with people who either totally deny the need for masks, or wrongfully believe they can skirt the issue by wearing a mask around their neck or by holding one in their hand. Some are outside leaning against the Dunkin Donuts building sipping their coffee without a mask. Others are just hanging out without masks, shouting to their friends across the street. Still others cough or exhale smoke

from their cigarettes directly on me as I pass by. On my slow walks, I am scared by what I see and am exposed to.

Pre-pandemic, we could all be in close quarters with strangers as well as loved ones. Now, in the middle of the pandemic, your Ms. Love is scared of being close to anyone. Others with and without disabilities should be careful, too. Yes, I remain your Ms. Love, believer in love and intimacy, but the most important love to practice right now is the love of pandemic safe practices:

- Wear your own protective gear each and every time you leave your house.
- If someone in the household is sick or if you are receiving or giving personal care, consider wearing some protective gear even in your own home.
- Physically distance from others as much as possible.
- Wash your hands often or use hand sanitizer.
- If others touch your mobility devices, keep them clean and sanitized.

Oh, what changes this pandemic has brought to my slow walking commute. I do my essential errands and go to appointments, but I'm always thankful to get home. In the lobby of my building there is a small mountain of Amazon boxes and other packages for people that are having the world delivered to them. I push aside some packages that are overflowing into the pathway to the elevator and in the way of my walker. When I finally enter my unit, I doff my protective gear and pray for the day of return to my more peaceful, pre-pandemic slow walking commute.

Be well, dear readers, be well.



readers. Please send all comments, questions and suggestions to Ms. Love at 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.



Transportation Options During the Pandemic

By Sandy Alissa Novack

If you live in Greater Boston and are a person with disabilities are you wondering what your transportation options are during the pandemic? I'm so glad you asked!

If you want to use your own vehicle to drive, you're all set. You don't even have to wear your face mask in your car if you are driving alone or with members of your household. If someone in your household is sick, then face masks should be worn.

For information about other forms of transportation, I look to [TRIPPS](#) - **Transportation Resources, Information, Planning &**

Partnership for Seniors (and adults with disabilities). TRIPPS is a program of the Brookline Council on Aging. During non-pandemic times, they rely on volunteer Brookline residents who are transportation savvy to educate others about their options. But they haven't stopped their efforts during the pandemic. TRIPPS volunteers are meeting virtually weekly to stay on top of the news about everything from walking, subway, and bus to paratransit and Lyft.

For this article, I interviewed **Maria Foster**, TRIPP's Community Outreach Specialist.

Sandy Novack (SN): Maria, what are the most common questions TRIPPS has been getting during the pandemic? What has the Town of Brookline been able to provide to meet unmet travel needs during the pandemic? Are other Councils on Aging in Massachusetts able to offer this type of resource?

Maria Foster (MF): The most common questions are about the specific transportation services we provide through the Brookline Senior Center. During the pandemic, Brookline lost its last remaining taxi dispatch service and so we had to pivot to other programs like [GoGoGrandparent](#) and [Lyft](#) to provide subsidized transportation. We also launched transportation for older adults who have medical appointments in Brookline and the Longwood Medical Area. We also get a lot of questions about accessing the MBTA's The RIDE service. As older adults researched their options, they were often doing their own risk assessments for what they felt was safe for them; in conversation with their primary care doctor, of course.

Most Councils on Aging across the Commonwealth of Massachusetts provide some type of information and referral service for transportation. Many also provide direct subsidized transportation. I think TRIPPS is unique in the deep involvement of our volunteers who are committed to the issues of transportation and help to develop programs. For example, TRIPPS volunteers were instrumental in

developing our current pandemic response to medical transportation service.



Maria suggested I speak directly with some of the TRIPPS volunteers who are passionate and knowledgeable about transportation issues. Here's what they had to say:

Monique Richardson (MR):

SN: Monique, I know you have been keeping tabs on the CDC and other resources during the pandemic. Can you summarize your recommendations for traveling during the pandemic and what our readers should consider?

MR: The first recommendation is to stay home unless absolutely necessary. If you are over age 60 or have chronic health issues and disabilities, think twice about leaving home. Before going out, ask yourself how prevalent the coronavirus is in your community and where you want to go. Is this an essential trip or can it wait? Essential trips include getting groceries, picking up medicines at the pharmacy, and going to medical appointments that cannot be delayed. Going out for short walks for exercise and to keep from going stir crazy is also essential. Going to get your hair cut is probably not essential.

Other factors to consider are: can someone else run your errands for you or is your presence absolutely necessary? Is physical distancing possible? Is ventilation possible or does the enclosed space have adequate HEPA filtration? Whenever possible, use transportation methods that minimize contact with others, such as biking, walking, driving alone, or riding with household members. Wash your hands frequently with soap and water for 20 seconds. I use these guidelines myself when I cannot use my car to drive someplace. I have cardiopulmonary issues and scarred lung tissue from multiple bouts of pneumonia, so I have to take precautions during this pandemic and flu season.

Pat Ahlin (PA):

SN: Pat, I understand you have been using Lyft during the pandemic. Why do you choose to use Lyft? Can you tell our readers about any tips you have learned?

PA: I found that the Lyft application was very easy to set up on my mobile phone. I put my credit card information in the app only once and I never had to repeat that process. I value ease of travel and I think Lyft is very user-friendly. It takes me less than a minute to order a ride and a car generally arrives in less than ten minutes. I try to use the service during non-peak hours to lessen the wait time. For some local errands, such as to the local supermarket, I walk to my destination to get some exercise and I use Lyft to take me home. When I have heavy grocery bags, I sometimes ask the driver to place them in the trunk for me. I also use a cloth shopping cart with wheels, which is cumbersome, so I ask the driver for help putting it in the trunk and taking it out. In general, the drivers have been very kind and willing to help. To show my appreciation I give them an extra cash tip in addition to the online tip.

I am in my 70's and have lupus and interstitial lung disease so I have to be especially careful to prevent even the slightest infection. For that reason, I limit my exposure to others as much as possible and always wear a mask. For safety, when I enter a Lyft car, I make sure the driver is wearing a properly fitted face

mask. I partially open the window for airflow, and I bring a disinfectant wipe to clean the seatbelt and door handle. Once I arrive at my destination, Lyft sends a message asking me to rate the driver and suggestions for giving an online tip. By the way, the driver is also asked to rate the passenger.

Nancy White (NW):

SN: Nancy, I understand you have been relying on the subway during the pandemic. Can you tell me how that has been going and any tips you have for our readers?

NW: I always wear a face mask on the MBTA. I don't wear a face shield, although a friend is always telling me I should. I don't wipe things down because I always wear gloves when I leave my house, not only when riding the MBTA, but even as I hold the railing going down the stairs in my building. I try, as much as possible, to ride during off-peak hours and to distance myself from other passengers. This helps me feel comfortable waiting inside stations and riding the T. Still, I only use the T when I absolutely have to.

I do my research to plan each trip. I suggest anyone who is taking public transportation to do the same. Useful planning tools are:

- [MBTA.com](https://www.mbta.com): Everything you want to know about riding the MBTA including [Coronavirus updates](#), [Trip Planner](#), [Alerts](#), and [Crowding Information for Riders](#). If you have additional questions, visit the [Customer Support](#) website or call 617-222-3200.
- [TransitApp](#): Download this App for real-time updates, including crowding information for buses.
- Value can be added to your CharlieCard or CharlieTicket [online](#) or call support services at 888-844-0355 or email charliecardonline@mbta.com.

To request a Senior, TAP, or Blind CharlieCard or replace a lost, expired, or damaged card and make deposits to RIDE accounts,

visit the [CharlieCard Store](#) at Downtown Crossing in Boston or call 617-222-3200. There are dedicated hours for seniors and people with disabilities.

In addition to providing information from the TRIPP volunteers, I will also share some information that I've learned based on my nine-year history of using [The RIDE](#), including during the pandemic. The RIDE paratransit service provides door-to-door, shared-ride transportation to eligible people who cannot use the subway, bus, or trolley because of a temporary or permanent disability. During the pandemic, The RIDE is frequently able to offer service to one customer at a time, instead of a shared ride. This helps to maintain physical distance between the customer and the driver. During the pandemic, the subway, bus, commuter rail, ferry, and The RIDE have experienced a considerable drop in ridership, but The RIDE has experienced the least drop-in service. This is because people are booking The RIDE for essential trips, mostly medical appointments, and trips to grocery stores.



The cost of The RIDE is currently \$6.70 for a round-trip fare for trips that approximate fixed-route trips on the subway and bus and is referred to as the ADA fare. The cost of the trip increases to the premium rate if you are going on a trip within the geographical coverage of The RIDE service but is beyond three-quarters of a mile from the fixed-route service. This point is especially important to note

during the pandemic because recently the MBTA has been considering cutting service to some bus and subway routes due to the MBTA's growing budget issues, partially as a result of the lower ridership during the pandemic. Let's say you now pay the \$6.70 round-trip fare for someplace you travel to. If a bus route is cut completely or if stops are relocated, your trip could become a trip that will cost the premium rate of \$11.20 for a round-trip fare.

There is no doubt about it, we all need transportation sometimes, even during a pandemic. The above interview with TRIPPS should help you understand some of your options. Your city or town may have more or fewer options for travel available in general, and especially during the pandemic. To find out more information, call your local Council on Aging or Center for Independent Living.

Additional travel tips and useful information:

[Is train travel a safer option this holiday? This is what experts say](#)
The Washington Post

['Existential Peril': Mass Transit Faces Huge Service Cuts Across U.S](#)
New York Times

[Opening Car Windows Can Cut COVID Transmission](#)
WebMD

*Sandy Alissa Novack, MBA, LICSW, ACSW, CSW-G
is on the Board of Directors of the Disability
Policy Consortium and volunteers with the Boston
Center for Independent Living.*



The Gifts of Kindness and Gratitude

By Joan Burrows

***"It is the history of kindness
that makes the world tolerable."***

This quote is on my desk, along with a couple of others, to remind me, especially in these times, to enjoy the good things in life. Many of these things are "little" but they feel like big ones.

Last December, I pulled out my Christmas list and began sending cards to long-time friends and those far away. I decorated each one, especially for the person. It was fun! Within a brief time, I began receiving notes back and phone calls too! It was an unexpected joy. At Christmas many of us send cards, but it's one-way communication. You read their news and they read yours, but no direct response, until maybe the following year. These notes were truly kindnesses being shared; little ones with big rewards!

In April, I continued reaching out to family and friends by sending

them little notes on pretty paper; one had a little tree with hearts. Then I bought more cards online; some with flowers, others with pretty scenes, and some plain that I added stickers to – hearts, and rainbows, and kitties, and more. I continued to do this until health problems began in July. Now that I'm recuperating, I want to start writing notes again.



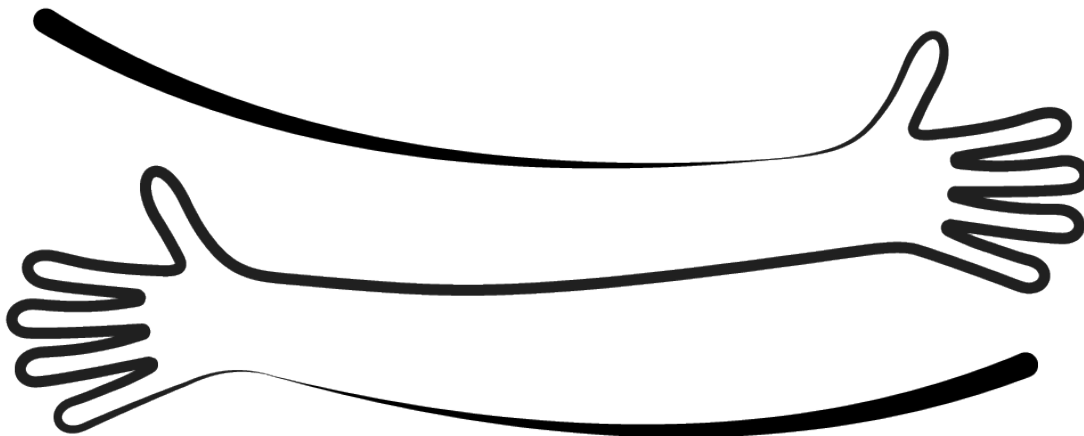
Many people do not know about my health issues and although I do not want to burden anyone, some might want to know. I am doing well now so it will be good. People who did know have been incredibly kind and thoughtful. It helped me a lot. I still have friends calling to see how I am doing and others stopping by with flowers, food, and treats. Each visitor and call are gifts; a gift of kindness.

In the fall of 2019, a new family moved into the condo where I live. I welcomed them as I do all new residents. Because of their work and school schedule, I didn't see them much last winter. Warmer weather brought more contact and we often stopped to chat. Last July, I began not feeling well and asked if the girls could water the plants on my terrace for me. They were happy to do it. My plants give me a lot of joy, so I was glad they were being cared for. As my health problems continued, requiring tests, surgery, a few days in the hospital, then a longer stay in a rehabilitation center, the girls and their mom continued to care for the plants. When I got home (to stay, I hope) in September, they kept up with the plant care. It really cheered me up to look out the windows or sit outside and see my flowers in all their glorious colors. It made me happy and hopeful.

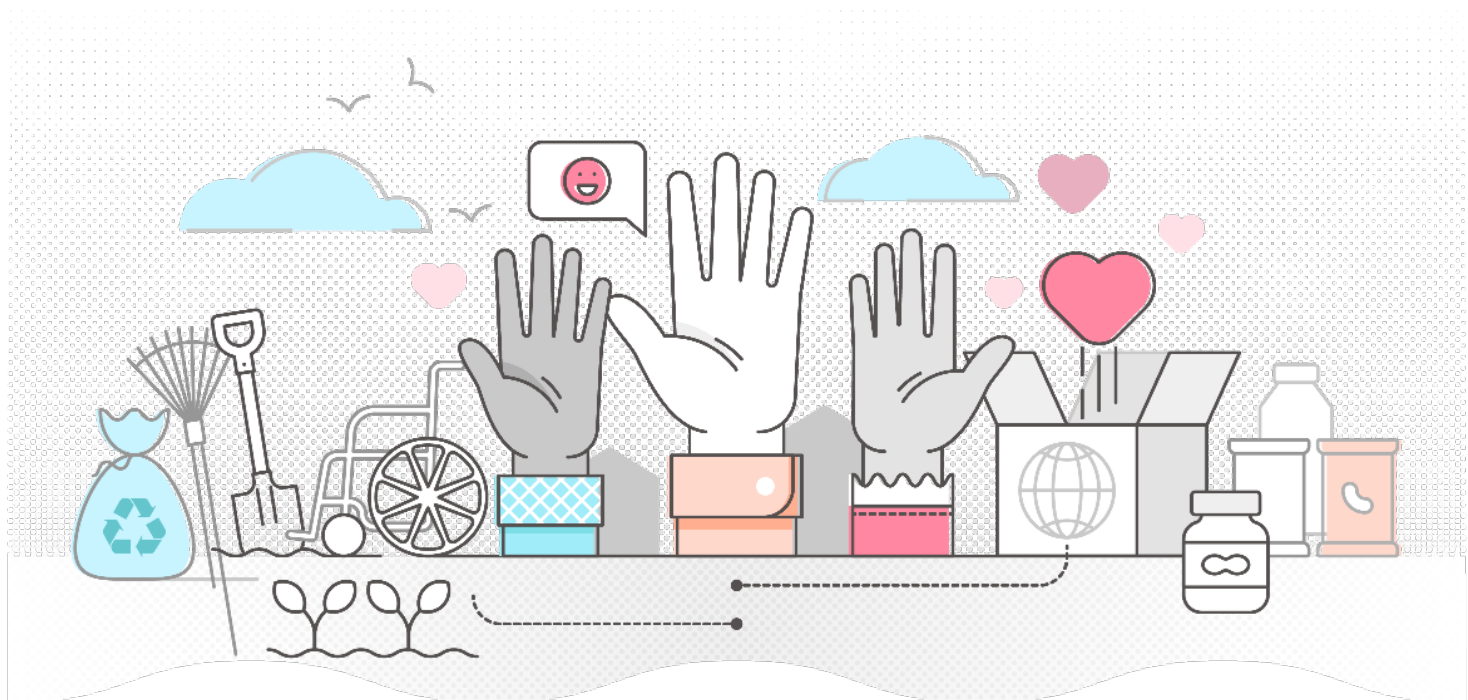
In preparation for coming home, my daughter talked with the family

who lives in the condo and asked if the high school girls had time to help me with things around the house. The girls have a half-day off from school every week and said they would be glad to help. They have come every week. On holiday weeks, they come earlier and stay longer. They will do anything I ask; go through papers and music, file, move boxes, vacuum, dust, wash dishes, and get my dinner. They are so willing and cheerful. Their presence in my life is a true gift!

One of the most loving acts of kindness was a recent visit from my granddaughter. She attends a college in Boston and is very busy, so her visits are cherished. We talked and she helped me with some issues I was having with equipment. When it got late, she got up to leave. We stood at the door a moment, and then she gave me a hug, a big hug. We both knew we weren't supposed to do that, but her hug was just what I needed, and it was most welcome! I can still feel her hug weeks later. I really can! I can also feel the warmth of all the spontaneous acts of kindness that I've received.



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.



In Appreciation for Acknowledging Me

By Penelope Ann Shaw

I only have to drive my power chair a few blocks to be at the center of my town. There are pharmacies, the post office, banks, the Town Hall, a supermarket, restaurants, parks, a lake, as well as hardware, clothing, and arts and craft stores. I frequent these places and am well-known. When I'm out and about in town, one of the truly

pleasant things that happen in my neighborhood is having unexpected encounters with strangers either on a sidewalk or inside somewhere. Since I have a visible physical disability, these encounters often involve my disability. **Here are some examples of what I experience:**

Some children are curious and ask, "What happened?" I explain as simply as I can that I can't walk. I compare my chair to their bicycles as a way to get places. I often let them test my horn.

When adults walk by, they may just nod or greet me with a wave or say "hello" and keep on walking. Others ask if I need anything or say something like, "Are you okay?", which is their way of letting me know they are willing to help me if I want help. Interestingly, a couple of people commented, "I saw you on [Boston evening] T.V." after I'd been interviewed as an advocate about conditions in the nursing home where I live.

Occasionally, sidewalk encounters are surprising. Like the time when a woman I had just seen in the pharmacy, now sees me outside. As she passes by, she deftly reaches into her shopping bag, takes out a candy bar, and gives it to me. The woman keeps on walking without saying a word. Or the time a smiling woman unexpectedly came up to me just to ask if I wanted a bottle of water.

Men have been equally generous. They have offered to pay for my ice cream at the local yogurt bar, I've had lunches at restaurants paid for anonymously, and offers to buy me a meal at the nearby McDonald's. At the local pharmacy, a man told the clerk that he would pay for my purchases. The man even asked me, "Is that all you want?"

People offer assistance when I can't reach something. They put my mail in a post office box, or hand me clothes off a rack when shopping, or retrieve items from higher shelves in the grocery store.

At the library, a woman sees me using a computer and comments,

"I'm impressed that you are out and about, not staying home feeling sorry for yourself."

Passers-by have rescued me in varying practical ways, including moving trash barrels so I can get by on the sidewalk.

Once, not thinking, I paused on an inclined sidewalk and shut off the power to my chair. My chair is fussy and will not power-up when tilted. A woman asked if she could be of assistance. She willingly followed my directions and moved the levers on my chair into manual, pulled me back to a flat surface, and put the levers back into power mode. I was then able to power-up again and be on my way.

I often reflect on these words, conversations, gestures, gifts, and practical assistance. They were all from individuals I did not know. Their helpfulness, kindness, generosity, and concern for me not only enhanced my well-being but continues to touch me substantively. These actions continue to benefit me by making me feel connected, safe, secure, happy, uplifted, included in, and belonging to, a friendly, livable supportive community.

For all those who have seen and interacted with me, I offer these words to you:

Even though I never learned any of your names, I can see you in my mind's eye.

I remember all of our interactions - what you did for me and said to me. I want you to know that I have not forgotten you. Memories of my encounters with you sustain me in a world that is not always kind. I publicly thank you for your many kindnesses.





Penelope Ann Shaw, Ph.D., has a complex physical disability from Guillain-Barre Syndrome. She is a state and national advocate who uses her personal experiences to push for public policies that will improve the lives of children and adults with all types of disabilities. In Spring 2020, she was appointed as a member of the White House Coronavirus Task Force's Coronavirus Commission on Safety and Quality in Nursing Homes.



INFO BRIEFS • INFO BRIEFS • INFO BRIEFS



Emotional Support for Stress

A recent CDC blog post, [3 Reasons to Phone a Friend Today](#), emphasizes the importance of staying connected as a way to cope with stress. Connecting with friends and family through phone calls

and video chats is a means of self-care that can help you and your loved ones feel less alone or isolated in stressful situations, like the COVID-19 pandemic.

The CDC recommends hosting a virtual celebration with friends and family who do not live with you. A virtual meeting might also be a good time to talk about how you and they are feeling. The [How Right Now](#) campaign has tips for how to have a meaningful conversation and listen with compassion any time of year.

Everyone reacts differently to stressful situations. If you or a loved one is feeling overwhelmed, get support. The **Disaster Distress Helpline** provides 24/7 confidential, free emotional support. If you or someone you know needs emotional support, call or text 1-800-985-5990.



Yoga, Disability, and Transformation

[Mind Body Solutions](#) is thrilled to announce a new offering!

Please join us for "Yoga, Disability, and Transformation" - a new online series designed specifically for people living with disabilities. Come explore the principles of yoga with internationally renowned yoga teacher and Mind Body Solutions founder, Matthew Sanford. **Practice**

along with Matthew as he weaves story, yoga practice, and wisdom earned while living with a disability for over 40 years into a seamless practice accessible to everyone. Care partners are also welcome to attend.

All sessions are FREE. No need to register in advance. Click [HERE](#) to join via **ZOOM**. Sessions will be recorded and made available on our [YouTube Channel](#), The Hub.

SAVE THE DATES!

January 13, 2021

March 10, 2021

May 19, 2021

July 17, 2021

September 22, 2021

*Each session is **3-4:30 PM EST***

For more information, visit the [Mind Body Solutions](#) website or call 952-473-3700 (voicemail) or email info@mindbodysolutions.org.





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Spaulding Rehabilitation Network is pleased to be an underwriter of *Disability Issues*, a free and independent newsletter. The Spaulding Rehabilitation Network is a member of Partners HealthCare and includes Spaulding Rehabilitation Hospital. Spaulding Rehabilitation Network, a member of Partners HealthCare, includes Spaulding Rehabilitation Hospital, its main campus in Charlestown, which is a national model for environmental and inclusive design as well as Spaulding Rehabilitation Hospital Cape Cod, Spaulding Hospital Cambridge and two skilled nursing facilities, as well as twenty-five outpatient sites throughout Eastern Massachusetts.

Spaulding has been awarded a Model Systems designation in three specialty areas - Brain Injury, Burn Injury Rehabilitation, and Spinal Cord Injury - by the National Institute on Disability, Independent Living, and Rehabilitation Research. Spaulding is a teaching hospital of Harvard Medical School as well as the official rehabilitation hospital of the New England Revolution. Spaulding is the only rehabilitation hospital in New England continually ranked since 1995 by U.S. News and World Report in its Best Hospitals survey with a #2 ranking in 2018-2019. Spaulding was recognized in 2018 by Disability Equality Index® as a company who scored 100% in the category of Best Places to Work™ for Disability Inclusion. For more information, please visit www.spauldingrehab.org

The ***Disability Issues*** newsletter is a free and independent publication. It is published quarterly and shares current information about the world of disability, new initiatives, and other helpful information to the disability community in Massachusetts.

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