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# DISTRICT FRAY

A D.C. LIFESTYLE • ENTERTAINMENT MAGAZINE • JUNE 2023

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# D.C. SUMMER



# Navigating the District with a Hidden Disability

**WORDS BY APRIL THOMPSON**

“I thought you were high as a kite,” the street cleaner said, shaking his head after hearing my story. “But I could see you really needed help.”

“You’re my guardian angel,” I said, laughing and crying as I climbed out of his ride — a trash can on wheels — in front of my building.

For nearly 20 years, I’ve suffered from ME/CFS, otherwise known as chronic fatigue syndrome, characterized by a systemic intolerance to exertion. I was in peak health and physical condition when ME/CFS hit — a multisport athlete who ran marathons at elite qualifying times, boxed competitively

and climbed mountains all over the world. A mild viral bug I picked up while traveling morphed overnight into a condition that left me so weak I couldn’t walk around the block.

In many ways, I am lucky. Three out of four people with ME/CFS, which has no known treatment, are too ill to work due to severe physical and cognitive dysfunction. One in four are housebound or bedbound, some too ill to speak or read, or feed and bathe themselves.

I am “mild” on the ME/CFS spectrum and can work full-time. Still, a small amount of physical exertion has the

A number of helpful programs exist for people with mobility challenges. Here are some I learned about after more than 10 years of chronic illness.

## **AMTRAK’S RED CAP SERVICE**

Amtrak’s Red Cap staff are dedicated to helping passengers with service issues, large or small. Call the number in front of Union Station for a Red Cap to whisk you in a motorized cart straight to your seat. Bring cash to tip them!

## **ASSISTANCE AT AIRPORTS**

All local airports have wheelchair attendants who will get you through security and straight to your gate. Tip them well if you can — they are underpaid for this important service job.

## **HIDDEN DISABILITIES SUNFLOWER LANYARD PROGRAM**

Other cities, in addition to a growing number of airports, have adopted a hidden disabilities sunflower lanyard program, a simple way for visitors and residents to self-identify as having a disability that might require a little extra help.

## **METROACCESS**

Most people with mobility challenges are eligible for this program, which offers discounted door-to-door rides throughout the DMV area. It is an imperfect system, but still a lifesaver.

## **TRANSPORT DC**

Registered MetroAccess users can call for same-day rides within D.C. limits for a \$7 flat rate through a partnership with local cab services.

## **WHEELCHAIR LOANERS**

Many venues, from the Smithsonian museums to The Kennedy Center, have free wheelchairs on hand to lend.

## **UBER**

Uber waives wait fees for passengers with disabilities, but you have to identify on the app as having a disability to put this in effect.

potential to make me ill for days, though on the outside I look perfectly healthy. Living with an invisible yet disabling chronic illness that fluctuates day to day, decade to decade, I never know when I will get stuck somewhere, unable to move without becoming further fatigued. And though riding in a trash can was a first, after two decades with ME/CFS I'm used to getting around D.C. by any means necessary.

And I'm not alone. I caught up with others who have hidden disabilities, who are also learning to navigate the DMV.

D.C. resident Ally Thompson was diagnosed with ME/CFS, Ehlers-Danlos syndrome (EDS) and postural orthostatic tachycardia syndrome (POTS), among other conditions in the past few years, and is still trying to find her comfort zone navigating the city.

"CFS has me exhausted and with POTS I experience syncope fairly often, which makes me nervous to go out alone," Thompson says. "While there are plenty of nice people in the city and most areas are populated, if I pass out and hit my head with no one around, it could mean a lot of trouble."

To get around, Thompson focuses on bus routes, which are typically less crowded than the Metro. Because catching other airborne illnesses can worsen her symptoms, she appreciates any concerted effort made by D.C. transportation.

"Small things like cleaner public bathrooms and more inclusive seating could make a big difference."

Vura Thuku-Jones, a hospice worker and resident of Centreville, Virginia suffers from avascular necrosis, a

debilitating condition caused by a preventable drug interaction her physician failed to detect many years ago.

"People like me want to come and support the arts and businesses in D.C., but it's always a hassle to park, even with our special plates," Thuku-Jones says. "I always plan ahead and have a plan B."

We all have to get creative with solutions. The day of the trash can incident, I'd successfully walked uphill one block to the 70 bus to take me six blocks to CVS. On the journey back, I was suddenly very ill from the exertion, and I accidentally took the 79 Express, which stopped one block further from my home than the 70. I begged the bus driver to stop one block earlier, letting him know just how ill I was, but he refused. I got out, demoralized at how far I'd fallen physically.

No bus route would take me the two blocks, and it was too short a distance for a rideshare to pick me up. I am a MetroAccess user — the door-to-door van for people with disabilities — but that requires scheduling a day in advance. I was just two blocks from home, and yet, worried that if I pushed through, I could be ill for a few weeks. That's when I spied my angel — a street cleaner wheeling a body-sized trash can — and begged for a ride down the block.

Thankfully, there are resources for people who are fully disabled for purposes of employment. While there is still progress to be made, D.C. can start seeing those with invisible disabilities along the way.

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