

The New Refugees

by MaryFrances Platt

I can often be found spending large spaces and places of time on the road, living in my van. I am a Girl Scout and outdoor education leader from way back, but my frequent camping forays are really about my heart and lungs requiring me to be a snowbird following the warmth, and about my MCS requiring me to be in a non-toxic environment.

My own home, which I have taken great lengths to make safe for myself, can easily make me ill in the winter with closed windows and less opportunity for clean air exchange, and more opportunity for perfumed personal care attendants and neighbors to send me into respiratory arrest with their hairspray or clothes detergent. Many years ago, a healer that I trust greatly told me that I simply could not live in a climate where the windows could not stay open. She was right. So every winter, off I go to warmer climates as my lease, health, and mobility allow.

Those of you who have attended ADAPT actions and other events that I have been present at know that I don't stay in hotels, but rather lay my body down in the back of my van. I do this no matter what the climate. Living with MCS, I can't just leave a cold-ridden toxic environment and find a nice cheap hotel or temporary apartment in a warmer climate. The normal scents and chemicals in your average hotel would render me extremely ill with respiratory and neurological symptoms.

Folks like me, with multiple chemical sensitivity, sometimes call ourselves the "new refugees." You'll find us moving from place to place, hoping to find somewhere we will not get sick. More often than not, there is no room in any inn that doesn't cause us to wheeze, hurl, whiz, puke, or pass out. And if we do find a place, all it takes is one unknowing or uncaring person using one squirt of some toxic hairspray to set us off and running again, in an MCS reaction, without a safe place to lay our bodies down. If we are lucky, we pack up what we have and set out in our vehicles. For many of us, our vehicles provide the only MCS-safe space available.

My baby-poop-yellow van "Pumpkin" is infamous. She is 18 years old. We have been together for 15 years. In two years she will be eligible for antique plates. It's not that I'm overly good to my vehicles; it's that I have not been able to find any other vehicle that doesn't make me ill.

I bought a newer van in the early '90s, tore out the carpet, cloth walls, and vinyl coverings. Still it made me sick. Today it sits in a yard in New Hampshire,

detoxing for the 15-year period it usually takes for something to outgas all its chemical toxicity.

I think I have spent more nights sleeping in Pumpkin than in my apartment of ten years! She is always there for me to run to — or with — as I need.

In my escapes across the country I have come across other MCSers living in their vehicles, trailers, or a combination of canvas and metal. I have found them in federal, state, and private campgrounds, and on so-called public lands that have no facilities at all. Many an MCSer has spent a winter dry-docked in the public lands outside of Tucson. I have been amazed at our ability to keep moving on, and yet I am not surprised when I hear of a new MCS suicide. We eventually reach the end of our ropes, with no place to live, no safe water, no food we can eat without getting sick, and no place to lay our weary heads at night.

Most of the medical establishment doesn't believe we have an illness. Those who believe we do still don't have a clue how to treat us, much less cure us.

I was living in an 8-by-10 metal storage shed for the winter on some "disabled women's land" and feeling a bit crowded until Margaret arrived. Margaret had been living in the same Volkswagen bug for 26 years — and yes, that's "bug" with a "g," not "bus" with an "s." Everything she owned was contained in that teeny tiny space.

Each night she would move everything from the inside of her VW bug, in their 15- and 20-year-old detoxed boxes and bags, to the outside so she could sleep in the bug. Her curtains were old, wrinkled, unscented paper bags. The blanket she used, as well as the clothes she wore, she washed by hand, no detergent.

Margaret loved animals but was allergic to their dander. Most mornings I'd awaken to find my cat sitting about 15 feet away from her, while she cooed at him, and he meowed at her, from a distance. If he moved closer, she'd tell him, "Now Mazel, you know I am allergic to you" — and he would back off. Margaret would pet my assistance dog, Lucy, by means of a long stick.

People were not as understanding as the animals were. Margaret never stayed too long at one spot. She had to be aware of what the water supply was doing in the area, as well as what chemicals were being sprayed where, as barely a sniff would make her very very ill. A migrant MCSer, she had to follow the patterns of the winds and the rains. After two months on the land where I stayed, it was time for her to move on as the pesticide spraying began. Off she went, to some Quaker land for another few months. This was her whole life, and she certainly made the best of it. My animals missed her immensely.

June developed MCS later in life. With her Social Security payments, she had the good sense to buy an old detoxed motor home which she lived in full time. The Airstream brand of old motor home is revered by MCSers for its low toxicity, and this is what June had. Many of us are allergic to new wood or any kind of wood; for us, metal living spaces are imperative. I lived in my 8-by-10 metal storage shed, others lived in their 22-ft trailers. June had a legitimate permanent address, yet she traveled around the country, staying in the warm western climates and living mostly on public lands.

"Public lands" are lands, generally owned by the National Park Service, that for the most part are legal to camp on. Some have limited stays, some you can stay a long time, some have loopholes that you have to figure out. Most of these type of lands have no facilities and no fees, so many people with MCS find their way to them. They also tend to be less populated — therefore one is exposed less to perfumes and chemicals.

It is best to have a legitimate "carry permit" if you frequent any of these spaces, though, as predators of the human as well as the animal kind tend to find their way there. I still hold a memory of June, one foot in her RV, one on the outside step, shotgun pointed at the figure walking toward her, asking him to "state his business, please!"

June over the years became an MCS activist. Now, after many years on the road, she longs for a stable, MCS-safe community. She has been unsuccessful but relentless in her efforts to organize this community. My guess is that she will succeed someday, but until it happens, she still jumps from one public land to another, as she can not afford campground or trailer park fees living on SSDI.

If one is disabled, and can prove it, one can acquire a pass that allows you to pay half price on national and federal parks. This includes national forests and conservation corps lands, as well as national parks

The depression and isolation one can feel from living with MCS is devastating. When every person you come in contact with may be a potential "germ" or bearer of toxicity, it becomes necessary to just stop connecting.

People with MCS, from necessity, live in incredible isolation. Yet we still manage to keep being independent and keep on keeping on. Sometimes I really don't know how the hell we do it.

People who find out about my disability-generated refugee lifestyle will say, "Gee — aren't you afraid to travel, live, be, fill-in-the-blank, alone?"

Of course I am! I tell them. I am a disabled woman traveling alone, camping out in isolated places and everyday campgrounds — of course I am scared! But I am more afraid of not being alive. And if I were to stay at home during the coldest part of the winter, I would die.

My MCS friends are in the same boat. If they remain in a toxic environment, they can die from neurological or respiratory illness.

Right now, very little is being done for people with MCS. Some of us try allergy-type treatments. Others use pain killers. Some of us get some supportive therapies. Mostly, though, even within the disability community, we remain isolated and segregated.

Two years ago, while camping at some national lands, I came across a man who never even told me his name. He appeared to be living out of the back of a truck that had a small camper on it with a homemade canvas awning that extended out almost over his whole site. It included quite an elaborate camp kitchen. The camping land on which I met him allows two-week stays — but you could stay there two weeks, pack up, leave for 24 hours, and then come back; you could do that three times (that is also the regulation for Florida state parks).

I stopped to chat with this gentleman a few times, and soon caught on to the fact that, whatever else he had going on, he also had some psychiatric disabilities. Since a lot of his stuff was camouflage-colored, I ventured to ask if he had been in the service. Yes indeed, he told me; he had been to the Gulf War. He informed me that he "suffered" from post traumatic stress as well as multiple allergies from exposure to unknown chemicals. He found that he could no longer live in houses, he said. He wasn't sure whether it made him sick, crazy, or a combination of both, but he felt better living in his truck, he said. I had a number of conversations with him, and often only a small portion of them could I really decipher, but I did figure out that he probably had MCS, and was affected neurologically by chemical exposure, both then and now.

He was receiving Social Security benefits, and was fighting for Veterans' benefits as well. I can only hope that now that they know about Gulf War Syndrome, he has been appropriately compensated, and is still managing to live his life, somewhere, somehow.

I have met many homeless crips hiding out in national and state parks. Some had MCS, some didn't. All were living in poverty, fleeing one place for another. What we all had in common was our tenacity for living.

‘We are the canaries in the mines’

One of the most painful things that crips with MCS have to deal with is the fact that most people with disabilities exclude us, discriminating against us in their non-air-filtered, carpeted independent living centers filled with crips who have dosed themselves in perfume, disinfectant, hairspray and the like.

The National Council on Independent Living has issued a policy stating that no scents or perfumes be worn at meetings. But just last week I spoke to an independent living center director, reminding her not to lay carpet in the new center being planned. They had planned on having one room remain uncarpeted, she told me. It would have a separate entrance.

I had to point out to her that in that case, folks with MCS would still not be able to work there.

This interaction is indicative of where disability rights appears to be regarding MCS access and reality.

My message to those of you involved in independent living centers — and in planning crip events — is this: Please stop excluding us. Please start taking MCS access seriously. Remember: we are the canaries in the mine, alerting others to what may soon be in store for them as well. You too could catch this "disease" just from living in the toxic environment of the 21st century.

The next time you make the decision to put down "sick-making" carpeting in your office, remember: the next person it could be making sick — and segregating — is you.

MaryFrances Platt is "a drooling, plugged-in, wheeling, broke-down, radical crip who often lives in her van and writes about it!"

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