

# Too Sick for Help?

Getting a bed-bound person to the doctor should not be impossible.

by Galen Warden

One of the greatest challenges for every person with Severe ME (Myalgic Encephalomyelitis) is getting medical care. It's almost impossible to get care for standard injuries or medical problems if you can't get into a wheelchair. If you can't sit up at all, suffer with extreme neurological overstimulation, can't tolerate light, sound, or conversation, you will not get help for your injured foot, your irregular heart, your broken tooth, or your infected eye. No specialist will come to your home.

So maybe they'll let you come to their office on a gurney. Not all of them allow this. Let's say they do allow it. Who will come to your house to pick you up from your bed, put you on a gurney, and drive you to the appointment?

If you live in the US and don't have Social Security Disability and Medicaid, the answer is very likely no one. No private non-urgent medical transport wants to come to your house and take you to a doctor's office on a gurney.

The most severely disabled, suffering the most every moment of every day, are completely abandoned by a healthcare system that assumes anyone not needing the emergency room can get in a wheelchair.

My son, James Strazza, has Severe ME. He has been 100% unable to get out of bed since January, 2020. He can't sit up. He can't use a wheelchair. Here is the story of James getting to the MUSC Dental Clinic one year after his filling fell out, and four months after the same tooth broke in half. This is what it took to get a bed-bound person with Severe ME's teeth looked at in the U.S. in 2022.

## The Worst Possible Service

After his June 27th, 2022 Dental Clinic, which James had waited eight months for, was cancelled because our non-urgent medical transport failed to come, I made numerous calls to Modivcare, the Medicaid transportation provider in South Carolina. I posted my flaming outrage in every feedback form.



The van Warden rented to transport her son to the hospital on a mattress when ModivCare failed to come.



Warden installed a ramp prior to the appointment, in case not having a ramp had scared off medical transport companies who failed to come.



James Strazza in the MedTrust ambulance, thanks to the heroic efforts of many individuals.

I even used a form for employees to report abuses on the job. I got calls back where I further detailed the injustice and harm they had done by failing to provide a ride for James to the dental clinic he'd waited nearly a year to get into.

I said to one woman, "Take a little hammer, doesn't have to be big, and knock on your tooth so it breaks in half. Now wait eight months to go to the dentist because you have special needs and no normal dentist will see you.

"Next, don't go to the appointment you've waited eight months for because you have no ride, and wait four more months so that you have exactly one year from injuring your tooth to getting it looked at. Use all the pain management available to try to calm the tooth on bad days. Eat only soft food and nothing with little pieces, like rice, that can get into the hole, for the next four months. That's what you've done to my son."

I learned that this is a national company with government contracts in many states, including Florida and Georgia as well as South Carolina. I found newspaper exposés, 1-star ratings, too many complaints to remember. In other words, the government is giving millions of dollars to a wholly incompetent provider. A provider for the poor and the disabled... a too-sick-to-fight vulnerable population. We are expected to lie down and take the worst service possible. Not providing the service at all, with zero consequences, is the worst possible service.

The MUSC Dental Clinic had rescheduled James for October 31st, and I had two people at Modivcare working to help ensure that James had a ride, a national customer service person and someone in South Carolina. Between the two of them I was guaranteed to have a ride. Guaranteed, I say, to have a ride for the newly scheduled Monday, October 31st Dental Clinic appointment at MUSC in Charleston.

### Another MotivCare Ride Cancelled

At 5pm on Friday, October 28th I got the call. The transportation provider to whom Modivcare had assigned our ride could not come on Monday. Their one gurney had broken that day and they had no gurney. I was absolutely dumbfounded. I asked the guy on the phone, "When did it break? At 5pm? Or did it break at 11 am and you're just telling me now?" He told me he didn't know. He just had me on a list to call.

What kind of options do you think are available at 5pm for gurney transportation the next business day? Zero. Zero. Zero.

I'd tried in the past to use the 911 ambulance service, in spite of how awful it would have been for James to go through the Emergency Room for his appointment. But no 911 call made in Beaufort will take us 50 miles away to MUSC in Charleston for an "emergency." Their distance is limited to the closest hospital.

So, with no time to call and rail at Modivcare regarding their "guarantee," I immediately switched into mama bear mode. I was going to do whatever it would take to get my son to that appointment. I called all the South Carolina transport companies I had in my phone –

from before and after James got Disability and Modivcare – to see if anyone happened to have Monday morning available. We'd made the new appointment for 10 am, in case that 4am pick-up time had been a factor when the ride in June failed to come. But no one was available on Monday. I begged. Believe me, I begged.

### Mama Bear Desperation Mode

Next, I began searching my area for a panel truck I could rent and put a mattress into. I found one only a couple of towns away and reserved it for Saturday morning. I have a sweet foam mattress on a single bed in my guest room, so that seemed like the next best idea.

Just when I was celebrating my genius work-around, I ran into the next hurdle. The firemen, who had often come to lift James from his bed onto the gurney and down my front steps, would not come. They said they really wanted to help, but their supervisor prevented them from putting James into an unsafe vehicle. A van with a mattress isn't exactly "standard of care" for a disabled patient. And it was futile to promise that someone would ride with him and keep him safe in the back.

In three hours I had failed with other transport companies, booked a U-Haul van online, and spoken to the fire department. It was now around 8pm Friday evening. I posted an urgent message in my neighborhood Facebook Group looking for volunteers to help me get James from his bed to the van. I live in a fantastic little neighborhood right between two military bases with many wonderful young marines among my neighbors. I soon had volunteers willing to help, but they had a lot of concerns as well. No one felt the mattress idea was safe.

One of my neighbors is an EMT (Emergency Medical Technician). She reached out and volunteered to find a company that would take us. She spent Friday night calling friends at ambulance services from Savannah to Charleston whom she'd worked with in the past. She came up empty.

Saturday morning my friend took me to pick up the van. It felt so optimistic to see it sitting in my driveway: one sure thing. I figured as long as I had the van, I had the rest of Saturday and Sunday left to figure out getting him into it. Until someone brought up an additional challenge. Sure, the hospital would take him out of my van and put him on a gurney and into the hospital, but would the hospital folks put him BACK in my van, or consider it too unsafe?

I called the hospital. The person who answered the phone told me they thought it would be ok. There was really no one to ask. They said it would be up to whoever was there at the time. That was not a guarantee, but it was good enough for me to continue on my only known path of the mattress in the van.

### Heroes Appear

It was sometime late Saturday afternoon when I got another call from my neighbor, the EMT. She said she couldn't sleep Friday night thinking about James, but when she saw

the van in my driveway Saturday morning, that took her to a whole new level of concern and determination to help. So far, she had not found anyone to come Monday morning, however she did have one company she was really working on. She felt like she might get somewhere with them because she was friends with the owner. She told me she was not giving up and encouraged me not to give up either.

Sunday morning, that's right, Sunday! I got the call from her that the owner of MedTrust Ambulance Service had decided to be our hero. She gave me a number to call, and told me exactly what to say. But the guy who answered the phone would not book us. He said no equipment and no personnel were available Monday morning. I told him the owner had told me to call and he was arranging everything, which was what I was supposed to say, but he didn't buy it.

My neighbor had convinced the owner to be our angel in that moment of need. He'd called in favors to make it happen. None of his equipment was available to book, but he had found someone willing to loan him an ambulance. No people were available in the schedule, but he'd found two people to come who were not supposed to be working Monday. I can't help weeping as I write these words. All of these heroes are emblazoned on my heart.

The ambulance cost just under \$2,000 for the roundtrip ride, and I had already paid \$300 to rent the van in my driveway. But I didn't care. Nothing was stopping me from getting James to that appointment.

### Dental Clinic Appointment

Monday morning came and everything went so smoothly. The ramp I'd had installed that same month, just in time for this exact appointment, made it much easier for everyone, including James. Bumping the gurney down my front steps was always very difficult on him. The driver and the person who rode with us in the back were so kind and gentle with James. As always, I had prepared them for being super quiet, even though he had his headphones on.

Because this was an ambulance, they had to be available for emergencies and couldn't wait for the duration of the appointment. I would need to call dispatch and wait for the ride home when James was done with his procedures.

When we arrived, the dentist, anesthesiologist, and surgeon were all wonderful. We discussed exactly what would happen, starting with general anesthesia. While out, they would clean his teeth, x-ray him, do all the fillings he needed and extract any teeth that had to come out. They assured me his black satin eye mask and noise-cancelling headphones would come off after he was out and be put back on before he woke up.

I waited in the vending machine lounge on the same floor. I lingered calmly. A boxed cob salad—surprisingly good—and a couple of bags of chips later, I got the call that he was ready, and everything had gone well. The head of the clinic met me outside of the little room they were able to put James in post-op. I gave her a big hug. I felt so seen and so

held by her. She had traveled this whole journey with me, through the crisis of not getting the ride in June, me crying on the phone, to finally getting there and taking such good care of James. I called the MedTrust dispatch line and was told that, unfortunately, it would be a couple of hours. But I didn't care. James was resting quietly in his own little recovery room off of the larger area.

### Rage, Tears, and Relief

Our transportation saga became the topic of discussion in the post-op area when I had to be escorted into the hallway because Modivcare called. I had left a message over the weekend for the customer service person who had "guaranteed" our ride. When she called Monday afternoon, I was standing in the post-op area outside of James's room.

I went into such an emotional zone when I heard her voice that I became unaware of my surroundings. Two of the nurses gently escorted me out into the hall as my volume rose, one on each, side gently touching my elbows. My face turning red, tears starting to flow, I described my weekend to the woman on the phone. She didn't have much to say, except to confirm that I had found a ride after all. Yes, I had hired a private ambulance service at the very last minute. Like a miracle. When I got off the phone I realized I was standing in the hallway. I was both emotional and furious. Did this woman think, "All's well that ends well" because we did get a ride?

I put it out of my mind. I had said my piece. I took a deep breath and leaned hard against the smooth tiled wall. If there had been a chair in the hall I would have sunk into it like a passed-out drunk. I was out of it, so wrung out with emotion. It was over. James was ok. We had made it. I had said my piece to the woman who had failed me.

We waited for about three hours for the ride that would take us home. It was dark when they came. James was well cared for, though. Now and then a nurse sprayed Chloraseptic in his throat because it was sore from the breathing tube. They gave him IV Advil for pain and Zofran for nausea until they took the IV out. A male nurse helped him pee in a urinal. Warm blankets kept coming. Seriously, I felt like we were in a spa, not a hospital, with all the kindness and attention we were getting.

We were the last to leave, the other outpatients had their rides already. One of the nurses lowered the lights for James as we left his little room and passed through the larger post-op area. I wanted to send them flowers, but life being life, I never did.

On the long ride home, I stared out the windows of my dark, quiet gift of an ambulance. Alongside the road, low-country tidal waters reflected a cloud-draped crescent moon and a few of the brightest stars twinkled between upcroppings of spartina grass. I learned in gently hushed conversation that the people taking us from MUSC to Beaufort that evening had come from Greenville – three hours away.