

*From Your Editor.....*The Joys and Perils of Travel

I just returned 2 days ago from a weekend at the "Rivah", (that is Richmond speak for "River"), and I have decided to set aside the column I had written and create a new piece. My son-in-law, Neil, is far more disabled than I. We had a good discussion about our stay and how our disability affects our travel. I learned about roadblocks that I have not encountered. I thought it would be good to address some of those. Before I do that, I'd like to comment on a few trips I've taken.

Now, if you remember some of the things that I have written you will know that I have had some experiences that were totally joyful. I went by train to NYC in '03 in the middle of a blizzard. The streets were almost empty. There were no lines in front of the Christmas windows. Cancellations were the order of the day and we were able to go to great places with no reservations. When I was stuck in a snowdrift in front of the Plaza, some men came and lifted the wheelchair out of the drift! All was good.

My husband and I took a train out of Washington to New Orleans in the 90's. That was a little iffy only because there was a sewage smell in the bathroom in the compartment and we were stuck with that compartment. The train home was better. Our "accessible" room in New Orleans was accessed via a ramp that seemed almost perpendicular. Coming back down the ramp in the a.m. was a rather dangerous wild ride. We had them change our room. I'd rather not have grab bars, etc. than take my life in hand each day. Still, it was a great trip.

Twice we have rented houses at Nags Head. The first time was perfect. The second time, the elevator stuck between floors. It could not support the weight of me, (don't ask), and the wheelchair. I just sat there stuck until the motor cooled. Then I pushed the down button. When I reached the ground floor I rolled out. Since I can walk a bit, I left the chair on the ground floor and rode the elevator to the living area. It was not perfect like the first house but it worked. However, if Neil had been there in early days of his illness, it would not have worked for him.

Now I no longer try and rent a house. The family has increased and multiplied and they are down there in several houses (no elevator). So, there are times I go and do driveway visiting. We might go out for a meal and then I visit in the driveway. Then Neil, Sue and I go to a motel. Not great but it is good to visit.

You get the drift. So, let's go back to this past weekend. Neither my chair nor Neil's chair fit through any door into the house. (I forgot my crutches but one entrance had a tiny step and a rail.) My sons helped Neil up the steps. We

found chairs and pretty much spent the weekend sitting and watching everyone run around as they paddled kayaks, fished, boated, crabbed and swam. We were limited in our activities (reading) but we enjoyed the family, especially the children.

Although Neil did not have polio, he did have GBS, French Polio, and his paralysis was every bit as devastating as mine was and his recovery cannot hold a candle to the recovery I made as a child. After I returned home, I called Neil and had him tell me more. (I think it is good to remember that we are constantly changing and it might be good to look at other travel options.) I asked him to walk me through some of the preparations he and Sue make to take a big trip. This is the 3rd. summer that they have flown to National Parks since he became ill. Each year it is a tad easier but not by much. Since Sue is working, Neil is in charge of scoping out things for the trips. He starts by finding a city near the area they wish to visit that can provide them with an accessible van. He has had good luck with "Wheelchair Getaways". Then he looks for power chair rentals in the same city. That tends to be a bit harder as some places have scooters but they think of them as wheelchairs. Neil cannot manage a scooter because one needs the use of one's hands. So, he has the agency send him a picture of the rental chair to make sure it is a chair! After that he investigates flights and hotels/motels.

They mail a bath chair out to their first stop. Since they were using it this past weekend and are leaving for California in a few days, it cost \$60 to mail it so it would arrive in time. (It usually costs about \$15.) One big stumbling block for them, at first, was finding "family restrooms". Until recently Sue had to help in a bathroom. At LAX two years ago, they had to use the airline employee's restroom as there was no bathroom that would work for him.

Fortunately Neil is a list maker. Now that they have travelled a bit, he can almost use his old lists. He needs spoons and a strap that attaches to his hand and holds the spoon. He can't read a real book so he has to bring an e-reader. Sue has to do the medicine packs. And the list goes on and on.

He won't ship his good chair in the belly of the plane. That is why they rent a chair. He needs a pushchair to get him into the airport and to the gate. The first year he needed an aisle chair. Now they get seats right by the door and he can take the few steps to the seat. I asked him how he manages the restroom on the plane. He says he does not. He restricts fluids the day before the flight and the morning of the flight. The first year he had a condom-like external catheter that was connected to a bag that was strapped to his leg. Now, he just hopes he will be o.k.

Neil thinks one downer is that there is not much room for spontaneity. What happens to their reservations if they decide to stay extra days in a favorite spot? Anyone can have things go awry but when it happens to us, the disabled, it can have a huge affect.

I talked to one of our support group members and asked how he handled some of these problems. He immediately started to talk about the difficulty of using a restroom when one needs help and the person assisting is of the opposite sex. He said you just do whatever you have to do. Once, when he was still able to handle things himself, he slipped on a slippery floor. It took so long to get him back on his scooter, that he left and realized later he had been so discombobulated that he forgot to use the facility! He and his wife have had a few unsettling experiences regarding accessible restrooms.

This article is not meant to discourage travel because travel can bring great joy and renewal. There are hoops to jump through and mountains to climb and, with careful planning and a realization it might not always be easy, one can meet those challenges. I suppose I am in awe of the amazing spirit of those of us who face many obstacles and soldier on to a fullness of life.

Mary Ann Haske

P.S. I just received a picture of Neil & Sue in Yosemite. The rental wheelchair is so huge it could hold Sue & Neil. They had to remove one arm so he could fit in the van and through doorways. I guess the agency thought, when he said he was 6'5" that that was his width!