



I Get Around

ELIZABETH ANN SCARBOROUGH

I became urgently and personally interested in disabilities, in particular limited mobility, at age 60. That's when my knees announced to me that I was not a kid anymore, and I was going to find out what aging and pain were all about. I had no medical insurance, and had not had any for the previous 20 years because I couldn't afford it.

Even after I got into the Veterans Administration health care system, due to my time working in the Army Nurse Corps on the orthopedics ward in Vietnam during the war, they ironically would not help with my knees, which were not considered a "service-incurred disability." They gave me a few exercises, a knee brace that kept slipping down my leg and arthritis medicine my lab work showed was damaging my kidneys, so I had to stop. Oh, and they gave me a walker so I could sit and catch my breath just to make it around the hospital. My request to talk to an orthopedic surgeon was out of the question. This was not encouraging.

In spite of the exercises and the Tylenol, my knees grew increasingly painful. I even began to deliberate about how badly I needed to leave the couch to walk the few steps to another room in my small house. I could drive, but a trip to the grocery store was torture until a friend, who had been disabled for some time, told me to stop being an idiot and to use the mobility shopping carts I thought were for "really disabled people."

My body wasn't the only problem. I was depressed. I couldn't concentrate to write, which is my profession. And the pain greatly limited my abilities to do other things.

I felt as if I'd been short-circuited by my knees; I still had a lot to offer that I no longer could. Instead of helping me return to productivity, society was throwing me away, much like the joke about the rich man who trades in his car when the ashtray is full. I was short-tempered and impatient, and ashamed of myself for being that way.

Finally, my knees began buckling at times, and

that was scary. I decided to see an orthopedic surgeon outside of the VA system. He told me to have both knees replaced as soon as possible, because the bones in my legs were eroding from the bone-on-bone friction. He considered it enough of an emergency that he and the hospital both donated their services, for which they have my eternal gratitude.

MOBILITY MATTERS

With "bionic" knees and physical therapy, my legs are much stronger than before the surgery. I can drive and do chores on my own, but I still need to sit down frequently to catch my breath and ease my back. If I must go where I have to park a few blocks from my destination, I usually enlist a friend to take me there.

It's inconvenient but it has made me acutely aware of similar problems other people might experience, compared to which my own are fairly mild and uncomplicated. I communicated with more than a half dozen friends and acquaintances about the ways environments and transportation provide barriers to their mobility, in the hopes that health care systems and communities will modify or better provide services to those with impaired mobility. I left last names out of this article to preserve the privacy of those who shared their sometimes very personal stories.

Two of my friends are polio survivors who have coped with pain and limitation much of their lives. In addition, both are diabetic and have to consider how to accomplish something well ahead of time to travel where they need to go, to





acquire and transport necessities or to keep medical appointments.

I've known Susan when she could get around on her own with a cane, and later crutches, then a walker until now when she needs a motorized wheelchair. Although she loves the access bus provided by Kitsap Transit in Washington, its shocks aren't the greatest, and it hurts her to ride very far strapped into her chair. She wears a neck brace to lessen the impact of bouncing around when the bus hits bumps or potholes. She pays two dollars in each direction or purchases a paperless pass for \$25 a month.

With 24-hours advance notice, the access bus takes her most places she wants to go, and it has a reputation for staff who get passengers safely to their destinations. But recently the switch on her power chair broke, so she can't brake. If she can't apply the brake, she can't take the bus. "Til it's repaired, she's stuck at home. A mutual friend brought her groceries and took her out in her manual wheelchair, but the friend lives too far away to be able to help often.

TIRING TRAVEL

Jessica, the other friend who had polio as a child, has had an adventurous life. She spent much of it in Norway and Scotland. She is a writer, an illustrator, a healer and a teacher. Her skeletal and joint problems are not as much a factor as chronic shortness of breath and pneumonia, pulmonary after-effects of the polio. Doctors in Scotland advised her to return to the States, to a place with a milder climate. Poverty has complicated her ability to cope with some of the physical problems until recently, when a kind neighbor "adopted" her. She describes eloquently what it was like for her before that happened. With her permission, I include some of her account in her own words. Jessica begins by saying her father gave her his old Volkswagen dune buggy:

"... I was 45 miles from the nearest supermarket. To go shopping, I had to drive into town, rest a half hour in the car, go into the store and gather part of what I needed, rest another half hour, finish shopping and get things in the car, rest another half hour, drive home, rest again, unload the car and put food away, feed the cats and collapse in bed until the next day."

She was unable to return to work, collapsing when she tried. She was asked to write a book to accompany a deck of tarot cards a friend and former student was creating. The advances allowed

her to pay rent, feed her cats and buy a bit of gas, although often she was too exhausted to drive. Her children wanted her to move closer to them.

"During this time, I had regained most of my mental and emotional balance, but never really gained much physically, so transportation kept being a large problem — and it got worse. My car died as soon as I got here, and I had to take the bus.

"It took walking a half mile to the bus stop, one bus into the edge of town and another bus to the store. I couldn't manage a week's groceries on the bus and walk, so I had to have a taxi bring me home. Of course, taking a taxi meant spending less and getting cheaper food. I still remember how I had to add the food up as I shopped so I'd still have enough for the taxi. There was one month when it basically amounted to buying only raw beans.

"Even without the money problem, fixing myself decent food was never easy — standing and walking were both very painful. Then I got pneumonia again and was completely out of it for three months."

She said she became so depressed during that illness, she wasn't certain she wanted to live any more. Her cats brought her comfort, and she reminded herself that they depended on her. As she recovered, she realized that a good part of the depression was caused by the pneumonia itself.

Others described their own challenges.

My online friend Susan Mac has recently had a stroke, and she laments that her town has only school buses — no public transportation for people like her. She relies on her husband to provide transportation to the doctor and therapy.

Gloria, another friend, takes three buses, spending five or six hours on buses for a one-hour appointment with her doctor. To get to the Bargain Market three-tenths of a mile from her house, she must: "Uniform-up service dog. Take cart down off wall. Walk over to store, shop, return home pushing cart full of food. Put food away, then rest for an hour before doing anything else."

A PATCHWORK OF OPTIONS

Kevin, a resident of downtown Indianapolis, lives in an apartment on a main street and uses a walker because of an arthritic hip. He lives by routes for three buses and details the different buses he must take and transfer between to get to where he's going. Two of those bus routes aren't within two blocks of a grocery store, though one is.

"These buses go by a clump of shops including a small Safeway, a CVS, a branch of my bank,

a kids' bookstore, a cafe/bakery and some other shops. The next stop past this clump is a private club with pools, exercise room and dining facilities. Membership is about equal to 'the Y' so I can get to someplace to exercise, if I'm so inclined ... I can get off at one stop and hike three blocks to my doctor's office building on one side of the street and across the street, the hospital where I have an appointment twice a week."

Kevin uses Open Door service, a minibus with a wheelchair lift and door-to-door service. People must arrange for a ride on it the day before and pay a fare.

"And if the bus is full of other riders, it can take hours to get home — they have to take people all over town. My ID for this service gets me free rides on the regular bus, which is good."

CURB CUTS AND TURF WARS

Even if you're able to drive yourself most places or can catch a ride, there are still issues waiting to trip you up, sometimes literally. Several people mentioned struggling with curbs that don't have cut-outs. These are pretty tough for a wheelchair or power chair-bound person to navigate, especially if unaccompanied. Curbs that were too high and lacking any sort of hand rail are also difficult and dangerous for someone with knee, hip or certain back injuries.

At outdoor events and at cemeteries, wheelchairs, crutches, canes and some power chairs sink into the ground, rendering the sites inaccessible. One woman said, "Fairs are always in the turf. I cannot maneuver the turf with my contraption. So no Kids' Fest, no Farmers Market." She's also limited by the two-hour limit on her supply of portable oxygen.

Cooper, a property owner in a small town, said he has six tenants with disabilities. The nearest hospitals are 15-35 miles away. "There is no regular bus service to one hospital, semi-regular bus service to another, and none to the rest. They [the tenants] live here because they can't afford to live anywhere else."

The tenants usually have at least a hospital visit or two a year. He said most of the time he closes his business to take them or pick them up, if they've had surgery, so they don't have to take a taxi home. The tenants, especially two with heart conditions, struggle to complete the distance from a handicap parking spot to the waiting room. He

brings a stool so they can stop and rest if needed.

Karen, who is in a wheelchair, wrote, "The worst part of being disabled is becoming an involuntary social recluse. My 'social' life is online, period. There are supposedly groups/meetings, etc., but as far as I've been able to find out, all of them require that one provide one's own transportation."

Susan, my polio survivor friend, has a different take on that subject, however. After we first spoke about how she coped with her transportation situation, she called me back and said, "I forgot to tell you a really important part of my use of the access bus. It's the social aspect of it. I am a shy person and had been very isolated until I started taking the bus. At first I just kept quiet when I rode. Then one day I asked another woman a question, and she consulted someone else and pretty soon we had a discussion going. Now it's like all of the people who ride the bus, including the driver, are my good friends. We look after each other too. If someone doesn't appear when they normally do, the driver will ask the transit company to look into it, maybe even call for a health and welfare check by the police. People really care about each other, and we understand each others' problems. I really miss my bus friends when I haven't seen them in awhile."

Accomplishing tasks and making the trips that "temporarily able-bodied" people may take for granted is more difficult for those with disabilities, but it seems such trips are necessary for more than their immediate goals. Whether it's the need to reach out to someone for help, or to bond with others over common needs, staying connected in spite of the difficulties does require people to break through the barrier of isolation that can turn physical disabilities into life-threatening states of mind. Important as the goal of a journey may be, how you make the trip can be less important than who you go with or meet along the way.

ELIZABETH ANN SCARBOROUGH lives in Port Townsend, Wash., a Victorian seaport town popular with retirees. She became a registered nurse in 1968, then joined the Army Nurse Corps, serving as a clinic and med-evac nurse in Alaska as well as in Vietnam. She has published over 40 novels and numerous short stories and articles. Awards include the prestigious Nebula Award for her 1989 novel, *The Healer's War*.

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