

## 9

# Daily Life

While homemaking and running errands involve things most people take for granted, such routine activities can be a lot more complicated for people who are deaf-blind. A hearing-sighted person can pick up the phone and call a plumber when the kitchen sink leaks or hop in the car when it's time for an appointment with the family doctor. But how would you handle these things if you had multiple sensory disabilities?

Some deaf-blind people are fortunate enough to have someone to help them with their daily activities, but many do not, and all have to rely on themselves sometimes. Even the most mundane tasks can create significant stress for people who are deaf-blind and require far more effort and problem-solving thought.

Here, the contributors talk about how they approach managing their homes and tending to errands.

### Angela C. Orlando

Homemaking is a topic that makes me want to cringe. I've seen professionals and non-deaf-blind people talk about homemaking as an indicator of success. Barbara Walters marveled over how incredible a certain deaf-blind man was, simply because he could cook a meal.

Well, guess what? I don't like to cook, and I don't like to clean. It has nothing to do with ability and success. I'm just not interested. I'm never going to be. Yes, I can do it. I've lived in an apartment with other young women. I lived in an apartment with a man. I lived in a house with my husband and son. I took care of my home. I just didn't like doing it. It has nothing to do with my disabilities. It's just who I am. Some people like to do chores and some don't.

I live with my parents now. It's their home. My dad does the yard work and home repairs. My mother does most of the cooking and

cleaning. My job is to care for my son, keep our rooms clean, and put away laundry. It works for me.

I've had training in cooking and cleaning. I have many kitchen gadgets to help me. For example, I have a George Foreman grill, microwave cooker for rice and pasta, and a microwave gadget that hard-boils eggs. I have Braille measuring cups, tongs for the toaster, other utensils, and long-armed oven mitts. People who are deaf-blind can use many of the same items that blind people use. We just need to avoid the "talking" ones.

I have Braille labels on food and cleaning items. These labels have both Braille and print. That way, my parents can put the labels on while putting away groceries. I rely heavily on these labels to identify what I need. Sure, I can use my sense of touch and smell. But there are some items I just don't want to sniff.

I have an electric sweeper. It works on both hard floors and carpets. I don't have to worry about sweeping messes into a dustpan. It goes right into the machine. I just remove the bag when it gets full.

I don't cook and clean as much as I should. But I *can*. I've got the skills. I just lack the desire. Someday, my parents won't be around to help me as much. That's when I'll have to do more of this on my own.

My parents drive me to appointments or shopping. They'll take me wherever I need to go. They also help a great deal in getting my son to his many activities and parties or play dates.

Earlier this year, I began using our local transportation service to get to my ASL classes at Kent State. I ride on door-to-door service. They pick me up at my house and take me to the exact location I need to go. I'm the first deaf-blind person ever to use this transportation service here. They had a difficult time understanding my needs at first. They have to come into the building and tap me on the shoulder. It's the only way I'll know the bus is there (I have no vision and cannot hear speech now). They also must take me to the exact location and the exact same door every time. Otherwise, I won't know where I am or how to find where I need to be in the building.

We've had so many issues. They wouldn't tap me, so I missed the bus, because I never knew it was there. They took me to the wrong door, so I'd be confused and not able to find my classroom. One time, they took me to the wrong building altogether and left me there.

It's been rough, but they finally seem to be getting the idea. This semester has been fine, no serious problems yet. I love riding the bus to class, because it's something I can actually do on my own. I don't want my parents to have to escort me to the classroom—that's embarrassing. I'm an adult; I can do things on my own. I just need a little extra help. The transportation service makes it possible for me to achieve this bit of independence. And that makes me feel a little bit more like a normal person.

### Christian S. Shinaberger

Mostly, I've lived in houses. When I lived in a dormitory for three years at UCSD, I used the cafeteria and going out with friends for meals.

I liked the laundromat on campus. The washers had three choices: cold, warm, and hot, and I could remember which was which without the benefit of vision. Doing my laundry was very easy.

In the dorm, I always got a single, which suited me just fine. I didn't have to worry about my Braille equipment being stolen.

I also had an experience in high school one summer when I lived in an apartment for one month, alone. My mobility instructor helped set it up. I was already familiar with basic laundry and cooking, although I didn't cook much when I was alone.

As for homes, they have so far always been with my immediate family. I currently live at my mom's house.

I help out with cleaning in the kitchen. Cooking isn't something I do a lot of, but I do enjoy cooking with someone else, and I like to use our propane grill. We just got a new dishwasher here, and I don't have it marked with tactile labels yet. I'm sorry our old one finally died after about thirty years. It had real push buttons, which is damned hard to find on appliances these days (as opposed to touchpad buttons that cannot be felt). I still can't read Braille that well, even after the carpal tunnel surgery. Of course, some things just need a few raised marks.

I'm estranged from my sister, and most of my relatives live back east, or should I say, down south (in Georgia).

Yard work . . . well, I don't do much there. But on occasion, I do things alone, like trimming bushes. And sometimes, I help my mom do things outside. She often supervises what I do in the yard. We have gardeners at the present, so we don't have to do too much out there. My

regular outdoor work consists of taking the trash out front on Tuesdays. Nothing special involved here. We have three cans: recyclable stuff, general trash, and garden trash. I've tied a shoelace around the one for recycling, so I can identify it. The garden can has a dent in the lid, and the regular trash can is smaller than the other two.

I prefer gas stoves with real knobs when cooking. That is the most important thing for me. I should label things in the kitchen, but I don't cook that much. I'd like to find an easy-to-use talking thermometer for the grill and perhaps the oven. I use the grill more than the oven. But I really don't have any special gadgets for cooking at the moment.

Separating laundry without sighted help is the one task I dread the most. I can't tell the difference between dark and light colors. At the dorm, I had everything pretty much match, so it didn't matter what I grabbed to wear. But at home, the laundry is more complicated. Once someone helps me sort the colors out, I can handle the rest of the job on my own.

## Christy L. Reid

After leaving college and beginning my first full-time paying job, I moved into an apartment and lived on my own. The job was located in Baltimore, and my parents drove me from Poplar Bluff, Missouri, to Baltimore to help me find an apartment in an accessible location. We found an ideal apartment complex in a very good location that would make it easier for me to live on my own. The apartment complex grounds were set right next to a subway stop, and tenants received a key to the private gate.

There was a supermarket about a mile down the road from the apartment, and it was easy for me to walk there on the sidewalk. But getting back to the apartment with groceries was a different matter. I usually purchased a good supply of groceries, so my grocery shopping trips would be less frequent. I devised a sign using a big piece of cardboard and wrote my apartment address on it with a black marker. I taped the sign to my front door (I had a ground-floor apartment with a private patio) and left the outdoor light on over my door. Then I set off on foot for the grocery store. After completing my shopping, I asked the person assisting me to please call a taxi for me to take me home. I didn't

really like using cabs; I almost always had to wait for them for a long time. But there was no other way to get all those groceries home, so I was prepared to wait. When the taxi finally showed up, I would give the driver a printed note with my address and told him to look for the sign on my door. Thus, the cab drivers always found my apartment without trouble.

I didn't need any special equipment to help with household chores. But vacuuming the carpet and sweeping the kitchen floor were difficult and my least favorite chores. I used a broom to sweep under the kitchen counters and then vacuum up the dirt, but not before I checked the floor with my fingers for anything that might break the vacuum. Cleaning the carpet was a tedious job. Because I couldn't see if there was something that would damage the vacuum, I always had to brush my hand over the carpet first.

I enjoyed cooking and didn't really have any adaptive equipment in the days of my first apartment. I did have an electric wok and liked to stir-fry chicken and vegetables. Using an electric wok was easier to manage than a wok on the stove, and I could use my senses of touch and taste to help me know when the food was cooked.

I also had a crock pot, which was another easy way to cook my meals. In the morning before I left for work, I would put some chopped carrots and onion in the bottom of the crock pot and place a whole chicken over the veggies, add a bay leaf, cover and set it on low heat. This made a delicious, healthy dish that would last for a few dinners.

After living on my own for a few months, I married Bill, and we eventually moved to Silver Spring, Maryland, where we rented an apartment. We found an ideal location that enabled me to travel independently. I got a part-time job at Gallaudet University and also took a few courses in education. I was able to walk to a nearby Metro subway stop from our apartment and travel to Gallaudet. However, there wasn't a nearby grocery store, and Bill, who is hearing and sighted, would drive us to the store, so we could do grocery shopping together. Bill didn't mind cleaning the apartment's hardwood floors, so we had a sort of mutual agreement that he would take care of the floors, and I would do our laundry. Likewise, whenever Bill cooked dinner, I would clean up, and when I cooked, he cleaned up. This agreement has continued throughout our marriage.

After living in an apartment, Bill and I rented a small two-bedroom house near enough to the campus of the University of Arkansas at Little Rock (UALR) for me to reach on foot. I had enrolled at UALR to study deaf education, and the location of our house met my needs.

However, living in a house was different from living in an apartment. For one thing, it wasn't easy to find neighbors whenever I needed help. I had to either cross the street and find someone's front door or walk to the house next door. But most people were friendly and went out of their way to help. For example, I liked to put my son, Joe, in his jogging stroller and go for a walk in the neighborhood. One day when I decided to turn into an alley behind our house, I somehow got disoriented and got lost. I walked on and on, trying to find a familiar landmark. I really felt lost and started looking for someone who might help me. I finally turned onto an asphalt street with a white line near the edge that looked familiar, and as I walked a little further, I passed a woman who was getting something out of the trunk of a parked car. I stopped and asked her if she could please show me my house, telling her the house number. When she took my elbow to guide me, I realized she was a neighbor that lived a few houses down the street from us, and I knew exactly where I was.

As a deaf-blind mom, homemaking became busier. I learned a lot from caring for my first son, Joe. I decided before he was born that I would breastfeed him. I figured that, as a deaf-blind mom, it would be easier to nurse my baby than to make bottles, and I had read that nursing the baby strengthens the bonding between mother and child. Plus, there were the nutritional and immunization benefits of breastfeeding. All in all, it was a very good decision. But it was more comfortable than having to get up, get a bottle, and sit with the baby. As he got older and began eating baby foods, it sometimes got frustrating for me. I couldn't see his mouth and always missed my target, making a big mess. But mother and son learned together. After a while, my baby learned to grab the spoon with his mouth, so he could eat the food.

I had two more babies after Joe, Ben and then Tim. I cared for each baby very similarly to how I had cared for Joe. The main difference was that I got a cochlear implant (CI) before Ben was born, and, thus, I could hear Ben and Tim. When Ben or Tim cried or laughed, I heard it, unlike with Joe. I used a baby cry device to alert me when Joe was crying, though it wasn't that reliable. Usually, Bill would tell me when Joe was

crying, or I would keep Joe within arm's reach, so I could check on him. Maybe that wasn't such a good idea, because when he got older, he liked to sneak away. But with the CI, things were less stressful. I could leave Ben in his bassinet near our fish aquarium, which he enjoyed, while I worked in another room in the house. I could hear him if he cried.

When I go shopping on my own, I always go to the customer service counter and request shopping assistance. Even though my speech is good, I give whoever is working behind the desk a note that explains I'm deaf-blind and would like an assistant to help me find the things on my list. Then I show the person my shopping list and wait. Usually, the people working behind the customer service desk know what to do. They pick up a phone and talk into it; then a few minutes later, a store employee approaches me, takes the list, gets a shopping cart, and we're off. In my experience, the assistant usually gave me items that were on my list, so I could put them into the cart myself. After collecting all the items on my list, I would ask the assistant to help me go through checkout and write the cost of my purchases in very big numbers with a black marker on white paper that I always had handy. After paying for my things, I would give the assistant a taxi company's number and ask him or her to call and request a cab to pick me up. This all usually went smoothly, but it also always took a great deal of patience on my part. Having to communicate with people who don't know sign can be a little slow, and then the wait for the cab can take an hour or longer.

But this routine didn't always go according to plan. Once when Bill was out, I used my TTY to call and requested a cab to come and take me to the grocery store. The cab arrived and took me to the store. I got an assistant from customer service, and everything went very smoothly, until after I paid for my purchases and the assistant called the taxi company for me. The assistant spoke into the phone, and I assumed he was requesting the cab. Then he looked at me and took my notebook and black marker, printing in large letters, "Your address?"

To my great embarrassment, my mind went blank, and I couldn't remember my address! Flustered, I told him I couldn't remember. He turned back to the phone and spoke into it some more, while I wondered what in the heck was I going to do? I didn't know anyone to call for help; other family members were out of town that day, too. Gosh, I felt like a fool.

Finally, the assistant hung up and took my notebook again, printing, “Cab company found your address in their records.” Whew!

When we lived in Pittsburgh and Ben was almost four years old, I took him to all his doctor appointments at the children’s hospital there. Bill was in culinary arts school and working as a cook. I was a full-time stay-at-home mom, caring for Joe and Ben. I used the local transit bus service to take Ben to the hospital, because it was safer than public bus service and cost less than a cab. The driver of the transit bus helped to set up Ben’s car seat in the bus and then would leave the car seat in the lobby of the hospital. An interpreter would meet us and guide us to Ben’s appointment.

When I was pregnant with Tim, I had help from a woman who worked as a doula, a woman who helps a pregnant woman with prenatal visits and any other things and with labor. She didn’t know sign, but I taught her finger spelling. She drove me to most of my prenatal doctor visits, and Ben came, too, if he wasn’t in preschool. An interpreter would meet us at the hospital and help with communication.

I first experienced white cane training when I was thirteen years old and a student at the Missouri School for the Blind in St. Louis. I learned basic cane skills, like trailing the cane up and down stairs and sweeping the ground in front of me. I also learned how to cross intersections by following traffic patterns. However, I didn’t start to seriously use a white cane until I was in college and went off-campus to restaurants and shopping malls. At first, I found that the white cane was more like an ID, helping other people to understand I was visually impaired. Without the cane, I looked pretty normal—until I bumped into someone I didn’t see or couldn’t find the handle on a door. The cane helped other people to understand, and I appreciated that.

In the fall of 1997, I went to Leader Dogs School in Michigan, where I met Milo, my first guide dog. He was a seventy-pound yellow Labrador retriever, and he was the guide dog of my dreams. I had read quite a lot of stories about blind people’s experiences with guide dogs, and I was very inspired to have one of my own. Milo was a great match, very patient, calm, always wanting to please, and adaptive to different things we encountered together.

For example, Bill and I went on a long road trip along the western coast of Florida to Key West. Joe was about three, and he stayed with



my parents. Milo enjoyed the adventure. Wherever we stopped to explore, he was game and guided me along, following Bill. When we finally reached Key West, we went out on a sunset cruise on an old schooner. The sunset cruise trip offered free beer and champagne. It was mid-February, but I hadn't bargained for cold water and wind. The sun had been so warm that I was surprised at how cold it was on that schooner, and the waves were moderately rough, making the boat rock and the ocean spray hit me. Bill was busy behind our video camera, filming the beautiful sight of the Keys as the schooner moved around them. But I couldn't sit still while getting wet and cold. Milo helped me walk from side to side of the boat, trying to avoid the spray. I found the drinks table, and the free champagne helped to warm my blood. It was an exhilarating experience to have Milo guide me to wherever I wanted to go.

Usually, whether I used a white cane or guide dog, people didn't try to grab or steer me. Most people would stop near me, and I knew they were asking if I needed help. If I knew where I was going or if I was just waiting for Bill or someone, I would say, "I'm fine, thanks." If I really did need help, I would look for someone to help, like with a big intersection. In that case, I'd have a note to show a passerby that would ask the person to please help me cross the street. But I have encountered people who were too aggressive or too persistent with wanting to help me. On a Baltimore subway platform, a woman noticed me with my white cane. A train pulled in, but I knew it was the opposite direction from where I wanted to go. The woman grabbed my wrist and tried to pull me onto the train, but I shook her off and said I was waiting for the other train. Finally, she gave up and ran into the train as the doors closed.

After a little over eight years of working, Milo retired. I got a second guide dog, but unfortunately, he didn't work out, and I had to send him back to Leader Dogs. Now I use my white cane again, but because of my deteriorating balance, I use a support cane more often and feel more confident if someone is guiding me. My younger sons, Ben and Tim, like to hold my left hand, while I hold the support cane in the other, and we walk around in the neighborhood near our home. I may return to Leader Dogs for another guide dog, but for now, my children keep me busy enough.

## Judy Kahl

At the age of sixty-four, I can tell you I am independent only in my home. I do not venture out of the house without the aid of a sighted person. I am with my husband, friend, or one of my three adult children. They are all trained and know my limitations. It is difficult, especially in new surroundings.

Restaurants, unless they are fast food places, are normally too dim or too noisy for me. We always ask for their brightest table with the least amount of noise, and most of the time, it is satisfactory. If we're at a new restaurant, my husband will check out the table first before taking me to it. He guides me with his hand on my shoulder, or I hold his hand and walk behind him. I usually take one of my girlfriends' arms and ask them to walk just one or two steps ahead, so I know if they are going up or down a step.

As for shopping, it is best if there is a cart, like in Target or TJ Maxx, so I can stand behind the cart, and my companions pull the cart. This way, I can walk and look side to side so I don't miss anything and don't have to worry about obstacles.

I do find shopping exhausting, and I am always happy to return to my familiar surroundings. I also do not ask to be taken anywhere, but I have friends with whom I go to the manicurist, petite-clothes shopping, bargain shopping, etc. I try to spread myself out, so I am not too much of a burden to any one person—they don't like it when I talk like this, but it's the reality of it. I know it would be a drag to be a sighted person and have to tag someone along, so I try to be a positive, fun person and always pick up the tab for lunch and explain I'm not paying for gas. Sometimes they accept, and many times they refuse, but we very seldom go to a fancy place, as we are too busy shopping, so it could be a drive-thru.

I miss being able to drive (I could drive until my vision became too limited, due to Usher's syndrome), and I miss the independence. But once again . . . what are my choices? So I must make the best of it. This is just another reason I have chosen to keep myself busy and why I am so driven to make my BEE project successful—raising funds for FFB. It is only the funds that slow down progress, and I'm working myself silly, so we can wipe out blindness.

## Mark Gasaway

I have lived in the average American home as an adult, This includes a small home on my parents' land, a room rented from the facility I was employed by, several apartments (after getting married), and a condo. At each of the places, except the apartments and condo, I lived by myself. At the apartments and condo, I lived with my wife and a dog. Now I am divorced and share a condo with a friend.

I did not and still do not need any special equipment or technology to help me with any housework. I do everything the old-fashioned way!

I cooked and still do, but again, I do not need any special equipment to help me. I cook like other people might cook. However, reading oven and stove dials and frozen food containers is not easy. To help me with setting the oven and stove temps and reading heating instructions on containers, I use a handheld magnifying glass. I know where all the utensils and cooking things are kept, so it is not hard for me to find things. The kitchen is kept organized, as well as the entire home.

Sometimes, the vacuum cleaner would not work properly, and I had to do some tinkering to make it work. To do the tinkering, I had to rely on what I could feel rather than see to fix things, and did well in that category. At times, my vision was not good enough to see what I was doing, so I had to get down on hands and knees to feel.

Getting around is one thing I do the best! I have been able to get around independently ever since I can remember. As a youth, I walked down to the post office, food store, bank, and anywhere else I needed or wanted to go. I also rode my bike down and around town. My vision was good enough for me to do this safely, and I enjoyed the exercise.

Then I moved to Atlanta, where there is not much space to ride a bike the way I could in the small town. I learned my way around an area near a shopping center near where I lived in an apartment. That area also had a bus I learned to ride, and I still ride the bus a lot. I miss riding my bike the way I used to; I can only ride it when traffic is light on the street I live on. During the day, my street is crazy!

Where I live now (in a condo), there is a shopping center just down the street and a mall not too far from there. The mall has a lot of good stores.

My primary doctor is in a medical center not far from my condo complex, and I have a choice of walking there or riding the bus. If I need to go to another doctor or specialist, I can take the bus to a hospital not too far from my area.

Going out in public for me is a real confidence-booster and helps me learn where to go and remember how to get to certain places. It takes time and practice, but once I learn how to do it, it becomes easy, and no stress is involved.

I do not use any type of paratransit system [a low-cost transportation service for the disabled that provides rides, scheduled in advance, within a limited region] and do not think I will ever use it. I am on the transit authority advisory committee and have heard a lot of unpleasant stories from paratransit users. It is hard for them to use paratransit when it does not arrive on time or get them to a certain destination on time. These users spend a lot of time traveling on the paratransit (because of long routes that are designed to include other passengers, rather than go directly to an individual person's destination). A fifteen-minute direct trip by car can take an hour or more with paratransit.

I use both a cane and a dog, but only one at a time. I do not use the cane too much, now that I have a dog. My dog is a hearing dog but understands the guiding role, too. [Hearing dogs are trained to alert deaf people to certain sounds, such as a knock on the door or a telephone ring, but do not have guide training.] I use a cane when I go out without the dog but only in unfamiliar places. When I go out in familiar places without the dog, I just go as if nothing is wrong with my vision. It is not that I am uncomfortable with the cane; it is that I just know where I am and just want to feel "free." I am quite comfortable with the cane and dog.

Being guided by a sighted person is fine by me, provided this person is able to guide well and knows what to do when something happens. It is important for sighted guides to know sign language, as well, because I want to be able to communicate with them. Not being able to communicate with a sighted guide frustrates me and can lead to problems when something doesn't go the way I expect.

When strangers try to help by grabbing my arm and "steering" me, I simply reverse what they are trying to do and tell them what I want to do by grasping their upper arm or placing my hand on their shoulder for support. I tell them to walk in front of me or to the side so as not to be

in my way. If they continue to grab my arm, I stop and just stand there and let them understand what they are doing wrong.

## Melanie Bond

My husband does the shopping. Sometimes, I accompany him to the grocery store. Usually, he'll pull the cart along, while I hold onto the handlebar. When I go to DB (deaf-blind) camps and on DB cruises, I do my shopping with the help of an SSP (support service provider).

I don't have a problem taking a bus or paratransit, if a car is not available. I still have two good feet and don't mind walking to wherever I want to go.

I love eating out! I love walking the 17.5-mile riverwalk/rail trail in Bay City, Michigan. I love searching the online library catalog, which allows me to order library books and place a hold on them so that those books are set aside for me. My husband usually takes me to the library to pick up my books and drop them off when I'm finished with them. I always feel confident, as long as I'm with someone. I enjoy knowing that I can get out and do things like everybody else, for the most part.

I used to be real good about taking my white cane everywhere I went. But whenever I go out with my husband, I never take my cane because he loves to hold my hand and guide me. The cane is nothing to be ashamed of, although I do wish we could personalize our canes by choosing our favorite reflective colors. At first, I did feel a little embarrassed about using such a bright red and white cane, but I quickly learned that using my cane was like parting a sea of people, so that the way before me was cleared. I no longer care what other people think about my cane, because safety should be the most important consideration for any person who is blind or deaf-blind.

I do like being guided by a sighted guide. It's nice holding hands with my husband. It's nice being guided by an SSP who knows how to guide deaf-blind people properly to keep them safe.

When strangers grab my hand and start to pull me against my wishes, I shake their hands off and tell them that I prefer to place my hand on the back of their arm, just above the elbow, and tell them where I want to go. It's always so important to educate anyone that you come into

contact with, so they can learn more about our deaf-blind culture and ways of doing things in the safest manner possible.

I can see myself moving to a deaf-blind community and possibly to an assisted-living center that would provide me with deaf-blind services and accessible communication, if I ever find myself without a mate. I would not want to depend on my siblings or my grown children to look after me.

## Patricia Clark

In my teenage years, my disabilities were not severe enough to limit me in public. I was living at home with my parents so I did not deal with tradesmen or domestic shopping. Job interviews were horrifying and usually did not go well.

The years passed and I left home, and my sight and hearing became worse. The supermarket took care of domestic shopping, although I could not always find what I wanted or read the prices and could not ask questions, as I was unable to hear the answer. I simply found alternatives.

Appointments with the GP went quite well, but it's surprising how many specialist doctors do not understand the word "deaf" and just go on shouting when I ask them politely to write down what they want to say. In hospitals, I wear a badge that says, "My sight and hearing are impaired," as it seems easier for receptionists and others to read the badge rather than listen to what I say.

As well as being deaf-blind, I am now arthritic and can't walk far. Public transport is quite beyond me, but I can fetch a taxi with the telephone relay system. I ask the operator to let the driver know about my special needs. Drivers are almost always polite and helpful. I now rarely go anywhere alone, though.

I use a walker, and when I am out with service providers or even with friends, they may try to "steer" me. It annoys me, and you need to have a chat about it later. Sometimes, the helpers who are supposed to be helping will let a door slam in my face or fail to warn me of obstacles. Some are too zealous. Others don't think ahead at all.

I have spent most of my adult life living alone with increasing disabilities, and it has made me self-reliant. Since the age of twenty-five, I have been too deaf to use voice telephone, and to be alone without

help available in an emergency has been frightening. I had a TTY, but very few people had them in the 1970s. The computer with email and the telephone relay system have made life much safer for me.

Now that I'm of retirement age, the difficulties are closing in. My sight loss will soon prevent me from using the Internet for shopping, banking, accessing news (normal print is beyond me), and much more. My Braille display on the computer will give me text files, but it is impossible for a totally deaf-blind person who uses Braille to get training for Window-Eyes. My blind instructor can't write, and I can't hear speech or audio. Without help, my life will soon be very, very limited. I'll have nothing but Braille books and a stuffed toy for company.

### Tonilyn Todd Wisner

At different times in my adult life, I have lived in different apartments and a number of homes. At first, I was living in my family's home alone. I had already been diagnosed with Meniere's disease and become deaf but still had sight. I was limited in what I could do only by the fact that the Meniere's disease causes your body to use a lot more energy than normal. I did just basic dusting, really, and washed clothes and dishes. I cooked for myself without any special aids.

When the Meniere's disease became so severe that I couldn't live alone, I moved into my dad's apartment. He did all the cooking, and I helped with laundry and dishes. I also did the housework for the most part, just a little at a time.

Once I rehabilitated but was still limited, I moved away to a different state. My homemaking changed drastically then. I wanted my apartment to be clean, and most people I knew cleaned once a week. But I could only clean for about one hour at the most before I became too dizzy and nauseous. So I started cleaning one room a day. I had four rooms, so I was cleaning four days out of the week. I did my own laundry and dishes. I cooked for myself, but more often than not, it was TV dinners—I didn't like cooking for one person.

I was unable to drive and had my groceries and prescription medications delivered. That was the only help I had back then.

When I moved back to Louisiana years later, I got my own apartment, and everything was the same as in my previous apartment. A few years

after that, I met my future husband and eventually became engaged and moved in with him. I had someone else to cook for, so I started cooking again. I did all the housework—dishes, laundry, and housecleaning. The housecleaning became more rigorous, because he had six cats, two large litter boxes, and six medium-to-very-large rooms. I was still just as limited by the Meniere's disease, so I was pretty much cleaning and doing laundry and scooping litter almost every day—five or six days a week! It was hard, but I enjoyed knowing that my house was—hopefully—clean.

A year later, I developed the constant vertigo and was mostly bedridden for two years because of this. I mostly still made my own lunch when I could manage to get out of bed and attempted some housecleaning, but that was all I did. My fiancé, Keith, had to do everything else. It was during this time that I became blind.

After two years, the doctors found the problem and operated to fix it—which worked for a while. I didn't have vertigo, except for occasional Meniere's attacks. After I recuperated, I picked up where I left off. I started cooking again without any special aids. I cooked on the stove, in the oven, and in the crock pot. I cut things by myself. I developed my own safety techniques.

Then we moved to a smaller home, as the large house was becoming a big burden to take care of. It's not much smaller but a little more manageable. I was completely blind by this time. The vertigo returned, coming and going, and began to limit me again. But I continued to do all household chores. I cleaned one room every day, if I felt up to it.

I did the laundry myself, almost a daily chore, and Saturday was bed-sheet day. I had my washer and dryer labeled with Braille stickers, so I could do laundry on my own. I used powder detergent, because it is easier to measure by feel. I put Braille labels on my clothes. I pinned the labels that have the colors listed on the front of my clothing with a safety pin, took it off and put it on a shelf by the hamper when I wore the clothes, and then when I got ready for bed at night, I put the pin back on before putting the clothes in the hamper.

I had my oven, stove, microwave, dishwasher, clothes washer and clothes dryer marked in Braille. For some buttons I just learned what they mean, instead of marking them all.

Following my divorce, I moved into a new apartment and have been living alone there. I had to do the Braille labels all over again. My daily



routine hasn't changed much, though, except that my dad helps me a lot with groceries.

I do *have* to have my morning coffee, so I use a one-cup coffee-maker. I fill the water container by using my liquid-level indicator and have learned what the buttons mean. I measure my coffee (I drink instant, so I only use the machine to make the hot water, but have used ground coffee in it, too) by leveling a spoon with the amount I need. I can feel when the water is heated by the way the machine feels, so I know when to press the button for water. I can then tell by feel when it is done pouring and know how to turn it off.

When I became completely blind, it changed my previous level of independence—temporarily, because I am *determined* to regain my independence! I am finding it hard to do many things on my own, but I have been able to make certain adaptations in my home that really help me keep some of my independence.

I don't go anywhere out of the house by myself yet. Mostly, it's because I am not very social yet, as I am nervous about being completely blind and not understanding speech very well with my cochlear implant. Any time I go to the doctor or need to go to the store, etc., my dad, who lives close by, takes me.

### Wendy Williams

As an adult, I have mostly lived alone in apartments with my dog guides. There were a few occasions when my living quarters were boarding-houses and college dormitories that I shared with other students.

While I had residual vision, I needed little in the way of home accommodations, other than adequate lighting. But it became quite the challenge when I began to lose the rest of both my vision and hearing because traditional methods no longer worked for me. I already had had homemaking training while wearing shades at a blind rehab agency about a decade earlier, and these skills were of later benefit in that I had little fear of the stove without sight. Still, I sustained minor burns, but they were learning experiences. For example, when I removed hot dishes from the oven using oven mitts, I burned my arm against the top of the oven, so I switched to elbow-length mitts.

There were a few occasions when I almost tripped over my dog guide while carrying hot food. So she was banished to the kitchen doorway to observe from that vantage point.

Determining when water was at the boiling stage was through feeling the faint vibrations of the bubbles through the pot handles, along with the steam.

Previously, I had placed Braille Dymo tape on my measuring cups and spoons, and these were now a necessity. I then put Braille labels on spices and other food items. I carefully measured (non-oil) liquid ingredients over the sink to prevent excess moisture in my recipes. It is easier to measure some liquid ingredients, like oil, when it is cold. Also, immediately replacing the caps on bottles prevented me from later potential spills, lest I happen to bump into them and knock them over.

I found I had a poor sense of thoroughly mixing the batter with utensils, so I used my clean hands to complete this step. Parchment paper allowed more uniform cooking and minimized food sticking to the pans.

I learned to use the senses of smell, touch, and hearing (with cochlear implants) to tell me when food was cooked. For example, ground beef changed from big, soft clumps to small, firm ones. I used a talking thermometer to ensure other meat (e.g., chicken) was cooked. One problem with this device is I cannot distinguish between the spoken numbers “150-something” and “160-something” with my implant.

I was willing to tackle sensitive recipes, such as stollen (Christmas bread), from scratch, using yeast, beaming with pride over my finished and tasty product. On the weekends, I prepared hot dishes, so I had nutritious lunches at work to give me the energy to get through my days of employment.

As for housecleaning, I discovered initially going over the floors with a sweeper prior to vacuuming picked up any fallen treasures I did not want to disappear into the vacuum. It also helped ensure that unknown soiled messes (e.g., dog poop) did not make their way into the vacuum.

My sense of feel was a big part in determining if sinks or floors were clean, using the grid pattern. I preferred safe cleaning agents in place of potentially harmful ones that could splash into my eyes or burn my hands. I try to keep up with cleaning, as it is easier and quicker to take care of messes, such as the indoor grill, shortly after it cools down.

## Deaf-Blind Reality

As for management of my personal business and duties, I relied on an SSP to help me with reading and responding to mail and doing errands (e.g., grocery shopping). For washing bedding and other large items, the SSP assisted me in going to the laundromat and operating the larger, commercial machines to avoid the many steps up and down the stairs of the apartment building with its standard machines and competing tenants.

Earlier, I had residual vision and wore hearing aids, and upon the diagnosis of Usher's syndrome, I received O&M training to learn to use a white cane. Up to that point, it had been so habitual for me to walk around without the cane, bumping into people and objects, that I continued this means of traveling alone, until I stumbled off a curb in a shaded area and sprained my ankle. After that, I preferred to use the cane, though it annoyed me when its tip lodged in cracks, causing its handle to hit me in the stomach. When I was feeling fatigued or under the weather, the cane hitting things resulted in overstimulation and heightened anxiety.

When I began to have fearful close calls with vehicles coming from the left and right, I applied for a dog guide. Either with or without a cane or dog guide, I thought nothing of traveling anywhere, be it the doctor's clinic, the grocery store, or work. Five days a week, my dog guide and I walked a mile to work and home again, in all four seasons. Occasionally, in adverse weather conditions or distances longer than a mile within the community, we took the small city bus. If I needed to venture out of town to attend continuing education workshops, I paid drivers from a local church.

Within all facilities, I relied on my residual senses to locate things independently. Strangers usually provided me with verbal directions if need be. I would beam with pride if they asked me questions about my dog guide.

As I began to lose the rest of both my residual vision and hearing, traveling became a bigger challenge. It was increasingly difficult to localize traffic at busy, lighted intersections. Turning more to my tactual and olfactory senses resulted in me getting lost, even on familiar routes. I could no longer find my way in buildings or hear people giving me directions in them, causing me to feel insecure, frustrated, and discouraged.

## Daily Life

Bilateral CIs obtained in 2000 and 2005 then enabled me to better hear vehicles on quieter streets. Audible and vibrating signals were installed to assist me with busy traffic flows, though distracted and impatient drivers are becoming a concern.

An SSP drove me to businesses, guided me within them, and located desired items and services for me. She also assisted me with participating in some community activities, such as martial arts and the Thanksgiving banquet for deaf-blind people. A hired driver helped me with medical appointments.

I hope, in the future, that accessible cell phones and GPS will be more affordable and manageable to permit me to travel more independently within my community and revive my confidence.