Of Eggshells and A Living Room Rug: Considering Informing the Senior Blind

by Lauren Merryfield

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From the Editor: We know that seniors comprise the largest group of blind people in the United States, if not the world. Yet, compared with other age groups of blind people, few pieces of literature exist to give this group advice and support.

Lauren Merryfield is a blind senior, and she shares encounters she has with other seniors who have lost or are in the process of losing their sight and how they and their families handled it. She tries to provide encouragement and hope along with a few tricks and techniques to those she meets and provides a senior’s perspective of what vision loss and age can team up to take from us. There’s an old saying about old dogs and new tricks, but Lauren is of the opinion that an old Federationist is a much different creature. Here is what she says:

In my intergenerational journey in life, I spend as much time around people my age and older as I do with those much younger, including those young enough to lie in my arms. I don’t know how often someone who is older will say to me, “I just don’t see so good anymore.” They not only say it to me, but they will often let others know too. Sometimes the person will rather quickly add, “But I’m not blind (or visually impaired) like you.” Making a distinction seems to be quite important to them since they still identify as sighted.

Most people are not really informed enough to tell the person that yes, they can still do most if not all of what they were doing formerly. The person might need to learn new ways to do things, but the people they say, “I just don’t see so good anymore,” to do not know any better.

One lady I met on the train several years ago said her family asked her not to cook anymore because one day she accidentally got shells in the scrambled eggs. On another occasion she was informed that her floors were dirty, and she had a dirty living room rug because she couldn’t see to guide her vacuum cleaner to get the dirt off. Believing that they would find her home in shambles, they did not come over to visit very often anymore. They assumed that the problem was blindness, when actually the issue was that the woman had not been trained to function well as a blind person because she was just in the process of losing her vision. Her family thought that things would be a mess from now on, not allowing that she could learn to adjust to being blind.

So, rather than banding together to learn how Mom could learn alternative ways to continue cooking and cleaning, Grace’s family humiliated her by no longer allowing her to do so. Their blanket statement was, “Mom, you’re going blind. You can’t expect to cook and clean anymore.”

Almost afraid to ask, Grace nearly whispered, “Do you cook? Do you clean your own home?” I told her that as a senior I don’t do much cooking now, and I have someone who comes in to clean; however, I did cook and clean for many years. I explained that I could feel the heat of the burner, I put pan handles to the side so they didn’t stick out, I used recipes in Braille or from the computer, and I labeled many items in Braille. I further explained that I picked up my place by hand before running the vacuum. I learned how to guide the vacuum so that I reached the entire floor area, not missing spots as she said she did now. She said, “Oh! You are so amazing.” I explained that I was not a chef, just cooked on a level commensurate with most average cooks. I was not a trained housekeeper, so I probably did just an average job cleaning my place—nothing amazing. However, I did inform her that there are blind chefs and blind professional-level housekeepers out there.

Though there is an affiliate of the NFB in every state and chapters in many local areas, and there are programs focusing on training older blind people to adapt to blindness, often the information is not readily available, and a helpful connection is not made. If those of us in the NFB make a concerted effort to get the word out, many negative experiences can be avoided when the person going blind gets proper assistance.

One time I talked with an older man named Jeff. He used to drive his grandkids out in the country and into the woods where they could play. Sometimes they went down to the river to fish. When his vision started to deteriorate, his children were afraid their own children would get hurt. A tree could fall on them. They could fall in a hole. They’d get a fish hook caught in their hand. They’d slip into the river and drown. The main point was that Grandpa no longer had control of the situation; he could no longer supervise his own grandchildren. It never occurred to them that those kinds of things could happen to the children while supervised by a fully-sighted person. They never considered that it would be important to let him find other ways to take care of what his eyes could no longer do.

We hear quite often about the dreaded day when the car keys are taken away from mom or dad because they can no longer see well enough to drive or their memory is failing them. They often keep the vision-related fears, worries, and pronouncements a secret to the rest of the family, their friends and neighbors, and their pastor if they have one. Some families hide their blind relative because they are ashamed.

On the other hand, some people who are going blind do not let their family and friends pull the rug out from under them. I met Pat, a spunky eighty-some-year-old in a class I took not long ago. She said that her family tried to short-change her life because of their fear. She said, “They made my blindness all about them, when it is my blindness, not theirs.”

She had taken the bus to class. Though rather slow, she was learning Braille. Her kids had bought her a flip phone, but she went and bought herself an iPhone. Although she struggled and struggled with it at first, eventually she had it down. She figured out that the reason she struggled so long was that in spite of herself, little fears kept creeping in about, “Can I really learn this? What if I can’t do this?” When she noticed that I was using an iPhone, she proudly said, “Oh! I have one, too! Looky here. Mine is just like yours.”

I met Dr. Tom, as people called him, while waiting for a baseball game to begin. He had seen my husband and me and decided to come over to talk. He said he was a retired doctor, and at first his family tended to think his life was “pretty much over.” He said he had been an independent thinker and doer all his life, and that wasn’t stopping now.

Dr. Tom figured out how to use public transportation; he began receiving talking books from the Library of Congress; he continued going to the gym, going out to movies, and he still loved to fish. When he noticed that he was trying to look at something, he purposefully stopped himself, thinking, “Now how can I do that with my eyes closed?” Often he figured out an alternative on his own. He told me, “If you look for ways you can’t do something, then you can’t. If you look for ways that you can do something, you can.” He said he went by that kind of rule throughout his practice as a physician, and that wasn’t changing now.

Much depends on the circumstances around the oncoming blindness such as other medical or health issues, level of pain, becoming easily flustered or being doggedly determined, the support systems around them or lack thereof, whether the person is alone with their blindness or if others are around in their lives.

Donna, a lady I met on the train, began talking to me because she had a sister, Jackie, whose marriage was in trouble because the husband, Don (still sighted) could not deal with his wife going blind. He said that, “The lights went out in her life, and she’s not the same person I married.” He resented driving her places, reading the mail to her, and describing shows on the TV that were not audio-described. He felt like he was doing so much for her, but she wasn’t doing anything in return. I asked him what his wife did to pass her time. He said she still knitted, read Braille books, fixed their meals, washed their clothes, and kept the furniture nice and clean, including making the bed. “She didn’t do anything?” I asked incredulously. I reminded him that those things Jackie was still doing were ways she was contributing to her family.

There is now an epidemic of younger families alienating their parents and grandparents. Quite often, these older family members do not even know their grandchildren anymore. Dr. Joshua Coleman, an expert in this psychological phenomenon, holds weekly webinars for parents and grandparents who have been shoved out of their younger family members’ busy lives.

The hurtfulness of this is compounded when a parent or grandparent loses their vision. They are put out to an even further pasture than they were already in. These families do not want to be inconvenienced by their older family members. They don’t want to feel obligated to help. The idea of their family member gaining independence rarely occurs to them. They feel better if the older blind person is in some type of facility, receiving assistance from outside the family, no matter how expensive it is. Though in the past, grandma or grandpa would live with the younger family or switch back and forth between them, now expensive retirement centers are so full that there are waitlists to get in.

Nearly everyone I’ve met or heard about who has gone from fully sighted to blind seems to agree that going blind is difficult, scary, and sad. They mention how the blindness affects their family life and how life in general is now more difficult. Many of them do not identify as “blind” strongly enough to join us in the NFB. Some say, “Maybe I will when I lose the rest of my vision.” Often they allow their lives to be more difficult, scary, and sad than they need to be.

Because of the lack of a connection between seniors losing their vision and those of us who know about blindness, it is good for us to have print information available for sighted families and friends. However, it is also important for us to have accessible information available to those in the NFB who lose vision when they become older. The transition can be made much more smoothly this way.

Then there are multiple disabilities that sometimes scramble our minds and bodies like the eggs with shells in them. Although we may know how to function well as a blind person, managing other disabilities can be difficult for us. Because the NFB focuses on blindness, some older blind people continue to focus only on blindness, avoiding or ignoring the onset of other disabilities. As one who has dealt with multiple disabilities all my life, one of the most difficult issues is not the disabilities, but the confusion around them. Many people assume that whatever bothersome thing happens is automatically blindness-related, as if blindness runs our lives.

If I fall, it is said to be because I am blind. Some will say, “I would fall too if I couldn’t see.” I explain that I lost my balance because I was dizzy or my knee buckled under me. When I drop something on the floor, someone is likely to say, “I would drop things too if I couldn’t see.” I answer that it wasn’t blindness that dropped the item; my fingers let go of it. For me, as is the case with other blind people, blindness is no reason not to get out. Blindness is not as limiting as some other disabilities. Blindness does not cause pain, though some conditions causing blindness are painful. Blindness does not cause weakness, dizziness, low stamina, chronic infections, leg problems, heart problems, and so on. Though we may have learned how to function quite well as blind people, we may be less successful in managing other disabilities as they come into our lives due to the lack of appropriate information. That’s when we need to use the problem-solving skills and alternative techniques we already know to find new ways to continue our lives as multi-disabled blind people. This is still a work in progress for me.

This is not the time for others to abandon us because we don’t measure up anymore. This is the time when we may actually need more companionship and support. This is the time when we might need more understanding, sympathy, empathy, kindness, and patience.

We say that the NFB is a family. Families have their younger members who come along, however, we also have older members. We need to make sure that they are not put out to pasture and left there to flounder. We need to include them as much as possible and, in some cases, allow them to include themselves. Instead of focusing on what we have lost, we need people around who support our dignity, diversity, and value. We need to honor our older blind, those who have not joined us yet, and those who have been around for years. Let us make sure those scrambled eggs have no sharp shells of unkindness in them. For we all matter. We are all equally valuable. Let us acknowledge and honor the Federationist in all of us, for it is still there. The senior blind want to live the lives they want as much as our younger members do.