What Do They Say?

by Lauren L. Merryfield

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From the Editor: Lauren Merryfield is a long-time Federationist and intermittent contributor to the Braille Monitor and Future Reflections. Her article “What Color Is the Sun?” was the title article for the first Kernel Book. Her book There’s More Than One Way to Be Okay: A Blind Woman’s PURRspective On Life is available in audio at www.audible.com. Lauren has served as secretary in several chapters of the NFB. Because she moves around, she has been involved in helping to resurrect or establish several new chapters. She currently lives in Carmichael, California, with her three cats: Maryah (Mariah with a Y), Tobias (Toby), and Lelaynya (Laynie). Lauren is an online pastor and Jesus follower. In addition, she has earned an MSW degree and certification in pet loss and bereavement. She counsels people online and has held pet memorial services using Skype.

Lauren does not like getting old but is not ready for the alternative, stating that she would rather be over the hill than under the hill. She says she will never be an “old fogy,” intending to remain young at heart. In this article Lauren discusses the almost-universal problem blind people encounter when receiving health care; the staff see our blindness and secondarily the condition we expect them to treat. Although they know quite a lot about their area of expertise, they often know little about how to treat a well-adjusted blind person, and our compromised health can limit our ability to do much to educate them. Here is what Lauren has to say about her recent health experiences:

When I was young, I strongly believed that once blind people demonstrated to the sighted world that we could do a thing, we would be believed, and we could live the life we want without constantly having to confront doubt. It is many years later, and I feel quite disappointed that we too often find ourselves dealing with the same issues we did back when we were young. Though the NFB certainly helps the public make progress, there is still a long way to go for some of us.

Each time we push the envelope so that we can more readily live the life we want, we help make it better for the next blind person coming along. I might not say much if an incident or set of incidents affected only me, but when I know how they could affect other blind people, I am less likely to be quiet about the situation. A case in point:

For the last two years I have had the misfortune of living with what the medical people call "venous insufficiency" in my legs. My legs and feet swell up—at times like balloons—and they occasionally develop wounds and cellulitis. It has been necessary on far too many occasions for me to be hospitalized in order to be given IV antibiotics to combat the cellulitis.

Being a patient has been stressful for me, mainly because, overwhelmingly, staff insists that I be treated like a two-year-old just because I am blind.

The last two times I was hospitalized, the staff kept repeating, "Now don't get up unless there is someone in the room." One nurse wanted me to pee into pads on the bed. I felt embarrassed about that. She said that if I needed anything from my suitcase, she would get it for me.

I, not being the most obedient person to such demands, would sometimes get up on my own to visit the restroom or retrieve an item from my suitcase. I was told later that when I did this sort of thing, a report was written up on me. I was not particularly taken aback by that.

However, as one shift followed another and one day and night followed another, I got tired of this treatment. Over and over again I would say that I was ambulatory and that I could find the restroom and my suitcase by myself. However, they kept insisting that I use my call button to have someone else help me with these things.

During my second hospitalization, I had three separate roommates who stayed overnight following surgery. In each case not only were these women allowed to get up out of bed; they were practically forced to do so as part of their recovery—quite a contrast from how it was for me. When I would point this out to the on-duty nurse or CNA, I was always confronted with the argument that, "Well, they can see."

When it came time for discharge, I was invariably confronted with the argument that "We can't discharge you to go home, living alone blind. That is too much of a risk. You could fall. You can't handle your medications." They rarely asked me if I often fell or if I had difficulty managing my medications; they stated these things as facts. I would correct them at every possible opportunity, but it was like they just did not hear me.

When I would finally make it home, without falling and without having any problems with my medications, I would be barraged by the home health care nurses who continued the same litany.

About a week ago a social worker visited me. Although I have a master's in social work myself, I still tread on thin ice when a social worker comes to visit me. I never know which side of the fear-mongering they will be on. The latest visitor had heard from the home health care nurse that it was dangerous for me to live alone because I could fall, the reason being that I have quite a lot of stuff in my apartment. She also informed the social worker that I had difficulty with my medications because I couldn't tell them apart and could take the wrong ones. The nurse had written in print the names of my medications on the top of the bead box that I keep them in. The social worker laughed, stating that this was not exactly helpful to me. I said that if I needed to write them down, I could put Braille labels on the top of the bead box; however, I was the one who placed each medication into each receptacle, so I knew where my medications were located. I further was aware by the shape of the pills which one was which. For me there was really no problem. The social worker asked me when last I fell. It had been a year ago when my office chair dumped me out—forward. It had absolutely nothing to do with blindness, and I was not hurt.

We decided that since I was not constantly falling due to blindness and was not having difficulties with my medications because I am blind, that she would report to the nurse—what do they say?—if it ain't broke, don't fix it.

I have subsequently filed a complaint with the hospital because it is obvious that its staff is not trained in how to treat blind people. It has been suggested that the floor on which I was a patient and could be again will undergo training. I suggested that, while they were at it, it might be a good idea to train all of the units in the proper way to treat blind patients. I am hoping that this will be accomplished soon.

Before Easter I was quite insistent about my discharge from the hospital. My doctor understood my strong desire to be home with my cats, plus my desire to attend my church. She was able to make arrangements for me to have IV antibiotics only once a day as an outpatient. This arrangement meant that I could not leave town for Easter; however, I was able to attend church and experience the freedom of being at home. I am hoping that this kind of arrangement can be made again if or when I am dealing with another bout of cellulitis.

Ironically, in the place I live, I am on the independent living side so that getting help is not all that easy. Therefore I am not smothered, and the staff is aware that I come and go on my own. This is quite a contrast from my hospital experiences. I realize that the hospital staff believe they are protecting themselves from liability. The problem is that there is no evidence that blind people fall more often than sighted folks or that they mess up on their medications more than sighted patients do. So, as far as I am concerned, they are barking up the wrong tree.

I am further aware that many of the blind patients with which the staff interacts are people who are in the process of losing their vision or who are newly-blind. When they are met with someone like me, blind since birth, they see me through the lens of someone newly-blind, which is quite inappropriate.

Fortunately I have not had as much trouble as an outpatient. In the infusion clinic I was just another patient who was a hard stick who needed IV medication. I am hoping and praying that this will be the route I go for any further IV treatment.