TO-ed at the OT [Ticked off at the Occupational Therapist]

by Lauren Merryfield

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From the Editor: Many of us have stories about dealing with healthcare

professionals and social workers that rankle us. As we get older and often

see more of these folks, the occasional inconvenient comment and the

possible threat represented by it grow frequent and even more threatening.

This is not a comfortable topic, but it is one well presented by Lauren.

Here is what she says:

I remember as a young Federationist how we would laugh so hard we

couldn't stop during our banquet speeches. The one giving the address would

bring up totally ridiculous things about blindness that someone wrote in to

the National Center or mentioned to someone over the phone. What they said

was so absurd it was humorous because all of us blind people were gathered

in one room where we supported each other-so we could laugh. It happens

every year. I know, because even when I am unable to attend our national

conventions, I listen to the banquet speeches after they've been delivered.

But when you are living through one of these anecdotes on your own,

it can be totally frustrating and even maddening. The usually patient

person I am can, after so much low expectation talk, want to throw in the

towel. So far, I've always hung in there when I am well enough to do it.

Now that I am an older blind person with medical issues, over and

over again I am reminded that healthcare professionals just are not being

trained in how to work with blind people. What's more, the problem is

pervasive. I've had similar experiences in several different states where

I've lived. Though I sometimes feel frustrated by some of the repeated

experiences, at least I hope I am helping to educate one person at a time.

Sometimes they just don't get it, but now and then they do.

The other day there were four healthcare professionals in my

apartment with me. I was outnumbered in a major way. Three of them were

pounding me with expressions such as: "Lauren, you have to be able to see

to cook the right food." "You have to see to manage your medications." "You

have to see to safely move from one room to the other in your apartment.

There are fall risk situations in here, and you need someone with you who

can see ..."

One of them even asked, "Are you the only adult in this home?" to

which I answered "No, there is me, and there are two adult cats."

I'm not kidding about the things they pummeled me with that day. How

one has the audacity to tell me what I need vision to do is beyond me. It

smacks of disrespect toward me. It is negativity brought into my happy home

with just me and the cats.

I finally felt quite ticked off about the things the OT (occupational

therapist) was saying. So I said, "Well now wait a minute," and I asked

Vicki where she got all of that information about blind people, and was it

really fair for her to come into my home and dump all of that on me? At

least she shut up for a few minutes.

I wonder again what closet they think I've been in all these years. I

also wonder why more of them can't be humble enough to admit that they have

no idea how I manage, and simply respond by saying "Please tell me. I'll

listen and learn from you." I haven't heard that one yet. They all assume

the worst for me.

During this onslaught of healthcare professionals, I was also

informed that I needed someone to coordinate my clothing and help me get

dressed. I couldn't see which clothes were clean and which were dirty.

What?

I was told that it was a fall risk for me to hurry to the bathroom

and that I needed someone to take me there because it would be faster and

less of a safety risk. I'm not kidding!

I was told that I couldn't do my own showers because I wouldn't know

where my shampoo, soap, etc. were, and I'd have trouble locating the hand-

held shower head. At one point the OT said I'd have trouble locating the

handheld shower head when I had it in my hands. I would have trouble

figuring out what it was because you had to see to do that. She further

said I wouldn't know when I was clean because you have to see to know that.

Again, I am not kidding.

Finally, I stood up (which is very painful now), and I said it was

time for show and tell.

I showed them that I could walk around by myself in my apartment with my

cane or a walker. I showed them my talking items. I typed a note on my

computer which they couldn't understand, but at least they saw me doing it.

I showed them how I cook, clean my dishes and sink, and so on. I didn't

mind explaining to them or showing them. On some occasions I do not have

the luxury of being able to show healthcare professionals how I function,

especially when I am in the hospital. But in my own home! They were going

to hear from me whether they liked it or not!

What I had trouble with were two things-1) that they were so very

uneducated about how blind people function and 2) how the OT Vicki was not

convinced. Neither was Judy, the nurse.

Lisa, the caregiver, did speak up on my behalf. She said, "I had no

idea what to expect the first day I started working with Lauren, but she

does a lot of things by herself, and she does them well. I could have

walked in here deciding she couldn't do anything, but I didn't do that. I

decided to wait and see what she needed me to do and what she didn't."

The social worker, Carol, sat typing away on her computer. I was

concerned about what she was typing, but I did not ask. She hadn't said

anything quite so ridiculous as the others yet.

While I was up demonstrating blindness skills, I did remark that it

seemed odd and out of place for all of them-the OT, the nurse, the

caregiver, and the social worker-to be there in my home all at the same

time; I doubted that this would be happening if I could see.

Now I just have to say this: my cats never come up with all of this

negativity. They know I can't see, and they just work around it, like the

caregiver I currently have. I appreciate their having the confidence in me

to realize that if I can't do something one way, I'll do it another, but

I'll still do it.

It has occurred to me that "live the life you want" isn't exactly

what is happening in my life; however, I am going to do it to the best of

my ability when and while I can. I realize I'm slowly winding down toward

the end of my time here (aren't we all?) However, I'm not going to let

these people cut into my living the life I want in my own home! Even in the

hospital, I'm going to say something as long as I can. When my time is up,

if one person gets it, that will be good.