

Communication: A Patient's Story

I have cerebral palsy. My speech is difficult to understand. I call it my "cerebral palsy accent." Many times when people initially can't understand me, they give up. They stop asking important questions and therefore don't get information they need for my medical care. The following is a summary of a hospital experience I had. It's not meant to vent or complain, but to show how someone with a disability may not get the best care they can.

One evening, I was run down with flu-like symptoms. I went to bed, but began throwing up. I sent an email from my bed to see if I could get help from friends in the area. I received no response. Since I was alone, I hit Lifeline.

In the ER, I was asked to give a urine sample, but the nurse left the urinal on the end of the bed and walked away without inquiring if I needed assistance. Therefore, when I urinated and filled the bottle, the bottle fell. This left me wet and required the staff to change me. An initial inquiry would have prevented this situation, but I think the nurse was uncomfortable trying to communicate with me.

As the hours passed, I noticed that the staff was not addressing my primary complaint of having flu-like symptoms. I was hard to understand because of my "cerebral palsy accent" compounded by congestion. I had a surgical consult, inquiring into my bowel frequency and history. My bowel schedule has never been regular. (This is due to my cerebral palsy and two cervical spinal cord injuries, and was already noted in my medical records). After palpating my stomach, the intern attempted to manually stimulate my bowels. This turned into the first of many "fishing expeditions."

Whenever I am in a medical situation, I bring all of my health and insurance information in my wallet and in my binder. In the best outcomes, this information helps medical staff in treating me. When it is not looked at, things don't go as well. The records from my previous hospital visit would have indicated that I had the same tests and that chronic constipation is symptomatic of cerebral palsy and cervical spinal cord injuries. I came to the hospital because of the flu, not because I was constipated, but neither I, nor my records, were able to communicate this to staff.

When I was admitted, I was put into a room with an inaccessible bathroom. The staff gave me a commode. The staff was not sure how to move me and didn't ask me about the best way to do this. Again, I think the staff was uncomfortable trying to communicate with me and chose not to try. The directions on how to move me were in my records from my previous surgery. The records included my stand/pivot transfers and bathroom routine. If those records were looked at, the staff would have better information on how to treat me.

I was admitted to the hospital with flu-like symptoms, but I was given enemas, suppositories, laxatives, liquid diets, and an invasive bowel disimpaction. In one nerve-wracking encounter, an intern was very abrupt with me. Within a minute of meeting me, she said, "I don't understand you...write it down." After she was repeatedly prompted by friends to address me rather than other people in the room because I was capable of understanding her, she told me that I needed three more enemas that night or I would "blow up" and die. Her parting words to me were, "I talk to my patients very directly." I actually don't mind being spoken to directly. It is not being listened to that can be frustrating and harmful to my care.

On the day of my departure, a nurse's aide made an effort to understand me and we were able to successfully communicate. It takes patience, but I can be understood. It's vital to my health that I can be.



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Nurse Practitioner's Reaction

This commentary is by a nurse practitioner who was asked to read and respond to Mr. Kunzier's story.

One of the more frustrating parts of this patient's experience was that most of it was preventable. Mr. Kunzier had anticipated difficulty communicating with hospital staff. He had therefore brought his old records in an attempt to make everything go more smoothly. This collection of documents that he thoughtfully carried to the hospital was to avoid a situation just like this one. Yet the healthcare providers did not make use of it.

Some of the information that the staff would have known about Mr. Kunzier if they simply looked through his binder:

- ▶ What activities of daily living does he need help with?
- ▶ What is this patient's typical bowel routine? Normal bowel patterns vary greatly from person to person.
- ▶ What tests and diagnostic procedures have already been done?
- ▶ What is the best way for the nurses/aides to transfer him to the commode?

Hospital staff did not give Mr. Kunzier ample opportunity to communicate his needs verbally. The hospital can be a hectic environment; doctors and nurses are usually in a hurry to see other patients. However, it wouldn't have taken long to ask Mr. Kunzier a few yes/no questions to determine his basic needs. The aide at the end of his story proved that it is, in fact, possible to communicate with him. Perhaps other staff felt too awkward because of his "cerebral palsy accent" and didn't want to try. But ignoring the patient, and especially addressing questions to people accompanying him, is inappropriate.

Mr. Kunzier's primary reason for coming to the hospital--his flu symptoms--was not addressed, and was often ignored. The hospital staff instead focused on what they thought was his most important issue: his bowel movements. Often without meaning to, healthcare providers dismiss patients' concerns and exhibit a "doctor knows best" attitude. The intent of this behavior may be to reassure the patient, but it is often perceived as condescending. In Mr. Kunzier's situation, it contributed to the unspoken message of "you don't understand your body as well as we do."

Reflection Questions

- ▶ How would you treat a patient with cerebral palsy differently now, having read this story?
- ▶ What actions would you avoid if you encountered a patient with a similar disability and/or symptoms?

Resource Sheet No. 1

Inclusive Health Care was developed by the Institute for Community Inclusion at the University of Massachusetts Boston and Boston Children's Hospital. We have decades of experience in workforce training and specialized consultation related to disability inclusion.

