

A Patient Calls for Greater Awareness

by Michelle, a person who has SMA and lives in Massachusetts

I have Spinal Muscular Atrophy, or SMA. Because of this, I'm paralyzed from the neck down. I have limited use of one hand, and I get around with a power wheelchair.

Most of the time when I go to the hospital, they don't really understand my disability. The staff don't seem to believe the level of assistance I need. For example, if I need to get up onto an exam table, they expect me to transfer myself. But I can't do that—I need a personal care attendant (PCA), or someone else, who is physically able to lift me. Or I need to use a Hoyer lift. And most hospitals and doctor's offices don't have Hoyer lifts available.

My insurance won't let me bill them for a PCA if I'm in a hospital. So I don't have a way to pay for one. If I have to go in, I'll usually bring a family member. If no family member is available, I'll need to bring a PCA anyway and pay for their time myself. I sometimes bring my own Hoyer lift, too.

I remember one time when I was at the hospital, sitting up in bed. The staff person brought in the lunch tray, and my mom was helping me eat. She was cutting up the food and getting ready to feed me.

Then a nurse walked in, looked at us, and said to my mom, "Oh, now I've seen it all. Don't tell me you're actually going to feed her now too!" It was clear the nurse felt that I should be feeding myself. But due to my paralysis, I'm not able to do that.

My mom said, "You didn't read her chart." The nurse looked confused and left the room. My mom saw her talking to another staff member, who showed her my chart. Then the nurse looked embarrassed. But she didn't come back in to apologize.

Some patients are going to need more assistance in every way. If I go somewhere where they don't have staff who are well-trained around disability, they should bring in a PCA for me. And an appointment for me will take longer than an appointment for most other people. So staff should budget that time when scheduling my visit.

Honestly, I avoid hospitals as much as possible. With my SMA, there's no way I can go into the average hospital or doctor's office and get the care I need. It shouldn't be like that, but unfortunately it is.

Nurse's Reaction

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

It is the hospital's responsibility to provide a safe environment for each patient. Every hospital should be equipped with a Hoyer lift or ceiling lift. If these lifts are unavailable, sufficient staff should be provided to safely transfer a patient such as Michelle from stretcher to bed and back as needed.

It is also the hospital's responsibility to meet the patient's needs during their hospital stay. It sounds like Michelle requires full care for cleaning, eating, and repositioning. This means that supplies and staff must be provided to care for her during her stay.

Having a person's PCA provide direct medical care is a liability concern. If the PCA is just washing and feeding the patient, the hospital should not have any objection to the assistance, and staff should appreciate the extra help. However, if the PCA gets involved with unsupervised transfers or medication administration, this can lead to a liability on the hospital's end.

The hospital is required to meet certain requirements and to monitor at a certain level. If the PCA is attempting a transfer Michelle without hospital staff there, and Michelle were to fall, that is a hospital liability. It not only affects the care of the patient, but hospital reporting and reimbursement. With these issues, the hospital should be proactive about providing staff support.

The comment made by the nurse about Michelle's mother feeding Michelle was rude and showed lack of knowledge on the nurse's part. The nurse should have reviewed Michelle's chart before coming into her room. At the very least, she should have come back later to apologize, after she realized her mistake. We all mess up from time to time, and taking responsibility for that goes a long way to winning patients' respect.

With a patient who requires extra care and time, we must avoid making them feel that they are an inconvenience. As health care providers, we should provide comprehensive service, even if it requires a little extra time, additional staff, or increased effort.

Reflection Questions

- ▶ What are some activities staff might view as an inconvenience when caring for a patient? Brainstorm ways to accommodate the patient without making them feel difficult.
- ▶ How do you keep your patients involved and informed to prevent feelings of being an inconvenience?

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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.

