

QUESTION: *My sister who had polio in 1953 at age 17 was affected from the waist down. She also struggles with bipolar disorder. Last winter she was hospitalized on a behavioral health floor for 44 days. Her crutches were taken away because they were considered weapons. She spent the days in a wheelchair and did not receive any physical therapy. Upon her release, we found she has lost what strength she had and now uses the wheelchair all of the time and is in a nursing facility. It is difficult to convince hospitals to allow the use of the usual assistive devices or equipment, and even more so, when it is a mental health facility. Do you have any advice for the family members who are advocates?*

Response from Stephanie T. Machell, PsyD:

To be an effective advocate, you need to understand the environment you're entering. Because people are admitted to psychiatric hospitals when they are a threat to themselves and/or to others the unit's focus is on safety. Because almost anything can be used in suicide attempts and/or assaults many seemingly innocuous objects are banned or allowed only with strict precautions. This means that staff may see a crutch not as an assistive device but as a weapon, or even something that can be broken down into dangerous pieces.

Psychiatric units have rules about what a patient is allowed to have. These rules are inflexible, though exceptions can be made based on human rights (which denying a person with a disability his or her assistive devices would be) provided the safety of others is not compromised.

Because hospitals are hierarchical you need to advocate with the correct staff member. For family members this is usually the unit social worker. This person, usually the only staff member trained in patient advocacy, can help you find out the unit's concerns with crutches and work with you on resolving them.

If these concerns can't be resolved on the unit, with or without the social worker's help, you can speak with the hospital's patient advocate, director of nursing, or a hospital administrator. If that doesn't provide resolution you can speak with a Department of Mental Health human

rights officer, legal services for people with disabilities, and/or the Joint Commission on the Accreditation of Hospitals (JCAHO, pronounced JAYCO).

If crutches still aren't allowed, a compromise might be. Patients should be allowed to exercise. Forbidden objects are almost always allowed under staff supervision. Perhaps your sister could be permitted daily supervised use of her crutches for exercise and/or physical therapy.

No matter who you speak with, it helps for the advocate to consider herself an ally, not an adversary. Maintaining a non-defensive tone and attitude conveys your confidence that both you and staff want the best for your sister, even when you have different perspectives.

There are some "magic" words and phrases advocates can use. "JCAHO regulations" causes hospital staff to pay close attention, especially if you have done your research and can refer to specific regulations. "You and I both know ..." privileges the person you are speaking with as someone who shares your knowledge.

Before hospitalization is needed again you might help your sister discuss her options with her providers. The best option for a person with a physical disability in need of a psychiatric hospitalization is a medical psychiatry unit, where staff may be more comfortable with assistive devices. Your sister's providers might know which units are disability-friendly. In a crisis she would have to accept whatever bed



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is available and later she might be able to transfer.

If you haven't already, it might be helpful to connect with advocacy groups for people with mental health issues. Family groups of the National Alliance on Mental Illness (NAMI) are full of others like you who can help you navigate the system.

Response from Rhoda Olkin, PhD:

To address this question I want to talk about the relationship between the person and her assistive devices or technology (AT). There is a range of AT from simple and common devices like compression socks, slightly more specialized equipment such as grab bars and crutches, to more sophisticated and complicated technology such as lifts and electric wheelchairs.

Adoption of any of these often carries significant psychosocial implications. For those with disabilities, AT can be an important part of daily life. Service providers often emphasize how AT can promote functional independence, but users tend to emphasize the psychological benefits.

For example, a service provider might say "this will enable you to walk a block" but to the user the benefit might be framed as "I can live at home." Service providers might say AT provides greater safety, while the user believes falling is embarrassing. These differences in language suggest that service providers and AT users see AT differently.

Several studies have demonstrated this difference. For example, hospitalized patients felt they were discouraged from exercising, that staff was not keen on having patients traipsing up and down the hall, or to have persons with dementia using electric wheelchairs. This was true even though a key to independence in

care facilities is the ability to be mobile independently.

Virtually all those who have gone from being barely mobile (with or without crutches) to use of a wheeled device talk about the new freedom they feel, and all the things they can now do that they couldn't do before. But that is after the fact, after the psychological shift that allowed the adoption of AT.

Before adoption, it is hard to know this in advance, or to see that the trade-off is worth it. But once AT is adopted, it rapidly becomes a part of the person, much like a body part. The body definition and boundaries now include the device. As such, someone moving or removing the AT is intrusive and presumptuous. Taking away a mobility device is like taking away people's eyeglasses – an unwelcome invasion of private body space.

The reactions of other people to someone who uses AT cannot be overemphasized, and is a big factor in resistance to adoption of AT. But it is also a factor in how the AT itself is viewed.

A crutch could be a weapon, but then so could a leg or a fist. Removing AT that reduces mobility and independence further infantilizes a mental health patient at her most vulnerable. I can see the logic if a patient is being very combative, but not out of fear that the person 'might' use it as a weapon.

When hospitalized, one takes on the role of patient, which is in many ways the opposite of independence. Convenience to staff can take precedence over patient autonomy. This may be okay for a short hospital stay, but for a longer care facility the person's access to the AT is important both physically and psychologically.

Strong advocacy will be necessary. ■

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PHI asked Dr. Maynard the same question. See his response in "Ask Dr. Maynard" on page 10.

