

SIT YOUR ASS DOWN!:

BALANCING FUNCTION AND REHAB

Teri A. Adams, J.D.
Assistant Director,
Office of Accessible Education
Student Disability Resource Center

I was born with a spontaneous genetic mutation which causes a skin disorder called *epidermolytic hyperkeratosis* (generically “congenital ichthyosis”) in 1957.

- This disorder causes the body to make skin cells too rapidly
- Those skin cells don’t break down properly, so there is a lot of flaking and callusing of the skin
- It also causes blistering anywhere there is a lot of friction, such as that caused by walking – it wasn’t until I was in my 30’s, however, before I got mobility assistance
- I was in segregated “handicapped” educational programs until after high school (although I was *mostly* mainstreamed in high school)

Osteoarthritis is a bonus disability for me; it is unrelated to my original disability.

- Except that there was underlying hip dysplasia that probably accelerated the joint deterioration that no one identified – I think because they were too distracted by the skin condition
- Even though I told my primary care doctor in 2007 that I was taking tons of NSAIDS for arthritis pain, he didn't suggest an x-ray until May of 2008 when I insisted on getting a formal diagnosis of arthritis
- Most people don't go from initial diagnosis to total joint replacement in essentially one office visit – which gives you an idea of how bad it was by then

In August 2008, I had total hip replacement surgery:



The number one thing I was worried about, related to the surgery:

- That physical therapists and nursing staff would hurt me physically because they didn't understand my disability, such as:
 - ▣ Try to make me do things in physical therapy that would hurt my skin
 - ▣ “Manhandle” me and accidentally hurt me (in fact a friend of mine who is in medical school said “you wouldn't believe how they throw you around once you're unconscious – you need to tell them to be careful of your skin”

This fear was reinforced by how they reacted when I tried to explain to nurses/therapists what the skin condition was.

- When I said “I was born with this skin condition”, they would nod, and then say, “so you’ve had it all of your life?” (I thought “congenital” was too big a word.)
- It would sometimes take 2 or 3 times before they would get that:
 - ▣ My skin condition was completely unrelated to why I was in the hospital/SNF
 - ▣ I’d always had the skin condition and they could trust my assessment of my present state in that regard (not that they had a clue about what to do in any case)

Hostility/fear in the face of a disability are 2 sides of the same coin.

- When I was first admitted to the Skilled Nursing Facility (or SNF, where they send you for rehabilitation after getting out of the hospital) I sensed a pervasive hostility from the nurses
- Only later did I realize that the hostility was based on their assumption (just by looking at me) that I was going to be a lot of extra work for them and they were already overworked and understaffed
- Once I established that I was actually pretty low-maintenance, they liked me.

The paramedics that transferred me to the SNF did me a huge favor.



On brief acquaintance, people often don't (or can't) listen very well to a person with a visible disability.

- They take you from the hospital to the SNF in an ambulance. On the way, I told them about my skin condition, since none of them had ever seen anything like it. One of them was still in training; he was particularly interested in hearing about an unusual condition.
- In explaining my disability, I mentioned, among other things, how I was prone to overheating, because I don't sweat – I can't cool off properly.
- The first room the paramedics were directed to in the SNF was really warm, because my “roomie” was an older person who was cold all the time. The lead paramedic told the admissions person that they couldn't put me in a hot room.
- So, they moved me into a room with a vacant bed next to the air conditioner.
- I really believe if I had just complained about the warm room, they would have given me less credence than they gave the 20-something paramedic.

I lucked-out with the physical therapists; they asked me what my goals were and respected my limitations.

- You only get about an hour of PT a day in the SNF.
- They would also provide about an hour a day of OT – which I refused.

You might want to check out this Wiki definition and article about Occupational Therapy(ists): http://en.wikipedia.org/wiki/Occupational_therapy

I was able to run off OT that came to see me in the hospital in less than 10 minutes. “Been there, do that everyday, yada yada.” (Only more polite, of course.)

In the nursing home, it took a half-hour one day (I agreed to an assessment, at the end of which the OT agreed she couldn’t help me), and dogged determination the following day, when the OT’s supervisor made her come back for a second try with me.

I was nice (she looked all of 12 years old to me), but firm. I offered to talk to the supervisor myself, but none ever appeared.



People with long-term disabilities are constantly problem solving:

- Adapting existing tools/devices to serve new/additional purposes;
- Simple is better;
- Cheaper is better;
 - Unless you have unlimited funds, you never know for sure if you'll find a "payer" for new equipment
- Non-specialized equipment is better than equipment that is so specialized that it is only useful to a very discrete demographic, or for a very limited purpose.

I bought this chair out-of-pocket, and used it in my house, before and after my hip surgery in Summer 2008. Best money I ever spent.

Since my insurance pays for a power wheelchair, I have to buy any additional equipment “out of pocket”.

A “Breezy” manual chair (by Quickie) costs around \$300 online (Spinlife.com).

I actually have 2 of these – one that goes on short excursions with me when I have someone to push me, and the other lives in the house and has the wheel-rims removed to give me a narrower profile for getting through my unmodified doorways.



I tried to get the surgeon's office to order me a commode before the surgery, but the bottom line was –they didn't know how, because the nursing home always does it.

The purpose of this is to raise the height of the toilet (you put it over a regular toilet and remove the bucket) so you don't have to bend as much.

My insurance was billed around \$200 – I could get one online for around \$58 + \$6.00 shipping.

But, if I just ordered it myself, I could have waited indefinitely to get reimbursed.



Similar story for this, a walker with forearm attachments. I could have used this at home pre-surgery, but couldn't get anyone motivated to order it for me.

And, even though everyone knew I needed this equipment when I was transferred from the hospital to the SNF – and my doctor ordered the equipment -- I didn't receive it until 6pm on the night before I was to be released to go home.

They had attempted the delivery of the equipment the day before, but the commode was “so broken I didn't even take it off the truck”, and the walker was missing one of the forearm attachments. (“Are you sure you need 2??”)

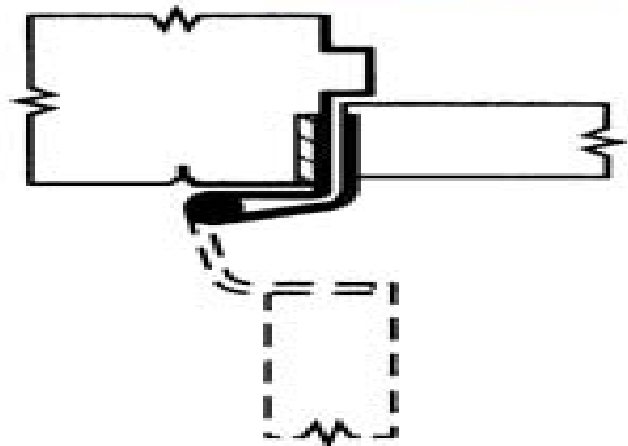


I had a DIY-handy friend put these special hinges on my bedroom door, to ease clearance for my walker (and wheelchair).

I'd been aware of these hinges for a long time. I shopped for them on the Internet, finding prices ranging from \$28-\$50 for ONE PAIR OF HINGES.

I finally found them on a weird little site for \$16 + shipping, and they were perfectly fine.

No PT or OT ever suggested or mentioned anything like this to me.



I brought these with me to the SNF, along with a small pair of scissors – again, my adaptations, not suggested by “professionals”.

For picking stuff I dropped off the floor; much easier for me to handle than the tools designed to be “grabbers” for people with disabilities.



For opening bottles of water and soda



Key Observations, Lessons and Immutable Truths

- On a practical level the person with a disability must be flexible;
- Must be able to figure out multiple ways to accomplish tasks, with and without assistance, if possible;
- Must be able to explain with a high level of detail exactly what is needed, whether in regard to services or tasks that need to be accomplished;
- Business-like transactions for services is a better system than the charity model – for both parties involved.
 - Particularly true if disabled person is a professional

When you're designing assistive technology, or trying to assist someone in your life with a disability, keep these things in mind:

- How long has the person had a disability?
 - ▣ Someone with a congenital disability is much more likely to have figured out adaptive ways of performing ADLs (activities of daily living) than someone who has become recently disabled.
- What are the person's goals?
 - ▣ Don't impose your own vision of the person's life on them – what is their vision of their life?
- Who will pay for the device you're developing?
 - ▣ Don't let the money thing stop the creative process, but you've got to look at the funding issue realistically. Only people with their own funding are likely to be able to obtain equipment that is expensive and/or specialized.
- As others have said, over and over, consult extensively with the potential end-users of your designs, not just “professionals”, like OTs and PTs.