

Introduction

- Former elementary school teacher who retired at age 62, after 35 years of teaching
- Was diagnosed during her last year of teaching
- Sees a personal trainer twice a week
- Both are UW grads, with degrees in business (Tom) and education (Carolee)

What are some challenges when transferring?

- Has to lock knees to walk → hyperextended knees creates bone to bone contact
- Can stand for up to 10 seconds, but needs support (via Tom or her walker)
 - Body can't maintain being upright

Biggest challenge for Tom?

- Bathing transfers are the most difficult
- Helping Carolee requires less strength, more facilitation

Have you ever fallen from standing to sitting? What happened?

- Fell down the stairs a while back - broke leg
 - If she begins falling, she has no way to stop it from happening, as her muscles don't have the same reflexes
 - Isn't able to navigate stairs: place in Seattle doesn't have stairs, place in San Juan has an elevator
- Generally, she is "really careful" → always uses her walker, goes very slowly

What is the model of the freedom chair? Dimensions? Special functions?

- Motorized, and can go up and down
 - Uses the upward motion to align herself, then transfer to her walker
- Chair can swing from side to side (in place)
- She owns three of them - in Seattle home, San Juan place, and her office
- Made in Iowa, and costs \$2,000

Can you walk us through your morning routine? Can you tell us about the different transfers?

- Has a "unique way of getting out of bed" → immediately transfers to walker to go to the bathroom
- While taking her pills, uses a wine glass to drink water
 - Her hand can support the stem of the wine glass, but Tom is looking for a more lightweight version
- Has a power toilet, to lift her up
- Spends most of the day on a kitchen barstool
 - Tom swings her legs over and onto the chair
 - He calls her a "prisoner" of the chair
- Uses a wheelchair to transfer to the car (from her chair)
 - Tom created a makeshift "transfer board" to facilitate that transition
- From Freedom Chair to walker, lifts chair up and brings walker closeby before switching

- Bath Lifter (name?) - motorized and battery-powered
 - Backs up walker to tub → Tom lifts under both her arms to transfer her onto the lifter
 - To get off: uses a yoga block to lift cheek → grabs onto the sink → “propels” herself to Tom
- Doesn’t have the strength to use many traditional devices, so Tom and Carolee get creative

Do you have any ideas? Anything in mind?

- Tom used to look up ideas/devices on youtube → most weren’t suitable for Carolee’s condition, and required some form of muscle strength

What do you do to support yourself as you transfer from standing to sitting?

- Brings walker over to Freedom chair and “plops” down
 - Due to her muscle weakness, she has no way to flex her muscles and lower herself down slowly

How can your transfer experience be improved?

We want to consider affordability what would be an ideal price for a assistive technology

Do you ever transfer w/out Tom’s assistance?

- At this point, no: needs Tom’s assistance for most/all transfers

Would you plan to use assistive technology outside of your home? Is compatibility and transportability important?

- Yes; Tom should be able to put it into the car

Can you talk to us about chair yoga?

- When first started chair yoga (about 1.5 years ago), would use garden mat (?) to get on and off the mat
- Became increasingly difficult to transfer up and off the mat → instructor proposed chair yoga
- Is in a chair yoga class with about 8 others, mostly elderly
- Involves a lot of stretching, twisting, and mediation
- Tom sits next to her in a folding chair → lifts her arms during the appropriate exercises
- When instructor tells class to stand, Carolee pretends to stand
 - Allow practice of muscle tensing (both Tom and Carolee find it very helpful)
 - Dr. Steele: “motor imagery”

Can you describe how this process of transferring has changed in the past year?

- Before using a wheelchair, used to have a walking stick
 - Previously, used her arms a lot more
- Head neurologist at UW recommended switching to a walker

- Discovered the Freedom Chair via myositis newsletter

Looking forward in the year, what are your primary concerns/worries?

- **Losing arm strength in particular**
- Not being able to use her walker
- Having limited mobility with a power wheelchair
- Tom: for the future, we are “working toward immobility”
- Other challenges:
 - Neck is affected → when in the car, must tilt head to avoid it snapping back (?)
 - Swallowing is tricky → eats slowly and takes small bits

Things to consider

- She has good core strength → can lift knees up to her chest
- Tom: understand her limitations, as she doesn't have much muscle strength