# WELLSTONE Life Hacks 2025

# Travel& Transportation

- Spring loaded seat cushion (for restaurants, conferences, friend's house)
- Portable bathtub seat lift
- Foam or plastic toilet riser (Truck stops for shower/washroom)
- Slide boards
- Yoga blocks to raise bed
- Easy Spirit Travel-time shoes- They are slip on, comfortable, and have a rubber bottom for grip.
- Use a "care cane" to help get in and out of most vehicles. A small removable handle that fits most cars
- Use a Go-Go travel scooter for travel. It disassembles into four pieces for easy transfer into a car trunk. Great for air travel too.
- Cover the seat of your car with a silky fabric for less friction when sliding in-out of the car.
- When your scooter is stuck in mud or snow, slide your seat forward and back quickly to generate momentum and pack a "runway".
- Keep a gait belt in the glove box of your car
- Reserve an accessible room and call to confirm they have it reserved for you. Set your customer profile on hotel websites to "accessible room" preference.
- Before booking hotels and resorts, check pictures on Trip Advisor and look at guest photos to determine true accessibility.
- Use Google Maps Street View to see the layout and accessible routes before you get to your destination.
- Call ahead even if they say they are accessible, and ask details about entries, doorways, single steps, etc. Most places will also measure doorways of you ask.
- Wearing slip-on shoes/ballet flats. They look nice and are easy to put on, take off, and walk in

## Travel& Transportation

- Google image search when attending major venues (concerts, sports venues) to check things like which section have handrails, how steep certain sections are, how close sections are to the concourses, and how close sections are to accessible parking (comparing images and Ticketmaster seats).
- TSA Cares (855-787-2227). Call ahead before a flight to schedule to meet an agent at the airport. They will assist and facilitate your passage through security.
- Ask for DME to be a carry-on.
- Get to the airport early and check in at the gate. Ask if you can board early and move closer -95% of the time they will do it for free.
- Use packing cubes or roll clothes to fit more in a smaller bag.
- A portable folding ramp is helpful when visiting friends and relatives.
- Use 1"x5" boards keep them in your car so when you go to other homes, you can build small stairs to assist in getting up a 7-inch step
- · Use a walking stick bought at a sporting goods store for stability when walking
- Folding cane for easy transport and use as needed. Helpful in a crowd since people can visually see you have poor balance so are less likely to run into you.
- Travel with a small (square foot) size tract mat. It will allow you to step into a wet tub, bit its light weight and dries quicker than a full mat
- Request gate to gate transfer and then politely request they follow through all the way to the next gate.
- Don't travel late or ask when assistance for wheelchair assistance leaves for the day.
- Folding power wheelchairs can be a good option for travel. Some available options include:
  - Jazzy Carbon and Ultra Light
  - Golden Cricket
  - Fold & Go
  - Air Hawk
  - EZ Lite Cruiser
  - Feather Power Wheelchair
  - Whill

#### Work:

- Get to know the maintenance staff where you work (and live)- they're very helpful!
- · Communicate your needs!

# Home Management & Housekeeping:

- Hand bars and rails
- Bar stools with backs
- Lower the island counter
- Pullout microwave/drawer
- Use a grabber/reaching aid to pick things up off the floor to avoid needing o bend and always have an extra one!
- Threshold ramp for doors/sliding doors
- Furniture risers (look like cups) to raise your bed to make it easier to get out of bed (Home Depot)
- Bed rail- slides in between mattress and box spring to help get out of bed easier (Amazon)
- · Store dishes, pans, plates, and cups at counter height so easy to reach and use
- Furniture sliders under chairs to help move me under the table when sitting in a chair. It is easier for me and easier for the helper (Home Depot)
- Pub/counter level table and chairs for easy access at mealtime
- Get a power lift chair/recliner to use in the living room
- · Silk pajamas of sheets, less friction makes it easier to roll over and get out of bed
- Put boxes in all cabinets to keep things from going so far back that it becomes hard to reach
- · Yoga block under feet at kitchen table
- Custom made wood furniture risers for couches, chairs, etc. can be painted to match the color of furniture legs: <a href="https://furniturerisers.com">https://furniturerisers.com</a>
- IKEA's line of accessible furniture: <a href="https://www.ikea.com/ma/en/new/the-story-of-the-omtaenksam-collection-pub26ccle90/">https://www.ikea.com/ma/en/new/the-story-of-the-omtaenksam-collection-pub26ccle90/</a>
- Mangar Health Elk: to help lift from a low position: <a href="https://mangarhealth.com/us/by-winncare/patient-lifting/at-home/elk-lifting-cushion/">https://mangarhealth.com/us/by-winncare/patient-lifting/at-home/elk-lifting-cushion/</a>
- Upeasy seat lift: <a href="https://carex.com/collections/lifting-seats">https://carex.com/collections/lifting-seats</a>
- Human floor lift- lift up from the floor independently: <a href="https://indeelift.com">https://indeelift.com</a>
- Electric seat riser on wheelchair
- Pillows between knees (with Velcro) while sleeping
- Use a knee/ankle wrap (elastic, breathable) to wrap at knees while sitting on scooter or in car to keep knees closer together

# Home Management & Housekeeping:

- Customize your chair height-stackable chairs can be used to adjust chair height.
   If a regular single chair is too low, try stacking two chairs to get a slightly higher position
- Stair lifts
- Smart homes
- Connect with others and plan 4-5 years ahead
- Portable telescoping ramps are lightweight and easy to transport when visiting
  homes with stairs if you have a 4-wheel scooter or wheelchair that in line front to
  back wheels. 3-wheel scooters require a second set of ramps. Cut a stick to length
  as a gage for quick ramp setup. With all portable ramps, keep smooth consistent
  throttle, theory being that jerking the throttle can cause a kickout.
  - Examples: <u>DMI 5 ft. Telescoping Wheelchair Ramps 517-4094-0000 The Home Depot</u>; <u>Amazon.com: gardhom lPair 7FT Adjustable Wheelchair Ramp 84" L x 7.4" W Telescopic Ramps for Wheelchairs 600 lbs Portable Wheelchair Ramps for Steps Home Threshold Doorways Steps Stairs with Carrying Bag : Health & Household</u>

# **Emergency Planning:**

- Paramedics plus non-emergent paramedics
- · Communicate with local fire department
- First Aid in your car
- Wear an Apple Watch so you can call or text someone if you fall and cannot reach your phone
- Seek Fire Department help in advance... have agreement for them to provide help getting you up- use Know Box to get in: <a href="https://www.knoxbox.com/">https://www.knoxbox.com/</a>
- MDA's Emergency Preparedness for People with Disabilities includes a checklist to fill out in case of an emergency:
   <a href="https://www.mda.org/sites/default/files/publications/Emergencies\_Checklist\_10">https://www.mda.org/sites/default/files/publications/Emergencies\_Checklist\_10</a>
   <a href="https://www.mda.org/sites/default/files/publications/Emergencies\_Checklist\_10">https://www.mda.org/sites/default/files/publications/Emergencies\_Checklist\_10</a>
  - https://www.mda.org/sites/default/files/2019/07/MDA Emergency Preparednes s Toolkit 2019.pdf
- Keep your cellphone on you whenever you are alone in case of emergency. Tell 911 operators you just need a lift-assist, no sirens please.

#### Online resources:

- Blog-My Sandy Trail
- Blog-Little Miss Turtle
- Blog-Curb Free with Cory Lee
- · Make your own caregiver training videos for home or school aide
- Movement class- University College London- specific to people with neuromuscular conditions:
  - Standing: <a href="https://www.youtube.com/watch?v=MN5OJs-ZHm8">https://www.youtube.com/watch?v=MN5OJs-ZHm8</a>
  - $\circ \ \ Seated: \underline{https://www.youtube.com/watch?v=tebCn3a7Hf8}$
  - Lying: <a href="https://www.youtube.com/watch?v=yaZ2aJsCZ8Y">https://www.youtube.com/watch?v=yaZ2aJsCZ8Y</a>
- Shelley Mockler's Pilates/movement:
  - <a href="https://www.youtube.com/watch?v=yuk3MYkyNjs">https://www.youtube.com/watch?v=yuk3MYkyNjs</a>
- Mind Body Solutions adaptive yoga:
  - <a href="https://www.youtube.com/watch?v=4ZyZEAtp-Cs">https://www.youtube.com/watch?v=4ZyZEAtp-Cs</a>
- Adaptive Yoga LIVE- designed by disabled people:
  - https://adaptiveyogalive.com
- Online chair and adaptive yoga classes:
  - ·https://www.youtube.com/@LEAPService

  - https://www.youtube.com/watch?v=F TleDibkr8&list=PLdAl5SsVkdocMLUUPFfqXXUzQ57UlJp7y&index=28
- Gentle Yoga
  - <a href="https://www.youtube.com/watch?v=C2RAjUEAoLI">https://www.youtube.com/watch?v=C2RAjUEAoLI</a>
  - https://www.youtube.com/watch?v=YbAYMQC\_ZaE&list=PLui6Eyny-Uzy7DfaE9gPTzdP2Nm\_brTXj&index=3
  - $\begin{tabular}{ll} \bullet & \underline{https://www.youtube.com/watch?v=xuOLowlurcU&list=PLui6Eyny-Uzzfg2uL--\\ \underline{Z\_2Ep2Is9kRInT&index=3} \end{tabular}$
- Stretching and Mobility Focused Sessions
  - https://www.youtube.com/watch?v=BlzuiUN6fxg
  - <a href="https://www.youtube.com/watch?v=UHldH2J66Dc">https://www.youtube.com/watch?v=UHldH2J66Dc</a>
  - <a href="https://www.youtube.com/watch?v=NA3TKgdrVS4">https://www.youtube.com/watch?v=NA3TKgdrVS4</a>
  - https://www.youtube.com/watch?v=pciXaO4wtug
- Accessibility app (hotel, restaurant)
- Roll mobility app
- Travel Advisor app (handicap filter)

#### Life Hacks for Parents & Children:

- When our daughter got too old for bibs, we found lots of cute aprons on Etsy to use instead. She gets to wear fashionable, age-appropriate prints or solids and it protects her lap too.
- No matter what your child with MD says, they will get tired after a big day and will want to be carried. Save your back and bring the wagon and stroller.
- Ask teachers to provide child-size chairs throughout the classroom for kids to sit
  without having to get all the way down and back up again. For example, at group
  times when entire class is sitting on the floor.
- As a parent, moved into a one-story home and install a ramp from the garage into the house.
- For parents with young kids that still need to be carried, TUSHBABY is a shelf carrier that helps save your back: <a href="https://tushbaby.com/">https://tushbaby.com/</a>
- · Use a grabber to pick up kids' toys and to clean rooms
- MiniMeis chair that sits on a parent's shoulders. It is easy to put a child into and take them out of. They are supported and buckled in. Allows them to see in front rather than the backpack view: <a href="https://us.minimeis.com">https://us.minimeis.com</a>
- Caregivers... use your legs, not your backs when lifting!
- For young children with g-tube extensions- use a small sweat band to keep the tube in place on their leg (this can keep your child from grabbing the tube and chewing on it or opening the port)

# **Shopping:**

- · Check with your installer/vendor to know what is compatible
- Second hand and consignment stores
- Facebook marketplace
- Estate sales
- Amazon prime- Free delivery of anything too heavy for me to carry.
- Get a hand-truck stored in a hallway closet to roll heavy items where you want them to go.
- For carting groceries and other items, try a CLAX cart. it keeps your items up high (not low): <a href="https://claxcart.com.au/clax-cart-2/">https://claxcart.com.au/clax-cart-2/</a>

#### **Destinations:**

- Take beach vacations to places with Mobi-mats so you can get on the beach (Florida has many!)
- I get the cheapest ticket to any concerts and plays. I tell the usher I need to stay in my scooter, and they give me a free upgrade almost 100% of the time!
- Free national parks access for US citizens with a permanent disability. America the Beautiful National Parks Access Pass: <a href="https://store.usgs.gov/access-pass">https://store.usgs.gov/access-pass</a>
- Wheelchair Getaways offers accessible vehicle rentals

#### **Transfers**

- Slide boards
- Gait belts
- · Hoyer lifts
- Slings
- Chuck pad/sheet to help roll in bed (cornel handles)
- · Ceiling lifts
- · Glide sheet to help with turning and moving in bed

## Socializing:

- Online meeting time (zoom, X-Box, etc.)
- Your words can hurt people, but they can also build people up- it has a double feature!
- Kabooti Chair cushion- lightweight and portable: <u>https://www.contourproducts.com/kabooti</u>
- Sit at counter height tables and chairs
- When at restaurants and sitting at bar or counter height tables, bring along a collapsible stool to rest your feet on. But also remember to take it home!
- Just say "Hi" 😜
- · Go meet people!
- Just tell strangers you have a "muscle" problem. They don't need to know the whole story, and this will satisfy their curiosity.
- When ordering food from anywhere, call from the parking lot when going to pick up, and ask if they will bring it to the car for a tip. Works 100%
- Review menu online in advance.
- Diary of a CEO and other material from Vanessa Van Edwards can help develop skills for connection with other people
- Camp Promise offers in-person and virtual events, including gaming events, for children and adults with muscular dystrophy

### Bathroom Management & Accessories:

- Toilet seat riser
- Portable rails
- Go Girl Urinals and Lady-J Female urinating gadget or Shewee. Allows women to
  pee standing up. Other options: <a href="https://shop.traveljohn.com/traveljane/">https://shop.traveljohn.com/traveljane/</a>
   <a href="https://sanigirl.com">https://sanigirl.com</a> Adding a little bit of tubing with duct tape to avoid leakage on
  legs or pants.
- Condom catheter (Coloplast)
- Power Toilet Aid
- Toilet lifts to help make it easier to get off the toilet:
  - The Warren Lift (power toilet) <a href="https://mikewayllc.com">https://mikewayllc.com</a> (manufactured in Burlington, IA) and they will customize to fit individual needs
  - Lift Seat
  - Heron shower commode chair (by R82)
- Get the Hurricane Spin Scrubber to make cleaning your shower or tub easier while standing (it's an electric scrub brush on a five-foot-long pole)
- Place a TOILEVATOR under the base of your toilet. It is designed to raise the toilet by 3.5". It is a spacer between the floor and toilet base.
- · Use a long-handled bath pouf to reach your legs and back when showering
- · Use an electric toothbrush, light weight hairdryer, and light weight hairbrush!
- Modify home bathtub into a walking shower (Luxury Bath or Bath Fitters)
- Foot grips/shower shoes or grip mat/shelf liner
- Shower chain
- Use a towel holder to put your elbow on when brushing your hair.
- Drawer liner or Dycem <a href="https://dycem.com">https://dycem.com</a> put a non-slip mat in front of the toilet or tub... also good for travel
- BathLyft raises and lowers you in the bathtub...safely! You can bathe again!
   Website also has videos showing how to go from the floor to sitting to standing <a href="https://solutionbased.com/products/bathlyft">https://solutionbased.com/products/bathlyft</a>
- Bath lift (Bellavita by Drive Medical) can also be used for gardening and other outdoor activities
- Bidet for toilet!
- Get a chair height toilet (ADA)

# Living with MD:

- · Electric wine opener
- · Electric can opener
- For needle biopsies: elevate your leg and rest as much as possible the day of the procedure, limit walking on it that day. Have someone drive you home as driving a long distance can cause swelling
- 101 Tips for Living with Pompe: good book <a href="https://agsd.org.uk/news/pompe-101-tips-in-italian/">https://agsd.org.uk/news/pompe-101-tips-in-italian/</a>
- Bra offering a little upper back/posture shoulder support:
   <u>https://shop.lululemon.com/p/women-sports-bras/Energy-Bra-High-Support-Zip-Front/\_/prodl1690178?color=69013</u>
- Aqua therapy- gentle stretches and exercises in a heated pool to maintain range of motion and strength, and improve stability
- Music therapy
- Bring your handicap parking tag with you!
- · Keep your head up and dance!
- Positive affirmations: Find something-social media, a book, meme, Grumpy Cat to start your day on the right foot!
- Standing up-when you need to rise, turn around on the chair and push off to get up.
- · Use a cup with a lid and handle. Easier to hold, carry, and less likely to spill
- Invest in water bottles such as Camelback so you don't have to lift and tip a bottle up
- Patrick Moeschen blog <u>Muscle Memoirs: LGMD Experiences Patrick Moeschen</u> | <u>Muscular Dystrophy News</u>
- Don't expect your muscles to perform the same way every single day; there will be good days, bad days, and in between days. Check in with your muscles on an as needed basis to see what they are able to do for you in that moment. Don't forget to thank them/send loving gratitude to them they, like us, are up against a lot and need praise and appreciation too.