ZEBRA MEAL · THE DAZZLE MEMBERSHIP

The Wheelchair & Mobility Aids *Toolkit*

You do not know what you need until you know what your choices are.

A member deep-dive from Julie Griffis, PT, the full companion to the free "You're Allowed to Use a Wheelchair" Snack. The menu of chairs, the configuration choices that fit a POTS body, the insurance pathway step by step, and the language that helps a real case get seen.

PART ONE · WHY UPRIGHT IS EXPENSIVE

The physiology under the *permission*

STRETCHY VEINS, AND WHERE THE BLOOD ACTUALLY GOES

Your veins are soft and squishy like the rest of your connective tissue, and they rely on their own walls plus the squeeze of surrounding muscle to push blood back up against gravity. When the walls are too stretchy, gravity wins: blood pools in the lowest point, your feet when you stand, your hands when you walk. Your brain, sensing the loss up top, tells your heart to race, making up in speed what it cannot make up in pressure. Unsupported standing is precisely the position where your brain treats this as a crisis, which is why the STAND test is done standing still: every time you stand, you are running a crisis protocol.

THE POSTURAL WORKLOAD

Holding a body upright is its own job. The postural endurance muscles work all day, and in a hypermobile body they also moonlight as ligaments, stabilizing joints that do not hold themselves. Standing is never "doing nothing" for you. It is two shifts, worked simultaneously, billed to the same small budget.

A THREE-QUESTION SELF-CHECK

The honest qualifier for a mobility aid is not "can you walk at all." It is these three questions. **Is your walking reliable**, or does it vanish on bad days without warning? **Is it safe**, or does attempting it risk a faint, a fall, or an injury? **Is it affordable**, or does it cost so much energy that the day collapses around it? If any answer makes you wince, a tool belongs on your menu.

THE REFRAME THAT RUNS THIS TOOLKIT

Using a wheelchair some days, a cane other days, and nothing on the good days is not you getting worse or getting dependent. It is you using the right support for the moment your body is in, which is exactly the skill. The phrase is **unreliably ambulatory**: some days you can walk and some days you cannot, and both are allowed. External supports are information, not crutches; they give your nervous system better data, and when the information gets clearer, the body stops bracing for threat.

Reaching for the right tool at the right moment is progress. In my notes it counts as progress, because it is.

PART TWO · THE MENU OF CHOICES

Four avenues, one *principle*

AVENUE	PAID BY	THE HONEST PICTURE
Custom ultralight manual chair (usually with power assist)	Insurance	The workhorse. Portable, lightweight, fitted to your body, and genuinely function-extending. When the features are mapped to real impairments and medical necessity for POTS, these get approved: in my own practice, every custom ultralight request I have submitted this way has been approved.
Fully powered chair	Insurance (high bar)	Right when someone truly cannot self-propel and has the infrastructure for it: these chairs are very heavy, do not collapse, and need ramps, a van lift, or a trailer. The evaluations are specific and individual.
Off-the-shelf manual chair	Private pay	A lightweight standard chair. It will not fit perfectly, but if coverage is out of reach, it beats nothing.
Portable powered travel device	Private pay	Foldable, transportable, battery and joystick (for example, Paiseec). A newer category; long-term durability for daily use is not yet known, so it suits someone who needs it for certain outings rather than every day. Prefer a company with a return policy and a trial period.

THE EVERYDAY AIDS NOBODY COUNTS

The perching stool at the stove. The shower chair. The folding stool that lives in the bag. The rollator with the built-in seat. These are mobility aids too, prescribed by the same logic autonomic cardiology clinics already use when they tell POTS patients to sit while cooking, because prolonged standing is a known trigger.

THE GUIDING PRINCIPLE

The best wheelchair for you is the one you can **safely and effectively use**. It has to match your body's ability (a perfect ultralight is useless if shoulder, hand, or wrist problems keep you from propelling it) and fit the structure of your life (how you will transport it, where you will use it). Body ability and life infrastructure, together, decide the right chair. That is why the real choice happens with a PT and an assistive-technology professional, not alone in a browser tab.

PART THREE · THE POTS BUILD, SPEC BY SPEC

Every feature has a *reason*

This is the component set I most often assess for POTS. Your own build comes from your own evaluation.

CHOICE	THE OPTION	WHY IT MATTERS FOR THIS BODY
Frame	Rigid or folding	Rigid is lighter but bulkier for a car trunk (wheels often come off to load it). Folding is slightly heavier but collapses smaller. An SUV or minivan can often take either assembled, depending on what you can lift.
Foot hangers	Low profile, 70, 80, or 90 degrees	Angle set to your comfort at the evaluation.
Seat width	Often wide enough to sit crisscross	Getting the legs up avoids the dependent-leg pooling problem. This is the blood-pooling logic made physical.
Wheels	Semi-pneumatic	The sweet spot: no flat tires, still cushions bumps. Vibration can be a mast-cell trigger, and in EDS bumps can provoke joint instability, especially at the craniocervical level.
Seat dump	Back of the seat pan slightly lower than the front	Postural stability for less effort. It lowers the energy it takes just to sit in the chair.
Push rims	Ergo-grip rail style, or traditional	Driven by your hand joints. Traditional rims have gaps a finger or thumb can catch in; rail-style rims are smooth like a handrail.
Cushion	Low-profile, pressure-relieving	Comfort-grade unless skin breakdown is an actual concern for you.
Armrests	Desk-length or full-length	Desk-length pulls up to a table; full-length gives more room to push up for safer transfers.

THE ENERGY-MATH CENTERPIECE: POWER ASSIST

Here is the counterintuitive part: self-propelling a manual chair is upper-body cardiovascular work, which is exactly the thing an exercise-intolerant body cannot spend freely. So I almost always include a **power assist**: a detachable motor on a bracket under the seat, with an on and off control. You still propel and steer with your arms, but the motor does more of the work, so there is less work to get propelled. It is what makes hills and longer distances possible, and it protects the shoulders. The unit I use is the **Empulse R90 by Sunrise Medical**, compatible with both rigid and folding frames.

PART FOUR · THE PROCESS, DEMYSTIFIED

The insurance route, *step by step*

1. **PT wheelchair seating evaluation.** This is where your body's abilities and needs get documented.
2. **Assistive technology (AT) evaluation,** usually at a wheelchair clinic or vendor, with a certified specialist.
3. **The PT and AT work together** to complete the prior-authorization and medical-necessity forms your insurance requires.
4. **Your primary care doctor signs** the packet and submits a prescription for the chair.
5. **It goes to insurance.** Most of the time the wheelchair vendor handles the submission and follows up.
6. **Insurance reviews** and approves or denies, and responds to the vendor.
7. **If approved,** the vendor confirms any deductible or copay with you before ordering. You approve the cost first.
8. **The chair is ordered** and assembled when it arrives.
9. **Fitting appointment:** the components are confirmed and everything adjustable is tuned to your body.
10. **Later needs** go through the vendor: repairs, changes, and add-ons. An add-on after approval either goes through the insurance process again or you pay for the part privately.

IF DENIED

A denial is often a request for more information, not a final no. Insurance may ask for additional documentation; your PT and AT can provide it and resubmit for reconsideration.

THE PRIVATE-PAY ROUTE

Choose your avenue, then shop around. Prefer a company with a **return policy and a trial period**, so the chair proves itself in your actual home before you commit. One patient of mine skipped worrying about push rims at assessment, then found her thumb catching in the traditional rims on every push; she went back for smooth rail-style rims. Real life is the final evaluator.

PART FIVE · WHAT INSURANCE WANTS TO SEE

The case is about *function at home*

Medicare is the template most insurers copy, so its logic is worth understanding even if your plan is different. Coverage turns on a **mobility-related activities of daily living (MRADL)** limitation: on your bad days, walking is so compromised that it risks injury or cannot get you through the basics of your home, the toilet, dressing, bathing, feeding yourself. The frame is your home, even when the reason you want the chair is to have a life outside it, so useful examples anchor to home tasks: the stove, the bathroom, the distance from bed to door.

A LIMITATION COUNTS IF IT DOES ANY ONE OF THESE

- It prevents you from doing the activity at all, or
- Attempting it puts you at heightened risk of harm (falls, injury, fainting), or
- It keeps you from completing it in a reasonable time.

"Unreliable ambulator on bad days" lives squarely in the second and third prongs, and so does this population: the danger is not that you can never walk, it is that attempting it risks a faint or costs so much that the day collapses.

WHAT ACTUALLY STRENGTHENS THE DOCUMENTATION

- **Concrete, bad-day-honest home examples.** Not "I get tired" but "on a bad day I cannot stand at the stove long enough to cook a meal without my heart rate spiking and having to lie down."
- **Objective numbers.** Orthostatic vitals, your STAND test heart-rate rise, documented subluxations. The same numbers that help your doctor also strengthen a wheelchair request.
- **Why a cane or walker fails, in mechanism terms.** The limitation is not a bad knee a cane could offload. Being upright itself is the problem. Naming that distinction is the whole argument.
- **Your honest self-propulsion picture.** What your shoulders, wrists, and endurance allow on a good day and a bad day. Limits of strength, endurance, range of motion, coordination, and pain are what move a case from a basic chair toward the custom ultralight, power assist, or a powered chair.
- **The team.** A custom ultralight specifically requires a specialty seating evaluation by a trained PT or OT plus a RESNA-certified assistive technology professional, in person. The right team is a coverage requirement, not a luxury.

SAY THE TRUE THING

The most common reason a legitimate case gets denied is under-documentation, not ineligibility, and people with invisible, fluctuating conditions chronically under-report out of habit and shame. Telling the true, specific story of a bad day is not exaggerating. It is finally being accurate.

PART SIX · TROUBLESHOOTING AND THE NEXT STEP

When the path *snags*

THE SNAG	THE ROUTE
The request is denied	Ask what information was missing; your PT and AT supply it and resubmit for reconsideration. A denial is a request for a better-documented case more often than a closed door.
You cannot self-propel (shoulders, wrists, endurance)	The answer is not to push harder. It is power assist, a fully powered chair if your life infrastructure supports one, or the portable powered middle path.
No insurance, or coverage out of reach	The off-the-shelf lightweight chair or the portable powered device, ideally with a trial period. Imperfect fit still beats no tool at all.
The chair needs a change after delivery	Back to the vendor. Fittings adjust; components can change; your needs are allowed to evolve.
Other conditions in the constellation	This toolkit is the POTS component set. hEDS, ME/CFS, and MCAS bodies often need evaluation for additional features; bring the whole picture to your seating evaluation.

BOTH THINGS ARE TRUE

There can be grief here, and it does not need to be tidied away with a well-at-least. You are allowed to grieve the version of the day that did not need wheels, and to feel the freedom the wheels hand back, in the same hands, at the same time. Neither one cancels the other.

THE NEXT STEP, IF YOU ARE PURSUING A CHAIR

Choose your avenue: insurance or private pay. For the insurance route, the door in is a **PT wheelchair seating evaluation** plus an **assistive technology evaluation**, and your primary care provider writes the prescription. You arrive at that room already knowing the menu, the specs, and the questions, which is exactly the point of this toolkit. When one path is blocked, you do not push harder into the wall. You change the route.

The tool did not shrink your life. It gave it back to you.

SCOPE, SAID WARMLY

This toolkit is information to help you understand your choices, not medical advice, insurance advice, or an assessment of your needs. Coverage criteria vary by plan and change over time; your PT and assistive technology professional carry the paperwork, and you supply the honest functional picture. The free Snack holds the permission; this Meal holds the map.