



Charcot-Marie-Tooth Association

2700 Chestnut Parkway
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www.charcot-marie-tooth.org
1-800-606-CMTA

Helpful Ideas for Things that Work

By J. D. VEATCH

Here are things that work for me and might for you. We all have different manifestations of our neuropathy; so not all of these products and devices will suit you. But they may spark an idea for an alternative that will allow you to function more comfortably and efficiently.

AFOS

I've evolved to the lightest, thinnest, most flexible plastic that will withstand nearly unrestricted and constant activity. I've snapped and had to replace six different orthoses since 1995, but the flexibility and minimal weight of my current pair far outweigh their relative fragility. And, I've managed to salvage two back-up pairs, one for each of our homes.

After struggling with heavy, bulky buckles to secure the AFO around my calf, I specified 2-inch Velcro tape only, with the catch piece on the back of the AFO. I thread a felt pad onto the tape crossing my shin to avoid contact with and abrasion of the skin. In addition to being easy to secure and remove, the Velcro becomes almost invisible under over-the-calf socks. In fact, at least in my mind's eye, the slight bulge of this fastening system simulates the appearance of well-developed calf muscles.

I wear the thinnest, synthetic fabric quarter sock to keep my feet from sticking to the PPT cover on the foot pad. I've found Wal-Mart/K-Mart tube socks to be the ideal, inexpensive outer sleeve for my AFOs, but turn to soccer or over-the-calf, wool dress socks when I want color variety. I wear shorts in Florida most of the year and don't feel overly conspicuous in my knee socks. I occasionally affect a slight British accent to complement the ensemble.

Three clever tips from a *CMTA Report* article by Dana Schwertfeger that appeared a couple of years ago have resulted in immeasurable improvement in my AFOs. Molding the plate of the AFO to the contours of the bottom of my feet has virtually eliminated chronic and painful metatarsal calluses, and drilling ventilation holes in the back of the braces has made them much more comfortable in hot weather. Cutting off the footplate just behind the toes allows me to wear a full half-size smaller shoe. This places the ball of my foot in a more correct, forward position in the shoe and does away with clown shoe flap.

FOOTWEAR

Blucher style Rockport dress shoes have served me well, although in retirement I'm favoring L.L.Bean's Blucher Moc in walnut nubuck. The flat, beveled-edge sole and absence of an elevated heel make them surprisingly stable for a relatively shallow shoe. For some reason the walnut nubuck model is much softer and more flexible than the

brown model. They're not great for long walks, but fine for less-than-formal evenings that involve minimal walking and standing. A thin insole makes them even more comfortable.



My favorite everyday shoe is the New Balance 810 Walking Shoe. This shoe is light, flexible, and deep and wide enough to accommodate my AFO. When new, I remove the insole for more break-in room, but replace it when the shoe begins to feel too roomy. I may be the only guy in the world who puts shoe trees in his sneakers, but I've found that they maintain the needed width and original shape.

The most comfortable and accommodating footwear I've come upon in years are L.L. Bean's Moosehide Soft Sole Mocs. I wear them exclusively in and around the house without my AFOs. As advertised, they are truly "buttery soft" and mold immediately to the shape of one's foot. They have no tacky/sticky, sharp edged sole to catch on carpet or tile joints and don't impede the slide/drag gait common to many people with CMT.

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HELPFUL IDEAS THAT WORK

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I make mine even more comfortable by inserting the best insole on the market, SPENCO Everyday or Thin Soles. The slipper's "Soft Sole" becomes very sticky when wet and will stain light-colored carpet. I wear through the sole about once a year, but could get better wear if I removed them before taking my daily saunter down the driveway for the newspaper.

Because we spend a lot of time on our ocean beach, I tried a number of department and drugstore water/beach shoes that were consistently ill fitting and more of an impediment than an aid. I finally found a light, mesh body and rounded/beveled rubber sole water shoe at my REI, Inc. store in Northern Virginia. Unfortunately, REI advises that they are no longer carrying "my" shoe, at least on their website, and I'll have to wait until we return to Virginia to determine whether they are still in the store,

The surprise bonus these beach/water shoes provide is that they are great for light lawn chores, gardening, and car washing. I put a pair of those wonderful SPENCO insoles in them and find that I can get around the property or the car without my AFOs. These are tight-fitting water shoes that stay on in the surf and are difficult to pull over my high instep when new. I stretch the elastic mesh instep panel with a pair of old baseballs until I can comfortably pull them on. I'm confident that you can find similar water shoes at any good outdoor sporting goods or diving store.

EMERGENCY WADING STAFF

What? That's what Orvis calls it because it was designed to assist trout fishermen wading in fast rushing, slippery-bottomed mountain streams. My wife calls it my "pokey stick" (I'm always lagging behind and/or she gets an occasional nudge in the backside), and it's the best thing I've ever used for long walks, walking over uneven terrain, climbing steps with no railing, waiting in long, slow-moving lines, standing in museums admiring the works on display, and even standing at cocktail parties. Mine has six black anodized aluminum sections that automatically lock in place with spring cord tension. It's easy to break down and comes with a leather holster with a belt loop. It's



a great aid for maintaining balance and provides an extremely effective leveraged boost for climbs. It's much more comfortable than a cane and has a lot more panache.

It's not cheap (about \$130), but I've had mine for over 12 years and it snaps in place just like it did on day one. A note of caution: it comes in two sizes, 50" for under 6' and 59" for over. I inadvertently sent my 5'8" brother the longer model and he called me asking if I was suggesting he take up pole vaulting. You'll be a lot more popular with your friends who have hardwood floors if you add a rubber tip, because it comes with a sharp tungsten-carbide tip. It'll fit in a large fanny pack, which is sometimes more convenient and secure than the holster.

GARDEN KNEELER

This terrific, versatile kneeler-stool caught my eye in the Improvements catalogue about a year ago and I've used it several times a week ever since. It has a sturdy steel frame that locks in place with spring-loaded catches and a double-sided rubberized cushion. The steel frame arms/legs form a hand-hold at the top and are the perfect height for raising yourself back to a standing position. Flipped over, it becomes a comfortable stool for chores like scrubbing car wheels and rocker panels. It is advisable to sit down gingerly when using it as a stool. If you plop down, you will, more than likely, go over backwards...only embarrassing in the middle of the yard but potentially painful in the driveway or on the deck.



RESOURCES

All of the brand names I've mentioned have easy-to-navigate websites that can be accessed by searching with the name. To see the "pokey stick" on the Orvis site, you have to enter the slightly haughty "Wading Staff" in their Search box. You can see the beach/water shoes on www.deepseeinc.com, a wholesale distributor. Click on "Boots" and then "Beachwalker." I've asked DeepSee for the name of retail stores and Internet sites, but haven't received a reply yet.

If you have questions or want amplification, e-mail me at jdveatch@ucnsb.net. Keep pushing. Stay active. ★

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