

Drag and Drop: Running with Foot Drop & AFOs

Drag and drop is a function that makes our computing lives easier. But what if that function is part of your everyday physical life? In other words, your foot drags and drops, and you fall if you're not quick enough to catch yourself. This condition is called "foot drop," and it's a common symptom of MS that compromises mobility.

It triggers fear of falling and has potential to cause serious injury. Fortunately, there are devices that can help mitigate foot drop and keep a person upright even during exercises like running. One of these is the ankle-foot orthosis (AFO). And for those living with MS, like the resilient people we talked to below, the AFO helped them continue their passion for exercise.

Heather had been a nationally classed runner. One year, while training for Boston Marathon, she started tripping and falling over her foot. She was referred to a neurologist and subsequently diagnosed with MS. Her neurologist, also a marathoner, knew exactly how to keep Heather in the running game. After being referred to an orthotist, Heather was promptly fitted with her first AFO.



Heather

Not everyone is lucky to have a neurologist who understands a runner's mentality of never giving up. Others like Ellie, Carrie and Vanessa said none of their healthcare providers suggested solutions for foot drop. They advocated for themselves and conducted research to find ways to exercise safely. Vanessa said she read several articles about runners with MS but did not notice stories on running with foot drop until she came upon the MS running team, "Run a Myelin My Shoes" (RAMMS) and saw teammates participating in races wearing AFOs. That gave her hope.

Koreen is a cyclist at heart and has ridden Bike MS in all 50 states. She took up running as an alternate exercise during off-season, but started staggering while running long distances. She went to a physical therapist, but the rehab drills did not help. She felt like "damaged goods." Koreen aggressively searched for a solution and saw an orthotist. The AFO she received, however, was a bulky military-style device that was not made for dynamic activity. It left her feeling hopeless, so she stopped running.



Koreen

Carrie had a similar disheartening experience with her first AFO device. Like Koreen's, it was a clunky and rigid AFO that bruised and blistered her foot. But she persisted and in the span of five months tested four different AFOs until she found the best one for her specific gait. Since Carrie also contends with muscle weakness in her thigh, she practices the run-walk technique to keep pushing forward to the best of her abilities.



Carrie

Ellie's first AFO also gave her trouble. Though it was marketed as a "sport device," she repeatedly cracked the carbon-fiber AFO in half. After many failed AFOs and a growing neuroma issue that caused painful numbness in her toes, she found one that worked, and she has now been running in it for a year and it's still standing strong. She jokingly tells the kids next door it is a "bionic leg!"



Ellie

Heather's disease has progressed since that first AFO fitting and now needs AFOs on both legs. She must wear her AFOs every day for all activities of daily living. Despite setbacks, she reinvented herself every time. Heather started with one AFO, then transitioned to a functional electrical stimulation device. As MS progressed further, she incorporated trekking poles to maintain balance while competing in half marathons. When MS tried to knock her down yet again, Heather responded by getting a custom pair of matching pink AFOs. It is her stylistic way of never giving up.

Vanessa is new to the world of AFOs and just started wearing one. She was under the impression she would pick-up her running career right where it left off two years ago. She quickly realized it takes a lot of hard work to learn how to run wearing such a device. As Carrie can attest, you may have to go through a lot of heartache and failures before you find the right solution.

One of the hardest parts about toeing the start line of a race wearing an AFO is that people think your MS isn't serious. What they don't realize is the trial and error, the tremendous amount of hard work and the dedication required before an AFO-user can even get to the start line.

What are the results from all this hard work? Ellie said she uses MS to push her to accomplish difficult things and has completed 5 marathons. Koreen hiked the 2,200-mile Appalachian Trail last summer. Her philosophy is to set a bar and keep nudging it higher. Heather said exercise helps her "keep it together" and recently acquired a walking bike and fighting her way back to running form. In the meantime, Carrie and Vanessa are both scoring personal victories as they slowly take incremental steps to defeat the dreaded (foot) drag and drop.

About Run A Myelin My Shoes

Connect with the ladies featured in this article, as well as many other AFO-users living with MS!

RAMMS was formed in 2018 to participate in the Detroit Marathon, Half and 5K with 96 members across 16 countries and 25 U.S. states. For 2019, 287 teammates participated in the Richmond Marathon, Half and 8K and represented 12 countries and 44 U.S. states. Plans are underway for an all-virtual event for the weekend of November 7-8, 2020.

A RAMMS team-member can either be living with MS (our "MS Warriors") or be a supporter of those living with MS (our "Support Heroes"). They can participate in-person or virtually. We can provide physical assistance when needed, such as pushing a wheelchair or working with event staff to design a route of whatever distance you can accomplish. If you are interested in being a Warrior or Hero either in-person or virtually, contact us at the email below.

The team is on a mission to show the world what is possible with MS and to give the newly diagnosed hope. The only qualifications for membership are a desire to have fun and an aspiration to break barriers.

Please visit runamyelinmyshoes.org or email info@runamyelinmyshoes.org to learn more.

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Run a Myelin My Shoes

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