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Finding fashion options that accommodate AFOs

Practitioners know patients who feel that ankle foot orthoses (AFOs) hinder their sartorial style are less likely to be compliant, but many clinicians feel ill-equipped to give fashion advice. That's when the expertise of a stylist, seamstress, or personal shopper can come in handy.

By Shalmali Pal

The name Frida Kahlo conjures up some clear imagery: the Mexican artist's preference for colorful ethnic fashions, including ankle-length skirts; elaborate hairstyles adorned with flora and fauna; and those dramatic eyebrows. Her look wasn't just affectation. Kahlo contracted polio at age 6 and it left her right leg weaker and smaller than her left. As a child, she compensated by wearing multiple pairs of socks and a shoe with an elevated heel on her right foot. As an adult, she adopted her signature style to draw attention away from her lower extremity issue. In that respect, Kahlo may just be the patron saint of fashion-conscious wearers of ankle foot orthoses (AFOs).

Patients and practitioners struggle with balancing a person's need for sartorial splendor with the clinical need for AFOs: Patients lament how the devices limit their ability to express themselves through their clothes, while practitioners may wonder, "Why the fuss? The AFOs will greatly improve your function, and isn't that the most important thing?"

Of course, the issue is not that simple. *LER* spoke with a host of experts—practitioners, style mavens, and AFO wearers—about figuring out the fashion challenges of AFOs.

"When you make a device, you've got to fit it to a person's limbs and to their head," pointed out Kate Muller, CPO, FAAOP, of K&M Clinical Services in Mission Viejo, CA. "So there are two different fittings going on: The physical part and the emotional part. The patient needs to understand the function of the device, but they also have to be willing to accept it. There's a very delicate balance between making a brace for function and making compromises to accommodate a person's lifestyle."

The device does not wear Prada

Bethany Meloche, 21, was diagnosed with Charcot-Marie-Tooth (CMT) disease at age 12 years and began wearing her carbon fiber below-the-knee AFOs when she was 15. Although she wasn't overly fashion conscious at that age, Meloche said, "AFOs were unthink-

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Figure 1. Pants are a popular, versatile fashion choice for both male and female AFO wearers.

able so I delayed getting them. My first pair was made of this very thick plastic and I thought they were so ugly...I couldn't bear the thought of having to wear them."

But bear it she did, spending many years hiding inside long, baggy pants even after swapping the bulky plastic AFOs for more streamlined models. The turning point came for Meloche a few summers ago when her boyfriend noticed her sweltering in her long pants and asked why she didn't wear shorts. Her initial response was "I can't wear shorts because of the braces."

"He didn't understand the logic behind that because I was causing myself severe discomfort to hide a part of me that isn't something to be ashamed of. So it was really about me getting over my shame of having to wear AFOs," said Meloche, who is the social media director for the CMT Association and creator of the Bare Your Brace blog (bareyourbrace.com).

That sense of shame drives many AFO wearers to take a defensive position when it comes to their clothes. But it's important to remember that the goal is to dress the complete person, not just the device, stressed Marc Bronson, a manager at Neiman-Marcus in Beverly Hills, CA, and a freelance stylist.

"Whether someone wears a brace or not, I would ask that person to look at the same qualities: What are the five colors that look great on you? What's your body type? What's appropriate for your age? Do you tend to hang on to clothes that don't suit you anymore, for whatever reason?" Bronson said.

Stylist Alexandra Evjen of AVE Styles in Phoenix, AZ, agreed.

"What you choose to wear for the day is based on your personal style and comfort in your clothing," Evjen explained. "I always recommend that people dress in a way that helps them exude confidence. If that requires hiding the device, that's fine, but I would not let the device hinder self-expression."

And that self-expression can extend to the AFO itself, Muller noted.

"There are different kinds of AFOs available," she said. "The standard is the opaque, off-white color. But you could do black and that can be lower profile. There's also a color that's called 'Caucasian' but it's more of a peach."

However, she cautioned that, in her experience, the addition of pigment to the AFO plastic might shorten the lifespan of some devices.

"The plastic with the pigment incorporated into it tends to crack and show signs of stress much sooner than the standard color," she said.

Another option is transfer decals that can cover the entire brace. Designs and patterns range from the logo of a favorite sports team to a floral motif to cartoon characters. Transfers also don't affect the AFO's structural integrity because they are applied to the outside, Muller said.

"Tattoos have become more popular over the years, so transfers are one way to personalize the AFOs and increase a person's acceptance of the device," she added.

Function vs fashion

AFO fit and function are the main concerns of practitioners, so discussing a wardrobe overhaul with a patient isn't typically in their wheelhouse. But the issue is bound to come up, and healthcare professionals need to address it because of its impact on compliance.

"There's a relationship between how much benefit the patient derives from the device and their willingness to compromise on aesthetics," said Tom DiBello, CO, regional manager for Texas and the Gulf Coast at Hanger Clinic (formerly Dynamic Orthotics and Prosthetics) in Houston. "We have to consider the psychological ramifications of wearing a brace. Some folks think that the way they walk without orthoses does not impact their appearance as greatly as the cosmetic aspects associated with wearing them."

In the short term, DeBello said, a patient's acceptance of AFOs will depend largely on how well the device normalizes her gait, and the onus is on the orthotist to make that happen.

"We need to be able to show the patient a distinct difference in their gait, improving stability and function, with the orthoses because once you've achieved that, it will overcome some of the cosmetic issues," he said.

In the long term, DiBello predicts that advances in orthotic materials and functional capacity will render devices better at normalizing gait and increase patient cooperation to some extent.

"[But] we are a long way from having orthoses that look like a part of the patient's body," he cautioned. "So it won't be possible to meet everyone's need for cosmesis any time soon."

AFO wearer David Tannenbaum concurred that being able to walk better with a brace far outweighs his concerns about fashion. Tannenbaum is in his 50s and was diagnosed with CMT in his late teens, but did not begin wearing his carbon fiber knee-high AFOs until his 40s.

The New York City-based Tannenbaum happens to be a psychotherapist and suggested that practitioners need to really consider the emotional toll a brace takes, especially when dealing with a noncompliant patient.



Figure 2. Bethany Meloche goes for a sporty, summer style. (Photo courtesy of Bethany Meloche.)



Figure 3. David Tannenbaum generally prefers pants, but will adapt to the occasion. “I recently visited friends in Florida and wore a bathing suit because I didn’t want to miss the opportunity of going into the pool,” he said. “So there was a situation where I didn’t let concerns about my braces being seen stop me from enjoying myself.” (Photo courtesy of David Tannenbaum.)

“There can be this sense [for patients] that wearing braces means a kind of weakness or vulnerability... when you have a lower extremity issue, you have to deal with the impermanence of the body in a direct way, and that is not easy,” he explained.

He recommended talking to the patient about himself as a person and not just as an AFO wearer.

“Start by asking: ‘What are your strengths? What’s important to you? How do you perceive yourself?’ You have to help this person along in

confronting some of these issues, because I think the ultimate goal is for him to see that his identity isn’t solely derived from the fact that he has to wear braces,” Tannenbaum said.

Getting personal

Back in the dressing room, there is help out there for fashion-challenged healthcare professionals and their patients. Bronson advocated engaging a personal shopper at a department store.

“Once you make that appointment and discuss your needs with a personal shopper, they will go through the store and set clothing aside for you to try,” Bronson said. “Their only focus is to make you look good. I also think it would be great if healthcare professionals made arrangements with personal shoppers to refer their patients if they see them struggling with clothing choices.”

Bronson and Evjen also recommended that patients and practitioners forge relationships with local tailors and seamstresses.

“These people can be quite gifted at customizing clothes. Maybe it’s just a matter of buying a dress a size larger and then having it properly tailored,” Bronson said. For instance, the hem of the longer dress can be taken up to give the legs and AFOs some clearance. A frock in a bigger size may also be longer for AFO coverage, but the tailor would fit the garment in the torso and arms if appropriate.

Evjen also suggested that practitioners team up with local stylists, perhaps offering in-office seminars for their AFO-using patients. Both stylists recommended using the Web to search for the term “stylist” plus the name of the closest metropolitan area.

“Fashion stylists exist to help men and women feel confident with their appearance, and make the sometimes complicated world of fashion simple,” Evjen said.

Meloche recommended buying in bulk; if she finds a pair of boot-cut jeans she likes that work with

her AFOs, she snaps up several pairs (particularly crucial given that skinny jeans are all the rage). She also warned against assuming that any clothing that completely covers an AFO is a good thing.

“I tried longer skirts and they actually caused some problems,” she explained. “It affected my balance; maybe it was the extra fabric swishing between my legs. Also, the skirt would get caught on the Velcro [on the AFO straps].”

For men, Bronson suggested being open to different cuts of trousers rather than beelining for baggy pants. Tannenbaum noted that he prefers pants [to shorts] because he finds that the feel of the fabric on the legs balances out some of the numbness associated with CMT.

When it comes to footwear, encourage patients to bring in multiple pairs of favorite shoes for assessment.

“My protocol is, at the first appointment, I look at the person’s existing shoes so we can fit the shoes during the AFO fitting,” Muller said. “We can certainly try to work with the shoe to accommodate the AFOs; maybe removing the Ishoel insole, stretching the width if possible; discussing the difference between lace-ups and slip-ons.”

Both the fashion experts and healthcare professionals agreed that an AFO wearer’s best friend may be the department store Nordstrom. Evjen touted the store’s excellent customer service, while Muller noted that it will sell shoes in mismatched sizes (in-store only) so that the larger shoe can accommodate the AFOs. The retailer is also known for its generous return policy.

There will come a time when a patient will decide that fashion trumps function and inquire about not wearing their AFOs, particularly for a special event. Practitioners said it’s not necessarily out of the question, but the decision must be carefully considered.

“I have patients who say they want to wear their heels to church on Sunday without their AFOs,” said Tracey Vlahovic, DPM, who practices in Philadelphia and is an associate professor at Temple University School of Podiatric Medicine. “And if it’s for a couple of hours and they are going to be sitting down, I won’t say no. But I do ask them to think about their safety and comfort before they go without their AFOs.”

Muller uses the importance of the occasion as the tipping point between fashion and function.

“I tell patients, ‘The AFOs will allow you to have the energy to function longer because it’s going to be a huge day for you,’” she said. “If there is a small window where you want to take them off—walking down the aisle, the first dance—then you can do that, but just make sure that...you are safe. If you can’t safely walk 10 feet without the AFOs, then you have to decide which is the greater faux pas: Walking down the aisle with the AFOs on, or tripping and falling without them on?” 

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Figure 4. An AFO wearer shows off her stylish wardrobe.

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