

Reel life with MS



A young filmmaker focuses his sights on making the world more accessible.

by Alison Dale



Jason DaSilva recently addressed an audience about his film, “When I Walk,” which he says is about overcoming challenges with

triumphs.

Photo by Michael Varhol

Documentary filmmaker Jason DaSilva was only 25 when he was diagnosed with primary-progressive multiple sclerosis, a disease course in which a person experiences no relapses or remissions. In the span of just a few years, his symptoms rapidly worsened, and he went from using a cane to a walker, then a wheelchair, and now, a scooter.

With these drastic changes, DaSilva quickly discovered his previous fast-paced lifestyle was no longer an option. “It’s hard being 25, living in New York City and getting a debilitating disease. All of a sudden you’re not going to clubs and parties like you used to,” he says. “And friends don’t stick around.”

So the young filmmaker decided to turn the camera on himself to make sense of what was happening to him through the art of cinema. The result is “When I Walk,” a feature-length documentary that details the progression of his disease, the difficulties he faces as a result and how he copes with them. The film premiered at the 2013 Sundance Film Festival and had its theatrical release later that year.

The decision to film himself didn’t come easily for DaSilva. “It took me about two years from diagnosis to really ramp up. I mean, I started just filming bits and pieces, but I really didn’t want to start filming this film. You can see why,” he says, hinting at the difficulty he had in coming to terms with his progressing symptoms. But his passion for filmmaking won out and he committed himself to documenting the changes that MS was causing in his body, his career, his relationships and his life.

The show must go on

As DaSilva’s mobility challenges increased, so did his first-hand knowledge of how difficult the world can be for people who have disabilities, especially in New York City.



[“When I Walk”](#)

**premiered
at the 2013
Sundance
Film**

Festival.

Photo
courtesy of
Jason
DaSilva

“When I Walk” follows DaSilva as he tries, unsuccessfully, to accomplish tasks that many people take for granted. For example, he’s unable to use the subway system because of the stairs that lead down to most stations; and he also can’t depend on taxis because most can’t accommodate wheelchairs or scooters. Even when he could get to where he wanted, he found many businesses inaccessible because they had steps and no ramps. As he wrote in an opinion piece in The New York Times last year: “It’s not the MS that exhausts me. It’s the barriers that prevent me from conducting my daily activities.”

After a while, DaSilva realized that he was becoming housebound and isolated. In an effort to get out and connect with others who had MS, he ventured out to an MS support group, a decision that would change his life forever.

There, he met Alice Cook, who was in the group because her mother lives with MS. Before long, Cook became DaSilva’s collaborator, co-writing, co-producing and co-starring in the film, which was already underway, and eventually performing the editing tasks his own fingers no longer could. After completing the film, the pair developed an even deeper partnership: They married in 2010, and are now the parents of a 1-year-old son, Jase.

Cook says they were able to collaborate so successfully because they shared the same vision. “We were both really adamant about not wanting it to be a medical film. We wanted to focus on the emotional aspects of living with MS.”

“At the end of the day, my film isn’t just about MS. It’s about disability and overcoming challenges with triumphs—big ones and little ones,” DaSilva points out. “I really hope it’s going to make people start thinking about the disabled community as being the same as everyone else.”

Advocating for the rights of people with disabilities has become DaSilva’s mission. “People who have disabilities should be able to live their lives like everyone else,” he says emphatically.

Mapping progress

That concept sparked an idea in DaSilva. What if people everywhere could share information about all the accessible places that they know—businesses, restaurants, subway stations, restrooms and more—and that information was available on a mobile device?

The idea became a reality when DaSilva partnered with Google and launched an app, called AXSMAP (pronounced Access Map), about a year ago. “It allows people with canes, walkers or wheelchairs, even moms with strollers, to instantly find accessible places wherever they are,”

he explains. DaSilva hopes to begin to change the world of accessibility. “There are a million people like us. That adds to the urgency.”

Alison Dale is a Los Angeles-based writer who has lived with MS for more than 30 years.

Catch **When I Walk** on the PBS series [“POV”](#) when it is broadcast on June 23. Check local listings for times.