

Lives in transition



Trans people with MS face misunderstanding and discrimination in society, in their communities and in their doctors' offices. But they're determined to make life better for themselves and for others.

by Elaine Shelly

The summer of 2020 was marked by worldwide demonstrations protesting the killing of George Floyd, a Black man, by a white Minneapolis police officer. It was the same summer that Andrea Jenkins was serving her first term as a Minneapolis city council member and the first openly transgender Black woman to be elected to public office. Jenkins met that historic moment by working to bring calm to her city. As city council vice president, she attended endless meetings to address Floyd's killing as well as the unrest that occurred afterward. She called racism in Minneapolis a "public health crisis." Jenkins, who is now city council president, lives with multiple sclerosis.

"Minneapolis was literally on fire. We were also in the middle of a pandemic," Jenkins recalls. "Our city was facing multiple unprecedented challenges."



Jenkins stands in George Perry Floyd Square in Minneapolis. Photo by Joel Maisonet

Having faced so many challenges in her own life, Jenkins was perhaps uniquely suited to the task. Being a transgender person living with MS can be overwhelming — in the biases and lack of knowledge and understanding transgender people with MS face in society in general as well as in the healthcare services they must navigate.

Jenkins handles the pressures calmly and with grace. Since she had been out as transgender for 30 years when she started experiencing MS symptoms in 2016, she already had

supportive healthcare providers in place. She went to her primary care physician with questions about pain in her feet. She also wanted to know why her left leg would tire so quickly. She had been athletic her entire life and wanted help so she could continue playing tennis regularly. Within a year of that doctor visit, Jenkins had an MRI that revealed lesions on her brain and spinal cord.

https://momentummagazineonline.com/wp-content/uploads/2023/06/momentum-andrea_jenkins-540p.mp4

Despite a calm outer demeanor, she mourns her MS-related losses. Jenkins would walk around three of Minneapolis' many lakes in a day and continue her other activities unfazed by the exercise. "Now I can barely walk to the corner," she says.

Managing the disease

Jenkins, who decided to run for city office because she wanted to make life better for Black and brown people in Minneapolis, manages her MS symptoms by taking her disease-modifying therapy (DMT) and changing some of her habits. She stopped smoking and drinking, things she says aggravated her MS. She also plans to make positive changes to her diet and carve out time for exercise.

"It's difficult to maintain a consistent workout," she says of her busy schedule.

Jenkins was fortunate to already have a primary care physician who took her concerns seriously when she started having symptoms. But people who haven't begun transitioning or are in the process of transitioning may not have supportive healthcare providers and can have traumatizing experiences as a result.

Caleb Esquilin, who lives in Long Island, New York, started having MS symptoms as a 10-year-old, but wasn't diagnosed until 15 years later in 2018. He came out as transgender a few years before his MS diagnosis. Coming out wasn't easy. He was still presenting as female and married to a woman when Esquilin realized he was a transgender man. He was afraid to come out, not knowing how his family and friends would react.

Difficulties finding care

Getting medical care was also difficult. Esquilin was seeing a neurologist as he was transitioning, but the neurologist refused to acknowledge his new name, instead calling him by his previous name, a practice known as "deadnaming" (someone's birth name that they no longer use is their "dead name"). Nor would the neurologist use Esquilin's proper gender pronouns.

"My previous neuro was horribly disrespectful, including his staff," Esquilin says. "It was a horrific experience. It's like night and day with my new neuro."



Caleb Esquilin and his wife, Kristi. He was diagnosed with MS in 2018 and came out as transgender a few years before.

Photo by Stefan Radtke

A study published in 2022 in the *International Journal of MS Care* found that there was no published guidance about care for trans people with MS and offered recommendations for inclusive and comprehensive physical and mental healthcare. The recommendations were based on the care given to a young person presenting as female who was diagnosed with MS as an adolescent and later transitioned to male as a young adult. The study concluded that culturally sensitive and inclusive care is important throughout trans people's healthcare experience, beginning with the moment they are greeted by staff.

One of the study's co-authors is Alexa Kane, PsyD, a clinical psychologist at the Mellen Center, an MS clinic in Cleveland. She says she and her co-authors, also from the Mellen Center, wrote the research article after some changes were made at the clinic to be more welcoming to transgender people, even though the clinic has not treated many transgender patients at that point.

The article is one of a handful of research papers that focus on MS in transgender people. Kane says that while the authors were gathering information for the article, they had a hard time finding research relevant specific to transgender people living with MS.

It took two years of submissions and rejections before a publication accepted the article.

“We developed practice guidelines in the event more people come to us,” Kane says. “Usually, people have a pretty poor experience. We hope to educate our fellow neurologists and support staff.”

Negative experiences

Kane says that, unfortunately, she was not surprised by the negative incidents transgender people experience in medical settings. Misgendering, invalidation and either under- or overemphasis on their identity are all too common.

Henry Ng, MD, director of Transgender Surgery and Medicine program and a primary care physician at the Cleveland Clinic’s Center for LGBTQ+ Care, also points out the negative experiences transgender and nonbinary patients (people who don’t identify as either specifically male or female) may face when seeking care for autoimmune disorders.

Ng says transgender and nonbinary people often are misgendered or addressed by names they do not use because treatments typically are based on the assumption that people are only either male or female. “Treatments in healthcare are often based on sex-binary systems and may reference the patient’s sex assigned at birth rather than their gender identity,” he says.

William Conte, MD, treats people with MS at Methodist Hospital in Merrillville, Indiana. He “makes the rounds” in presenting workshops and lectures to his colleagues and students about treating transgender patients. Conte says that because they carry the baggage of discrimination, it’s especially important to establish with transgender and gender nonconforming people that they are in a safe place to open up.

“It’s important to ask, ‘How do you want to be addressed?’ ” he says.

Conte tells his colleagues that they are going to make mistakes when using pronouns. He encourages healthcare professionals to approach pronouns with an air of curiosity and to apologize and fix mistakes when they do happen.

Esquilin says neither his first neurologist or the healthcare staff offered any apologies or made any corrections about his name or pronouns. Esquilin says his neurologist also blamed his MS flares on the testosterone therapy he was taking.

Benefits and risks

While there is very little research on transgender people with MS, studies have shown both benefits and risks in taking estrogen. A study published in the 2016 Multiple Sclerosis Journal

shows that there could be an increase in the risk of getting MS in people who take estrogen hormone therapy. The study looked at the medical records of more than 3,000 transgender people in the United Kingdom between 1999 and 2012. The study was not conclusive but indicated that people who take estrogen may have an increased risk of getting MS, similar to cisgender women. Both Conte and Ng agree, however, that the benefits of transitioning surpass concern for possible autoimmunity.



Esquilin and his wife, Kristi, spend time together when Esquilin isn't working at one of his two jobs. Photo by Stefan Radtke

Some studies suggest that oral contraceptives with high amounts of estrogen appear to reduce inflammation in cisgender women with MS, which is in line with studies in the laboratory. On the other hand, studies of hormone replacement after menopause have been largely inconclusive.

There don't seem to be negative implications for people with MS who take testosterone therapy. In fact, the 2016 Multiple Sclerosis Journal study indicated that people who take testosterone may benefit from its neuroprotective qualities and experience a decreased rate of brain atrophy. Currently, there are no studies that suggest either of the hormone therapies cause MS relapses or alter the course of the disease.

Esquilin's symptoms include pain, fatigue and difficulty with balance and coordination. He works at a home improvement store and at a grocery store. He has reasonable accommodations at his jobs that help him throughout his day, such as getting frequent breaks and avoiding heavy lifting.

Rebuilding a life

Initially, Esquilin was afraid of coming out as transgender. He wasn't sure how his friends and family would respond. When he summoned his courage, his family readily accepted the news, but some of his friends stopped talking to him and they haven't communicated with him since. As Esquilin transitioned, he rebuilt his life. His wife, Kristi, stayed by his side. It also helped when he found a good fit with a new neurologist.

"I feel safe with my neurologist," he says. "He works at New York University, and they are very respectful of trans people."

Esquilin no longer worries if his neurologist will blame Esquilin's MS flares on his transition. In fact, Esquilin believes his transition had a positive effect on his MS.

"After my hysterectomy, that helped without menses," he says. "My period always made my MS symptoms worse."

Negative stereotypes

Payshunz Nagashima, a marketing analytics director with the National Multiple Sclerosis Society who uses they/them pronouns, had a reaction to their testosterone therapy that was similar to Esquilin's.

"I discovered that I have had a chemical imbalance my whole life," Nagashima says. "I felt more aligned with how I thought. My energy level started to improve, as well."

Nagashima was working in a restaurant when they first noticed they were falling and running into things. "I was trying to figure out why I had this clumsiness."



Jenkins has been making lifestyle changes amid her busy schedule to manage her MS. Photo by Joel Maisonet

Nagashima told their doctor about clumsiness, fatigue and insomnia. They were sent to a rheumatologist, an orthopedic physician, a neurologist and eventually, a pain clinic. They had numerous tests, but never an MRI. They did have discouraging and hurtful experiences along the way.

They were hopeful when they first saw a rheumatologist, who initially discussed numerous options and referrals that could be made in figuring out what was wrong. But when Nagashima returned to the doctor for lab results, they discovered they had only been tested for sexually transmitted diseases (STDs), and the doctor made no referrals. The doctor's sole focus on STDs showed that the doctor was "wrapped up in negative stereotypes for transgender people," Nagashima says. "I recognized that I wasn't heard. And I still had to pay for that."

Nagashima was eventually referred to an MS clinic in Houston, where they were diagnosed with MS in 2008.

Respectful experiences

While Esquilin and Nagashima had bad experiences in doctors' offices, Oscar Cato has problems in other areas. Cato was already out as transgender in 2019 when he started experiencing neuropathy, foot drop and vision problems. Cato has a family history of MS, and his primary care physician referred him to a neurologist. The physician told the neurologist about Cato's gender and pronouns ahead of the appointment. Cato says he's fortunate that his personal experiences have been respectful.

https://momentummagazineonline.com/wp-content/uploads/2023/06/momentum-caleb_esquilin-540p.mp4

He's cautious about some medical literature about MS that he says "is often casually or unintentionally transphobic," and might alienate people, preventing diagnosis and treatment.

As an example, Cato pointed to a brochure about MS that stated "more women are diagnosed with MS than men." Instead he suggests more inclusive language such as "MS is more prevalent in individuals producing more estrogen or progesterone."

In addition to physical health issues for trans people with MS, there are mental health concerns as well. Conte says he has been treating anxiety among many of his transgender patients.

Mental as well as physical health

Ng says he also spends a fair amount of time at visits addressing mental health issues with transgender patients. He says that the depression and anxiety he sees in transgender people with MS stem from their experience of discrimination, rejection and bias based on their gender identity.

Nagashima says that one of their past employers valued their input and expertise, but made sure the company's customers never saw them, a female-presenting employee with a masculine appearance.

Neisha Fredericks, vice president of diversity, equity and inclusion with the Society, says the Society has a role to play in making sure transgender people with MS are well-served in their healthcare.

"What can the Society do? Lead in the conversation to help build awareness; and keep the conversation going."

Important conversations

Fredericks says the conversation around diversity and inclusion can sometimes be

uncomfortable, because it calls for “owning where we have, knowingly or unknowingly, contributed to harm.” But those conversations are a vital part of making sure everyone is respected and feels welcome.

Nagashima hopes to see more research on trans people with MS.

“I’m a numbers person, and we don’t have a baseline understanding of transgender people living with MS,” Nagashima says. “We have to keep putting it out there that we exist.”

Jenkins hopes to see more places where transgender people can find not only information about MS, but also safety and acceptance.

“Highlighting trans people and gender nonconforming people in publications is important. Communication is important,” she says. “Talking about trans people who are living with MS is important.”

Resources for trans people

The following resources offer information and support for transgender people, including those who live with multiple sclerosis.

Transgender-specific resources

- [The National Center for Transgender Equality \(NCTE\)](#): Know your rights and find self-help guides
- [The Sylvia Rivera Law Project \(SRLP\)](#): Legal help with name changes, IDs, immigration and more
- [Transgender Legal Defense & Education Fund](#): Legal assistance regarding name and gender changes
- [Transgender Law Center](#): Information on litigation, policy advocacy, educational efforts and programs

LGBTQ+ support groups and centers:

- [Parents and Friends of Lesbians and Gays \(PFLAG\)](#)
- [GLBT Near Me](#)
- [LGBT Community Centers](#)

National Multiple Sclerosis Society support groups

Self-help groups

- [LGBTQ+ MS Support Group \(Bay Area, California\)](#)

- [Seattle LGBTQ+ MS Connection Group \(Seattle, Washington\)](#)
- [LGBTQ+ Peer Connection Group \(New York\)](#)

Online communities

- While [these groups](#) are not specifically for the trans community, they are open to all people affected by MS
- [MSFriends program](#) connects a person affected by MS with a volunteer who understands life with MS

Writer Elaine Shelly was diagnosed with MS in 1991.

Read an [interview with trans neurologist Em Harrington](#).