

Helping Patients Overcome Barriers to Treatment

It's hard enough to live with a progressive disease. Patients don't need roadblocks to getting treatment that can help them. Emmanuelle Tiongson, MD, clinical assistant professor of neurology at Children's Hospital Los Angeles, offers tips on how to help patients with neuromuscular diseases overcome barriers to care.

Speeding diagnosis

For most patients, the biggest barrier to receiving treatment is a delay to diagnosis. "When we're talking about areas such as potential genetic therapies, time is of the essence, and it's really important to refer them to the right place," Dr. Tiongson says. Education on signs of neuromuscular disease for healthcare providers who might make referrals can quickly get patients to the right providers.

An accurate diagnosis is essential to determining the best course of treatment. A documented genetic diagnosis also helps get patients' treatments authorized by health insurance.

In Dr. Tiongson's practice, all patients with a neuromuscular diagnosis receive genetic testing as part of the standard of care. "It's about having all the evidence needed to get the diagnosis confirmed and get treatment approved," she says. "We have all information available in documentation or testing, so we don't get pushback from insurance providers that can lead to interruption of treatment. We try to see patients every two to six months to avoiding having drops in care because authorization is contingent on frequency of follow-ups and documentation of care."

Removing access barriers

Many treatments, especially gene-targeted therapies, have a high cost. It's important to understand regulations, requirements, and services in your area. For example, in California, a program called California Children's Services helps cover the cost of care for children with certain diseases. Dr. Tiongson also uses peer-to-peer calls and appeal letters to overcome insurance denials when necessary. But she has noticed that insurers have become more receptive to genetic testing, which now is often considered part of standard care.

Many patients face social barriers to treatment in addition to cost. "In our MDA Care Center and in our MDA multidisciplinary clinics, we try to get at this from multiple aspects," Dr. Tiongson says. "We have a social worker who is very good at sorting through social barriers, like childcare issues and getting to the hospital on time for treatments."

If getting to the hospital is a barrier, "we can try to arrange access to transport services through their insurance," Dr. Tiongson says. "We have patients who require periodic infusions and can't get here. Our home infusion teams do a great job with almost any situation we have presented them with. For long-distance travel, for example, they often use the Ronald McDonald House. For a multidisciplinary clinic, we typically have the patient come the night before and then have them see everyone the next day."

Educating a patient and their family about a diagnosis also can help reduce barriers. In Dr. Tiongson's office, the Child Life Team plays an important role in this. "This is about explaining to the child and family, in understandable terms, what's going on and what's required," she says. "This is in conjunction with our nurse care manager who arranges all the appointments and explains why they are important."

When it comes to barriers, Dr. Tiongson emphasizes that patients have enough on their minds. "We want the patient to focus on their health," she says, "not worrying about whether they'll get the care they need."