

BEST PRACTICES

TO IMPROVE

ACCESS TO

CARE



According to the Institute of Medicine, access to healthcare means “the timely use of personal health services to achieve the best health outcomes.”

In an environment where neuromuscular diseases (NMDs) are rare and healthcare often is fragmented, many people living with NMD do not have adequate access to healthcare. Many patients struggle to connect with providers who understand their conditions and are knowledgeable about the best care practices. This may be attributed to a variety of reasons: distance from a clinic, inability to take time off work, or lack of childcare or transportation, to name a few.

MDA Care Centers bring together expert clinical care and medical research, as well as an array of programs and services to support individuals and families living with neuromuscular disease (NMD). We recognize that making sure all individuals with NMD have access to the care and services at MDA Care Centers is a challenge, and many healthcare providers in the MDA Care Center network are actively looking for ways to improve access to care. We talked to some of them about their best practices for reaching NMD patients in underserved communities.

1. Bring care to the patients.

Patients living in rural areas often must travel hours from home to get to an MDA Care Center, and some are far enough away that an overnight stay in a hotel is necessary, adding to the cost and inconvenience.

“Living in a rural area shouldn’t prevent patients from getting the best quality care that they deserve and need,” says Aravindhan Veerapandiyan, MD, assistant professor of pediatric neurology and director of the comprehensive neuromuscular program at Arkansas Children’s Hospital in Little Rock. He helped expand the Arkansas Children’s-based comprehensive neuromuscular clinic in Springdale, located in the northwest corner of the state. This helps bridge gaps in access to care in a state where families often travel up to four hours for expertise in neuromuscular disease.

Even patients living near an MDA Care Center may have difficulty accessing expert care due to inadequate childcare or transportation, or inability to take time off work. Flexibility in scheduling may help these families.

Consider these best practices to bring care to patients:

- Open a satellite clinic in an underserved area of the state.
- Offer more opportunities for telehealth visits by video or phone.
- To address lack of access to high-speed Internet or reliable phone service that is common in rural areas, offer telemedicine workstations in clinics located within those communities.
- Offer flexible scheduling options, such as evening or weekend hours, or allow patients to see multiple specialists over two shorter visits rather than a half-day appointment.

2. Provide holistic care.

Often, people in underserved communities have limited health literacy and major socioeconomic stressors, including limited access to affordable, healthy food and safe housing. If families face insecurity in meeting basic needs, such as food and shelter, they will have less energy and ability to manage a loved one’s chronic condition.

“It’s important to identify what challenges impact a family’s ability to engage in care and address each of those concerns at every visit,” says Leslie D. Delfiner, MD, pediatric neurologist and co-director of the MDA Care Center at Montefiore Medical Center in the Bronx, NY. “As clinicians, we need to engage with patients and their families as partners in care.”

Consider these best practices for providing holistic care:

- At every visit, in addition to addressing medical concerns, discuss topics related to wellbeing with patients and their families.
- Ask social risk screening questions in the context of care and care planning to address social determinants of health.
- Build individual treatment plans that work within each family’s specific circumstances.
- Develop strategies to connect patients with social services or government and community resources as needed.

3. Educate primary care physicians and other providers.

NMDs encompass a wide range of symptoms, and their occurrence rates range between relatively rare and extremely rare. Primary care physicians, and even general neurologists, might be slow to recognize the signs of NMD or be unfamiliar with the best course of care.

For this reason, Eduardo Ramos, MD, a sports medicine and spinal cord specialist at Instituto de Rehabilitación del Caribe, an MDA Care Center in San Juan, Puerto Rico, regularly reaches out to primary care providers, as well as physical therapists and occupational therapists, to educate them about neuromuscular disease.

"I try to give them confidence in terms of how they can identify a patient who might have a neuromuscular disease, and I tell them that our clinic can serve as a place for confirming the diagnosis," Dr. Ramos says.

At a recent annual meeting for local primary care doctors, he gave a presentation about potential signs of neuromuscular disease and genetic testing options. "It's important for them to understand that the MDA Care Centers are the primary centers for diagnosing and managing patients with different neuromuscular diseases. These clinics are updated on all the available treatment options and any clinical trials that are available to patients."

Consider these best practices for educating other providers:

- Share digital or print resources about NMDs with other providers, and present at professional seminars. Find professional medical education resources, including webinars, case studies, and speaker slide decks, at mda.org/meded.
- Tell providers about diagnostic techniques (including genetic testing), treatments, clinical trials for NMDs, and when and how to refer patients to a neuromuscular specialist.
- Make them aware of the benefits to patients of seeking care at an MDA Care Center.

4. Know your community.

These are just some examples of how MDA Care Center providers are working to improve access to care in their communities. Your community might face different barriers to care or require different solutions. Investigating your community's specific populations, challenges, and needs is an important part of taking a holistic approach to healthcare. There's never going to be a one-size-fits-all solution, but patient outcomes can be improved by removing everyday barriers to care.