



BEST PRACTICES FOR WORKING WITH LOCAL CAREGIVERS

How we can support healthcare providers when their patients don't have access to Care Centers

MDA is working to ensure that local healthcare providers are aware of the vast number of resources available at MDA Care Centers, located at more than 150 of the top healthcare institutions across the country. For these local caregivers, including pediatricians, family doctors, orthopedists, physical therapists and other providers, "the most important thing is that they know they can reach out to MDA," says Colleen Etou, LMSW, APHSW-C, a social worker at the MDA Care Center at Phoenix Children's Hospital.

Even if a patient is unable to physically access a Care Center, MDA makes many resources available via telehealth, phone consultation, or educational materials. The methodologies and resources that Care Centers provide can vary based on a patient's age and needs; however, the goal remains the same: maximizing the patient's ability to engage in life and reach their goals while living with a neuromuscular disease.

To accomplish this, Care Centers may assist with anything from supporting mental health, to ensuring safe and accessible living environments, to fostering self-determination and self-advocacy.

“For children, that may look something like getting them appropriately connected with educational supports at school, whereas for an adult we may be focused more on adaptations in the workplace or maximizing independent living skills,” Colleen says. She notes that increasing use of telehealth helps remove the barrier of distance for families who live far away from a Care Center. Insurance coverage often is another barrier. “In a few situations, I have made direct outreach to insurance case managers or eligibility workers to facilitate increased understanding of the neuromuscular diagnosis so that the patient was able to be approved for services,” Colleen says.

Education about neuromuscular diseases is perhaps the most impactful resource that Care Centers provide. Because neuromuscular conditions are rare, many people, including healthcare providers, are not familiar with neuromuscular disease signs, symptoms, and treatments. Care Center teams can provide education on genetic testing, symptoms, basic needs, medical equipment, patient’s rights, and more. Getting a confirmed diagnosis via genetic testing can help doctors understand potential disease progression, determine the best course of treatment, and help patients qualify for clinical trials.

“Our team is able to direct local pediatricians or neurologists on which genetic tests to order if they suspect a neuromuscular disorder and provide different resources that the family can turn to for more education and support if that diagnosis is confirmed,” Colleen says. MDA Care Centers can even help patients and family members connect with support groups or disease-specific Facebook groups.

MDA Care Center teams are made up of a variety of physicians and allied health providers who are dedicated to guiding individuals and families through their neuromuscular disease journey. Local providers may be able to collaborate with Care Center neurologists, psychologists, respiratory therapists, social workers, or other providers, depending on their patients’ needs. “It may be the clinic coordinator or the social worker who handles much of the outreach based on the role they hold within the clinic,” Colleen explains. “But all members of the Care Center draw on each other’s expertise and passion for improving the lives of those with a neuromuscular diagnosis. It’s truly a team approach.”