Non-Expert Care Settings: Important Information to Share with Community Providers

Neuromuscular specialists are a central part of the care team for people living with neuromuscular diseases (NMD), but they are rarely the only clinicians involved in a patient's care. Many patients also receive services from community providers with limited experience treating individuals with NMD, such as family physicians, internists, and OB/GYNs.

By proactively sharing important information, addressing common misconceptions, and supporting patient self-advocacy, neuromuscular specialists can help ensure that patients receive appropriate, coordinated care across all clinical settings.

Build a network of informed referrals

Establishing relationships with other providers and specialists in your community is an essential step in supporting high-quality care outside the neuromuscular clinic. Identifying clinicians who are comfortable managing complex or chronic conditions can streamline communication and improve continuity of care.

“Physicians should find out who is in their institution who does pregnancy care, women's health, or complex contraception,” says Loralei Thornburg, MD, a maternal-fetal medicine specialist and professor of OB/GYN at the University of Rochester in New York. She advises considering, “Who are the people that can assist your patients, and how can you help get your patients into care?”

Having an established referral network also makes it easier to share anticipatory guidance and address questions that may arise before or after a patient's visit in a non-expert setting. "The positive pregnancy test is not the time to scramble," Dr. Thornburg says. "These conversations need to be prospective, not retrospective."

Address common misconceptions about NMD

Misconceptions about NMD can influence care decisions in community settings. For example, Dr. Thornburg commonly encounters the assumption that all people with muscular dystrophy require cesarean delivery.

"Sometimes that's true, but not every time — even for people with significant muscular weakness," she says. "It depends on whether the condition affects smooth muscle or skeletal muscle. The uterus may work well."

She also notes that some providers assume people with disabilities are not interested in sex, pregnancy, or parenthood. "There's a fear of prescribing things or even asking if a patient wants contraception," she says. "The assumption is often that people with mobility differences aren't interested in sex or pregnancy, and that's simply not true."

Support patient self-advocacy

Neuromuscular specialists can play a key role in helping patients advocate for themselves in non-expert care settings. "Doctors must remember that each patient is the expert on their lived experience," Dr. Thornburg says.

"Even within a single disorder, patients can look very different," she adds. "What genetic variant they have, when they were diagnosed, and what their disease course looks like can all change the clinical picture."

Patients may also adapt to gradual changes in function and may not immediately recognize disease progression. "People with chronic disease have an amazing ability to adjust their lives to fit their needs," Dr. Thornburg says. "Sometimes they'll say they're doing fine, but when you dig deeper, you realize they've changed how they live. That's not the same as not having symptoms."

Beginning in adolescence, routine and developmentally appropriate conversations can also help normalize discussions about sexuality and reproductive health. "People with chronic medical conditions have sexual debut at the same ages as everyone else," she says. "If we're not having those conversations, they're learning elsewhere."

Prepare patients for community provider visits

Encourage patients to communicate with a provider's office ahead of an appointment to ensure that appropriate accommodations are available. "If the office staff doesn't know what a patient needs, they can't plan appropriately," Dr. Thornburg says. Patients may want to ask the following questions before visiting a primary care office or non-neuromuscular clinic:

- Are motorized or height-adjustable exam tables available?
- Can I schedule the first appointment time in the morning or afternoon?
- Can additional time be built into my appointment for dressing and undressing?
- Can I be seen in a larger exam room to accommodate my mobility device?
- Will staff be available to assist with transfers?

Some OB/GYN offices also have stirrups that support the entire leg, which is helpful for patients with lower-body weakness.

Considerations for pregnancy and reproductive health

Women living with NMD may face complex decisions regarding reproductive health. Because NMDs vary widely in type and severity, pregnancy recommendations should be individualized.

"I always start by asking, 'If this person were not pregnant, what would we do?'" Dr. Thornburg says. "Whatever the issue is, start from that place, and then adjust to what is safest during pregnancy."

She notes that this framework can help prevent knee-jerk avoidance of necessary care. "Not treating lung disease, cardiac disease, or nutrition issues is not going to help someone grow a healthy baby," she says. "The healthiest babies come from the healthiest parents."

Neuromuscular specialists can also support community providers by clarifying inheritance patterns and reproductive options. "Some disorders behave very differently across generations," Dr. Thornburg says. "Families may not expect that, and some practitioners may not be aware of these differences."

She also encourages early conversations around contraception and pregnancy planning. "You can tell patients, 'Maybe this isn't important to you now, but let's open the dialogue,'" she says.

Finally, Dr. Thornburg advises providers to anticipate postpartum needs. "Parenting is a new activity of daily living [ADL]," she says. "Breastfeeding should also be thought of as a new ADL, especially for patients with upper-body weakness."

A collaborative approach to care

NMD specialists share responsibility for helping patients receive appropriate care beyond specialty clinics. By building referral networks, addressing misconceptions, and supporting patient self-advocacy, specialists can help bridge knowledge gaps in non-expert care settings and help their patients thrive.

Resources for Community Providers:

- The MDA Care Center Network provides a directory of multidisciplinary neuromuscular care centers for referrals and care coordination.
- The ADA/HHS-accessible medical diagnostic equipment (MDE) Fact Sheet provides practical summaries of accessibility expectations for exam tables, scales, imaging equipment, and related clinic workflows.
- U.S. Access Board MDE standards are an overview of standards for accessible exam tables/chairs and other diagnostic equipment.
- ACOG's Access to Obstetric and Gynecological Care for Patients With Disabilities offers guidance on equitable access, accommodations, and reducing barriers to reproductive care.
- SMFM "Find an MFM" (high-risk pregnancy consults), a locator for maternal-fetal medicine specialists.