



The Truth About Neuromuscular Disease and Intimacy

Living with a neuromuscular disease (NMD) involves developing communication skills and learning new ways to perform activities of daily living. However, in this learning process, one topic that is often neglected is intimacy, according to James Nichols, who served as President of the Alliance for Disability Awareness at Ball State University and is currently earning his Master's degree in social work at Ball State.

“A lot of times, individuals with disabilities aren't seen as individuals capable of intimacy,” he says. “At Ball State, that was one of the things college students with disabilities asked about the most.”

Addressing misconceptions

“One of the biggest misconceptions about individuals with neuromuscular diseases is that they aren't capable of being intimate,” James says. “When you talk about disability and sex, people are like, ‘Oh, well that's not happening.’ It's an issue most people aren't willing to talk about or investigate,” James says.

He points to taboos around sex, as well as societal stigmas around disabilities and chronic diseases, for perpetuating misconceptions that people with NMDs are either not capable or not interested in intimate relationships. This misconception can affect how people with NMDs are treated by medical professionals and peers, as well as how they think of themselves.



“I found that in some of the clinics I’ve gone to for neuromuscular disease, they don’t even ask questions about sexual health,” says James, who lives with congenital fiber-type disproportion myopathy.

Healthcare providers should ask patients with NMDs the same questions they’d ask any adolescent or adult patient to check on their sexual health and safety, such as:

- Are you sexually active?
- Have you been tested for STIs, including HIV? Would you like to be tested?
- Would you like information about different types of contraception?
- Are you or your partner trying to get pregnant?
- Do you have any questions or concerns about your sexual functioning?
- Have you ever been coerced or pressured to have sex or do something you didn’t want to do?

Talking about sex helps people with NMDs understand that they are capable of intimacy and deserve healthy relationships.

Education for providers

To serve their patients, primary care providers and all healthcare providers who work with NMD patients should look beyond common misconceptions and educate themselves about disability and intimacy.

While people with NMDs typically have the same wants and needs as the general population regarding intimacy and relationships, they are less likely to ask about sexual health because of stigma and a lack of sex education.

“I definitely think that medical professionals should be educated because, in my personal experience, there are certain questions that I’ve wanted to ask but didn’t feel comfortable,” James says.

It’s incumbent on healthcare professionals to bring up sensitive topics and have the knowledge to answer questions and share resources.

While physicians on a neuromuscular care team can be great sources of information and knowledge for their patients, other team members are also well-positioned to help patients build intimate relationships safely.

“Social workers are great for providing resources, and physical therapists and occupational therapists understand body movement. They can also have those conversations,” James says.

Education for patients

According to James, many people who grow up with NMDs don't receive the relationship guidance and sex education others do, even when those around them have the best intentions.

"A lot of times, providers, family members, and friends are working to make you more independent," he says. "They focus on teaching you to live independently and manage your health. There's never really that conversation around relationship aspects of adulthood."



Healthcare providers can and should provide that education in the same way they would for any patient. Primary care providers typically talk with their adolescent patients about puberty and sexual development, safety and high-risk behaviors, and healthy relationships. They should have the same conversations with patients with NMDs.

"Teenagers are going to have questions," James says. Providing them with knowledge and resources about intimacy at the beginning of their journey toward adulthood will help them navigate it safely and confidently.

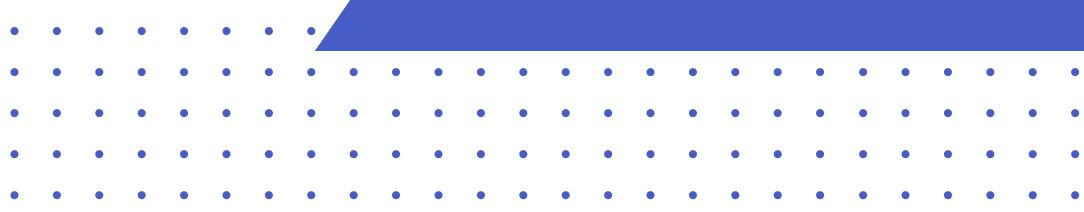
Adults with NMDs

People who develop NMDs in adulthood may have experience with relationships, but they also need education on how they can continue to experience intimacy.

"If you've had these experiences prior to a diagnosis, you may have a way you think things are supposed to go, and whether you're currently with a partner or not, things will change," James says. "That can be really scary because the person may think, 'My intimate life is over.'"

Healthcare providers can start conversations to help their patients understand that intimacy is still possible and learn how to adapt to fit intimacy into their lives.

"We're all entitled to those human relationships," James says.



Resources

- Resources for sexual health conversations and education: [Sex Positive Families: Disability](#)
- UCSF Office of Developmental Primary Care: [Our Sexuality, Our Health: A Disabled Advocate's Guide to Relationships, Romance, Sexuality and Sexual Health](#)
- YouTube channel from an interabled couple: [Squirmy and Grubs](#)
- Books:
 - [Disability Intimacy: Essays on Love, Care, and Desire](#)
 - [A Quick & Easy Guide to Sex and Disability](#)