

SEXUAL HEALTH

FOR PATIENTS WITH

NEUROMUSCULAR DISEASE

ADDRESSING THIS IMPORTANT TOPIC WITH KIDS, TEENS, AND ADULTS IS PART OF TREATING THEM AS A WHOLE PERSON

"It is my goal to make every person with a disability realize that they are a full and whole human being and have full access to their humanity," states Maurice Sholas, MD, PhD, principal and chief physiatrist at Sholas Consultants in New Orleans, Louisiana. He has worked in MDA Care Centers his entire career, developing a special rapport with children and young adults, especially in supporting their sexual development and health.

"The physician's office should be a place where people feel comfortable talking about their health and sexuality," Dr. Sholas says. "You have to focus on the patient's age and have developmentally appropriate interaction, being willing to answer the questions they ask. It is important not to add your sensibility to the conversation."

Starting the conversation

Your first discussions related to sexual health may occur when the patient is a young child, discussing their secondary sexual characteristics, including appropriate touch. With a preteen you might discuss what to expect during puberty. With teens, the focus might change to considering sexual activity. What choices are available and what are the consequences of those choices?

Take your cues from the language each patient uses. Do they use terms like "penis" or do they have euphemisms they prefer? Do they have blind spots in their thinking? Sometimes people who have physical disabilities are seen as asexual or even less than fully human. If you catch any such biases, you can help educate the family and caregivers, enabling them to support the patient's personal agency and autonomy.

Creating a safe space

Dr. Sholas states that part of being a resource for young patients is to let their parents know that, as their child gets older, they will spend time alone with their providers to talk about topics like sexuality, alcohol and drug use, and safety that may be awkward for them to discuss in front of their parents. To help young people feel comfortable talking about these topics, Dr. Sholas informs them that he can lock the portion of the appointment record relating to confidential discussions so no one else can access them.

As a clinician, it is critical that you be a safe person for the patient to talk to when they may feel unsafe. If the situation rises to the level where you become a mandated reporter, a clinical ethics professional can support you through that process.

While ideally discussions with a child, teen, or young adult will organically flow through the care process, Dr. Sholas recognizes that not every clinician is comfortable with discussing sexuality. In that case, they can access their local MDA Care Network case manager or social worker, who will have special training in supportive intervention and know which team members will be most appropriate for handling these discussions.

Learn more

Explore these resources to learn more about sexual health that is relevant to the neuromuscular disease community.

[NICHD Special Lecture: Sexual and Reproductive Health in Persons with Disabilities](#)

[Rowen TS, Stein S, Tepper M. Sexual health care for people with physical disabilities. J Sex Med. 2015 Mar;12\(3\):584-9. doi: 10.1111/jsm.12810. PMID: 25739683](#)