Talking about sex, even in a clinical setting, can be uncomfortable, unfamiliar, and confusing for patients and providers. Because of the taboos surrounding sexuality, some people shy away from these conversations, and others seek answers online, where the accuracy of the information can be murky.

Providers have a responsibility to help patients get the information and care they need to live healthy lives. With some practice and the right questions, providers can gain the confidence to treat their patients’ physical health and support their sexual and familial goals.

**Consider the whole patient**

With 20 years of experience as a neuromuscular specialist, Amanda C. Peltier, MD, MS, Professor of Neurology and Medicine, Chief of the Division of Neuromuscular Disorders, and...
Associate Vice Chair of Faculty Affairs at Vanderbilt University Medical Center, says the topics of sexual health and family planning frequently come up in neuromuscular disease support groups. Although they are on patients’ minds, providers may be reluctant to bring these topics up in appointments or simply assume that they’re irrelevant.

“I think physicians make assumptions that people with neuromuscular disease might not be sexually active, so no one thought to counsel them on birth control and reproductive options,” Dr. Peltier says. People with neuromuscular diseases need and want the same information you would offer to other patients on sexual and reproductive health.

How to talk about sexual health

Patients may not feel comfortable broaching the topic of sexual health or family planning with their providers. Dr. Peltier says once patients are of reproductive age, providers should lay the groundwork for those conversations by building a rapport with patients to help them feel comfortable talking about these sensitive topics.

“I think No. 1 is to say, ‘Have you had a conversation with your pediatrician or provider about birth control?’ That should be brought up more often,” Dr. Peltier says.

She recommends asking open-ended questions, such as:

- Are you sexually active?
- Do you have any questions about sexuality and your disorder?
- Do you have any questions about what could happen if you have a child?
- Are you thinking about having a family?

“You want to have that conversation in a private, closed room where you’re not going to be interrupted,” she says. In teaching environments, ask residents and fellows to step out. “It shouldn’t be tacked on to the end of a busy visit.”

When medications collide

Another important reason not to delay these conversations is to address medication side effects and contraindications.

Dr. Peltier recalls one patient taking medication for HIV exposure, and a side effect of the drug was elevated creatine phosphokinas (CPK). Elevated CPK levels are one marker of muscular dystrophy, but because Dr. Peltier was informed about the patient’s sexual and physical health, she was able to spot the likely cause of his elevated levels.
In other cases, patients may be taking immunosuppressant medications, but if they have goals to start a family, these therapies can harm a developing fetus. Helping patients manage their disease is just as important as helping them understand how their disease can impact or be impacted by their sexual health and family planning goals.

“Sometimes it’s hard, when you have a short clinic visit, to remember those things,” Dr. Peltier says. “Try to have a checklist of all the things you need to address. We often talk about having advanced planning and living wills; family planning when people are of reproductive age is just as important.”

**Finding family solutions**

There are many ways a person with a neuromuscular disease can manage the risk of passing on the disease to their children. Genetic counseling is a good place to start, as it helps people understand the probability of inheritance. A person’s sex, the genetic makeup of their partner or donor, and the inheritance pattern of their disease all influence the chances of their children inheriting their condition. Some providers who have genetics backgrounds, like Dr. Peltier, may feel comfortable having those discussions with patients. Providers can also connect their patients to a genetic counselor.

If a patient wants to have children but is concerned about inheritance, providers can help them find lower-risk alternatives, such as sperm, egg, or embryo donation; adoption; and in-vitro fertilization (IVF) with preimplantation genetic testing (PGT).

“Patients have come up with novel solutions,” Dr. Peltier says. “One young man had a strong family history of autosomal-dominant CMT. His family adopted an embryo, his wife had the embryo implanted, and they were able to have a child without the risk of passing on his CMT, so they were very happy about that plan.”

**Build confidence through practice**

Although conversations about sexual health can be awkward for patients and providers alike, they are crucial to the holistic well-being of all patients — with and without neuromuscular disease. Dr. Peltier says that providers can turn their hesitance into confidence with some practice.

“I think the more you get used to asking these questions, the less awkward you feel,” Dr. Peltier says. “One thing I’ve found is if you ask the question, patients are generally open to talking.”