



Resolving Bowel Issues in Patients with DMD

Duchenne muscular dystrophy (DMD) is the most common form of muscular dystrophy. It occurs in about 6 in 100,000 children, primarily boys. Beyond muscle weakness and cardiac and respiratory issues, it can cause complications with bowel movements, including severe constipation.

Not just a source of discomfort, constipation also can lead to accidents and the anxiety that comes with them, or even permanent damage to the bowels.

What can be done to improve the situation for patients with DMD? We asked Kent Williams, MD, a pediatric gastroenterologist at the MDA Care Center at Nationwide Children's Hospital in Columbus, Ohio, who treats patients and families with special needs, including those with neuromuscular disorders.

What contributes to constipation

According to Dr. Williams, constipation can happen in patients with DMD at any age. The exact cause of constipation in DMD is not clear, but it is likely related to loss of muscle and activity, as well as behavioral and sensory issues, especially in the very young. It may be most severe in nonambulatory patients who have difficulty accessing a toilet.

Nutritional issues also may contribute to constipation. Muscle weakness can make self-feeding difficult for patients with DMD, which affects their caloric intake. Dr. Williams recommends that families consult a nutritionist to ensure the patient's diet is well-balanced and that the patient be weighed every six months.

"As the condition progresses, those are the two areas that I focus on: How do we maintain good nutritional intake, and how can we help provide a good bowel regimen so they don't have to worry about having bowel accidents or being constipated?" he says.

Feeding

For those who need help eating, meals can take up a lot of time. "If you start spending an hour or more per meal, you're talking about spending four to six hours a day just to feed. We can do things to try to minimize that time to support the nutritional needs and allow patients to be more independent, with a better quality of life."

Dr. Williams often encourages patients and families to consider a surgically placed feeding tube, or G-tube, for supplemental nutrition. Families and patients may initially find the idea of a feeding tube daunting, but the end result and low risk of infection generally make for a significant improvement in the patient's life.

"I would not hesitate to get a G-tube," he says. "If you find out that you don't need the G-tube, it can be removed easily. But in my 20 years of doing this, I've never had anybody remove a G-tube. It's always been an improvement, and in most cases, the families and the patients wish they had done it sooner."

Addressing accidents

In young children, constipation may be due to behavioral or sensory issues. "Some children may withhold stool for various reasons, previously passed a hard stool, or may not want to take time from their activities, so they start to develop bad toileting behavior, which results in constipation or passing hard stools that hurt, which results in more withholding behaviors," Dr. Williams explains.

For older kids or adults, especially those in wheelchairs, the constipation may be a severe buildup due to years of difficulty. In such cases, accidents may happen more frequently. “We have to find a way of trying to keep the colon clear so they won't have to worry about having accidents throughout the day,” Dr. Williams says.

Common solutions, such as increasing fiber or prescribing laxatives, are not always recommended for patients with DMD. “If a person is in a wheelchair and not able to get to a toilet, you have to be careful with giving fiber because the fiber may actually make constipation worse,” Dr. Williams says. Likewise, laxatives, which stimulate the need to have bowel movements, can have a negative effect. “If this happens when not able to get to the bathroom, this can result in discomfort and, in some cases, may cause accidents,” he says.

For some patients, fear of having an accident is a source of emotional distress. “I met a young man who says he can spend up to 18 hours a day worried that he’s going to have an accident,” Dr. Williams says. “He’s only had two accidents in his life, but he worries so much about it that it keeps him from going out.” In cases like this, more serious measures need to be taken. Beyond addressing nutritional needs, the goal is to help patients keep their bowels empty enough that they don't have accidents. Enemas a few times a week can help. Another option is a colostomy bag.

Patients may be reluctant to consider a colostomy procedure, but, as with the G-tube, the result can be a genuine improvement in quality of life. “You can have a colostomy bag with a shirt over it, and no one around you would ever know,” Dr. Williams says. “There are studies showing that people will go from 20 hours a week of concern about bowel movements to less than 20 minutes a week with a colostomy. It keeps you from worrying about having a bad accident when you go out in public.”

As a clinician, his goal is not just to resolve constipation and bowel issues but to liberate his patients from concerns about those issues that hold them back. He tells patients: “I want you to be able to control your bowel movements; I don't want your bowel movements to control you.”

Feeding tube resources:

Read [“How to Approach Feeding Tube Conversations with Families”](#) for a clinical dietitian’s take on this nutritional and quality-of-life issue affecting patients with neuromuscular diseases and their caregivers.