

## NUTRITION IN NEUROMUSCULAR DISEASE CARE



Good nutrition can be a challenge for people living with neuromuscular diseases, many of whom are not able to be physically active or may have trouble feeding themselves or swallowing. Making sure neuromuscular disease patients are properly nourished is crucial not just for their overall health but also to slow disease progression. Low caloric intake leads to muscle breakdown, hastening the progression of disease.

A registered dietician can play a valuable role on a multidisciplinary care team. Dietitians build meal plans that address patients' specific feeding challenges and dietary needs, as well as suggest recipes and meal preparation strategies for families.

### Non-ambulatory needs

Patients who use a wheelchair often struggle with constipation because of weak stomach muscles. Laura Watne, MS, RD, CSP, a clinical dietician at the MDA Care Center at Children's Hospital Colorado, recommends well-balanced meals with adequate fiber to her non-ambulatory patients.

Patients with limited mobility also may be at risk for dehydration. "It's hard to get up to urinate, so they tend not to drink a lot," says Alicia Gilmore, MS, RD, CSO, LD, a dietician at University of Texas Southwestern Medical Center. She encourages her patients to drink water or tea instead of sweet, sugary beverages. "I'm very realistic, and if they swap out tea for a Coke, that would be a better choice, as it has less caffeine. We have to decide what's important."

## Feeding concerns

Spinal muscular atrophy (SMA), spinal-bulbar muscular atrophy (SBMA), amyotrophic lateral sclerosis (ALS), and many other neuromuscular diseases can lead to trouble with chewing and swallowing.

"I spend most of my time with patients who have difficulty chewing, swallowing, or feeding themselves," says Gilmore, who works with adult patients with ALS and other neuromuscular diseases. "As their disease progresses and it affects muscles and nerves, we have to pivot and discuss strategies to keep them strong and nourished."

Children with other congenital muscular dystrophies and myopathies tend to be born with more symptoms, often needing feeding tubes early on—sometimes at birth. Watne frequently manages tube feeding for infants and children as they grow and their nutrition needs change.

However, she notes that treatments approved by the US Food and Drug Administration (FDA) for SMA has changed the feeding prognosis for many children with that condition. "We used to tell parents as soon as a newborn was diagnosed with SMA type 1, 'Your baby will need a feeding tube.' But now, with Spinraza and Zolgensma, it's more of a 'maybe,'" she says. "Time will tell if their swallowing function can be preserved in the long term."

## Medication considerations

Medications a patient takes also can affect their nutritional needs.

"Boys with Duchenne muscular dystrophy (DMD) get placed on corticosteroids just as they're losing ambulation," Watne says. "In addition to the steroids causing their appetites to increase, they're burning fewer calories because their mobility is declining. It's very easy for them to gain a lot of unintended weight."

Watne counsels these patients on ways to manage calorie intake while still getting the nutrients their bodies need, such as avoiding sodas, juices, and sugary sports drinks. "They can't afford the extra calories, so the focus is on drinking mostly water."

Watne also educates patients and their families on appropriate portion sizes and encourages them to eat more fruits and vegetables that are high in nutrients and low in calories. "I try to approach nutrition as a family, so that the child with the neuromuscular disease doesn't feel singled out," she says.

Another concern Gilmore addresses is over-the-counter vitamins and supplements. She has encountered patients taking six to eight supplements a day. Other than calcium, vitamin D, or a general multivitamin, she says, "I don't recommend them. Supplements may cause more harm than good, and they're not regulated by the FDA, so you never really know what you're getting."

## Nutrition Education for Patients

While having a registered dietician on your team is ideal, MDA has resources that can help you educate your patients about proper nutrition for their situation. Some [MDA Engage](#) educational events address nutrition. Find upcoming events and view recorded events at [mda.org/engage](https://mda.org/engage).