

THE

IMPORTANCE

OF

MENTAL HEALTH

*Why proper mental health care is essential for neuromuscular disease patients*

Mental health is a crucial factor in overall wellness, regardless of a patient's diagnosis. "In medicine, we need to be thinking about the whole person, and when we think about treatment, we need to include mental health and well-being as part of that," says Julie Pajek, PhD, pediatric psychologist at MetroHealth. "It's not only about improving quality of life and life happiness/satisfaction; we know that mental health difficulties really impact medical outcomes."

Dr. Pajek says stronger mental health often leads to better adherence to the medical regimen and medications and a higher likelihood of continuing follow-up therapies and appointments.

Children and young adults with muscular dystrophy are particularly at risk for mental health difficulties. "We know there are higher rates of intellectual and learning disabilities as well as autism, ADHD, anxiety, and depression," Dr. Pajek says. "While many children and adults with muscular dystrophy are generally well-adjusted and lead happy, productive lives, many really struggle adjusting to the degenerative nature of the disease. Many struggle with anxiety and depression as a result."

Regarding the MDA Care Center's multidisciplinary approach to neuromuscular disease care, Dr. Pajek recommends integrating mental health care as part of the plan from the beginning, including a support system for family members.

"Neuromuscular disease diagnoses can impact family dynamics and can cause stress, anxiety, and depression for caregivers," Dr. Pajek says. "These types of diseases are disruptive emotionally and physically, in terms of the burden of providing care."

In addition to supporting the family early on, Dr. Pajek suggests engaging patients in conversations around their diagnosis and what it means.

"Normalize conversation about diagnosis from the beginning so that children understand what's going on and feel empowered and part of the decision-making," Dr. Pajek says. "We know it leads to good outcomes when patients feel really involved in their care."

That patient involvement directly ties into how well patients adhere to treatment plans and engage in the process.

As patients grow older, Dr. Pajek recommends regular screenings to identify patients and families who are experiencing anxiety, depression, and other difficulties.

"I think that any time you're talking about a chronic health condition, psychologists should be involved. We are not only able to address traditional mental health concerns like anxiety and depression, but we are also able to work with patients around motivation, behavior change, and pain management. We are well-positioned to help patients adjust and cope with the impact of the chronic health condition." Dr. Pajek says. "A muscular dystrophy diagnosis differs in many ways from, for example, diabetes, which has a relatively clear diagnosis and treatment. Muscular dystrophy is degenerative, and the stages of diagnosis may require more time for adjustment and ongoing support."

Dr. Pajek recommends providers utilize relaxation, mindfulness, and cognitive coping strategies.

“We know that quality of life and mental health has a lot to do with how you see things,” Dr. Pajek says. “It matters whether you see the positives and focus on what you have control over, or whether you focus on the negatives and loss of control. Working on perspective is something patients, families, and providers can do together.”

Visit [MDA's Mental Health Hub](#) for resources for health professionals and the MDA community.