Vaccination Considerations in Neuromuscular and Immunocompromised Populations

For people with neuromuscular diseases — many of whom are also immunocompromised — vaccination is a powerful but sometimes misunderstood tool in managing overall health. While vaccines are broadly recommended by health authorities like the Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO), patients with complex conditions often face nuanced decisions about when, how, and which vaccines to receive.

Claire Spahn, a clinical pharmacist at Stanford Health Care specializing in adult neuromuscular disease care, offers critical insights into the considerations, barriers, and best practices surrounding vaccinations in this unique population.

Understanding the risks

Vaccination in this group is not just a routine preventive measure; it can be lifesaving.

“Some of these patients may be at risk for respiratory muscle weakness, so we want to make sure we’re providing the appropriate vaccinations, especially against diseases like influenza, COVID-19, and pneumococcal infections, which can severely impact respiratory function,” Spahn says.

However, for immunocompromised patients, the type of vaccine is an important consideration. Some are available as live attenuated vaccines — a type of vaccine that uses a weakened form of the live virus or bacterium that causes the disease it is designed to prevent — and as inactivated vaccines. For example, the nasal flu mist is a live vaccine, while the flu shot is inactivated.

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"Immunocompromised patients should avoid live vaccines. We encourage these patients to opt for the inactivated vaccine, which is safe and the recommended option," Spahn says.

Even though immunocompromised patients may have weaker immune responses, there's still value in receiving vaccines. Spahn cites CDC data showing that shingles vaccine efficacy in the general population exceeds 90%, while it remains between 68% and 91% for immunocompromised individuals.

Conditional guidelines and shared decision-making

One challenge to making vaccination recommendations for immunocompromised populations is that many vaccine trials do not focus on them.

"The recommendation for the population at large might be based on strong evidence," she says, "but when you drill down into specific subgroups of patients, there might not be sufficient data to really provide such a clear recommendation."

In these cases, guidelines — like those from the CDC's Advisory Committee on Immunization Practices (ACIP) — may include "conditional or lower-strength recommendations," prompting clinicians and patients to engage in shared decision-making.

The clinical context is also important, of course. Spahn says that autoimmune conditions, such as myasthenia gravis (MG), are not contraindications for vaccination.

"They do recommend caution regarding a specific patient's immunosuppressant regimen, she says. "For example, a medication might require vaccines timed at specific intervals around medication administration, but there is generally no need to avoid vaccines. Indeed, they provide powerful protection for patients with additional risk factors."

Barriers to access and adherence concerns

While vaccine availability has improved, particularly through retail pharmacies, cost and communication remain significant challenges.

"Some vaccines are covered by insurance, like Shingrix [for shingles] with Medicare Part D, but others, like meningococcal vaccines required for complement inhibitor therapy, can run into the hundreds of dollars if paid for out of pocket," Spahn says.

Additionally, she often sees older patients who haven't completed age-appropriate vaccines, such as pneumococcal or shingles. There is no national organization that maintains vaccination records, but some states have registries (Immunization Information Systems) that include adult vaccines.

"Proper vaccine administration can be complex, introducing the risk of missed or inappropriate booster doses," Spahn says. "And with meningococcal vaccines specifically, interchangeability can be an issue — some types are not interchangeable, which creates confusion."

Vaccine hesitancy, fueled by misinformation and anecdotal stories online, is another roadblock.

"Sometimes patients may think, 'Oh, I'm immunocompromised, so I can't have vaccines.'" Spahn sees this as an opportunity to educate. "I'll say, 'This is an evidence-based recommendation.' But at the same time, I acknowledge that immunocompromised patients have significant complexities to navigate."

Concerns about vaccine safety can also arise, especially regarding preservatives or fears of long-term effects. Spahn attempts to counter those concerns by highlighting the robust systems in place, such as the FDA's Vaccine Adverse Event Reporting System (VAERS), a national early warning system that collects and analyzes reports of adverse events following vaccination.

"The FDA has rigorous ongoing monitoring pharmacovigilance programs," she says. "These are designed to flag any unusual or unexpected responses, which would trigger further investigation and result in updates to labels and clinical recommendations if required."

According to the CDC, healthcare providers are required to report any such incidents, ensuring that safety surveillance is continuous and transparent.

Special considerations: gene therapy and beyond

Patients preparing for gene therapy face even more complex timing issues. Each patient should have a personalized vaccine plan that ensures maximum protection against infection and minimizes interference with the therapy.

For these cutting-edge therapies, standardized guidelines may not yet exist. Spahn recommends consulting with infectious disease specialists and referencing institutional policies.

“These newer fields probably don’t yet have guideline support or a lot of evidence, so it may be more of a conditional recommendation,” she says.

The path forward

Flexibility and education are the pillars of vaccination success in this population.

“It’s not an all-or-nothing,” Spahn says. She encourages patients to consult their healthcare provider or pharmacist to ensure they have a plan they are comfortable with, such as receiving the flu, COVID, and RSV vaccinations together to promote adherence.

Ultimately, she says, the goal is to avoid missed opportunities: “Vaccines are one of the best tools we have to keep people with neuromuscular diseases safe.”

Resources

- MDA Quest Magazine: Why You Should Practice Shared Healthcare Decision-Making
- MDA webinar: Updates in Research and Care: Vaccines and Neuromuscular Conditions: Safety, Science, and Guidance (October 8, 2025)
- CDC: Clinical Considerations for Shingrix Use in Immunocompromised Adults Aged ≥19 Years
- European Journal of Paediatric Neurology: Vaccination proposal for patients on onasemnogene abeparvovec therapy