BLOG 3 · When Compensation Is Not Enough: Understanding Swallowing Rehabilitation in Myositis

Thickener doesn't strengthen anything.

If you've been handed a can of thickener and sent on your way, you received a tool — not a treatment plan. And the difference between those two things is the most important distinction in all of dysphagia care.

Two buckets, two jobs

Everything we do for dysphagia falls into one of two buckets.

Compensation manages symptoms. It makes swallowing safer in the moment, right now, at this meal. Thickened liquids, posture changes, smaller bites, pacing, eating rested instead of exhausted. These strategies are valuable and sometimes essential, particularly when aspiration risk is high. But they don’t work if we don’t use them and they have no long-term impact. Take the strategy away, and the underlying problem is exactly where you left it.

Rehabilitation targets the impairment itself. These are exercises designed to improve the strength and coordination of the swallowing muscles over time. Approaches include expiratory muscle strength training with the EMST-150, effortful swallows, chin tucks against resistance, neuromuscular electrical stimulation, and structured programs such as MDTP. They take effort, consistency, and professional guidance. And when they're appropriate, they're how function actually improves.

Most people with myositis-related dysphagia will use both. The key is knowing which one you're doing and why.

The honest thickener conversation

Thickened liquids deserve a moment of honesty, because they're the most prescribed and least explained tool in dysphagia care. What thickener does is slow liquid down, giving weakened muscles more time to protect the airway. For the right patient, identified through an MBSS or a FEES, that's genuinely useful.

What it doesn't do: eliminate aspiration risk, strengthen a single muscle, or address why your swallow changed. And the trade-offs are real: many people drink less because they dislike the texture, which raises the risk of dehydration, and recent research has raised honest questions about how reliably thickeners reduce risk in some populations, including IBM.

A thickened-liquid recommendation should come from an instrumental evaluation — a FEES or MBSS. If you're on thickener and nobody has looked at your swallow recently, ask for an updated evaluation. You deserve to know why it was prescribed, whether it's helping, and whether rehabilitation belongs in your plan.

The myositis-specific caution

Here's where myositis changes the playbook: exercise is not automatically good. In active or inadequately treated disease, pushing inflamed, fatigued muscles can worsen function rather than improve it. Swallowing rehabilitation needs two clinicians working together: the SLP assessing the swallowing deficits and the rheumatologist or neurologist managing disease activity. As your

disease comes under control, the window for rehabilitation often opens. The right exercise depends on exactly where your weakness is and how your disease is behaving right now.

Which is why I end every conversation about exercises the same way: don't guess. Get evaluated. An instrumental study tells us which muscles need work, which exercises match your impairment, and which ones to skip. Your effort deserves to go toward the right target.

What rehabilitation actually looks like

If rehabilitation does belong in your plan, here's the honest picture: it's a program, not a prescription. Your SLP selects exercises matched to your specific impairment, sets the starting intensity, teaches the technique until you can do it correctly, and builds a home program around it. You practice consistently, meaning most of the work happens at your kitchen table rather than in the clinic. You re-evaluate at intervals because the goal is measurable change in how your swallow functions, not effort for its own sake. Progress in swallowing rehab is often gradual and genuinely worth it: stronger airway protection, less residue, more foods back on the table, and meals that feel enjoyable again.

What to do this week

If you're using compensations, ask your SLP one question: “Is there a rehabilitation component to my plan, and if not, why not?” Sometimes the honest answer is that compensation is the right plan for your situation. But you deserve the conversation. The free comparison handout and the full Module 3 video walk through everything.

Safer now matters. Stronger over time matters more. Make sure your plan knows the difference.

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