

Difficulty swallowing (dysphagia) can occur in ME patients who meet the ICC. The disease involves neurological, autonomic, neuromuscular, and possibly brainstem dysfunction — all of which are important for normal swallowing. Swallowing is actually a very complex process requiring precise coordination between the brainstem, cranial nerves, muscles of the throat, breathing patterns, and autonomic regulation.

In ME, studies and clinical observations have reported abnormalities involving the brainstem, autonomic nervous system, muscle fatigability, sensory processing, and impaired neural signaling. This can lead to symptoms such as weak throat muscles, delayed swallowing reflexes, choking sensations, difficulty coordinating breathing and swallowing, food “sticking,” or worsening swallowing problems during PENE. Some patients also experience dry mouth, vagus nerve dysfunction, or hypersensitivity in the throat, which can further complicate swallowing.

Because dysphagia can also occur in other neurological or structural conditions, it should always be medically assessed rather than automatically attributed to ME alone.

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Difficulty swallowing in ME patients is usually assessed the same way it is in other neurological conditions — by evaluating whether the problem is muscular, neurological, structural, autonomic, or related to coordination. Assessment may include:

- *Clinical swallowing evaluation by a doctor or speech-language pathologist, looking at choking, coughing, voice changes, fatigue while eating, coordination, and whether symptoms worsen after exertion.

- *Videofluoroscopic swallow study (VFSS / modified barium swallow) — an X-ray study where the patient swallows different textures to see how food and liquid move through the mouth and throat.

- *FEES (fiberoptic endoscopic evaluation of swallowing) — a tiny camera through the nose allows direct visualization of swallowing function.

- *Neurological examination to assess cranial nerves, reflexes, muscle weakness, coordination, sensory abnormalities, and possible brainstem involvement.

- *Autonomic testing if dysautonomia is suspected, since autonomic dysfunction can affect esophageal motility and vagus nerve regulation.

- *Esophageal testing such as manometry or endoscopy if symptoms suggest lower esophageal involvement or another gastrointestinal disorder.

In ME, swallowing difficulties may fluctuate and worsen during PENE, so clinicians sometimes miss the severity if assessment occurs on a “better” day.

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Management depends on the cause and severity of the swallowing problem, but in ME ICC patients the focus is usually on reducing strain on the neurological and neuromuscular systems while maintaining safe nutrition and hydration. Common approaches include:

- *Speech-language/swallow therapy to teach safer swallowing techniques, pacing while eating, posture adjustments, and ways to reduce choking or aspiration risk.

- *Energy management/pacing because swallowing problems may worsen during PEM/PENE or when muscles are fatigued. Smaller meals and resting before eating can help some patients.

- *Texture modification such as softer foods, thickened liquids, or avoiding difficult textures if coordination is impaired.

- *Managing autonomic dysfunction (for example POTS or vagal dysfunction) since dysautonomia can contribute to swallowing and esophageal problems.

- *Treating contributing conditions like reflux, dry mouth, allergies, mast cell activation, muscle spasms, or nutritional deficiencies.

- *Hydration and nutrition support if eating becomes exhausting or unsafe. In severe cases, temporary or long-term enteral feeding may be considered.

- *Monitoring for aspiration because repeated choking or food entering the airway can lead to pneumonia or weight loss.

Since dysphagia can overlap with other neurological or gastrointestinal disorders, management is usually multidisciplinary rather than attributed solely to ME.

References

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