

## Breathing, Swallowing & Nerve Symptoms and M.E.ICC

- \* Difficulty breathing or “air hunger”
- \* Difficulty swallowing or chewing
- \* Paresthesias (tingling/numbness)
- \* Polyneuropathy
- \* Myoclonus (sudden muscle jerks)

Here’s how they fit:

### Symptoms commonly associated with ME-ICC

- \*Difficulty breathing / “air hunger”
- \*Fits under energy production/transport impairments and autonomic dysfunction.
- \*ME patients may experience shortness of breath, chest wall muscle fatigue, or the feeling of not getting enough air despite normal oxygen levels.

### Difficulty swallowing or chewing

- \*Can occur in ME due to neurological impairments, cranial nerve involvement, muscle fatigability, or autonomic dysfunction.
- \*Swallowing problems (dysphagia) are reported by some people with more severe ME.

### Paresthesias (tingling/numbness)

- \*Specifically included under neurological sensory disturbances in ME-ICC.
- \*Patients may experience burning, tingling, numbness, electric-shock sensations, etc.

### Polyneuropathy

- \*Peripheral nerve dysfunction is not listed as a required criterion, but neuropathic symptoms and small fiber neuropathy are increasingly recognized in some ME patients.

It may overlap with comorbid conditions.

- \*Myoclonus (sudden muscle jerks)
- \*Fits under motor disturbances in the neurological impairment section.
- \*Muscle twitching, jerks, tremors, poor coordination, and movement abnormalities are all reported in ME.

### Important context

The ME-ICC emphasizes that ME is a multi-system neuroimmune disease, so symptoms affecting breathing, nerves, muscles, sensory processing, and swallowing can all occur together - especially after exertion.

However, these symptoms can also appear in other neurological or medical conditions, so clinicians usually consider:

- \* neuromuscular disorders
- \* autoimmune disease
- \* electrolyte or vitamin deficiencies
- \* seizures/movement disorders
- \* dysautonomia/POTS
- \* neuropathies
- \* medication effects

if symptoms are significant or worsening.

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#### Management Approaches for Breathing, Swallowing & Nerve Symptoms in ME

Management is usually focused on reducing exertional stress, calming nervous system overload, improving autonomic stability, and preventing symptom escalation, since there is no single treatment that works for everyone with ME.

#### Breathing / “Air Hunger”

- \* Pacing is often the most important tool, as overexertion can worsen breathing difficulty.
- \* Resting before symptoms become severe may reduce autonomic strain.
- \* Upright intolerance can contribute, so some people improve with:
  - \* fluids and electrolytes
  - \* compression garments
  - \* lying semi-reclined during flares
- \* Slow, gentle breathing exercises may help some people avoid over-breathing patterns, but forcing deep breathing can sometimes worsen symptoms.
- \* Persistent chest pain, blue lips, severe shortness of breath, or sudden worsening should be medically assessed.

## Difficulty Swallowing or Chewing

- \* Eating smaller, softer meals may reduce muscle fatigue.
- \* Sitting upright while eating can help swallowing coordination.
- \* Avoid rushing meals when fatigued.
- \* Severe swallowing difficulty, choking, unexplained weight loss, or aspiration symptoms should be evaluated by a doctor or speech/swallow specialist.

## Paresthesias & Polyneuropathy

- \* Reducing PEM/PENE can sometimes lessen nerve irritation.
- \* Common things doctors may assess include:
  - \* B12 and folate
  - \* iron/ferritin
  - \* vitamin D
  - \* blood sugar
  - \* thyroid function
- \* Some patients find heat/cold management, gentle positioning, or avoiding prolonged pressure on nerves helpful.
- \* Neuropathic pain medications are sometimes used clinically, though tolerance varies in ME.

## Myoclonus (Muscle Jerks)

Often worsens with:

- \* sleep deprivation
- \* overstimulation
- \* PENE
- \* stress on the nervous system
- \* Protecting sleep and avoiding repeated overexertion may reduce frequency.
- \* Sudden severe jerking, blackouts, or seizure-like episodes should be medically assessed.

## Overall ME-ICC Approach

The ME-ICC model generally supports:

- \* strict pacing and energy management
- \* reducing repeated crashes/PENE
- \* managing orthostatic intolerance/dysautonomia
- \* optimizing sleep
- \* treating comorbid conditions where possible
- \* minimizing sensory and cognitive overload in severe cases

Many people with ME notice these neurological and autonomic symptoms fluctuate depending on their energy envelope and degree of post-exertional worsening.

#### References

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