Severe and Very Severe Myalgic Encephalomyelitis (ME) in Australia:

The role of Speech Pathologists in a neglected patient cohort

Heenal Narsey (MSP, MSPA-CPSP)

Why Severe and Very Severe ME Matters in Australia

- Represents the **most profoundly disabled group** within the ME spectrum
- Often **housebound or bedbound**, requiring extensive care
- Remains **under-recognised** in healthcare policy, research, and service delivery
- Leads to inequitable access and limited management options
- NHMRC Clinical Guidelines Project is a **critical opportunity** to embed evidence-based recommendations
- Improved recognition will guide clinicians, inform service models, and shape national policy

(International Consensus Panel, 2012; Drachler et al., 2009; Thanawala & Taylor, 2007; NHMRC, 2025)

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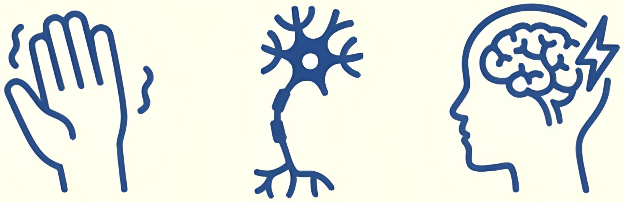
What is Severe and Very Severe ME?

- **Most debilitating forms** of ME with profound physical & cognitive impairments
- **Severe ME**: mostly housebound, reliant on mobility aids, difficulty with basic tasks (eating, speaking, self-care)
- **Very Severe ME**: completely bedbound, extreme sensitivity to light, sound & touch, may require **tube feeding & full-time support**
- Both involve **extreme post-exertional neuroimmune exhaustion (PENE)** — minimal activity → major symptom worsening
- Constant **pain, exhaustion, and sensory overload**
- Among the most **medically neglected and socially isolated** groups

(International Consensus Panel, 2012; Verma & Natelson, 2024)

Similar Clinical Presentations of ME with other Neurological Diseases



- People with Severe & Very Severe ME often have similar presentations with other Neurological diseases (e.g., **Parkinson’s disease (PD), Multiple Sclerosis (MS), and Traumatic Brain Injury (TBI)**

- **Language**: word-finding difficulties, reduced verbal fluency

- **Cognition**: slowed processing, memory difficulties, attention deficits

- **Voice**: dysphonia/aphonia from neurological exhaustion, similar to Parkinson’s hypophonia

- **Motor Speech**: slurred/imprecise articulation, resembling dysarthria in MS or TBI

- **Swallowing (Dysphagia)**: related chewing exhaustion, swallowing, saliva management difficulties

These parallels emphasise the **relevance of Speech Pathology** in ME assessment & management.

(Drachler et al., 2009; International Consensus Panel, 2012; Verma & Natelson, 2024; Threats, 2007; ASHA, n.d.; Carnaby-Mann & Lenius, 2008; RCSLT, 2019; Speech Pathology Australia, 2012)

Unique Clinical Presentations of ME among Neurological Diseases

- **Profound Post-Exertional Neuro-immune Exhaustion (PENE)**
  - Hallmark symptom, unique to ME
  - Minimal exertion → disproportionate, prolonged worsening (days–week
  - Pathological exhaustion involving nervous & immune systems
- **Neuro-exhaustion**: even basic activities (speaking, sitting upright, eating) may be intolerable
- **Orthostatic Intolerance**: dizziness, palpitations, presyncope, collapse when upright
- **Extreme sensory hypersensitivities**: light, sound, touch → severe pain & distress
- Many are **bedbound**, may be non-verbal, and require **tube feeding/full-time support**
- These features **set ME apart** from other neurological illnesses → demand **tailored, cautious, compassionate care** and highlights the need for **specialised Speech Pathology support**

(International Consensus Panel, 2012; Drachler et al., 2009)

Case Study – Communication & Swallowing Challenges in ME

- **Language**: increased word-finding difficulties → “could not pick up the right words” → disrupted flow
- **Cognition**: reduced short-term memory & slowed processing → difficulty following & participating in conversations
- **Voice**: neurological exhaustion → persistent dysphonia (very soft voice) & intermittent aphonia (loss of voice) → restricted functional communication
- **Speech**: increased slurring of speech particularly when neurologically exhausted → reduced intelligibility
- **Swallowing (Dysphagia)**: difficulties with mastication, swallowing food/fluids, and managing saliva → increased mealtime risks (choking and or aspiration)
- **Client perspective**: expressed interest in assistive technologies (voice amplification, speech-to-text with pre-programmed phrases)

Case Study – Therapy Recommendations Part 1

- **Language**:
    - Word-finding & communication flow strategies
- **Cognition**:
    - Supports for memory, processing speed, reducing cognitive load
- **Voice**:
    - Voice conservation strategies
    - Trials of amplification devices, speech-to-text, pre-programmed phrases
    - Routine building, support worker training, structured data collection

(Drachler et al., 2009; International Consensus Panel, 2012; Verma & Natelson, 2024; McEwin & Santow, 2018; Speech Pathology Australia, 2012; SPA, 2023; Threats, 2007; McEwin & Santow, 2018)

Case Study – Therapy Recommendations Part 2

- **Speech**:
  - Strategies to maximise clarity, especially during periods of neuro exhaustion
- **Swallowing (Dysphagia)**:
  - Personalised mealtime management plan
  - Texture modification, pacing, positioning, safe swallow strategies, environmental setup
  - Training for support workers → ensure safety & consistency
- **Generalisation**:
  - Strategies across daily activities (meals, ADLs, community tasks)
  - Ongoing refinement & updated support worker guidance

(ASHA, n.d.; Carnaby-Mann & Lenius, 2008; RCSLT, 2019; Speech Pathology Australia, 2012; SPA, 2023; Threats, 2007)

Clinical Challenges & Considerations – Assessment & Therapy in Severe and Very Severe ME

- **PENE (Post-Exertional Neuro-immune Exhaustion):** even minimal exertion → prolonged deterioration (clients may only tolerate very short, low-demand interactions)

- **Neuro-exhaustion:** inability to sustain activity; rapid decline in cognition, voice, and motor function

- **Inability to generate energy on demand:** cellular ion transport impairment → energy not restored with rest

- **Orthostatic Intolerance (OI):** symptoms worsen upright (sitting, standing - restricted assessment/therapy settings) → dizziness, palpitations, presyncope

- **Therapy must be:** highly individualised, low-stimulation, energy-conserving, flexible, and compassionate

(ME-ICP, 2012; Drachler et al., 2009; Vermeulen, 2018; Nacul et al., 2020; Thanawala & Taylor, 2007; Speech Pathology Australia, 2023)

Challenges & Clinical Considerations – Examples in Practice

PENE (Post-Exertional Neuro-immune Exhaustion)	**Neuro-Exhaustion**	**Inability to Produce Energy on Demand**	**Orthostatic Intolerance (OI)**
● **Challenge:** Even a small task worsens symptoms for days/weeks ● **Example:** 5 min picture naming → days of severe neuro exhaustion/pain/cognitive fog ● **Consideration:** Keep sessions micro-brief, extend recovery time	● **Challenge:** Rapid decline with minimal brain activity ● **Example:** After 2–3 questions → slowed responses, slurred speech, shutdown ● **Consideration:** Use yes/no supports; stop sessions at first decline	● **Challenge:** Energy not restorable on demand (ion transport impairment) ● **Example:** Client cannot repeat swallowing trial minutes later ● **Consideration:** Avoid repetitive drills; use compensatory strategies	● **Challenge:** Upright posture worsens symptoms (dizziness, collapse) ● **Example:** Therapy only possible reclined or bedside ● **Consideration:** Adapt posture, use telehealth/ support worker-mediated supports

Research Gaps in Speech Pathology & ME

- **Minimal research available** on speech pathology in Myalgic Encephalomyelitis
- Gaps include communication, swallowing, and cognitive-communication support
- Particularly concerning for **Severe & Very Severe ME**, where conventional therapy may be unsafe due to **PENE**
- Clinicians currently have **limited evidence-based guidance** to ensure safe, effective care

There is little research into Speech Pathology for ME, leaving patients without evidence-based care and clinicians without clear guidance.

(ME-ICP, 2012; Drachler et al., 2009; Nacul et al., 2020; Verma & Natelson, 2024)

Urgent Need for Research & Inclusion in Guidelines

- **Urgent need for targeted studies** into:
  - Safe & adapted therapy approaches
  - Assistive technology use
  - Support worker training & dysphagia management in energy-limited contexts

- **NHMRC Clinical Guidelines Project** is a critical opportunity to:
  - Embed ME-specific recommendations
  - Ensure evidence-informed, safe, and equitable care
  - Provide clinicians with guidance to adapt interventions to ME's unique pathophysiology

Urgent research and guideline inclusion are essential to improve outcomes and reduce neglect in pwME.

(Carnaby-Mann & Lenius, 2008; RCSLT, 2019; SPA, 2012; NHMRC)

Communication as a Human Right in Severe ME

- **Communication is a fundamental human right**

- People with **Severe ME face systemic barriers**:
  - Too unwell to attend clinics or tolerate standard assessments
  - Profound isolation limits ability to advocate for themselves
  - Needs often remain **invisible and unmet**

- **Role of Speech Pathologists**:
  - Clinicians *and* advocates
  - Ensure equity and accessibility in service delivery
  - Promote inclusion and recognition of ME within **clinical guidelines & health policy**

Communication is a human right. People with Severe ME face significant barriers to accessing this right, and speech pathologists must act as advocates to ensure equity, inclusion, and recognition within health policy and clinical practice.

(McEwin & Santow, 2018; Drachler et al., 2009)

Summary

- **ME profoundly impacts** communication, cognition, voice, and swallowing
- In Severe ME, individuals may be **unable to speak, eat safely, or participate in daily life**
- **Speech pathologists are vital**:
  - Support autonomy, safety, and quality of life
  - Provide tailored communication supports & AT
  - Deliver dysphagia management strategies
- **Current gaps**:
  - Very limited research
  - No condition-specific guidelines
  - Lack of specialist training and service access

(ASHA, n.d.; Carnaby-Mann & Lenius, 2008; Drachler et al., 2009; McEwin & Santow, 2018; RCSLT, 2019; Speech Pathology Australia, 2012, 2023; Verma & Natelson, 2024)

Moving Forward Together - Giving Voice to People with ME

- **Inclusion in Guidelines**: Support Speech Pathology representation in NHMRC Guidelines to ensure safe, evidence-based care
- **Equitable Access**: Advocate for improved service delivery so people with Severe and Very Severe ME are not excluded
- **Targeted Speech Pathology Research**: Urgent need for studies on communication, cognition, voice, and swallowing in ME
- **Awareness & Advocacy**: Raise recognition of ME's unique challenges across health systems and within the broader community
- **Collective Commitment**: Uphold the rights of people with ME by working together to ensure equity and recognition

(Drachler et al., 2009; Carnaby-Mann & Lenius, 2008; Verma & Natelson, 2024; McEwin & Santow, 2018)

References

American Speech-Language-Hearing Association. (n.d.). *Adult dysphagia (Practice Portal).* Retrieved from https://www.asha.org/Practice-Portal/Clinical-Topics/Adult-Dysphagia/

Carnaby-Mann, G., & Lenius, K. (2008). The bedside examination in dysphagia. *Physical Medicine and Rehabilitation Clinics of North America, 19*(4), 747–768.

Drachler, M. de L., Leite, J. C. de C., Hooper, L., Hong, C. S., Pheby, D., Nacul, L., Lacerda, E., Campion, P., Killett, A., McArthur, M., & Poland, F. (2009). The expressed needs of people with chronic fatigue syndrome/myalgic encephalomyelitis: A systematic review. *BMC Public Health, 9*(1), 458. https://doi.org/10.1186/1471-2458-9-458

International Consensus Panel. (2012). *Myalgic Encephalomyelitis: International Consensus Primer for Medical Practitioners (ME-ICP).* Retrieved from https://tinyurl.com/meicp2012

McEwin, A., & Santow, E. (2018). The importance of the human right to communication. *International Journal of Speech-Language Pathology, 20*(1), 1–2. https://doi.org/10.1080/17549507.2018.1415548

National Health and Medical Research Council. (2025). *Myalgic encephalomyelitis clinical guideline project.* NHMRC. https://www.nhmrc.gov.au/health-advice/me-cfs

Royal College of Speech & Language Therapists. (2019). *Dysphagia guidance.*

Speech Pathology Australia. (2012). *Dysphagia clinical guideline.* Retrieved from https://www.speechpathologyaustralia.org.au/resource?resource=125

Speech Pathology Australia. (2023). *Clinical guidelines for speech pathology practice.*

Thanawala, S., & Taylor, R. R. (2007). Service utilization, barriers to service access, and coping in adults with chronic fatigue syndrome. *Journal of Chronic Fatigue Syndrome, 14*(1), 5–21. https://doi.org/10.1300/j092v14n01_02

Threats, T. (2007). Use of the ICF in dysphagia management. *Seminars in Speech and Language, 28*(4), 323–333.

Verma, A., & Natelson, B. H. (2024). A signal for voice and speech abnormalities in myalgic encephalomyelitis/chronic fatigue syndrome. *Journal of Clinical Medicine, 14*(14), 4847. https://doi.org/10.3390/jcm14144847

Thank you

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