Associated New Zealand Myalgic Encephalomyelitis Society Incorporated

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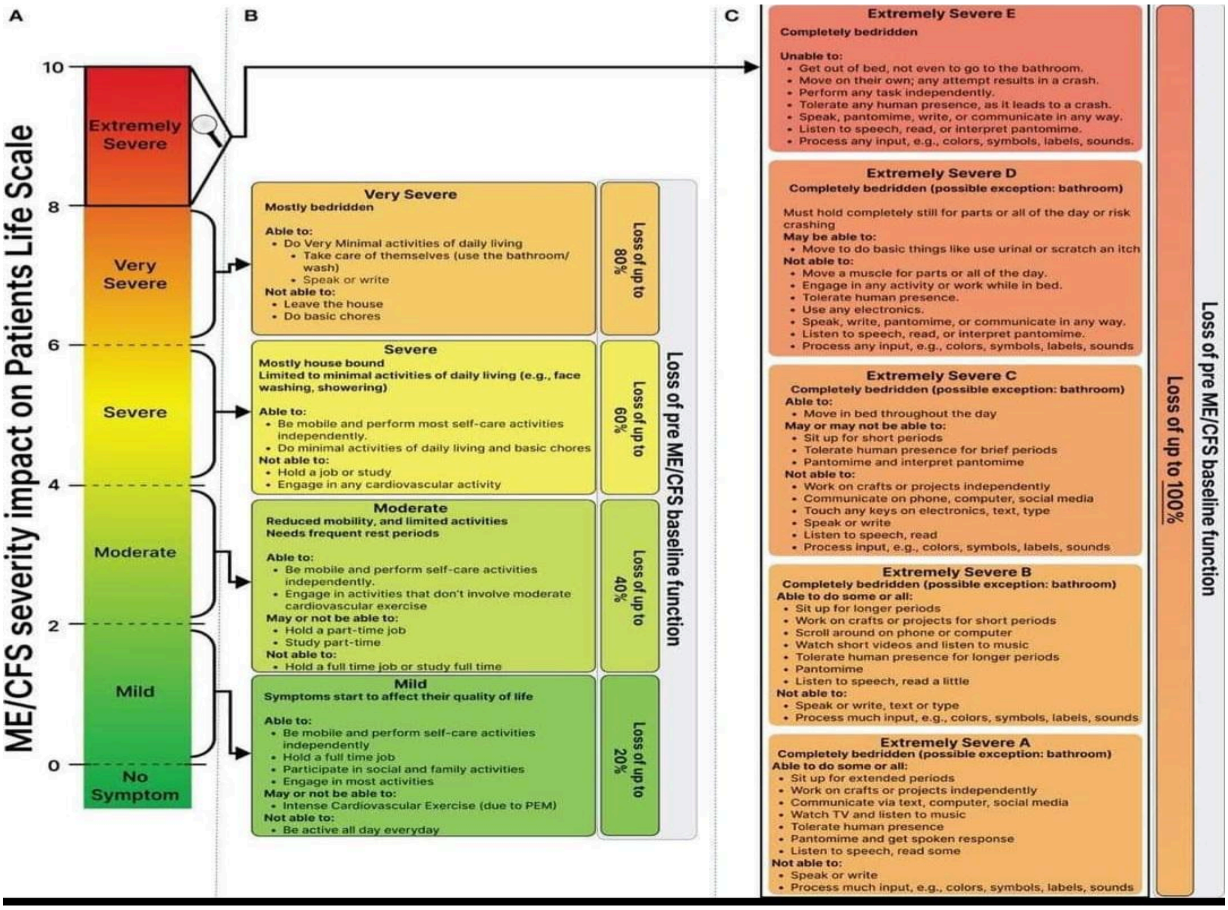
ME
ANZMES

# Severe-Very Severe ME/long COVID Resources:

## Best Practice Guidance and Care Plans

ANZMES One Page Resource for Hospital:
https://drive.google.com/file/d/1VUFCURZJgKeLQHQfjnklRxcUobqjCu4M/view
Explanation for Resource above:
https://anzmes.org.nz/press-release-anzmes-releases-essential-resource-for-healthcare-professionals-to-manage-hospital-stays-of-severe-me-cfs-and-long-covid-patients/

Figure 3 Proposed Framework for Personalized Severity Assessment in ME/CFS to Capture Variation in ME/CFS Severity and Life Impairment across Patients and Time.
https://www.frontiersin.org/journals/immunology/articles/10.3389/fimmu.2024.1369295/full



**Very Severe**
**Mostly bedridden**

**Able to:**
- Do Very Minimal activities of daily living
  - Take care of themselves (use the bathroom/ wash)
  - Speak or write

**Not able to:**
- Leave the house
- Do basic chores

**Severe**
**Mostly house bound**
**Limited to minimal activities of daily living (e.g., face washing, showering)**

**Able to:**
- Be mobile and perform most self-care activities independently.
- Do minimal activities of daily living and basic chores

**Not able to:**
- Hold a job or study
- Engage in any cardiovascular activity

**Moderate**
**Reduced mobility, and limited activities**
**Needs frequent rest periods**

**Able to:**
- Be mobile and perform self-care activities independently.
- Engage in activities that don't involve moderate cardiovascular exercise

**May or not be able to:**
- Hold a part-time job
- Study part-time

**Not able to:**
- Hold a full time job or study full time

**Mild**
**Symptoms start to affect their quality of life**

**Able to:**
- Be mobile and perform self-care activities independently
- Hold a full time job
- Participate in social and family activities
- Engage in most activities

**May or not be able to:**
- Intense Cardiovascular Exercise (due to PEM)

**Not able to:**
- Be active all day everyday

**Extremely Severe E**
**Completely bedridden**

**Unable to:**
- Get out of bed, not even to go to the bathroom.
- Move on their own; any attempt results in a crash.
- Perform any task independently.
- Tolerate any human presence, as it leads to a crash.
- Speak, pantomime, write, or communicate in any way.
- Listen to speech, read, or interpret pantomime.
- Process any input, e.g., colors, symbols, labels, sounds.

**Extremely Severe D**
**Completely bedridden (possible exception: bathroom)**

Must hold completely still for parts or all of the day or risk crashing
**May be able to:**
- Move to do basic things like use urinal or scratch an itch

**Not able to:**
- Move a muscle for parts or all of the day.
- Engage in any activity or work while in bed.
- Tolerate human presence.
- Use any electronics.
- Speak, write, pantomime, or communicate in any way.
- Listen to speech, read, or interpret pantomime.
- Process any input, e.g., colors, symbols, labels, sounds

**Extremely Severe C**
**Completely bedridden (possible exception: bathroom)**
**Able to:**
- Move in bed throughout the day

**May or may not be able to:**
- Sit up for short periods
- Tolerate human presence for brief periods
- Pantomime and interpret pantomime

**Not able to:**
- Work on crafts or projects independently
- Communicate on phone, computer, social media
- Touch any keys on electronics, text, type
- Speak or write
- Listen to speech, read
- Process input, e.g., colors, symbols, labels, sounds

**Extremely Severe B**
**Completely bedridden (possible exception: bathroom)**
**Able to do some or all:**
- Sit up for longer periods
- Work on crafts or projects for short periods
- Scroll around on phone or computer
- Watch short videos and listen to music
- Tolerate human presence for longer periods
- Pantomime
- Listen to speech, read a little

**Not able to:**
- Speak or write, text or type
- Process much input, e.g., colors, symbols, labels, sounds

**Extremely Severe A**
**Completely bedridden (possible exception: bathroom)**
**Able to do some or all:**
- Sit up for extended periods
- Work on crafts or projects independently
- Communicate via text, computer, social media
- Watch TV and listen to music
- Tolerate human presence
- Pantomime and get spoken response
- Listen to speech, read some

**Not able to:**
- Speak or write
- Process much input, e.g., colors, symbols, labels, sounds

Planned and unplanned admission process for severe-very severe ME/CFS
https://www.royaldevon.nhs.uk/media/nfapr5s4/planned-and-unplanned-admission-process-for-severe-or-very-severe-me-patients-clinical-guidance-v1-1b-007.pdf

Bateman Horne Center (2022). Medical considerations when treating urgently ill patients with underlying myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).
https://batemanhornecenter.org/wp-content/uploads/filebase/education/top_resources/ER-and-Urgent-Care-Considerations-for-MECFS-1.19.22-005.pdf

Montoya, J. G., Dowell, T. G., Mooney, A. E., Dimmock, M. E., & Chu, L. (2021). Caring for the Patient with Severe or Very Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Healthcare (Basel, Switzerland)*, *9*(10), 1331. https://doi.org/10.3390/healthcare9101331
https://pmc.ncbi.nlm.nih.go[1]v/articles/PMC8544443/

CDC (2024). ME/CFS Clinical Care for Severely Affected Patients.
https://www.cdc.gov/me-cfs/hcp/clinical-care/me-cfs-clinical-care-for-severely-affected-patients.html

World ME Alliance: Direction on hospital stays
https://worldmealliance.org/2024/08/hospital-mistreatment-of-severe-me-patients-globally-severemeday-2024/ and
https://worldmealliance.org/2024/08/safer-hospital-care-for-severe-me-severemeday-2024/

ANZMES Best Practice for the management of ME/CFS and long COVID:
https://anzmes.org.nz/national-advisory-on-me-releases-best-practice-guidance-with-clinician-and-researcher-support/

Grach, S.L. et. al. (2023). Diagnosis and management of ME/CFS. Mayo Clinic Proceedings.:
https://www.mayoclinicproceedings.org/article/S0025-6196(23)00402-0/fulltext

NICE guidelines revisions: https://anzmes.org.nz/the-nice-revisions

Sleep management for ME/CFS-long COVID by Dr. Ros Vallings:
http://www.drvallings.co.nz/uploads/5/0/8/0/50805589/sleep_management__doc_16_.pdf

Baxter, H. et. al (2021). Life-Threatening Malnutrition in Severe ME/CFS. *Healthcare, 9*(4), 459.
doi.org/10.3390/healthcare904059 | https://www.mdpi.com/2227-9032/9/4/459

Edwards, J. (2024). Management of Nutritional Failure in people with Severe ME/CFS: Review of the case for supplementing NICE Guideline NG206. *Qeios.* doi.org/10.32388/T9SXEU

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[1] https://pmc.ncbi.nlm.nih.gov/articles/PMC8544443/

Dr. Charles Shepherd and Dr. Abhijit Chaudhuri (2020) Nutritional assessment in ME/CFS: https://meassociation.org.uk/wp-content/uploads/NUTRITIONAL-ASSESSMENT-AND-MALNUTRITION-AUGUST-2020.pdf

Nutritional deficiencies in severe ME/CFS: notable studies listed here: https://me-pedia.org/wiki/Nutritional_deficiencies_in_ME/CFS

Dr. Nigel Speight (co-author of 2011 Primer and 2017 Paediatric Primer for ME/CFS: https://meassociation.org.uk/2024/03/failings-in-the-care-of-patients-with-very-severe-me-by-dr-nigel-speight/

## Home Visits by medical teams:

Kingdon et. al., (2020). Health care responsibility and compassion-visiting the housebound patient severely affected by ME/CFS
https://pmc.ncbi.nlm.nih.gov/articles/PMC7551603/
Speight (2020). Severe ME in Children https://pmc.ncbi.nlm.nih.gov/articles/PMC7551866/

## ME/CFS is a complex biomedical condition

ANZMES Biomedical basis of ME/CFS and long COVID: https://docs.google.com/document/d/1uVHWGXasSBspzosIErD3ZMimj6tqhw44ESml0tYhx4Y/edit?usp=sharing

Emeritus Professor Warren Tate's letter on ME/CFS as a serious and complex biological illness: https://drive.google.com/file/d/19TnD-e4ax0EG9AsxLAZoRI7OnoxzWjVP/view?usp=drive_link

Ministry of Health, Mental Health and Addictions 2022 letter regarding ME/CFS classification: https://drive.google.com/file/d/1Mkc7tIfXLcMaWQm63_aGRDhN8dEjSWwj/view?pli=1

Professor Warren Tate research - not psychosomatic. https://www.nzdoctor.co.nz/article/undoctored/proof-chronic-fatigue-syndrome-not-psychosomatic

Mildrad et. al; (2018). Poor Sleep Quality is Associated with Greater Circulating Pro-Inflammatory Cytokines and Severity and Frequency of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) Symptoms in Women. : https://pmc.ncbi.nlm.nih.gov/articles/PMC5258835/

## ME/CFS is a disabling condition / disability

ANZMES report to government outlining disability definitions and ME/CFS:
https://anzmes.org.nz/anzmes-speaks-to-parliament/

Health Select Committee report to government
https://drive.google.com/file/d/155lr1che5OQO4qw1ocZ_pp93wb7O-9UG/view?usp=sharing

UNCRPD 53c - recommendation to include ME/CFS in disability policy and practice:
https://docs.google.com/document/d/170Erm5G_FuPUQldvwrLTCR4p1Pr6WJwT/edit?usp=sharing&ouid=114381814050873976744&rtpof=true&sd=true

What is energy impairment and energy-limited chronic illness?
https://chronicillnessinclusion.org.uk/2021/04/28/what-are-energy-impairment-and-elci/

Guide for accessibility, inclusion for people with energy limiting conditions:
https://worldmealliance.org/2023/07/world-me-alliance-launches-a-new-guide-involving-people-with-me-and-other-energy-limiting-conditions/

## POTS (Postural Orthostatic Tachycardia Syndrome)

Diagnosis, management, actions, resources
https://drive.google.com/file/d/1sAHv8Vjg3ZAa4-TP4LNB8mw2PKCg2IIF/view?usp=sharing
NASA Lean Test
https://drive.google.com/file/d/1MRZhe8DDlkpXEhtG_yCkULl8IcrmTb_L/view?usp=sharing

## Long COVID red flags

https://drive.google.com/file/d/1gn6Av3NXtO-6L8TajGo8zGWkrTeWr7wU/view?usp=sharing

## Long COVID implications and impact

https://www.phcc.org.nz/briefing/long-covid-update-threat-continues-demand-strong-response

## Post Exertional Malaise

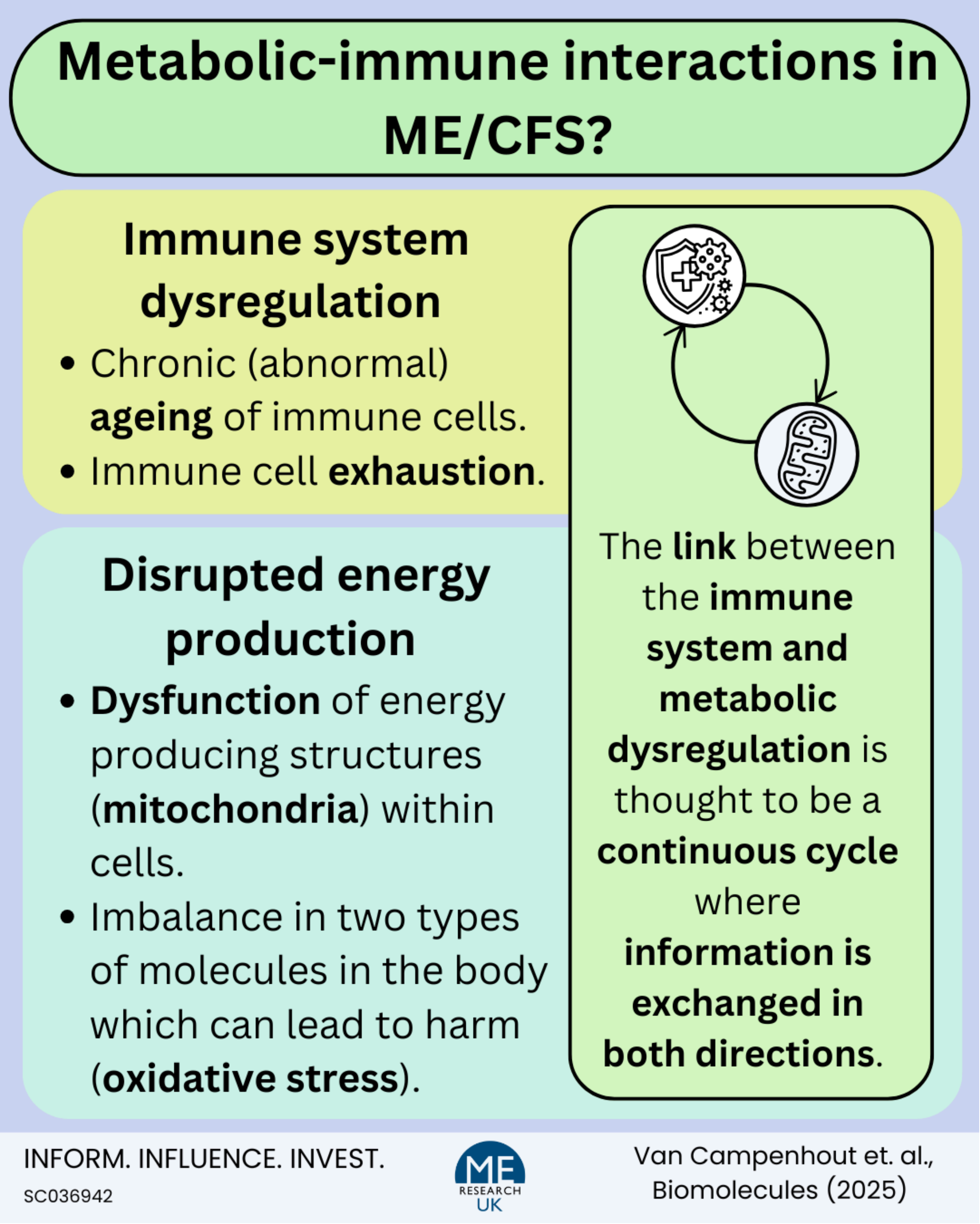
Diagnosis, management, action, resources
https://drive.google.com/file/d/1ZKXRzi4PFV6oXjF_giwhOrv4up44gD_a/view?usp=sharing

Community Experience: https://anzmes.org.nz/voices-of-me/

https://anzmes.org.nz/world-me-day-asks-you-to-learn-about-the-broken-energy-system-in-me-cfs-press-release/

Scheibenbogen C, Wirth KJ. Key Pathophysiological Role of Skeletal Muscle Disturbance in Post COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): Accumulated Evidence. J Cachexia Sarcopenia Muscle. 2025 Feb;16(1):e13669. doi: 10.1002/jcsm.13669. PMID: 39727052; PMCID: PMC11671797. https://pmc.ncbi.nlm.nih.gov/articles/PMC11671797/

Van Campenhout, J., Buntinx, Y., Xiong, H.- Y., Wyns, A., Polli, A., Nijs, J., Aerts, J. L., Laeremans, T., & Hendrix, J. (2025). Unravelling the Connection Between Energy Metabolism and Immune Senescence/Exhaustion in Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Biomolecules*, *15*(3), 357. https://doi.org/10.3390/biom15030357 Quick explanation can be found here: https://www.meresearch.org.uk/research/the-connection-between-energy-metabolism-and-immune-regulation-in-me-cfs/



# Metabolic-immune interactions in ME/CFS?

## Immune system dysregulation

- Chronic (abnormal) **ageing** of immune cells.
- Immune cell **exhaustion**.

## Disrupted energy production

- **Dysfunction** of energy producing structures (**mitochondria**) within cells.
- Imbalance in two types of molecules in the body which can lead to harm (**oxidative stress**).

The **link** between the **immune system and metabolic dysregulation** is thought to be a **continuous cycle** where **information is exchanged in both directions.**

INFORM. INFLUENCE. INVEST.

SC036942

ME RESEARCH UK

Van Campenhout et. al., Biomolecules (2025)

Toolkits for Health Practitioners and Patients

Know M.E. Series - CME
https://anzmes.org.nz/new-cme-accredited-series-for-health-professionals/

MyHealthHub - CME: Navigating the Complexities of ME/CFS and long COVID, Dr. Cathy Stephenson and Fiona Charlton
https://myhealthhub.co.nz/navigating-the-complexities-of-me-cfs-and-long-covid-2/

CDC - Assessment, What is ME/CFS and the Symptoms, Managing Symptoms, PEM,
https://www.cdc.gov/me-cfs/hcp/toolkit/index.html

Dr. Cathy Stephenson, and Rose Silvester: How to treat ME/CFS
https://static1.squarespace.com/static/5cae6a189b8fe8174438d696/t/61088ee6b71b5f76018ebed9/1627950841804/HowToTreat+MECFS+REPRINT.pdf

Breathing techniques for long COVID
https://drive.google.com/file/d/1fVJj98AYnMyi62_R5yrHIdl4cNjnB2xf/view?usp=sharing

Long COVID Physio Resources for Pacing, Exercise, PESE, Fatigue, Rehab, HR monitoring, dysautonomia, return to work, etc: https://longcovid.physio/resources

Pacing and Energy Management:
https://meassociation.org.uk/wp-content/uploads/PACING-Activity-and-Energy-Management-for-people-with-MECFS-and-Long-Covid-MAY-2023-1.pdf

Disability Rating Scale, ME Association UK:
https://meassociation.org.uk/2024/04/the-me-association-disability-rating-scale/

Patient Health Information Form for Hospital stays:
https://www.meaction.net/wp-content/uploads/2021/03/Health-Information-Form_Experience_blank324.pdf

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## Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a long-term, complex, multi-systemic and debilitating condition characterised by profound fatigue, post-exertional malaise (PEM), cognitive dysfunction, unrefreshing sleep, autonomic issues, and widespread pain. It often develops following viral infections, environmental triggers, or other stressors, leading to immune system dysfunction, mitochondrial impairment, and neurological disturbances. It affects the nervous, endocrine, autonomic, cardiovascular, and immune systems.[2] With over 100-200+ potential symptoms, the condition's impact can vary greatly, making diagnosis and management highly individualised. Roughly 25% of all ME/CFS cases are categorised as mild, 50% as moderate-severe and 25% as very severe.[3] [4]

ME/CFS significantly impacts patients' quality of life, with many experiencing severe disability and requiring ongoing symptom management through medications, pacing strategies, and supportive therapies. Despite its prevalence, ME/CFS remains underfunded and misunderstood, emphasising the need for greater awareness, research investment, and accessible treatment options.

### Post-Exertional Malaise (PEM)

Post-Exertional Malaise (PEM), also referred to as post-exertional symptom exacerbation (PESE) in the context of long COVID, is a debilitating response to normal, every-day activities in people with ME/CFS. For individuals with severe-very severe ME/CFS or LC, this can be triggered by sensory overload, such as exposure to light or even simple conversations.[5] [6] [7] Repeated episodes of PEM can exacerbate these already severe symptoms, and even minimal exertion can lead to significant setbacks for the patient's health and wellbeing.[8] [9] [10] PEM occurs due to immune system dysregulation, a

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[2] Grach, S.L., Seltzer, J., Chon, T. Y., & Ganesh, R. (2023). Diagnosis and management of myalgic encephalomyelitis/chronic fatigue syndrome. *Mayo Clinic Proceedings, 98*(10), 1544-1551. Link.

[3] Chang, C.J., Hung, L. Y., Kogelnik, A.M., Kaufman, D., Aiyar, R.S., Chu, A.M., Wilhelmy, J., Li, P., Tannenbaum, L., Xiao, W., & Davis, R.W. (2021). A Comprehensive Examination of Severely Ill ME/CFS Patients. *Healthcare*, *9*(10), 1290. DOI.

[4] As per footnote 1.

[5] Friedberg, F., Bateman, L., Bested, A.C., Davenport, T., Friedman, K.J., Gurwitt, A., Jason, L.A., Lapp, C.W., Stevens, S.R., Underhill, R.A., Vallings, R. (2014). Chronic fatigue syndrome myalgic encephalomyelitis: Primer for clinical practitioners 2014 edition. International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis IACFS/ME.

[6] Rowe, P. C., Underhill, R. A., Friedman, K. J., Gurwitt, A., Medow, M. S., Schwartz, M. S., Speight, N., Stewart, J. M., Vallings, R., & Rowe, K. S. (2017). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer. *Frontiers in pediatrics*, *5*, 121. DOI.

[7] Maeda, K. I., Islam, M. F., Conroy, K. E., & Jason, L. (2023). Health outcomes of sensory hypersensitivities in myalgic encephalomyelitis/chronic fatigue syndrome and multiple sclerosis. *Psychology, health & medicine*, *28*(10), 3052–3063. DOI.

[8] Friedberg, F., Bateman, L., Bested, A.C., Davenport, T., Friedman, K.J., Gurwitt, A., Jason, L.A., Lapp, C.W., Stevens, S.R., Underhill, R.A., Vallings, R. (2014). Chronic fatigue syndrome myalgic encephalomyelitis: Primer for clinical practitioners 2014 edition. International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis IACFS/ME.

[9] Rowe, P. C., Underhill, R. A., Friedman, K. J., Gurwitt, A., Medow, M. S., Schwartz, M. S., Speight, N., Stewart, J. M., Vallings, R., & Rowe, K. S. (2017). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer. *Frontiers in pediatrics*, *5*, 121. DOI.

[10] Maeda, K. I., Islam, M. F., Conroy, K. E., & Jason, L. (2023). Health outcomes of sensory hypersensitivities in myalgic encephalomyelitis/chronic fatigue syndrome and multiple sclerosis. *Psychology, health & medicine*, *28*(10), 3052–3063. DOI.

malfunctioning energy production system, impaired mitochondria with insufficient energy metabolism in muscles. [11] [12] [13]

## Long COVID

**Long COVID** is characterised by persistent, unexplained symptoms following infection with COVID-19 (SARS-CoV-2) lasting more than 12 weeks and not explained by an alternative diagnosis.[14] Both conditions share symptoms such as extreme fatigue, cognitive dysfunction, and post-exertional symptom exacerbation (PESE), with up to 50% of long COVID cases fitting the diagnostic criteria for ME/CFS.[15]

### COVID developing to ME/CFS

Up to 50% of long COVID cases fit the diagnostic criteria for ME/CFS.[16]
Using data from a long COVID research initiative run by the US National Institutes of Health (NIH), the incidence of ME/CFS is now considered 15 times higher than pre-pandemic levels, and that people with a history of COVID are almost eight times as likely to develop the chronic condition.[17]

## Dysautonomia

Dysautonomia is an umbrella term for disorders that affect the autonomic nervous system (ANS), which regulates involuntary bodily functions like heart rate, blood pressure, digestion, and temperature control.[18] When the ANS malfunctions, individuals may experience symptoms such as dizziness, fainting, abnormal heart rates, unstable blood pressure, and fatigue.[19]

## Common Types of Dysautonomia

1. **Orthostatic Intolerance (OI)** – A condition where the body struggles to regulate blood pressure and circulation upon standing, leading to dizziness, lightheadedness, and sometimes fainting.[20]

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[11] https://www.meresearch.org.uk/research/the-connection-between-energy-metabolism-and-immune-regulation-in-me-cfs/

[12] Bateman Horne Center: https://batemanhornecenter.org/wp-content/uploads/filebase/education/top_resources/ER-and-Urgent-Care-Considerations-for-MECFS-1.19.22-005.pdf

[13] https://ammes.org/tag/impaired-muscle-energy-metabolism/

[14] Abramoff, B., Joshi, S., Herman, E., Silver, J. (2024). BMJ Best Practice: long COVID. Straight to the point of care. Link.

[15] As per footnote 1 & 3.

[16] As per footnote 1 & 3.

[17] https://www.iflscience.com/people-whove-had-covid-could-be-almost-8-times-as-likely-to-develop-mecfs-77612?s=03&fbclid=IwY2xjawH9RcZleHRuA2FlbQIxMQABHdL_9nu-DJuPWUrAfSoT16bBhzDiWhnfxgX3E6eqYshXDYz2xHZi2aEJiQ_aem_oBwZAag9KRFaIljqeu5LGw

[18] https://ccisupport.org.nz/wp-content/uploads/2021/11/19-Dysautonomia-October-2021.pdf

[19] https://www.healthline.com/health/types-of-dysautonomia

[20] Same as 14

2. **Postural Orthostatic Tachycardia Syndrome (POTS)** – Characterized by an excessive increase in heart rate upon standing, often accompanied by fatigue, nausea, and chest pain. POTS primarily affects individuals assigned female at birth between ages 15–50.[21]
3. **Inappropriate Sinus Tachycardia (IST)** – A condition where the heart rate is persistently elevated without an apparent cause, leading to palpitations, dizziness, and anxiety.[22]
4. **Neurally Mediated Hypotension (NMH)** – A reflex-mediated condition where blood pressure and heart rate suddenly drop, causing fainting. Triggers include prolonged standing, emotional distress, or pain.[23]

Dysautonomia can occur on its own or alongside other conditions such as ME/CFS, Ehlers-Danlos Syndrome, Lupus, and Parkinson's Disease.[24] While some forms are rare, others—like POTS and OI—are relatively common and can significantly impact daily life.

## Mast Cell Activation Syndrome (MCAS)

Mast Cell Activation Syndrome (MCAS) is a chronic condition in which mast cells, a key part of the immune system, release excessive amounts of inflammatory mediators in response to triggers. These mediators can cause widespread symptoms affecting multiple organ systems, including skin reactions, gastrointestinal disturbances, cardiovascular instability, neurological symptoms, and respiratory issues.[25] MCAS is often associated with conditions such as ME/CFS, Fibromyalgia, Ehlers-Danlos Syndrome, and Long COVID.[26] Due to its complexity, effective management requires a combination of medications, mast cell stabilisers, antihistamines, and dietary modifications.[27]

## Fibromyalgia

Fibromyalgia is a neurological and musculoskeletal disorder characterized by widespread chronic pain, fatigue, cognitive difficulties ("fibro fog"), and sleep disturbances.[28] It is believed to involve dysregulation of pain processing in the central nervous system, leading to heightened sensitivity to pain and sensory stimuli. Fibromyalgia is often associated with ME/CFS and other chronic illnesses, and treatment typically includes medications for pain relief, physical therapy, sleep management, and alternative therapies such as low-dose naltrexone (LDN), CoQ10, and magnesium supplementation.[29] [30]

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[21] Same as 15

[22] https://www.eds.clinic/articles/types-dysautonomia-pots-oh-vasovagal-ist

[23] Same as 18

[24] Same as 14

[25] https://www.mastcellaction.org/mcas-bibliography

[26] https://link.springer.com/chapter/10.1007/978-3-030-54165-1_21

[27] https://bestpractice.bmj.com/info/

[28] https://www.mdpi.com/2227-9059/12/7/1543

[29] https://www.mdpi.com/2227-9059/13/1/165

[30] https://www.frontiersin.org/journals/medicine/articles/10.3389/fmed.2021.666914/full

## Hypermobility

Hypermobility describes joints that stretch farther than normal. A subgroup may experience unstable joints, soft stretchy skin, recurrent hernias, dislocations or subluxations. Hypermobility can cause musculoskeletal pain, dysautonomia, cognitive dysfunction, and fatigue.[31] [32] Currently limited research suggests that Hypermobile Ehlers-Danlos Syndrome (hEDS) is the more common disorder experienced by people with ME/CFS, versus classical EDS (a genetic connective tissue disorder).[33] [34] [35]

It is suggested that MCAS coupled with degranulation that occurs in both ME/CFS and long COVID results in hyperinflammation which damages connective tissue, worsening hypermobility.[36]

## About ANZMES

The Associated New Zealand ME Society is the National Advisory on ME/CFS. Established in 1980, ANZMES has been at the forefront of research, representation, and education for ME/CFS in Aotearoa/New Zealand. The organisation's expertise comes from its reputable medical team of advisors, which includes a world renowned expert and MNZM recipient, a fellow of the Royal NZ College of General Practitioners (RNZCGP) and a network of academic researchers, clinicians, and representatives from the ME community.

The organisation is a registered provider of continuing medical education with the Royal New Zealand College of General Practitioners (RNZCGP) and is dedicated to improving the lives of those affected by ME/CFS, long COVID, and associated conditions.

ANZMES is a founding member of the World ME Alliance, and a member of the Neurological Alliance NZ, NZ Carers Alliance, long COVID Alliance, Disabled Persons Assembly NZ (DPA), and Access Matters. ANZMES is affiliated with: Aotearoa COVID Action, and Ehlers-Danlos Syndromes Aotearoa New Zealand.

The organisation's **vision** is to live in a world where Myalgic Encephalomyelitis (ME)/ Chronic Fatigue Syndrome (CFS), long COVID (and associated conditions) are recognised, supported, diagnosed early, treated effectively, and cured.

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[31] Ganesh, R., & Munipalli, B. (2024). Long COVID and hypermobility spectrum disorders have shared pathophysiology. *Frontiers in neurology*, *15*, 1455498. https://doi.org/10.3389/fneur.2024.1455498

[32] https://solvecfs.org/new-study-using-solve-real-world-data-rwd-examines-joint-hypermobility-in-people-with-me-cfs/

[33] Mudie, K., Ramiller, A., Whittaker, S., & Phillips, L. E. (2024). Do people with ME/CFS and joint hypermobility represent a disease subgroup? An analysis using registry data. *Frontiers in neurology*, *15*, 1324879. https://doi.org/10.3389/fneur.2024.1324879

[34] Bragée, B., Michos, A., Drum, B., Fahlgren, M., Szulkin, R., & Bertilson, B. C. (2020). Signs of Intracranial Hypertension, Hypermobility, and Craniocervical Obstructions in Patients With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Frontiers in neurology*, *11*, 828. https://doi.org/10.3389/fneur.2020.00828

[35] https://www.ehlers-danlos.com/2017-eds-classification-non-experts/chronic-fatigue-ehlers-danlos-syndrome-hypermobile-type/

[36] https://ammes.org/tag/ehlers-danlos/

The vision focuses the organisation's **mission** as the trusted leader to fund and generate robust Aotearoa research, represent the global voice, and educate through best practice to improve outcomes.

The vision and mission drive the organisation's **purpose** as the leading National Advisory to produce and deliver quality, reputable, authoritative, evidence-based information, data, research, and education. We represent the needs of the community to ensure best outcomes are the primary focus of healthcare, legislation, and services that affect people living with ME, long COVID, fibromyalgia, and dysautonomia.

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