ME RESPITE
Making the everyday easier
Supporting those with ME/CFS to live their best life

ME ANZMES

Hospital Care Plan for Severe-Very Severe ME/CFS and long COVID (and associated conditions, e.g.: dysautonomia)

Resources

Introduction

A care plan for hospital patients with severe to very severe ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) or long COVID involves a multidisciplinary approach to address the complex and debilitating symptoms these patients experience.

ME/CFS is a complex and chronic medical condition,[1] often triggered by a virus (just as long COVID is triggered by SARS-CoV-2). In ME/CFS the most common viral trigger is Epstein Barr Virus.[2] ME/CFS can also be triggered by bacterial infections, adverse or allergic reactions to surgical anaesthesia, vaccinations, medications, chemical or toxin exposure, hormonal changes in pregnancy, childbirth, or peri(menopause), and environmental stressors such as trauma and abuse.[3] [4] ME/CFS affects multiple body systems including: immune, neurological, endocrine, autonomic, gastrointestinal, and cardiovascular.[5] [6] [7] This results in 100-200+ symptoms, and can be highly individualistic.

Those treating and interacting with patients with severe-very severe ME/CFS and long COVID must be aware these patients DO NOT want to be sick. This condition has highly impacted their quality of life.[8] Some are so incapacitated by the condition, that they are unable to care for themselves.[9] Patients in this category require 24/7 care.[10]

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[1] National Academy of Sciences. Beyond Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome. Redefining illness.(2015) Institute of Medicine of the National Academies. https://nap.nationalacademies.org/resource/19012/MECFS_ReportBrief.pdf
[2] Centers for Disease Control and Prevention. (2018). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Possible Causes. https://www.cdc.gov/me-cfs/about/possible-causes.html
[3] https://anzmes.org.nz/anzmes-release-resources-for-primary-care/
[4] https://www.cdc.gov/me-cfs/hcp/clinical-overview/index.html
[5] https://meassociation.org.uk/2024/03/america-me-cfs-is-unambiguously-biological-with-multiple-organ-systems-affected-dr-avindra-nath/
[6] https://www.health.harvard.edu/blog/is-chronic-fatigue-syndrome-all-in-your-brain-202402283020
[7] https://www.internationaljournalofcardiology.com/article/S0167-5273(11)01904-8/abstract
[8] https://forums.phoenixrising.me/threads/the-mild-moderate-severe-and-very-severe-levels-of-me-cfs.60746/
[9] https://www.frontiersin.org/journals/immunology/articles/10.3389/fimmu.2024.1369295/full
[10] https://pmc.ncbi.nlm.nih.gov/articles/PMC8544443/

Post-Exertional Malaise: The Defining Feature of ME/CFS and Long COVID

The cardinal characteristic of ME/CFS and long COVID is **Post-Exertional Malaise (PEM)**[11] [12] also known as Post-Exertional Symptom Exacerbation (PESE) or Post-Exertional NeuroImmune Exhaustion (PENE). PEM/PESE/PENE is a debilitating response to normal, every-day activities. For patients with severe-very severe ME/CFS or LC, this can be triggered by sensory overload, such as exposure to light or even simple conversations, and can occur immediately.[13] [14] For some PEM may be delayed 48-72 hours after the exertion. [15] Repeated or rolling 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.[16] PEM is thought to arise due to the many abnormalities occurring at cellular level, for example, low oxygen and blood volume, mitochondrial dysfunction, and muscle fatigability.[17] [18] [19] [20] [21]

Patients may have:[22] [23] [24]

- **Hypersensitivity** to - light, sound, touch, smell, movement, temperature changes, and chemicals/medications/food.
- **Extreme weakness** - severely reduced, limited movement
- **Severe and constant pain** - muscular, arthralgic, and neuropathic. Joint/muscle pain. Headaches/migraines. Touch can cause pain.
- **Reduced ability or inability** to chew and swallow foods and/or sensitivity to foods and lack of proper digestion.

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[11] PEM Timecourse for ME/CFS. Workwell Foundation. https://workwellfoundation.org/wp-content/uploads/2023/01/WW-PEM-Timecourse.pdf

[12] Davenport, T.E. et al. (2019). Chronotropic Intolerance: An Overlooked Determinant of Symptoms and Activity Limitation in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?Front. Pediatr., Sec. Pediatric Neurology, 7. https://doi.org/10.3389/fped.2019.00082 https://www.frontiersin.org/journals/pediatrics/articles/10.3389/fped.2019.00082/full

[13] 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.

[14] 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.

[15] 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.

[16] Solve M.E. (2021). Solve M.E. Patient and Caregiver Resource Guide: Post Exertional Malaise (PEM) and Rest. Link.

[17] Morris, G., & Maes, M. (2014). Mitochondrial dysfunctions in myalgic encephalomyelitis/chronic fatigue syndrome explained by activated immuno-inflammatory, oxidative and nitrosative stress pathways. *Metabolic brain disease*, *29*(1), 19–36. https://doi.org/10.1007/s11011-013-9435-x https://pubmed.ncbi.nlm.nih.gov/24557875/

[18] https://www.meresearch.org.uk/getting-their-due-the-muscles-in-me_cfs/

[19] https://meassociation.org.uk/wp-content/uploads/MEA-Summary-Review-The-Role-of-Mitochondria-in-MECFS-12.07.19.pdf

[20] https://www.healthrising.org/blog/2013/07/30/busted-exercise-study-finds-energy-production-system-is-broken-in-chronic-fatigue-syndrome/

[21] Rutherford, G., Manning, P., & Newton, J. L. (2016). Understanding Muscle Dysfunction in Chronic Fatigue Syndrome. *Journal of aging research*, *2016*, 2497348. https://doi.org/10.1155/2016/2497348

[22] https://www.nice.org.uk/guidance/ng206/chapter/recommendations#care-for-people-with-severe-or-very-severe-mecfs

[23] https://www.cdc.gov/me-cfs/hcp/clinical-care/me-cfs-clinical-care-for-severely-affected-patients.html

[24] https://www.mayoclinicproceedings.org/article/S0025-6196(23)00402-0/pdf

- **Cognitive impairment or difficulties** - inability to process information and communicate. Some patients become non-verbal due to inadequate energy[25] [26] to sustain communication and impairment to cognitive function. Brain fog, memory issues.
- **Sleep disturbances** - difficulty falling asleep and staying asleep, hypersomnia, altered sleep patterns, non-refreshing/restorative sleep. Sleep apnea. Delayed circadian rhythm.
- **Gastrointestinal disorders** such as irritable bowel syndrome, nausea, constipation, bloating, incontinence.
- **Neurological visual disturbances** - double vision, blurred vision, dizziness/vertigo, and other visual disorders.
- **Autonomic dysfunction** - Orthostatic Intolerance and dysautonomia such as Postural Orthostatic Tachycardia Syndrome (POTS), Neurally Mediated Hypotension (NMH), Inappropriate Sinus Tachycardia (IST) or other.
- **Palpitations, Chest Pain** - Irregular or rapid heartbeats, non-cardiac chest pain that can be sharp or dull. Costochondritis.
- **Shortness of Breath**: Difficulty breathing or a feeling of breathlessness.
- **Temperature Dysregulation**: Feeling excessively hot or cold, sweating, and chills.
- **Fatigue**: Persistent and unexplained fatigue that is not improved by rest.

Additional symptoms (not exhaustive list)[27] - the patient or advocate will be able to provide a comprehensive list. Be aware symptoms fluctuate.

- **Tinnitus**: Ringing or buzzing in the ears.
- **Earaches**: Pain or discomfort in the ears.
- **Sore Throat**: Persistent soreness or pain in the throat.
- **Loss of Taste and Smell**: Reduced or absent sense of taste and smell.
- **Skin Rashes**: Unexplained rashes or skin changes.
- **Hair Loss**: Unexplained hair thinning or loss.
- **Weight Changes**: Unexplained weight loss or gain.
- **Joint Pain**: Pain in the joints, often without visible swelling or redness.
- **Psychological Symptoms:** Patients may experience anxiety or depression as a result of being severely ill with an unrelenting and debilitating complex medical condition. They may experience stress about their situation, lack of quality of life, and experience. It is vital that their feelings are validated and Care/Treatment plans are adhered to minimise discomfort.

Comorbidities:

The most common comorbidities associated with ME/CFS is orthostatic intolerance or other forms of dysautonomia (POTS, NMH, IST, etc).[28] Other conditions that are worth further

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[25] Van Ness, M.J. et al. (2003). Subclassifying Chronic Fatigue Syndrome Through Exercise Testing" *Medicine and Science in Sports and Exercise*, *35*(6), 908 - 913. ISSN: 0195-9131. Available at: http://works.bepress.com/mark-vanness/178/

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

[27] Montoya, J. G., et al. (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

[28] https://www.medicalnewstoday.com/articles/fibromyalgia-chronic-fatigue-syndrome#diagnosis

investigation for potential diagnosis which have overlapping symptoms are: Fibromyalgia, and long COVID (if patient has been infected by SARS-CoV-2). Mast Cell Activation Syndrome (MCAS), Chemical/Environmental Sensitivities, Hypermobile Ehlers-Danlos Syndrome (hEDS) are also worth consideration.[29] [30] MCAS and histamine intolerance issues are potential drivers of the symptoms experienced in ME/CFS, and are treatable with medication and diet intervention.[31] Please read more here: https://batemanhornecenter.org/wp-content/uploads/filebase/education/top_resources/ER-and-Urgent-Care-Considerations-for-MECFS-1.19.22-005.pdf

Severe-Very Severe Presentation In Hospital Setting

Patients classified as severe-very severe may be hospitalised due to dehydration, undernutrition, malnutrition, or uncontrolled dysautonomia. Often they may need stabilisation, before returning home, or need long-term care if a safe and conducive environment is not available elsewhere. Most of these patients are dependent full-time on family carers, and provision for continued attendance by these carers in hospital may be required, with no available evidence that removal of carers is beneficial but much evidence to suggest it can induce major distress.[32] Patients with severe ME/CFS and feeding problems are faced with having an illness that nobody understands, some knowing that not everyone in their situation survives.[33]

Actions to take: When patients present at the hospital, the management priorities should be to: [34] [35]

1) Allow the patient to lie down, or sit with feet elevated. Provide a wheelchair for energy conservation when mobilising.
2) Stabilise the patient through rehydration (immediate intravenous administration of saline and electrolyte repletion). Treat as hypovolemic shock.[36]
3) Stabilise the patient through nutritional means (see section on NG tubes).
4) Stabilise dysautonomia.
5) Manage pain and sleep disturbances.

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[29] https://meassociation.org.uk/2021/10/iacfs-me-conference-dr-larry-afrin-on-an-overview-of-mast-cell-activation-disease/
[30] http://www.drvallings.co.nz/articles/mast-cell-activation
[31] http://www.drvallings.co.nz/articles/mast-cell-activation
[32] Edwards, J. (2024). Management of Nutritional Failure in People with Severe ME/CFS: Review of the Case for Supplementing NICE Guideline NG206. Qeios. https://doi.org/10.32388/T9SXEU
[33] Edwards, J. (2024). Management of Nutritional Failure in People with Severe ME/CFS: Review of the Case for Supplementing NICE Guideline NG206. Qeios. https://doi.org/10.32388/T9SXEU
[34] 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
[35] 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
[36] As above

6) Activity management (pacing, low stimuli, low interaction - be guided by the patient or their advocate about their capacity for movement). Graded Exercise Therapy is NOT recommended.[37]
7) Then other symptoms (as appropriate to improve stabilise PEM and minimise symptom exacerbation, and improve quality of life and wellbeing.

Creating an Environment for Validation and Empathy

The hospital environment is stressful for anyone and significantly more so for people with severe ME/CFS.[38] Always validate the patient's experience, and recognise that the patient may have considerable knowledge about their condition and what works for them. Show empathy and active listening, and consider the patient as a member of the team.[39] ME/CFS and long COVID are biomedical conditions not psychiatric. Admission to psychiatric wards is not advisable for these conditions (unless separate actual psychiatric disorders present). Admission to low stimulus neurological wards or general medicine wards is appropriate.

It is imperative that the **environment in the hospital setting does not induce PEM or exacerbate symptoms.**

Actions to take: Ideally patients with severe-very severe ME/CFS or long COVID require:[40] [41]

- Direct admission to a Ward (bypassing ED)
- A very quiet, darkened, single room environment.
- Stabilised temperature.
- Limited physical and mental activity.
- Medication/supplement plan that is kept to a minimum (very low doses are better tolerated with slow titration upwards.[42]
- Assessment of the risks and benefits of each medication or supplement.
- Assessment of potential risks of adverse drug interactions.
- Delayed sleep wake schedule that needs to be adhered to.

Patient Communication

Interaction needs to be at a level of their choice (this may be little or no social interaction). Some cannot communicate without support and may need to choose someone to be their advocate and

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[37] NICE. (2021). https://www.nice.org.uk/guidance/ng206/chapter/Recommendations#managing-mecfs

[38] Edwards, J. (2024). Management of Nutritional Failure in People with Severe ME/CFS: Review of the Case for Supplementing NICE Guideline NG206. Qeios. https://doi.org/10.32388/T9SXEU

[39] Kline, C.C. (2020). Professional Identity Formation: A Role for Patients as Mentors. *Academic Medicine, 95*(10). http://dx.doi.org/10.1097/ACM.0000000000003561

[40] https://www.nice.org.uk/guidance/ng206/chapter/recommendations#care-for-people-with-severe-or-very-severe-mecfs

[41] https://www.nice.org.uk/guidance/ng206/chapter/recommendations#care-for-people-with-severe-or-very-severe-mecfs

[42] 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

communicate for them. This can be a family member, friend, social worker, or other person of their choosing.

Actions to take:

- Schedule their day with minimum contact required from staff. Some may need lots of physical assistance while others need to be left alone to sleep and rest. More than one specialist a day can cause stress and deterioration.
- Incorporate alternative methods of contact such as email, phone typing, cue cards, and advocates.

Emergency Department Protocols

Patients presenting at emergency departments need to be assessed immediately. Due to the nature of ME/CFS, where even minimal exertion can trigger a significant worsening of symptoms, an emergency room visit only occurs for true emergencies that cannot be managed in the patients normal residence.

Reasons for presenting may include:

- A life-threatening complication
- Severe post-exertional malaise (PEM) leading to inability to perform basic functions
- Signs of infection or sepsis
- Severe pain that cannot be managed with standard pain medication
- Significant changes in mental status
- Severe orthostatic intolerance causing dizziness or fainting
- A significant worsening of symptoms that cannot be managed at home such as but not limited to:
    (a) a sudden decline in consciousness
    (b) severe respiratory distress
    (c) uncontrolled pain
    (d) inability to eat or drink due to fatigue or other complications

Actions to take:

- The patient needs to be moved to a quiet area with low lighting, away from the smell of chemicals and allowed to lie down. Overwhelming stimuli (lights, smells, noises, movement) in the ED department, can significantly worsen a severely ill patient who is already experiencing sensory overload.
- Patients are likely to benefit from timely administration of IV saline.[43]

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https://batemanhornecenter.org/wp-content/uploads/filebase/education/top_resources/ER-and-Urgent-Care-Considerations-for-MECFS-1.19.22-005.pdf

- Blood tests should be conducted promptly to assess any stressors which may be worsening the condition.
- Emergency department triage protocols need to include special considerations for people in the severe-very severe categories, in the event of an emergency. This includes:
    1. Ask patient if they have an emergency care plan.
    2. Check for allergies and sensitivities.
    3. Check if there are medications they need to get on time to prevent further complications
    4. Use aids such as bedpans, wheelchairs or trolleys to conserve energy.
    5. Prioritise access to a low stimulus environment with a bed.
    6. Health professionals to be aware of the diagnosis and treat the patient accordingly .
    7. Health Professionals to access evidence -based ME/CFS information or contact an ME/CFS specialist if possible .
    8. Avoid unnecessary procedures or tests that could exacerbate symptoms.

- It is important that those involved with ED are ME/CFS-aware staff (including paramedics, reception, nurses, and other relevant staff) to ensure immediate priority to a bed in an individual room in ED with low stimuli, priority to ward admission, and placement of IV fluids. The head nurse must be notified if a patient with severe ME/CFS is waiting in the waiting room or coming in via ambulance to ensure immediate processing to a safe space.

Malabsorption and Malnutrition in Severe Patients

People with severe-very severe ME/CFS are at risk of malnutrition or unintentional weight loss.[44] Malabsorption and malnutrition due to gastrointestinal and immunologic disease are common in severe-presenting patients.[45] Anorexia nervosa is often incorrectly diagnosed in these patients, especially when presenting with malabsorption.[46] Parenteral nutrition may be required; in such cases, refeeding syndrome should be considered.[47] Patients with severe ME/CFS may also require gastric tube feeding and intravenous administrations to avoid critical electrolyte imbalances, requiring total care in compatible homes or in nursing facilities.[48] Many with severe ME/CFS are too weak to eat, or eat sufficient amounts of required daily calorie count, or are unable to chew and swallow. There can often be a significant and unnecessary delay in implementing feeding, due to a failure in recognising that these problems are a direct

[44] https://www.nice.org.uk/guidance/ng206/chapter/recommendations#care-for-people-with-severe-or-very-severe-mecfs
[45] Grach, S.L. et al. (2023). Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Mayo Clinic Proceedings, Volume 98, Issue 10, 1544 - 1551. https://www.mayoclinicproceedings.org/article/S0025-6196(23)00402-0/fulltext
[46] As per 20.
[47] As per 19.
[48] Crosby, L.D., *et al.* (2021). Off-label use of Aripiprazole shows promise as a treatment for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): a retrospective study of 101 patients treated with a low dose of Aripiprazole. *J Transl Med* **19**, 50. https://doi.org/10.1186/s12967-021-02721-9

consequence of very severe ME/CFS.[49] **There is no reliable evidence to justify refusal of nutritional support on the grounds of speculated psychological theories.**[50] [51]

Actions to take:

- It's crucial to work with a knowledgeable healthcare team who understands the complexities of severe ME/CFS. Connecting with a healthcare professional who does domiciliary visits can be particularly beneficial, as they can provide personalised care and reduce the need for hospital admissions.
- Nasogastric (NG) tube feeding may be used to manage severe gastrointestinal problems and increase overall food and water intake. This method ensures patients maintain adequate nutrition and hydration, which is particularly crucial for individuals with severe ME/CFS to help prevent further deterioration and lessen both physical and emotional stress.
- Use the **NICE Clinical Guideline on ME/CFS** to help assess if a patient meets the criteria for nutritional support. It lists the nutritional problems which may be experienced by a person with severe ME/CFS. If oral intake is insufficient, consider medical nutritional support like gastric tube feeding or intravenous (IV) fluids early to prevent critical electrolyte imbalances. The NICE Guidelines suggests *'Nutrition support for adults: oral nutrition support, enteral feeding and parenteral nutrition'* for any patients who are nutritionally compromised.

The Potential Benefits of NG Tube Feeding

Malnutrition can lead to decreased immune system function, reduced muscle strength, delayed wound healing, increased risk of falls, and further exacerbation of energy levels and cognitive problems.[52]

Benefits of NG tube feeding include: [53] [54]

- **Ensures Adequate Nutrition**: NG tube feeding provides a direct way to deliver essential nutrients, fluids, and medications, helping to maintain a healthy weight and prevent malnutrition.
- **Reduces Swallowing Difficulties**: For those with severe swallowing issues, NG tube feeding bypasses the need to swallow, making it easier to receive necessary nutrition.

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[49] Baxter, H., Speight, N., & Weir, W. (2021). Life-Threatening Malnutrition in Very Severe ME/CFS. *Healthcare (Basel, Switzerland)*, *9*(4), 459. https://doi.org/10.3390/healthcare9040459

[50] As per 36.

[51] Edwards, J. (2024). Management of Nutritional Failure in People with Severe ME/CFS: Review of the Case for Supplementing NICE Guideline NG206. Qeios. https://doi.org/10.32388/T9SXEU

[52] Dr. Charles Shepherd and Dr. Abhijit Chaudhuri (2020) Nutritional assessment in ME/CFS: NUTRITIONAL-ASSESSMENT-AND-MALNUTRITION-AUGUST-2020.pdf

[53] https://www.swbh.nhs.uk/wp-content/uploads/2012/07/Nasogastric-tube-feeding-ML4763.pdf

[54] https://www.verywellhealth.com/nasogastric-ng-tube-1943087

- **Minimizes Physical Strain**: It reduces the physical strain associated with eating and drinking, which can be particularly beneficial for those with severe fatigue and limited physical endurance.
- **Prevents Pressure Sores**: By ensuring proper nutrition and hydration, NG tube feeding can help maintain skin integrity and reduce the risk of developing pressure sores due to prolonged immobility.
- **Improves Quality of Life**: Proper nutrition can help improve overall well-being, energy levels, and cognitive function, contributing to a better quality of life.

Who can help with Tube Feeding? [55] [56]

Provision needs to be made for tube replacement every 4-6 weeks to prevent complications like infections or dislodgement. This can be done in the community or by trained home carers to prevent unnecessary trips to the hospital.[57] [58] [59] [60]

1. **Primary Care Physician**: They can oversee the overall care plan and coordinate with other specialists.
2. **Gastroenterologist**: Specializes in the digestive system and can assist with the placement and management of the NG tube.
3. **Dietitian or Nutritionist**: Can create a tailored nutrition plan and monitor the patient's nutritional status.
4. **Nurse or Home Healthcare Nurse**: Can provide hands-on assistance with feeding, tube care, and monitoring for complications.
5. **Occupational Therapist**: Can help with positioning and mobility to prevent pressure sores and improve quality of life.
6. **Social Worker**: Can offer support with accessing resources, coordinating care, and providing emotional support to the patient and family.
7. **Home carer or family member***can administer NG tube feeding with proper training and guidance from healthcare professionals. It's important for them to receive thorough instructions on how to prepare and administer the feed, as well as how to care for the tube and monitor for any complications.

**Healthcare professionals, such as nurses or dietitians, can provide this training and support to ensure that the carer or family member feels confident and competent in managing the feeding process. Regular follow-up with healthcare providers is also essential to address any concerns and ensure the patient's nutritional needs are being met effectively. Hospital admission is only justified in the context of feeding problems if there are specific procedures that require it. Domiciliary provision must be preferable unless there are safety concerns.*[61]

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[55] https://wames.org.uk/cms-english/life-threatening-malnutrition-in-very-severe-me-cfs/
[56] https://ninkatec.com/enteral-nutrition-and-care-of-ng-tube-in-home-care-patients/
[57] https://www.hpp.moh.gov.sg/docs/librariesprovider4/default-document-library/digital_ngt-guidelines.pdf?sfvrsn=77b875bb_0
[58] https://www.rqia.org.uk/RQIA/files/c0/c0e32fdb-20da-4c3a-8b16-fef63c93bb5f.pdf
[59] https://www.healthinfo.org.nz/patientinfo/525334.pdf
[60] https://media.starship.org.nz/faqs-for-tube-feeding-families/FAQs_for_tube_feeding_families.pdf
[61] Edwards, J. (2024). Management of Nutritional Failure in People with Severe ME/CFS: Review of the Case for Supplementing NICE Guideline NG206. Qeios. https://doi.org/10.32388/T9SXEU

Placement of NG Tube:

Proper placement of NG tubes can be found in the footnote.[62] When an X-ray is not available or suitable (as many patients cannot tolerate being wheeled around the hospital), there are alternative methods to confirm the proper placement of a nasogastric (NG) tube:[63] [64] See also footnotes 49-52.

1. **pH Testing**: Aspirate a small amount of stomach contents through the NG tube and test the pH. Gastric fluid typically has a pH of 1.5-3.5, while respiratory secretions have a higher pH. A pH of less than 5.5 usually indicates correct placement.
2. **Visual Inspection**: Observe the aspirate for the presence of gastric contents, such as food particles or bile, which would indicate correct placement in the stomach.
3. **Auscultation**: While not recommended as a sole method, you can insufflate a small amount of air into the tube and listen over the stomach area for a "whooshing" sound. However, this method is less reliable and should not be used alone.
4. **Measurement**: Ensure the tube length is appropriate based on the patient's size and the distance from the nostril to the stomach.
5. **Ultrasound**: If available, point-of-care portable ultrasound can be used to visualise the tube in the stomach.

The Importance of 'Repositioning'

While severe ME/CFS leads to muscle atrophy, it's crucial to understand this is distinct from simple deconditioning caused solely by inactivity. Research shows muscle changes in ME/CFS and Long COVID differ from those induced by bed rest in healthy individuals, pointing to unique pathophysiological mechanisms like impaired oxygen delivery and blood vessel dysfunction, not just disuse. Unlike deconditioning, ME/CFS involves cardinal symptoms like Post-Exertional Malaise (PEM), widespread pain, and sensory sensitivities.[65] [66] [67] Overexertion can actually harm ME/CFS patients, particularly those severely impacted, pushing them beyond their extremely limited energy reserves.[68]

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[62] https://radiopaedia.org/articles/nasogastric-tube-positioning

[63] Boeykens, K. et al. (2023). Nasogastric tube insertion length measurement and tip verification in adults: a narrative review. *Critical Care*, 27(317). https://ccforum.biomedcentral.com/articles/10.1186/s13054-023-04611-6#citeas

[64] https://www.swbh.nhs.uk/wp-content/uploads/2012/07/Nasogastric-tube-feeding-ML4763.pdf

[65] 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/

[66] Van Campenhout, J., Buntinx, Y., Xiong, H.- Y., Wyns, A., Po li, A., Nijs, J., Aerts, J. L., Laeremans, T., & Hendrix, J. (2025). Unrave ling 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

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The profound weakness, almost constant pain, and severe limitations to physical and mental activity can make it difficult or impossible for patients to reposition their bodies independently, which increases the risk of developing pressure sores, also known as pressure ulcers or bed sores,[69] common in individuals with limited mobility, such as those who are bedbound or have long-term conditions.[70] Help with regular repositioning may be needed to prevent pressure sores in patients who are unable to turn over in bed.

Actions to take:

- Movement can help maintain range of motion, prevent contractures, and decrease stiffness.[71] It needs to be done carefully and gently, recognising the need to stay inside the patient's energy envelope. Passive range-of-motion exercises and gentle stretching can also help, if touch can be tolerated.[72] [73]
- Physiotherapists will benefit from reading physiotherapy guidelines for those with ME/CFS.[74]

[69] https://www.cdc.gov/me-cfs/hcp/clinical-care/me-cfs-clinical-care-for-severely-affected-patients.html
[70] https://www.britishjournalofnursing.com/content/pi-prevention/at-a-glance-pressure-injuries
[71] As per 38.
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