Learn about ME webinar

Thursday 6th March 2025

Dr Nina Muirhead, Dr Robin Kerr and Linda Campbell

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Content

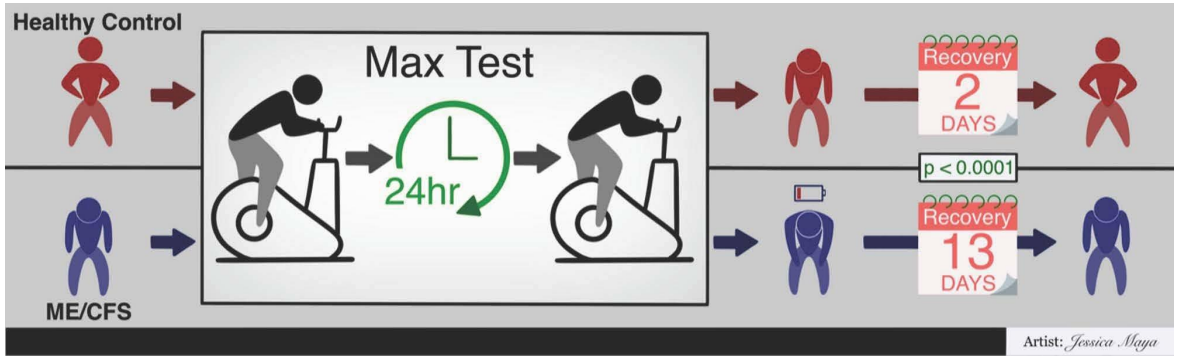
- What is ME?
- Symptoms
- Diagnosis and management
  - How patients present to GPs
  - Asking questions about post-exertional malaise
- Quality of life
- Pathophysiology
- Symptom management
  - Pharmacological
  - Non-pharmacological
- Information, support and resources
  - Learn about ME project
  - For ME/CFS
  - For employment, housing, finance and welfare benefits advice

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What is Myalgic Encephalomyelitis?

- Neurological disease
- Characterised by symptom exacerbation following exertion
- Range of severity can fluctuate
- Other main diagnostic criteria: Unrefreshing sleep, severe fatigue or exhaustion limiting function, cognitive impairment and post exertional malaise (PEM)

Recovery from Exercise in Persons with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)



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Symptoms of ME/CFS

- orthostatic intolerance and autonomic dysfunction
- dizziness, palpitations
- fainting
- nausea
- worsening symptoms on standing or sitting upright from a reclining position
- temperature hypersensitivity
- profuse sweating
- chills
- hot flushes
- feeling very cold
- neuromuscular symptoms, twitching and myoclonic jerks
- flu-like symptoms
- sore throats, muscle aches
- intolerance to alcohol, or to certain foods, and chemicals
- heightened sensory sensitivities, including to light, noise, touch and smell
- pain, including pain on touch, myalgia
- headaches, eye pain, abdominal pain
- joint pain without acute redness, swelling or effusion

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Diagnosis and management

- Early diagnosis based on history
- 3 months of symptoms

- Fatigue
- Unrefreshing sleep
- Post exertional malaise
- Cognitive impairment

- Management is supportive, mobility aids and care as needed

- Pacing and rest, managing energy

- Regular review for other co-morbidities

- Medication to treat problems with sleep, pain, orthostatic intolerance

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Patient interviews: how did you present to your GP?

- “I was too ill to continue.”
- “I got the flu, went back to work, then started getting pins and needles and other symptoms.”
- “I thought I was slipping away I felt so ill.”
- “Things can sometimes hit me for days or weeks at a time.”
- “My neck would get really stiff, tremendous headache and a fever.”
- “The next time it happened I thought: Oh well, I didn’t die last time.”
- “I kept going to the GP and saying: I’m not well… I’m not well.”
- “I had pneumonia and I wasn’t getting better… and I wasn’t getting better…”

“I was working… I was starting to feel really ill but I was pushing through. And then one day I decided to jog back home from school, the next day I totally collapsed and felt like I was dying.”

“[You] feel ashamed that you can’t live your life the way you want to.”

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What to ask the patient about post-exertional malaise

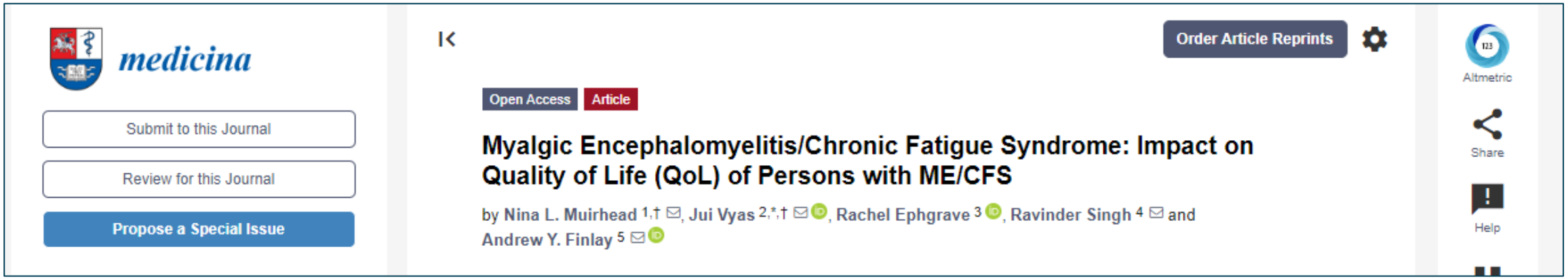
- What fraction of your pre-illness capacity (mental/physical) are you functioning at? What could you do before the disease versus now?
- How many hours a day/week can you function productively/do useful things?
- How many hours/day are your feet on the floor?
- What happens when you engage in normal/trivial (previously tolerated) physical or mental exertion?
- Do you avoid or change certain activities because of what happens after you do them?
- What can/can't you manage on a good/bad day?
- How long does it take to experience symptoms and to recover (be asymptomatic or back to baseline) after physical or mental effort?

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Quality of life research

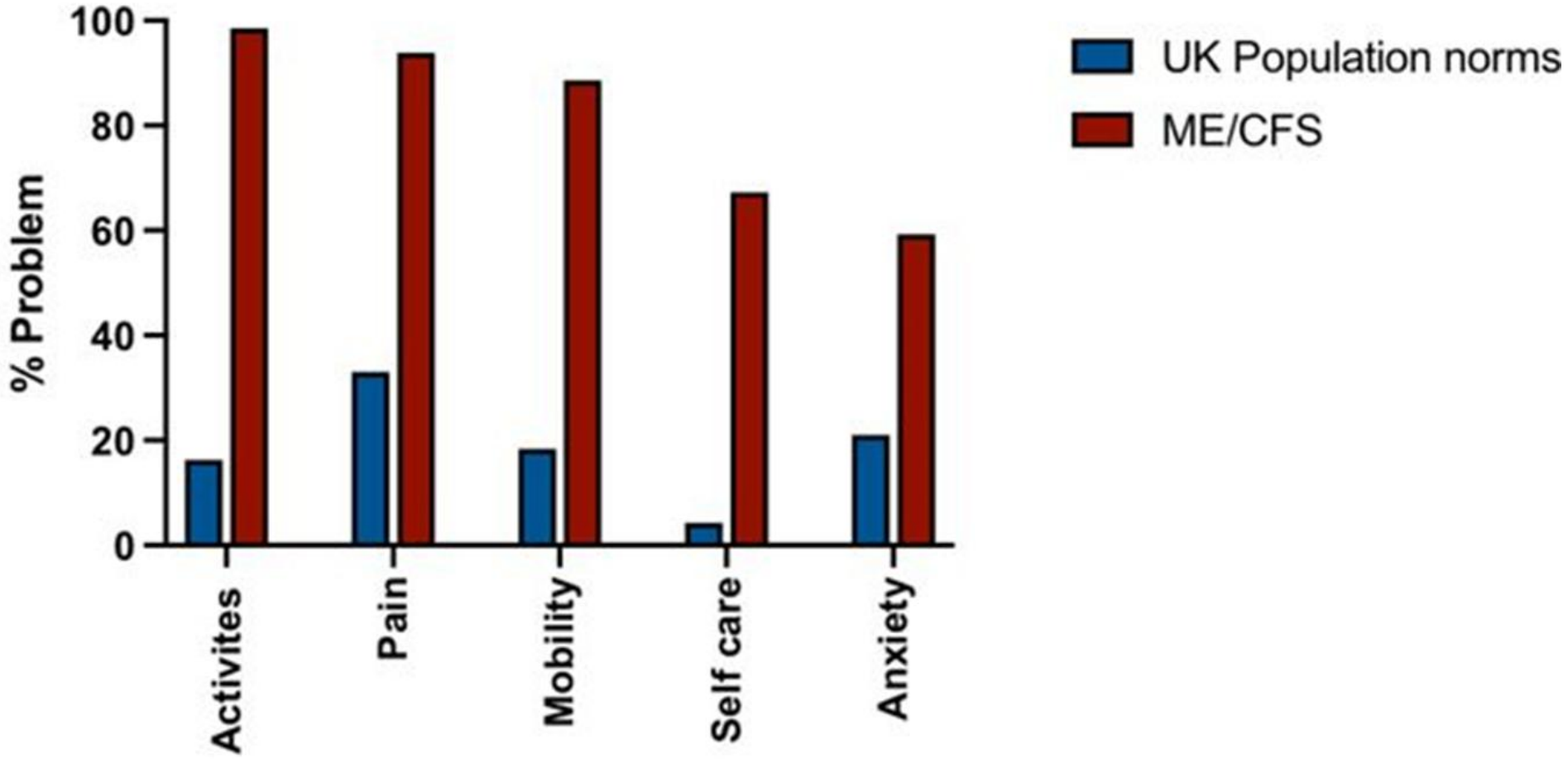




Medicina | Free Full-Text | Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Impact on Quality of Life (QoL) of Persons with ME/CFS (mdpi.com)

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Quality of life research



Jui Vyas et al. BMJ Open 2022;12:e058128

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Quality of life research



Jui Vyas et al. BMJ Open 2022;12:e058128

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Pathophysiology?



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ME patients have reduced exercise capacity on day 2; controls' capacity increases

Journal of *Clinical Medicine*

MDPI

Review

The Prospects of the Two-Day Cardiopulmonary Exercise Test (CPET) in ME/CFS Patients: A Meta-Analysis

Eun-Jin Lim [1], Eun-Bum Kang [2], Eun-Su Jang [1] and Chang-Gue Son [1,*]

[1] Department of Korean Medicine, Institute of Bioscience and Integrative Medicine, Daejeon University, 62 Daehak-ro, Dong-gu, Daejeon 34520, Korea; eunjinlimsydney@gmail.com (E.-J.L.); jang.ensu2@gmail.com (E.-S.J.)

[2] Department of Health and Exercise Management, Daejeon University, 62 Daehak-ro, Dong-gu, Daejeon 34520, Korea; kbume23@naver.com

* Correspondence: ckson@dju.ac.kr; Tel.: +82-42-229-6484; Fax: +82-42-257-6398

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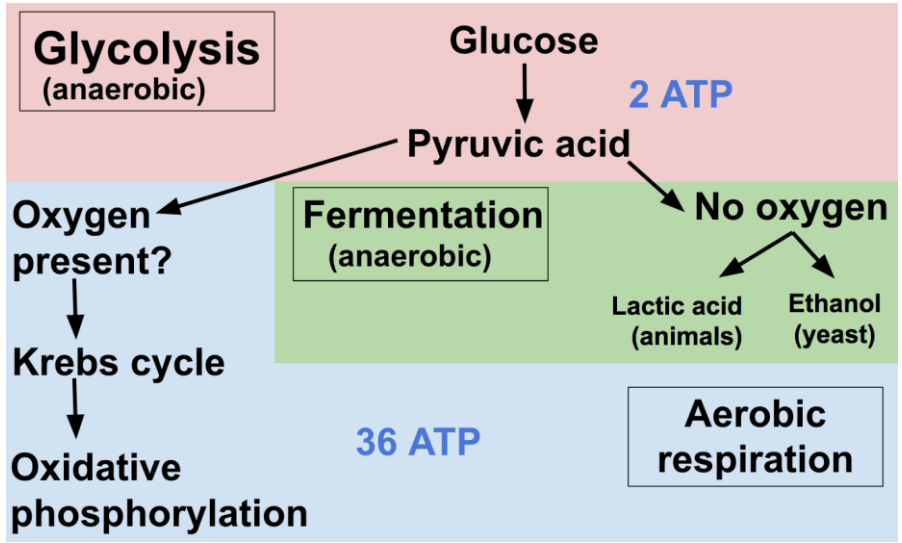
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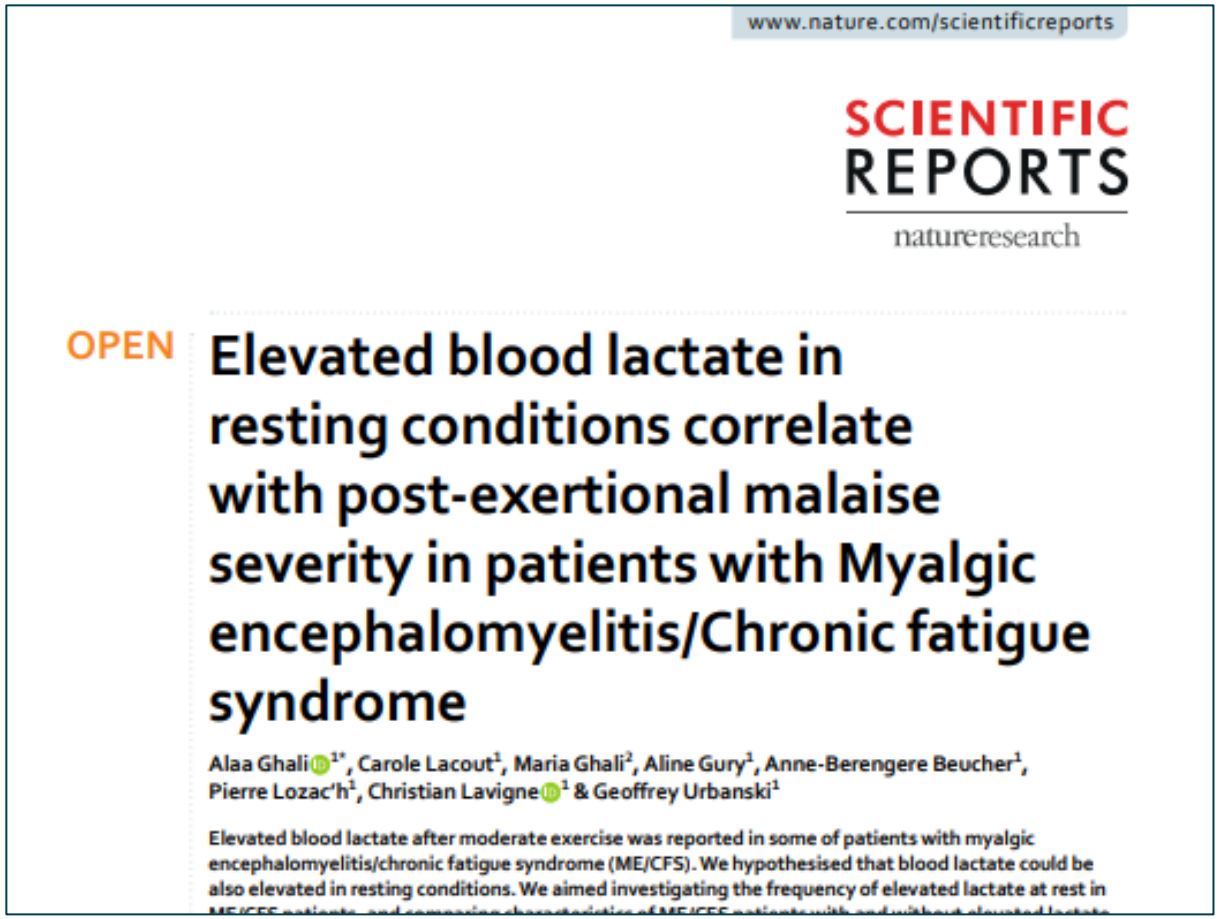
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ME patients with elevated blood lactate at rest are at higher risk for more severe PEM





www.nature.com/scientificreports

SCIENTIFIC REPORTS

nature research

OPEN

Elevated blood lactate in resting conditions correlate with post-exertional malaise severity in patients with Myalgic encephalomyelitis/Chronic fatigue syndrome

Alaa Ghali[1*], Carole Lacout[1], Maria Ghali[2], Aline Gury[1], Anne-Berengere Beucher[1], Pierre Lozac'h[1], Christian Lavigne[1] & Geoffrey Urbanski[1]

Elevated blood lactate after moderate exercise was reported in some of patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). We hypothesised that blood lactate could be also elevated in resting conditions. We aimed investigating the frequency of elevated lactate at rest in

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The reduction in VO_2 max in Long COVID patients is from a peripheral rather than a central cardiac limit due to impaired capillary oxygen extraction and not deconditioning

[Chest Infections Original Research]

CHEST

Persistent Exertional Intolerance After COVID-19

Insights From Invasive Cardiopulmonary Exercise Testing

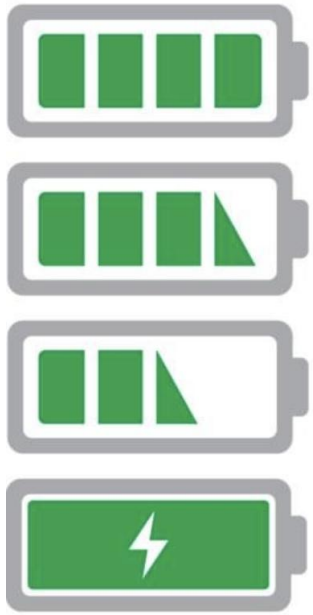
Inderjit Singh, MD; Phillip Joseph, MD; Paul M. Heerdt, MD, PhD; Marjorie Cullinan, RT; Denyse D. Lutchmansingh, MBBS; Mridu Gulati, MD, MPH; Jennifer D. Possick, MD; David M. Systrom, MD; and Aaron B. Waxman, MD, PhD

AND
de Boer E et al. Am J Respir Crit Care Med 2022; 205: 126–9. 131.
Heerdt PM et al. Br J Anaesth 2022; 128: e246–9. 132.
Singh et al. Pulm Circ 2023; 13: e12220. 134.
Schwendinger et al. Sports Med 2023; 53: 51–74.

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These studies offer a potential explanation for the post external symptom exacerbation (PESE) or post exertional malaise (PEM) suffered by ME/CFS and long COVID patients

Healthy



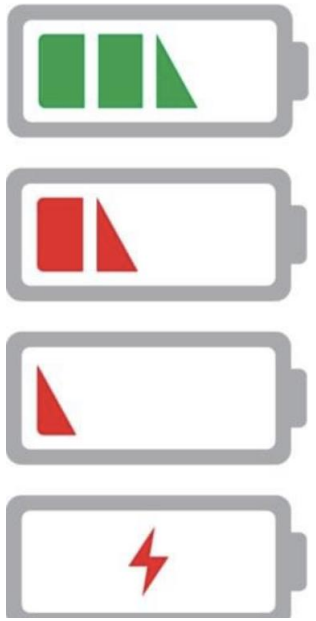
In the morning your battery is full.

In the afternoon energy is used for mental activities, but you still have plenty of energy left.

In the evening a substantial part of your energy is used.

At night your battery is recharged again.

ME/CFS



In the morning your battery is partly filled. This is your maximum attainable level.

In the afternoon after a few mental activities, your battery is almost empty.

In the evening, or sometimes even before, your battery is empty.

At night your battery tries to recharge, but it's not strong and cannot be fully recharged.

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What could be a peripheral cause of VO_2 max reduction?

ESC HEART FAILURE
ESC Heart Failure 2020; **7**: 1064–1071
Published online 10 March 2020 in Wiley Online Library (wileyonlinelibrary.com) **DOI:** 10.1002/ehf2.12633

ORIGINAL RESEARCH ARTICLE

Peripheral endothelial dysfunction in myalgic encephalomyelitis/chronic fatigue syndrome

Nadja Scherbakov[1,2,3,4*†], Marvin Szklarski[5†], Jelka Hartwig[5], Franziska Sotzny[5], Sebastian Lorenz[5], Antje Meyer[1,3,4], Patricia Grabowski[5], Wolfram Doehner[1,2,3,4] and Carmen Scheibenbogen[1,5]

[1]Berlin-Brandenburg Center for Regenerative Therapies (BCRT), Augustenburger Platz 1, 13353, Berlin, Germany; [2]DZHK (German Centre for Cardiovascular Research), partner site Berlin, Berlin, Germany; [3]Department of Cardiology, Charité - Universitätsmedizin Berlin, Berlin, Germany; [4]Center for Stroke Research Berlin (CSB), Charité - Universitätsmedizin Berlin, Berlin, Germany; [5]Institute of Medical Immunology, Campus Virchow, Charité - Universitätsmedizin Berlin, Berlin, Germany

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What could be a peripheral cause of VO_2 max reduction?

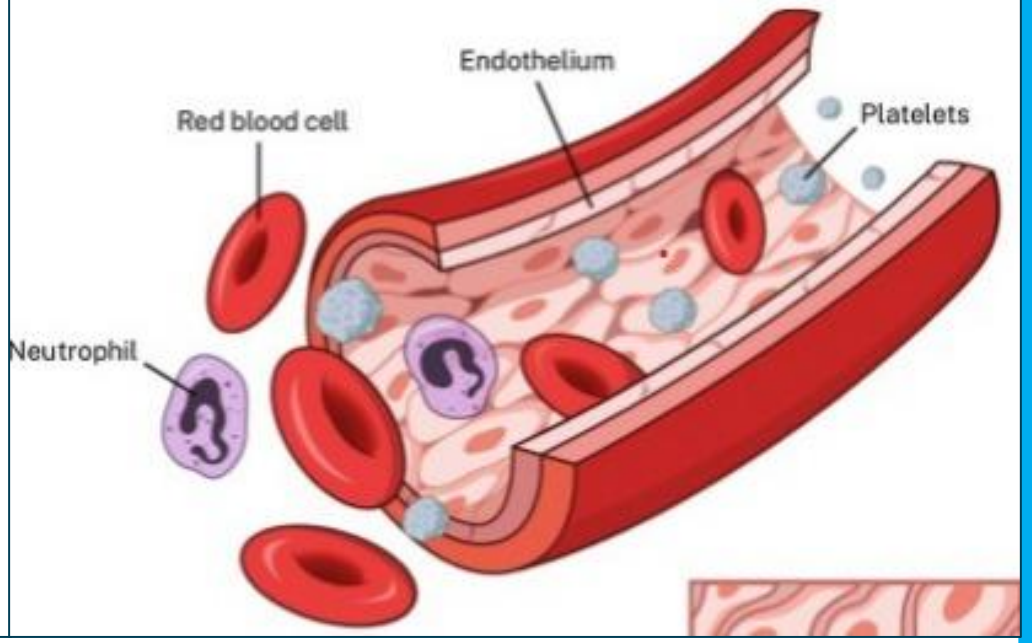
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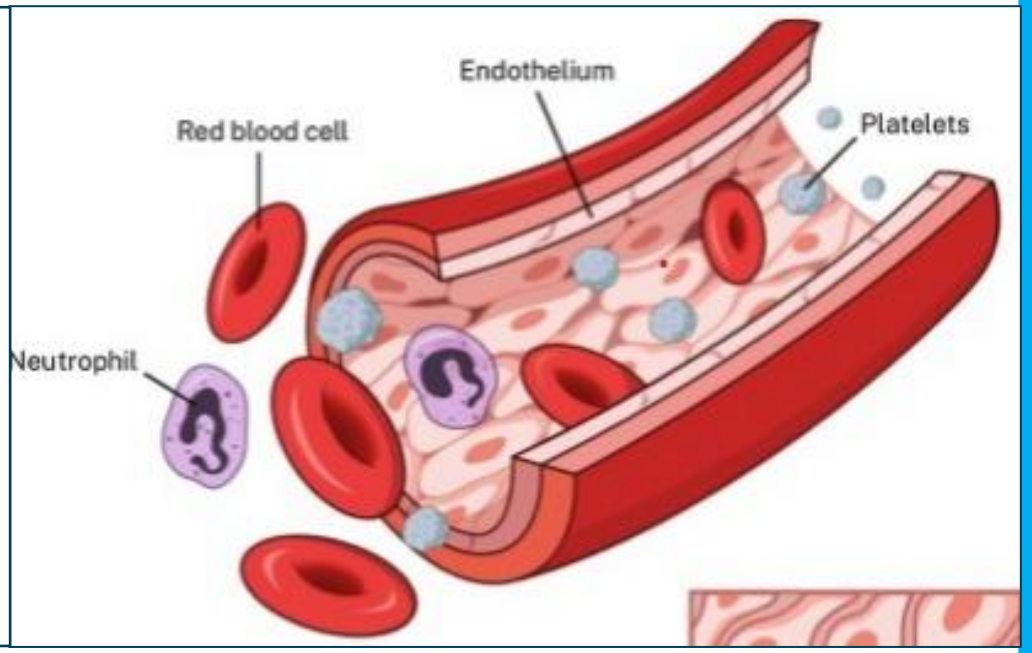
https://doi.org/10.1016/j.transci.2022.103368.

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What could be a peripheral cause of VO_2 max reduction?

Markers of endothelial damage in ME and Long COVID correlate with higher symptom burden and reduced exercise tolerance

Captur G, Moon JC, Topriceanu C-C, et al. eBioMedicine 2022; 85: 104293.
Fogarty H, Townsend L, Morrin H, et al. J Thromb Haemost 2021; 19: 2546–53.
López Castro J. Acta Médica Port 2020; 33: 859–859.
Prasannan N, Heightman M, Hillman T, et al. Blood Adv 2022; 6: 4041–8.
Ambrosino P, Calcaterra I, Molino A, et al. Biomedicines 2021; 9: 957.
Barrett TJ, Cornwell M, Myndzar K, et al. Sci Adv 2021; 7: eabh2434.
Charfeddine S, Ibn Hadj Amor H, Jdidi J, et al. Front Cardiovasc Med 2021; 8: 745758. Chioh FW, Fong S-W, Young BE, et al. eLife 2021; 10: e64909.
Haffke M, Freitag H, Rudolf G, et al. J Transl Med 2022; 20: 138.
Sollini M, Ciccarelli M, Cecconi M, et al. Eur J Nucl Med Mol Imaging 2021; 48: 1460–6.
Turner S, Naidoo CA, Usher TJ, et al. Infectious Diseases (except HIV/AIDS), 2022.



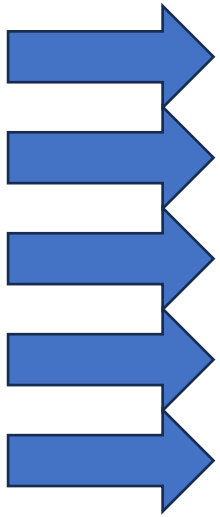
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What does the endothelium do?

Role

- Barrier/membrane
- Vascular tone
- Clotting control
- Host defence
- Inflammation



Potential consequence

- Reduced exercise capacity
- Autonomic dysfunction
- Coagulopathy, microclots
- Mast cell activation
- Organ damage

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Symptom management: pharmacological

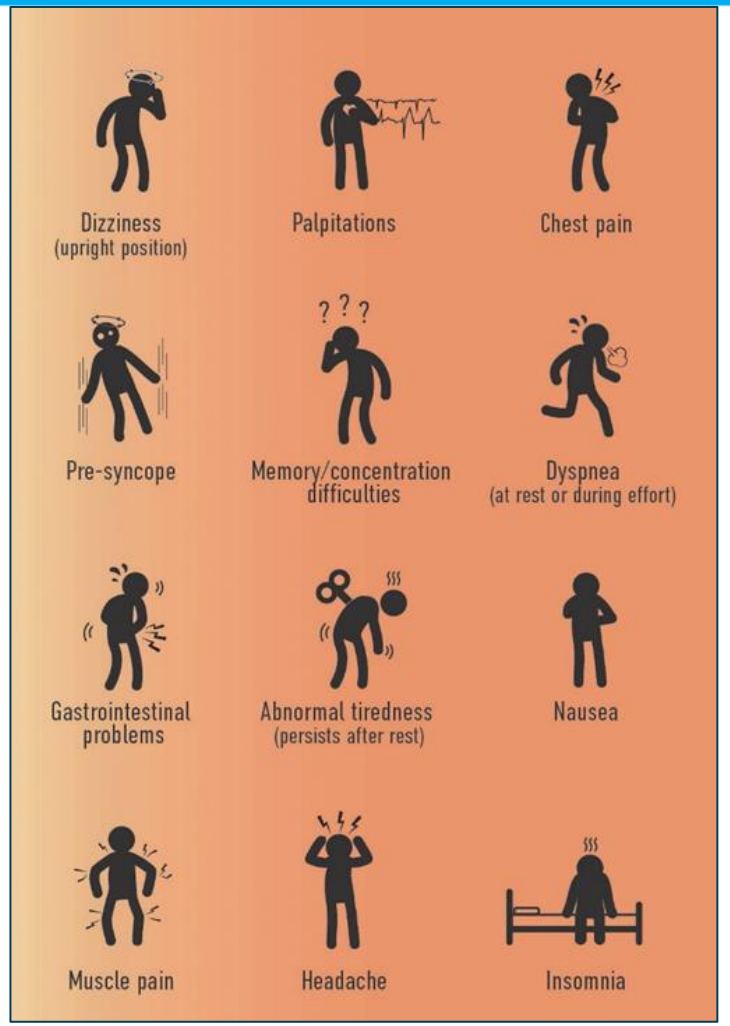


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https://doi.org/10.1111/joim.13566

Autonomic dysfunction

- Look for it
- Test for it with NASA lean test
- NASA-LeanTest-Instructions-April-2018.pdf (batemanhornecenter.org)





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Autonomic dysfunction

- Fluids
- Salt
- Recumbent exercises
- www.potsuk.org

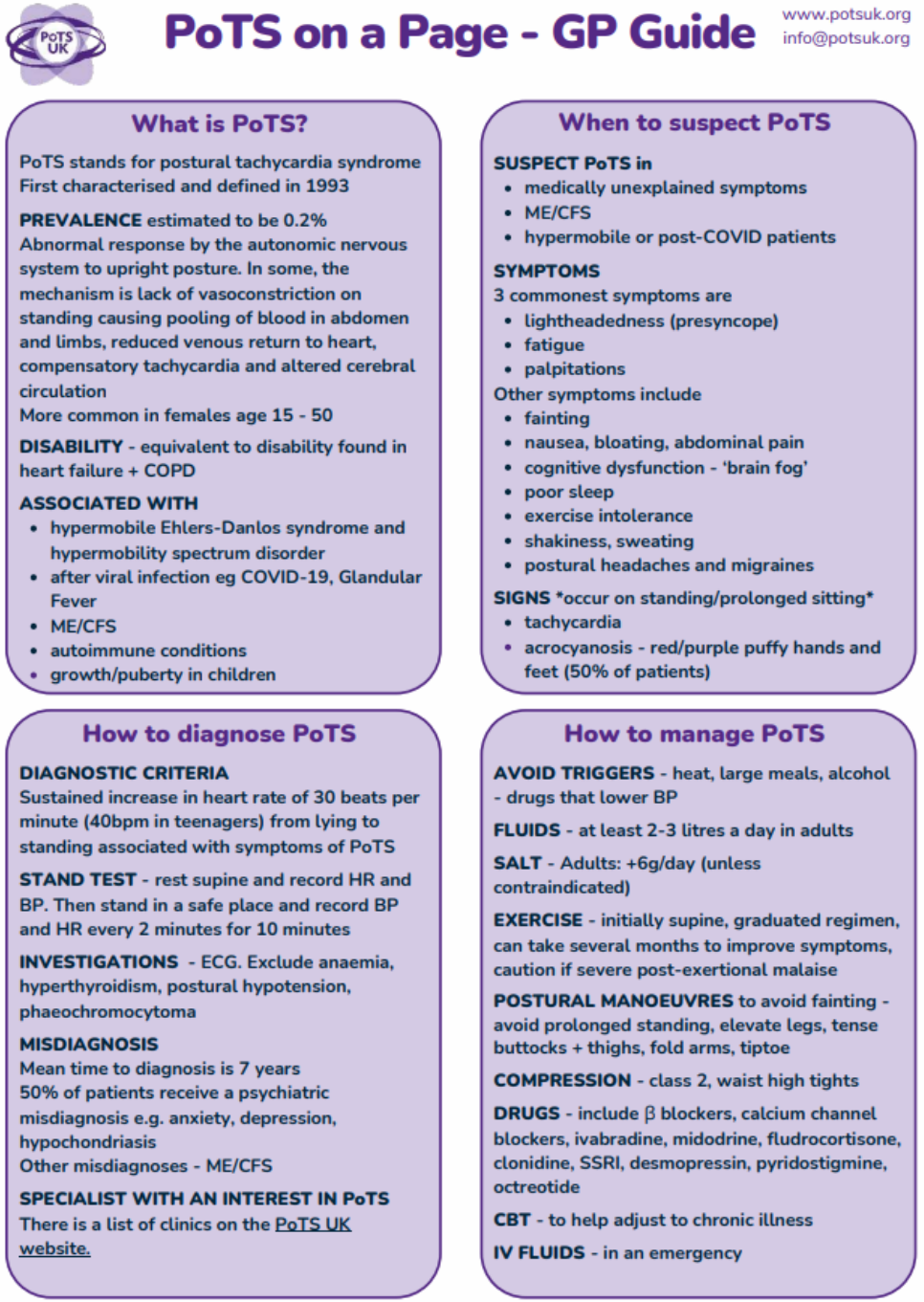
- Stop trigger meds
- Consider rate limiters
- Compression garments

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PoTS on a Page - GP Guide

www.potsuk.org
info@potsuk.org

What is PoTS?

PoTS stands for postural tachycardia syndrome
First characterised and defined in 1993

PREVALENCE estimated to be 0.2%
Abnormal response by the autonomic nervous system to upright posture. In some, the mechanism is lack of vasoconstriction on standing causing pooling of blood in abdomen and limbs, reduced venous return to heart, compensatory tachycardia and altered cerebral circulation
More common in females age 15 - 50

DISABILITY - equivalent to disability found in heart failure + COPD

ASSOCIATED WITH
- hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorder
- after viral infection eg COVID-19, Glandular Fever
- ME/CFS
- autoimmune conditions
- growth/puberty in children

When to suspect PoTS

SUSPECT PoTS in
- medically unexplained symptoms
- ME/CFS
- hypermobile or post-COVID patients

SYMPTOMS
3 commonest symptoms are
- lightheadedness (presyncope)
- fatigue
- palpitations

Other symptoms include
- fainting
- nausea, bloating, abdominal pain
- cognitive dysfunction - 'brain fog'
- poor sleep
- exercise intolerance
- shakiness, sweating
- postural headaches and migraines

SIGNS *occur on standing/prolonged sitting*
- tachycardia
- acrocyanosis - red/purple puffy hands and feet (50% of patients)

How to diagnose PoTS

DIAGNOSTIC CRITERIA
Sustained increase in heart rate of 30 beats per minute (40bpm in teenagers) from lying to standing associated with symptoms of PoTS

STAND TEST - rest supine and record HR and BP. Then stand in a safe place and record BP and HR every 2 minutes for 10 minutes

INVESTIGATIONS - ECG. Exclude anaemia, hyperthyroidism, postural hypotension, phaeochromocytoma

MISDIAGNOSIS
Mean time to diagnosis is 7 years
50% of patients receive a psychiatric misdiagnosis e.g. anxiety, depression, hypochondriasis
Other misdiagnoses - ME/CFS

SPECIALIST WITH AN INTEREST IN PoTS
There is a list of clinics on the PoTS UK website.

How to manage PoTS

AVOID TRIGGERS - heat, large meals, alcohol - drugs that lower BP

FLUIDS - at least 2-3 litres a day in adults

SALT - Adults: +6g/day (unless contraindicated)

EXERCISE - initially supine, graduated regimen, can take several months to improve symptoms, caution if severe post-exertional malaise

POSTURAL MANOEUVRES to avoid fainting - avoid prolonged standing, elevate legs, tense buttocks + thighs, fold arms, tiptoe

COMPRESSION - class 2, waist high tights

DRUGS - include β blockers, calcium channel blockers, ivabradine, midodrine, fludrocortisone, clonidine, SSRI, desmopressin, pyridostigmine, octreotide

CBT - to help adjust to chronic illness

IV FLUIDS - in an emergency

Author: Prof Lesley Kavi Published 19/04/2020 Updated 11/10/2023 Review Date 11/10/2026 Version 2

Mast cell activation

Original research

OPEN ACCESS

Long COVID following mild SARS-CoV-2 infection: characteristic T cell alterations and response to antihistamines

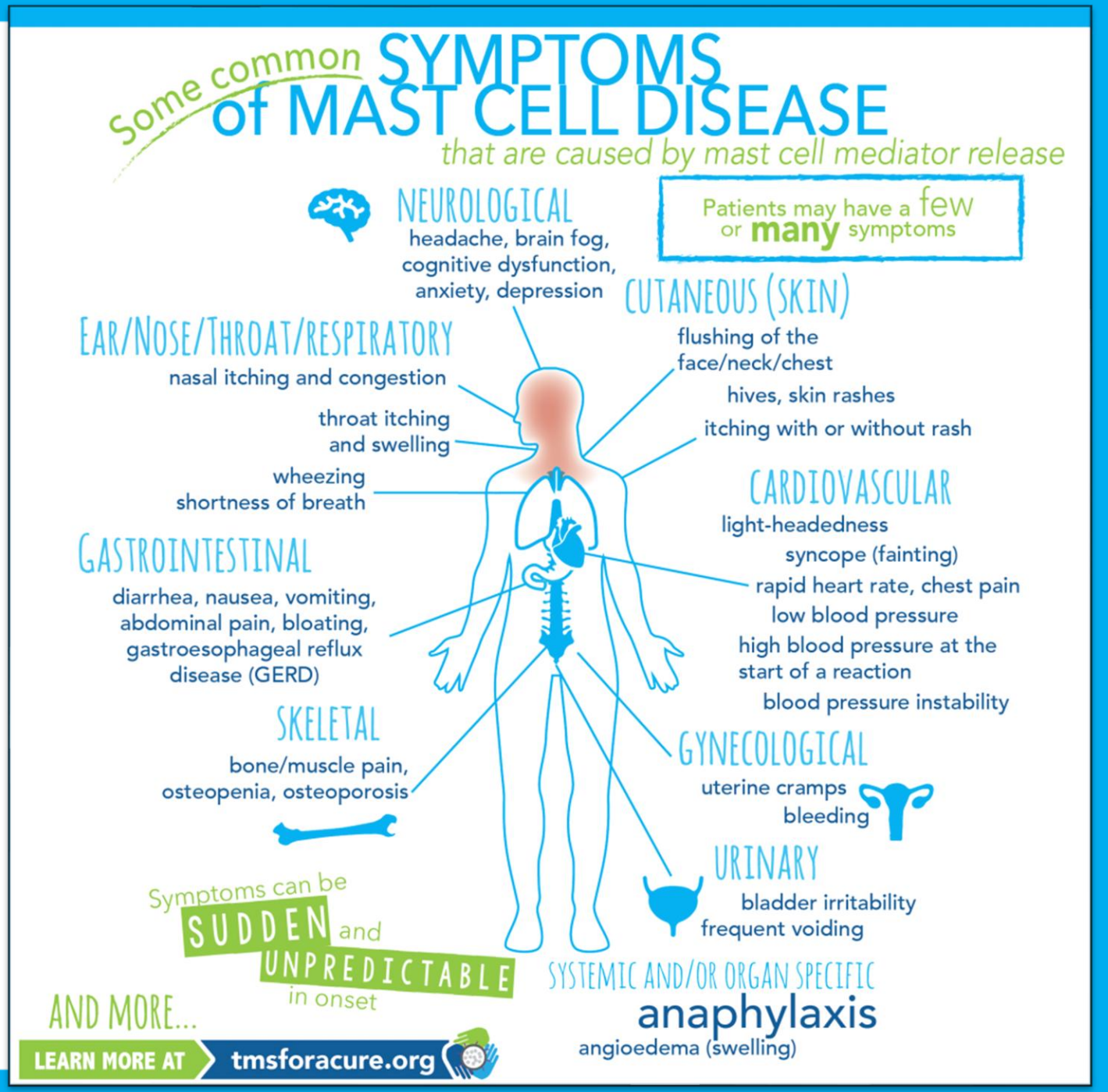
Paul Glynne,[1] Natasha Tahmasebi,[2] Vanya Gant,[3] Rajeev Gupta [4,5]

20% reported complete resolution of all symptoms,
52% reported some improvement

H1 receptor antagonists
loratadine 10 mg two times per day or
fexofenadine 180 mg two times per day

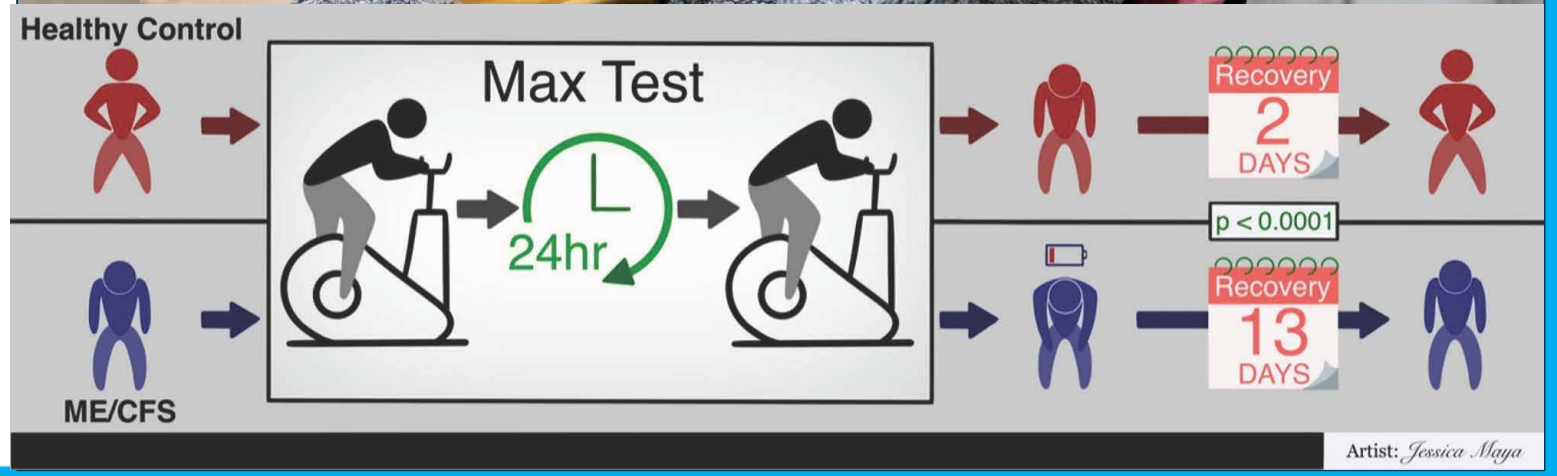
AND

H2 receptor antagonists
famotidine 40 mg once daily or
nizatidine 300 mg once daily



Symptom management: non-pharmacological





What ME/CFS patients need…



- Compassionate care and support to manage energy
- Regular medical review with a doctor
- Mobility aids
- Some will need full-time care
- People with very severe ME/CFS need help with personal hygiene and eating and are very sensitive to sensory stimuli. Some may not be able to swallow and may be tube fed.

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What people with ME/CFS need from social care

Reablement is contra-indicated for someone with M.E.

- Only specialists can input on activity due to risk of harm

Care plan that reflects their needs and is co-produced

- Clear record of who is involved and what happening; cognitive difficulties
- If buying in support from a PA then help with admin and managing support may be needed as may be too much

Support to manage symptoms

- Medication
- Energy management
- Rest
- Priorities and meaningful activity

Support to manage daily activities

- employment, family life, interests, caring roles

Support to arrange appointments or home visits with dentists or opticians

Aids to assist mobility and independent living – assessment for adaptions in home

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Aids and adaptations





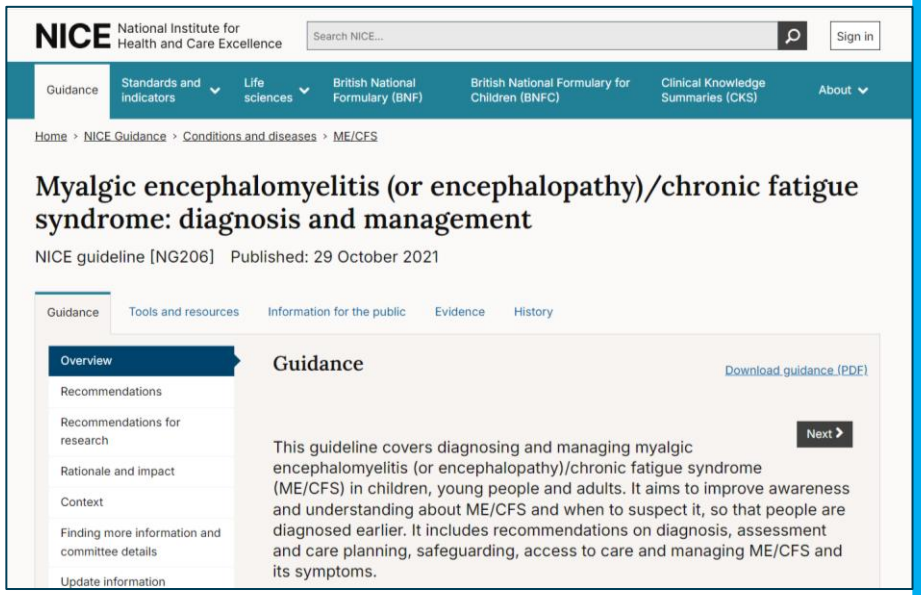




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NICE guideline for ME/CFS

1.16.1 Health and social care providers should ensure that all staff delivering care to people with ME/CFS receive training relevant to their role so they can provide care in line with this guideline. **Training should include helping them to understand what ME/CFS is and its diagnosis and management**; and the experiences of people with ME/CFS.



1.17.3 Personal care and support for people with severe or very severe ME/CFS should be carried out by health and social care practitioners who are **known to the person** and their family or carers wherever possible; and aware of the person's needs.

1.17.6 Service providers should be **proactive and flexible** in delivering services to people with severe or very severe ME/CFS, who may have particular difficulty accessing services and articulating their needs. This could include home visits, online or phone consultations, supplying written communication, and supporting their applications for aids and appliances.

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Learn about ME project



Funding from the Scottish Government supports charities to promote:

- Nina's online **FREE Learna module** of 10 clinical cases assessing your knowledge of ME/CFS (1 hours CPD) www.studyprn.com/p/chronic-fatigue-syndrome
- Learna's **FREE Question of the Day on severe ME** www.tinyurl.com/QOTDSevereME
- Learn about ME **FREE podcast series** www.buzzsprout.com/1717775
- Learn about ME **FREE webinar for OTs** www.actionforme.org.uk/OT-and-MECFS
- Learn about ME **medical student essay competition (winner Bhanu Wahi-Singh pictured left)** www.actionforme.org.uk/MECFS-essay-comp

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Information and support for people with ME/CFS and professionals

UK charities

- Action for M.E. Tel: 0117 927 9551. www.actionforme.org.uk
- ME Association. Tel: 0344 576 5326 www.meassociation.org.uk
- 25% ME Group. www.25megroup.org

Northern Ireland Charity and Support Group

- Hope 4 ME & Fibro Northern Ireland. Tel: 07712892834 (afternoons only). www.hope4mefibro.org/

Films

- An Introduction to M.E./CFS by Dialogues for ME/CFS, supported by the Wellcome Public Engagement Fund (14 min) www.dialogues-mecfs.co.uk/films/introduction
- Sensory difficulties (3 min) www.voicesfromtheshadowsfilm.co.uk/2018/animation-for-severe-me-day
- Discover M.E. – Hidden Lives Virtually Uncovered (6.39 min) Hope 4 ME & Fibro NI production https://tinyurl.com/DiscoverMEFilm

Webinars

- Myalgic Encephalomyelitis Webinar Series 1- 5 available on YouTube. Hope 4 ME & Fibro NI production. https://tinyurl.com/ME-Webinars

Resources

- Functional ability scale www.actionforme.org.uk/uploads/pdfs/functional-ability-scale.pdf
- NICE guideline www.nice.org.uk/guidance/ng206

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Employment, housing, finance and welfare benefits advice

- Turn2us https://www.turn2us.org.uk
- Advice Local https://advicelocal.uk/
- Child Poverty Action Group https://cpag.org.uk/
- Care and Support nidirect https://www.nidirect.gov.uk/information-and-services/health-and-wellbeing/care-and-support
- Shelter https://www.shelter.org.uk/
- Independent Living https://www.independentliving.co.uk/
- AskSARA - an OT online rapid-access self-assessment tool – Pilot project ONLY in Western Trust, Northern Ireland https://westerntrust.hscni.net/launch-of-new-occupational-therapy-tool-pilot-project-asksara/
- Disability Rights UK https://www.disabilityrightsuk.org/
- Disability Action Northern Ireland https://www.disabilityaction.org/
- Disability nidirect https://www.nidirect.gov.uk/information-and-services/benefits-and-financial-support/disability
- Disability Law Service https://dls.org.uk/

- Equality Advisory and Support Service https://www.equalityni.org/individuals
- ACAS https://www.acas.org.uk/
- Advice NI https://www.adviceni.net/

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